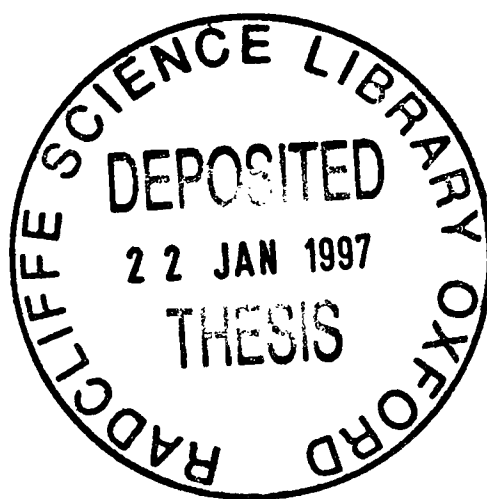


Cognitive and behavioural processes in health anxiety.

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Abstract

In this thesis a cognitive-behavioural model of health anxiety is used to investigate the psychological effects of bone densitometry, a health test which can provide an indication of future risk for osteoporosis. The cognitive-behavioural model of health anxiety proposes that people will experience relatively high levels of anxiety about their health if they have a tendency to make particularly negative interpretations of bodily variations and information which may be relevant to health. It was therefore predicted that people who have a pre-existing tendency to worry about their health would react more negatively to the results of bone density measurement. Consistent with this prediction, after a low bone density (“high risk”) result, women who reported high levels of pre-existing health anxiety gave higher ratings of anxiety about osteoporosis and perceived likelihood of developing osteoporosis in the near future than women with low levels of pre-existing health anxiety. (The two groups did not differ significantly in these ratings before the scan). Differences in the reactions of women with high and low levels of pre-existing health anxiety were still apparent 14 months after the scan. Women receiving a low bone density (“high risk”) result showed a “minimization” of the seriousness of low bone density; when individual differences were investigated, it was found that women with very high levels of pre-existing health anxiety did not show minimization. Furthermore, after a “low risk” result, women with high levels of health anxiety were only temporarily reassured. It thus appears that the new measure of health anxiety which was used in this thesis may be useful in helping to identify people who are vulnerable to experiencing distress after health screening. More specific pre-scan measures of beliefs about osteoporosis (derived from the cognitive-behavioural model) also predicted reactions to bone density screening. For example, pre-scan beliefs about the seriousness or burden of low bone density / osteoporosis were stronger predictors of anxiety about osteoporosis three months after the scan than the actual scan result. Factors such as the type of interpretation the woman makes of her scan result, and whether the woman is having her first or second scan, were also found to influence psychological reactions.

This thesis is dedicated to my family:

Valerie, Gilbert, Abigail and Melanie Rimes.

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Chapter 1: Health anxiety and applying a cognitive-behavioural model to health screening

1.1 Psychiatric conceptualizations of health anxiety

There are a variety of different ways of conceptualizing health anxiety. Severe health anxiety, or hypochondriasis, has long been classified as a distinct psychiatric disorder (the current criteria for which, according to the American Psychiatric Association, 1994, are shown in table 1.1). According to the DSM-IV criteria for hypochondriasis, a person may be classified as hypochondriacal if they are preoccupied with either the belief that they currently have a serious disease (despite medical evaluation to the contrary) or the fear that they will contract one. This distinction between “disease conviction” and “illness phobia” is to be found in many of the classifications of hypochondriacal symptoms that have been suggested (e.g. Pilowsky, 1967, Kellner, 1985). It is unknown whether these presentations represent separate syndromes; there is currently some controversy about whether or not these two aspects should be distinguished in the classification of hypochondriasis. The distinction may be important since different presentations may require different approaches to treatment. It has been predicted that in patients with illness phobia there will be a predominance of avoidant behaviours rather than reassurance-seeking, while in patients with disease conviction the pattern will be reversed (Salkovskis, Warwick and Clark, 1996).

An additional psychiatric diagnosis has recently been suggested by Barsky, Wyshak and Klerman (1990): “transient hypochondriasis”, for patients in whom hypochondriacal symptoms fulfil diagnostic criteria for hypochondriasis except for the criterion that the problem should have lasted for 6 months. The existence of transient health anxiety (e.g. in medical students perceiving the symptoms under study, patients waiting for diagnostic tests) has been seen as evidence consistent with a dimensional approach to health anxiety (Warwick and Salkovskis, 1990). In this view, hypochondriasis is not a qualitatively distinct problem but represents the extreme end of a continuum of health anxiety. In other words, the differences between hypochondriacal patients and people with less severe forms of health anxiety are viewed as quantitative rather than qualitative.

1.2 Prevalence of health anxiety

There are no community prevalence studies of hypochondriasis. In a sample of medical out-patients, Barsky, Wyshak, Klerman and Latham (1990) found a six-month prevalence rate of DSM-III-R (American Psychological Association, 1987) hypochondriasis of between 4.2 and 6.3%. Kellner (1985) estimated that prevalence rates ranged from 3% to 13% in different communities. With regard to health anxiety of varying

degrees of severity, Agras, Sylvester and Oliveau (1969) found that worries about illness occur in about 10% to 20% of the general population. Kellner, Abbott, Pathak, Winslow and Umland (1983-84) found that about 9% of patients in a family practice clinic said that they tend to disbelieve the doctor if he or she tells them that they have no physical illness.

Table 1.1	DSM-IV Diagnostic criteria for Hypochondriasis
A. Preoccupation with fears of having, or the idea that one has, a serious disease based on the person's misinterpretation of bodily symptoms. B. The preoccupation persists despite appropriate medical evaluation and reassurance. C. The belief in Criterion A is not of delusional intensity (as in Delusional disorder, Somatic type) and is not restricted to a circumscribed concern about appearance (as in Body Dysmorphic disorder). D. The preoccupation causes clinically significant distress or impairment in social, occupational or other important areas of functioning. E. The duration of the disturbance is at least six months. F. The preoccupation is not better accounted for by Generalised Anxiety Disorder, Obsessive-Compulsive Disorder, Panic Disorder, a Major Depressive Episode, Separation anxiety or another Somatoform Disorder. <i>Specify if:</i> With Poor Insight: if, for most of the time during the current episode the person does not recognize that the concern about having a serious illness is excessive or unreasonable.	

1.3 Effects of health anxiety

Anxiety is not only intrinsically unpleasant but can have various undesirable effects on the person's physical health (Totman, 1990). For example, in some individuals, health anxiety is associated with a failure to attend for health screening (e.g. Lerman, Rimer, Trock, Balshem & Engstrom, 1990) and delay in seeking help for possible cancer symptoms (Greenwald, Becker and Nevitt, 1978). Health anxiety can also have significant implications for health care resources. One expert estimated that the "worried well" are responsible for 50% of the cost of adult ambulatory health care (Barsky and Klerman, 1983).

1.4.1 Theoretical approaches to hypochondriasis

The term hypochondriasis came to mean "fear of illness" or "morbid preoccupation with the possibility of having a disease" in the nineteenth century. (Before this it had had various meanings at different points in time, such being seen as a disease located in certain organs of the body). With the emergence of psychoanalysis, the Freudian view of hypochondriasis became popular, in which it is viewed as the result of a withdrawal of libido from the external world into internal organs (Freud, 1914). Since then, numerous psychodynamic conceptualizations have been proposed, for which there is no empirical supporting evidence (Kellner, 1985). Some of these theories suggest that gain of some kind is a crucial factor in hypochondriasis.

This notion has no empirical support, can have pejorative connotations and often prevents a careful analysis of the phenomenon involved in each particular case (Warwick and Salkovskis, 1990).

Three of the foremost researchers into hypochondriasis and related phenomenon in the last few decades have been Kellner, Barsky and Pilowsky. Their approaches are described briefly below. Leventhal's self-regulatory model for how people cope with health threats is also described, followed by a more detailed description of a cognitive-behavioural model of health anxiety and a comparison between this model and the others.

1.4.2 Kellner's approach to hypochondriasis

Kellner (1986) suggested that there are various factors which may predispose a person to hypochondriasis because they make the person attend to his or her body, (although he does not specify the process by which this occurs). He suggests that predisposing factors include previous physical illness, disease in the family in childhood or more general features such as an unstable home life or bereavement in childhood. He considers the precipitant of hypochondriasis to be any event that leads to a new awareness of physical vulnerability or anything that produces anxiety, depression or another disorder with somatic symptoms. Kellner writes, "At some point after the somatic symptoms are perceived, the idea of disease may occur". He suggests that this idea is maintained by factors such as selective attention to bodily sensations (as a result of anxiety), iatrogenic reinforcement or the patient reading about illness and making his or her own diagnoses. The anxiety experienced "leads to more somatic symptoms which in turn lead to more anxiety, more selective perception and a vicious cycle".

1.4.3 Barsky's "somatosensory amplification" approach to hypochondriasis

Barsky and his coworkers have suggested that "somatosensory amplification" may have an aetiological role in hypochondriasis (e.g. Barsky and Klerman, 1983). They define somatosensory amplification as "the tendency to experience bodily sensation as intense, noxious and disturbing". Barsky (1992) says that hypochondriasis might be distinguished from other somatoform disorders by a characteristic heightened sensitivity to somatic and visceral sensation. He suggests that people with hypochondriasis have symptoms that are so intense and noxious that they mistakenly conclude that the symptoms must be pathological. This conclusion leads to further self-scrutiny and they selectively attend to those symptoms that confirm their hypothesis. In this formulation of hypochondriasis, the other clinical characteristics of the disorder are viewed as secondary consequences of the amplified somatic perceptions. Although there is a correlation

between Barsky's questionnaire measure of amplification and hypochondriacal symptoms, the direction of relationship has not been investigated. Furthermore, Barsky and Wyshak (1990) present evidence which they suggest indicates that amplification may not be a unique correlate of hypochondriasis that would distinguish it from somatisation in general.

1.4.4 Pilowsky's view of hypochondriasis as a type of abnormal illness behaviour

Pilowsky subsumes hypochondriasis under what he terms "abnormal illness behaviour" (the definition of which he developed using the concept of illness behaviour which was introduced by Mechanic and Volkart in 1960). Pilowsky originally used the term in an attempt to provide a framework for the study of conditions such as hypochondriasis, hysteria and conversion (Pilowsky, 1969), although he now uses the term to cover other aspects such as denial of illness. Pilowsky believes that although categorical approaches may at times be appropriate, it is also important to consider illness behaviour in dimensional terms. He created the Illness Behaviour Questionnaire (Pilowsky and Spence, 1983) to assess different elements of illness behaviour and factor analysis revealed seven factors- general hypochondriasis, disease conviction, psychological versus somatic focusing, affective inhibition, affective disturbance, denial and irritability. Pilowsky suggests that these are the seven most important elements of illness behaviour that need to be taken into account in any patient evaluation. Since Pilowsky's ideas focus on the concept of abnormal illness behaviour as a framework for research and treatment rather than as a theory, and since most of his research has been directed towards patients with chronic pain rather than hypochondriasis, his ideas will not be discussed further here.

1.4.5 Leventhal's self-regulation theory

Leventhal and colleagues have developed a "self-regulation theory", which does not concern hypochondriasis *per se* but does aim to guide research into how people cope with health threats (e.g. Leventhal, Nerenz and Steele, 1984). The model suggests that two largely independent processing systems are involved in reactions to a health threat - one which develops and deals with a representation of the health threat itself and another concerned with the emotions aroused by a health threat. One of the basic assumptions in the self-regulation theory is that people have representations of illness which will guide their reactions, although these representations will not necessarily reflect the views of the medical establishment. Illness representations are viewed as including at least 5 attributes: the identity of the illness (the label and symptoms); perceived cause; perceived consequences; perceived "time line" and perceived cure.

1.4.6 Cognitive-behavioural model of hypochondriasis and health anxiety

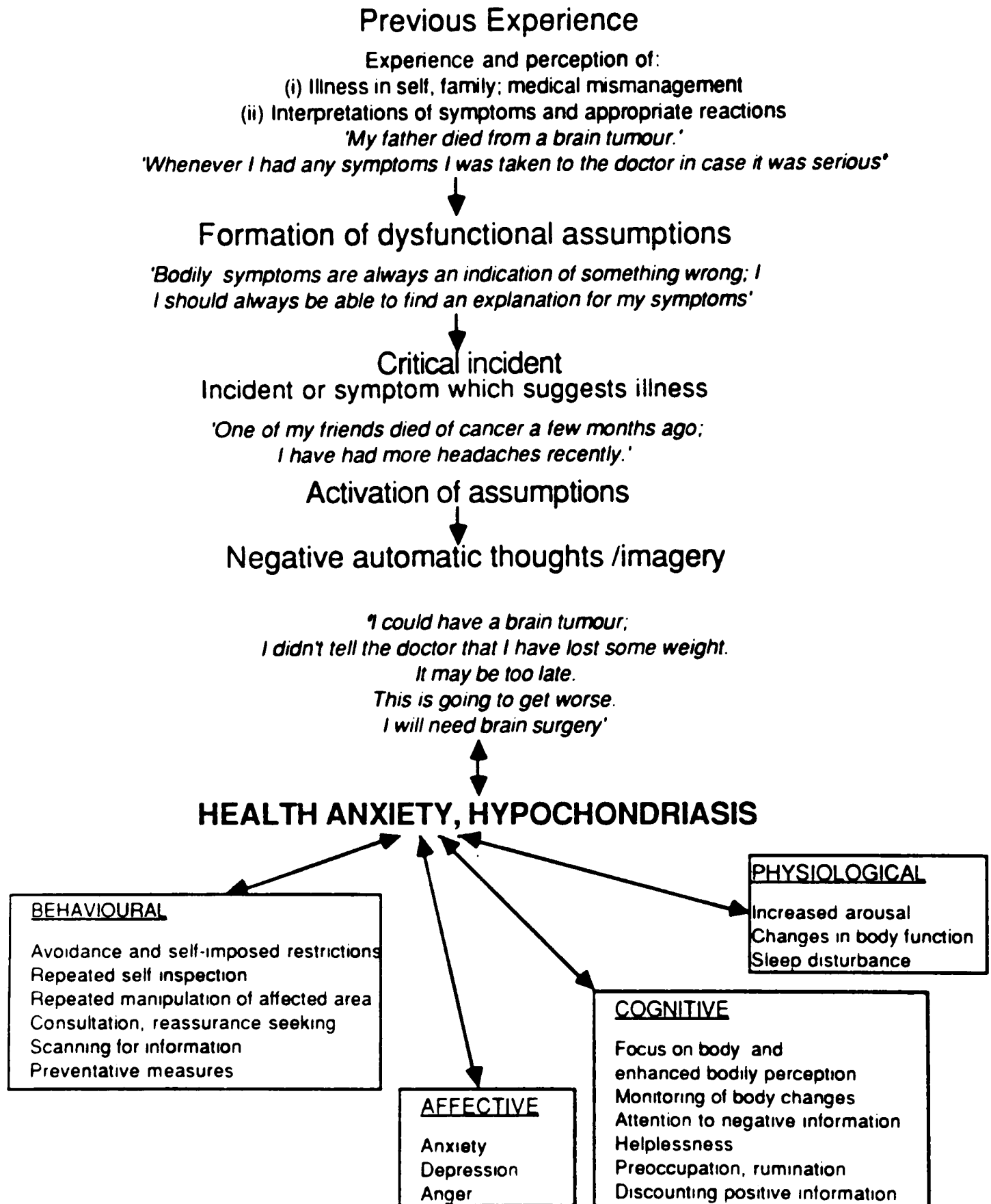
So far there has only been one published cognitive-behavioural theory of hypochondriasis and health anxiety, developed by Warwick, Salkovskis and Clark (e.g. Salkovskis and Warwick, 1986, Warwick and Salkovskis, 1990; Salkovskis and Clark 1993). Their work will therefore be referred to in the rest of the thesis as “the cognitive-behavioural (CB) model of health anxiety” or the “cognitive-behavioural model”. See figure 1.1 for a diagram showing the main components of this model.

According to the CB model of health anxiety, some people become severely anxious about their health because they misinterpret bodily variation (including bodily sensations) or medical information as more threatening than it really is (e.g. as a sign of illness). This occurs because the person has particular assumptions about health and illness. The model proposes that specific assumptions about illness, symptoms and health behaviours arise from knowledge of and past experience of illness (in oneself or others). Early experience may be particularly important but events in the individual’s later social network and cultural factors (such as the mass media) may also play a role.

Examples of potentially problematic assumptions about symptoms and illness are “Bodily symptoms are always the sign of something wrong”, “You should go to the doctor whenever you notice something unusual because otherwise it may be too late”, “Doctors often mistake serious illness for something more trivial”, “I’m certain to get cancer in my fifties because I’m very like my mother who died of it at that age”. Salkovskis (1990) found that hypochondriacal patients endorsed more dysfunctional attitudes about health and illness than non-clinical subjects and patients with social phobia.

The CB model of health anxiety suggests that dysfunctional beliefs may be a constant source of anxiety or may lie dormant until triggered by critical incidents such as illness in a friend, unfamiliar bodily sensations or new information about illness. Once assumptions have been “activated” they will influence the way in which situations are interpreted - there will be a tendency for the person to process information in a way which is consistent with the assumption and ignore or discount inconsistent evidence (a “confirmatory bias”). Thus once the dysfunctional assumptions are activated they will influence how the person interprets new bodily sensations, memories of previous symptoms, medical consultations and so on. When these factors “mesh” with the dysfunctional assumptions, (e.g. chest pain in someone who thinks that the most likely cause of chest pain is heart disease), this causes a particularly negative interpretation (appraisal) and a high level of anxiety will result.

Figure 1.1 The cognitive-behavioural model of health anxiety (from Warwick & Salkovskis, 1990; with permission)



The degree of focused anxiety is largely determined by particular components of the appraisal (Beck, 1976). The appraisal of threat, and hence level of anxiety, will be determined by beliefs about (a) how probable the disease is and (b) how adverse the consequences of the disease would be. This will then be modified by the person's beliefs about how well they think that they would be able to cope with the condition (internal coping resources) and whether methods of prevention or treatment (or other external help) would be available (see figure below).

Figure 1.2: Cognitive model of threat perception

Perception of threat is determined by:

$$\frac{\text{Perceived likelihood of illness}}{\text{Perceived ability to cope with the illness (Internal coping resources)}} \times \frac{\text{"Cost" beliefs - how adverse the consequences are perceived to be}}{\text{Perception of external coping resources (e.g. treatment, social support)}}$$

(X- this is used to indicate that the relationship may be synergistic, although the relationship between these beliefs is not established).

According to this cognitive model, one may feel anxious about an event which one expects to be only mildly unpleasant, if one perceives it as very probable. Alternatively, one may be anxious about an event which one thinks is fairly unlikely, if one believes that the consequences are particularly unpleasant. This distinction may help account for the difference between illness phobia and disease conviction which was discussed earlier. In people with disease conviction, perceived vulnerability beliefs are heightened, while the level of cost beliefs may or may not be elevated. In people with disease phobia, their perceived "cost" beliefs are likely to be unusually negative while perceived vulnerability may be at "normal" levels or only slightly elevated. Of course if a person believes that an illness is both very probable and extremely aversive, their anxiety will be particularly high, especially if they believe that there are no possible treatments and that they would find it difficult to cope.

This cognitive model can help to demonstrate how it is possible to view health anxiety a relatively more complex dimensional construct, for it is proposed that the four factors will vary in degree throughout the general population. It is expected that there will be considerable overlap in the perceptions of people who do and do not actually have a current illness, or between people who are and are not actually at risk for a certain condition.

Maintenance of health anxiety

Given that a negative appraisal of health information has occurred, the CB model of health anxiety proposes that health anxiety will persist as a result of various mechanisms which come into play after the initial anxiety has been experienced:

(1) Physiological arousal is likely to occur as a result of health anxiety and the symptoms of this arousal may then be misinterpreted as further evidence of disease (although this is thought to be relatively less important in people with general health anxiety and hypochondriasis than in people who have frequent panic attacks, where it is probably the primary maintaining factor). Physiological arousal may also cause more chronic symptoms (such as muscle pain caused by prolonged tension) which may be misinterpreted as a sign of illness.

(2) Selective attention to illness-related information (such as bodily sensations or changes) may occur. This may result in normal changes or previously unnoticed bodily features being seen as further evidence of illness. Consistent with this notion, Beunderman et al. (1988) found that patients who attended a cardiac emergency department with non-cardiac chest pain reported more chest pain in what are generally regarded as the “typical” areas for a heart attack (on the left of the body) than did myocardial infarction patients or patients with angina pectoris, who both reported more pain in the centre of the body. Ehlers and Breuer (1995) directly demonstrated attentional bias toward physically threatening stimuli in patients with an anxiety disorder (including patients with panic disorder).

According to the CB model of health anxiety, negative aspects of medical information may also be selectively attended to.

(3) Behavioural reactions designed to avoid, check for or totally exclude physical illnesses (e.g. frequent medical consultations; reading medical books; avoiding physical exertion or contact with disease; bodily checking, manipulation or inspection) will maintain anxiety and preoccupation. These behavioural reactions to a health threat are thought to increase or maintain anxiety in several ways. For example, they keep attention focused on fears about health and can as a result lead to elaboration of these fears. They can also increase the range and scope of catastrophic misinterpretation. In addition, the avoidance of situations which are perceived as risky will mean that the dysfunctional beliefs and misinterpretations are not disconfirmed (Salkovskis, 1991).

1.4.7 Differences between hypochondriasis and panic disorder

CB models suggest that catastrophic interpretations of symptoms can lead to the pattern of anxiety seen in either hypochondriasis and panic disorder (e.g. Salkovskis and Clark, 1993). If the sensations or signs are not those which increase as a result of anxiety (as a consequence of autonomic arousal) or the person does not believe that the catastrophe is imminent, then the reaction will follow the hypochondriacal pattern. However, if disaster seems imminent and symptoms which can be increased by anxiety are misinterpreted then a spiral of anxiety-induced symptoms and misinterpretation may occur resulting in a panic attack (e.g. Clark, 1988). Evidence consistent with this distinction comes from a study by Salkovskis (1990) which showed that hypochondriacal patients endorsed more negative health attitudes than negative anxiety-related attitudes while panic patients showed the opposite pattern. However, worries about anxiety-related symptoms can easily extend over time to encompass non-anxiety related ones (and vice versa) and there is evidence for a high degree of comorbidity between panic disorder and hypochondriasis (Salkovskis, Warwick and Clark, 1996).

1.4.8 Comparison between the cognitive-behavioural model and other models of hypochondriasis or reactions to health threats

While Barsky's amplification theory suggests that hypochondriasis is the result of a general perceptual tendency to amplify bodily sensations, the cognitive-behavioural model says that the person's *appraisal* of bodily sensation (or other health-relevant information) is the central feature in hypochondriasis. The CB model suggests that although there are likely to be individual differences in the perception of the intensity of bodily sensations, people who experience "amplified" bodily sensations are expected to interpret such sensations in different ways, depending on their prior experiences and the context in which the sensations occur. At the same time, some people who do not experience "amplified" bodily sensation will nonetheless incorrectly interpret their symptoms as a sign of illness. Furthermore, hypochondriacal misinterpretations can arise from bodily variations and medical information. According to the CB model, there are processes in some hypochondriacal patients which appear to correspond to amplification but these are processes which occur after the initial perception of threat and then contribute to the maintenance of anxiety, rather than being a primary cause. For example, the perception of threat (e.g. I'm developing throat cancer because I have difficulty swallowing) can lead to selective attention to bodily sensations (in this case throat sensations which may indicate difficulty in swallowing), which makes it more likely that they will be noticed, and can

lead to certain behaviours which may worsen symptoms (e.g. repeated deliberate swallowing creating more difficulty in swallowing). Furthermore, the physiological arousal caused by the perception of threat can worsen symptoms or cause new ones. When these further symptoms are noticed, the hypochondriacal patient's maladaptive beliefs make it likely that the sensations will be interpreted as a sign of illness, hence maintaining health anxiety.

Kellner's approach also shares some features with the CB model. For example, it includes the idea that selective attention to symptoms can be a maintaining factor and suggests that a vicious cycle of anxiety, selective attention and somatic symptoms may be occurring. However, an important difference between the two models is that Kellner's model is not based on the idea that particular pre-existing beliefs about illness play a role in hypochondriasis. While Kellner does not describe why thoughts of serious disease occur after somatic symptoms, or why this will only happen in some people, the CB model points out that thoughts of serious disease will arise if the person has some pre-existing beliefs about the meaning of symptoms. The CB model also suggests that somatic symptoms are not always present at the initial stages of health anxiety - sometimes medical information leads to thoughts of illness which result in health anxiety and the vicious cycle then begins. Furthermore, the CB model suggests other maintaining factors may be involved such as avoidance, attempts to suppress thoughts of illness, repeated manipulations of affected areas and so on.

Leventhal's self-regulation model has several important similarities to the CB model of health anxiety. Both assert that the individual's "representations" or "beliefs" about the health threat will determine the person's emotional reaction. Both therefore emphasize the importance of accessing the person's own beliefs about the situation in order to understand or modify reactions. Leventhal (1990) describes his model as a framework for research rather than a theory from which specific predictions can be generated. Although it asserts that anxiety will be determined by the individual's representation or beliefs it does not make predictions about the types of illness representations which will cause anxiety.

The self-regulation model may be particularly appropriate for research into responses to existing rather than anticipated health threats: although the self-regulatory theory has a component representing "causes" of a disease, it does not have a component corresponding to the perceived likelihood of oneself developing the illness, which makes it inadequate for the prediction of anxiety about a disease which has not yet developed. Leventhal's theory also does not specify factors involved in the persistence of distress, while the CB model explicitly proposes that certain behaviours such as avoidance, excessive reassurance-

seeking or attempts to suppress thoughts of illness will maintain anxiety.

1.5 Treatments for hypochondriasis

Clearly one of the reasons why it is important to understand the processes involved in health anxiety is that this may help in the development of ways of preventing or reducing it. The cognitive-behavioural treatment approach for hypochondriasis involves helping the patient to identify and correct a) their misinterpretations of bodily sensations; b) factors which are maintaining the anxiety and c) dysfunctional assumptions (Salkovskis and Bass, 1996). Cognitive procedures include: identifying and challenging the patients' evidence for their misinterpretations of symptoms and signs; helping patients to construct more realistic interpretations; restructuring images; and modifying dysfunctional assumptions. Behavioural experiments include: graded exposure to avoided situations, response prevention for repeated bodily checking and the prevention of reassurance seeking. In order to aid understanding of the effects of attentional focus, bodily focusing is used to induce innocuous symptoms.

Although various types of psychotherapeutic and pharmacological treatments for hypochondriasis have been attempted, the only controlled trials have involved cognitive-behavioural therapy. Warwick, Clark, Cobb and Salkovskis (1996) found that patients receiving a 16-session CB treatment improved significantly more than the waiting list control group. In a second study they found that CBT produced faster change than an alternative treatment (behavioural stress management-BSM) which also provided subjects with an alternative (non-illness) account of their symptoms. Preliminary analysis carried out for a conference presentation indicated that CBT may be superior to BSM on some measures at completion of therapy (Salkovskis, 1995).

1.6 Interpreting ambiguous health information

In order to examine the hypothesis that hypochondriasis and panic disorder both result from an enduring tendency to misinterpret bodily sensations or changes as being an indication of catastrophic harm, a questionnaire has been devised to assess interpretations of bodily sensations and given to hypochondriacal, panic patients, social phobics and non-clinical controls (Salkovskis, 1990). As predicted, it was found that hypochondriacal patients were more likely than the other groups to make misinterpretations of bodily sensations as an indication of illnesses involving long-term danger while panic patients were more likely

than the non-panic groups to make misinterpretations in a way which involved imminent disaster.¹

Although this experiment asked subjects to respond to (self-referent) hypothetical situations, it can be argued that this assessment measures a relatively enduring tendency to make such negative interpretations. If this is so, it would be expected that ambiguous real-life health information, such as the results of some types of health screening, may be interpreted in a more negative way by people who tend to be anxious about their health. In order to examine the CB model's hypothesis about interpretation further, in a non-clinical population, it thus seemed appropriate to investigate whether the cognitive-behavioural model could help to predict which individuals are particularly likely to experience high levels of distress after a health test. Risk factor testing was chosen as a suitable type of screening: a positive result from a test for risk factors is particularly open to different interpretations, since it can be viewed as anything from an insignificant, purely theoretical risk indicator, to a sign that serious illness is already developing. Before the predictions of the CB model are described in more detail, previous research into risk factor screening will be discussed.

1.7 Previous research into psychological reactions to risk factor screening

A survey of the current literature on the psychological effects of health screening for risk factors indicates various inconsistencies. (See Appendix A for a detailed summary of findings from these studies. Appendix B gives summarized information about the studies mentioned in Appendix A, regarding the study design, recruitment methods, the measures used, the proportion of screened participants who entered the psychological study and the proportion who returned follow-up questionnaires).

A number of studies have detected no significant changes in levels of psychological distress after screening while others have found psychological effects ranging from relief and reassurance through to intense anxiety, depression, worries about one's health and marital problems. Various factors may be responsible for the inconsistent results. For example, in some cases where no psychological effects were found, this may be due to the types of measures that were used- specific measures are perhaps more likely to detect effects than more global measures of psychiatric morbidity. However, this cannot be the only explanation for inconsistencies, since some studies with fairly specific measures failed to identify any

1

There has only been one other study which has attempted to examine the specificity of interpretations made by people with a tendency to worry about their health, by Hitchcock and Mathews (1992). They unfortunately used a distinction between "catastrophic" (e.g. heart disease) and "non-emergency" (e.g. influenza) illness interpretations in order to characterize the interpretations made by panic and hypochondriacal patients respectively, while the CB model in fact suggests that both type of patients make catastrophic interpretations- the distinction in the CB model is between the time course (imminent or insidious) of the feared illness, not the severity.

adverse effects of screening (e.g. Havas, Reisman, Hsu and Koumjian, 1991). Differences in the way in which risk information is conveyed and the nature of follow-up care are also likely to affect the distress experienced after screening and may be another factor contributing to the discrepancies between the results of different studies (see the sections in Appendix A on hypertension and cholesterol screening, for example). Another reason that has been suggested is that adverse effects are more likely to be detected where a whole population is screened (e.g. an entire workforce) than where people volunteer for screening, because in the latter case those who are more likely to react badly may choose not to attend (Rudd et al. 1987 and see review of the effects of testing for Huntington's Disease, in Appendix A). Similarly, there are indications that people who do not take part in follow-ups may be more distressed than those who do (e.g. Tyler et al., 1992), so in studies where the follow-up rate is less than 100% (i.e. almost all the studies), the observed effects may be underestimates of the distress experienced. Another factor which can make interpretation difficult is that many existing studies use a retrospective or cross-sectional design rather than a prospective one. The lack of baseline psychological characteristics not only makes it impossible to determine whether group differences were only apparent after screening but also means that the psychological characteristics of people choosing to attend screening cannot be discussed in relation to the general population.

There are noticeable gaps in existing research. Surprisingly, previous research has generally failed to examine the extent to which risk factor screening actually changes risk perceptions. Of the studies mentioned in Appendix A, only four report risk perceptions for the condition which was the topic of the screening (Hout and McDougall, 1988; Codori and Brandt, 1994; Avis, Smith and McKinlay, 1989; Lerman et al. 1995). There is also little research into the process of coping with risk information, except for laboratory studies into minimization of the health threat, which need to be replicated using prospective designs. Perhaps most surprising of all is the fact that very few studies have used any kind of psychological model when examining the psychological effects of health screening. Although it could be argued that a model is not necessary if one is only quantifying the effects, it seems likely that a model would guide the choice of measures to be used. If one wants to go further and try to predict reactions to health screening, a model is even more important, but again, little work has been done looking at individual differences in reactions to risk factor screening. Given the increasing numbers of different health tests that are being developed, it would be especially useful to have a general psychological model which could aid prediction of distress, for this could be applied to new tests as they became available. The cognitive-behavioural model of health anxiety might be appropriate for this task, for it can be used to derive specific predictions about the types of factors which make an individual vulnerable to experiencing distress after a health threat. Recent

treatment trials for hypochondriasis have shown that cognitive-behavioural treatment can be successful with even the most chronic and severe cases of health anxiety, so it is possible that a modified version of this kind of intervention could be used in order to help people who are vulnerable to developing health anxiety after health screening. It would be particularly valuable if preventative strategies could be developed using this model. The types of predictions about reactions to health screening which can be derived from the CB model of health anxiety are outlined in the next section.

1.8 Predicting reactions to health screening using the CB model

The CB model proposes that people who tend to worry excessively about their health do so because they make particularly negative interpretations of health-relevant information. One would therefore predict that people who have a pre-existing tendency to worry about their health will react more negatively (or less positively) to health-relevant information such as results from health screening. Presumably this would be because these people are likely to have generally negative assumptions about illness which are activated by the screening and its results. Thus by assessing the extent to which people tend to worry about their health, it may be possible to identify individuals who are at risk for experiencing distress after health screening, before they have had the test.

In addition to general maladaptive assumptions about illness (e.g. “worrying about possible health problems and keeping a careful watch on symptoms are the best ways of making sure that illness doesn’t get too advanced before I seek help”), which are reflected in an enduring tendency to be anxious about one’s health, certain specific beliefs about the condition in question are expected to influence reactions to health screening. The specific assumptions thought to be particularly important will involve the following aspects: one’s perceived vulnerability to the condition, the “perceived cost” of the illness, one’s anticipated ability to cope with it and beliefs about whether there are successful treatment / prevention methods. Risk factor screening is designed to influence the person’s vulnerability perceptions, but the CB model suggests that vulnerability perceptions after the scan will not simply be a product of the new risk information - pre-test beliefs will also influence the resulting appraisal of this risk information. Furthermore, the cognitive-behavioural model suggests that perceptions of risk will interact with perceptions of seriousness to determine the level of perceived threat. For example, in terms of risk factor testing which gives a range of results, someone who receives an “average” result and has very negative seriousness beliefs may be more anxious than someone with a very high risk result who does not perceive the problem to be very serious. Beliefs that one would be unable to cope if one developed the illness in question or had a certain risk factor are also

expected be associated with more adverse reactions, as are beliefs that there are no “rescue” factors such as effective treatment / prevention or social support.

The CB model of health anxiety also suggests that people who were previously very anxious about the disease (i.e. because they felt at high risk and/or perceived the consequences of the condition to be particularly aversive) may selectively attend to any negative implications of their result. For example, with regard to bone density screening, a woman who was not previously anxious might be satisfied to find her bone density is average for her age while those who were previously worried might be more likely to notice that the graph they are given implies that the bone density of the “average” woman will in fact fall below the “fracture risk threshold” in later life. It is therefore predicted that those who were more anxious before the scan will react with a more negative interpretation and hence more adverse reaction. This may occur even with a “good” result- clinical evidence with hypochondriacal patients suggests that there may be immediate reassurance after a negative test result, but worries tend to return later.

B. Maintaining factors

As discussed above in section 1.4.6, the cognitive-behavioural model suggests that particular ways of reacting to health threats may act to prolong the anxiety. Thus it is predicted that people who tend to selectively attend to threatening illness information, check their bodies for symptoms, focus on bodily sensations, seek reassurance from other people or medical books, avoid illness-related situations or stimuli, try to suppress the intrusive worrying thoughts or experience physical symptoms as a result of their anxiety which they then misinterpret, will be vulnerable to persistent anxiety after a health test.

1.9 Applying the cognitive-behavioural model of health anxiety to bone density screening

In order to examine whether the CB model could help to predict reactions to health screening, research was carried out into the psychological effects of bone density screening (which can indicate one’s risk of developing osteoporosis). This is the first time that the CB model of health anxiety has been used to derive predictors of reactions to health threats in the general population. Women who had volunteered for bone density screening were asked to complete questionnaires two weeks before the scan, immediately before and immediately after the scan, a week later and 3 months later. (A sub-group were also sent longer-term follow-up questionnaires at about 14 months after the scan). This prospective design was used to test the hypothesis that certain pre-existing beliefs and behavioural tendencies will be predictive of reactions to health screening.

One of the main aims of the study was to investigate the usefulness of the CB model in predicting

distress after health screening. Another aim was to provide a systematic, longitudinal description of reactions to bone densitometry, since very little is known about the psychological impact of this type of screening. It was hoped that many of the problems identified in previous research into risk-factor screening could be avoided. For example, the prospective design allows post-test group differences to be interpreted in the light of any pre-existing differences. Psychological outcome measures were designed to be sensitive to the kinds of specific psychological reactions which were expected to occur, (such as increased preoccupation with thoughts of osteoporosis and general mood effects) rather than measures of psychiatric diagnoses or “caseness”. The present study also assesses interpretations of the result and changes in various beliefs about osteoporosis, in order to examine reactions to risk-factor screening in more detail than most previous studies. The assessment of anxiety and beliefs at five different points in time (or six for some women) was designed to further understanding of the time course of reactions to a health information and to allow an examination of the relationship between early and later reactions.

The present study included a comparison with a control group who undergo a non-osteoporosis-related visit to a health professional, in order to control for the effects of medical consultation. The study also investigates the baseline psychological characteristics of volunteers and compares the baseline psychological measures of women who did and did not return their follow-up questionnaires. These comparisons help to indicate the extent to which the results may generalize to the whole of the population screened and the general population.

1.10 Summary

The cognitive-behavioural model of health anxiety was originally developed in order to help the understanding and treatment of hypochondriasis, but proposes that processes involved in the health anxiety of hypochondriacal patients are similar to the processes in less severe health anxiety. The research described in the following chapters investigates whether the cognitive-behavioural model can help predict reactions to a health threat in a non-clinical population - in individuals undergoing health screening. This work brings a much-needed theoretical model to the field of health screening research. The research also aims to investigate the process of reactions to health screening in more detail than existing research by investigating not only at distress but also interpretations of the result and changes in illness beliefs.

1.1.1 Overview of the thesis

- Chapter 2:** Before the health screening study began, a questionnaire was developed to assess symptoms of health anxiety. Research into the reliability and validity of this questionnaire are described. An earlier version of this questionnaire had been shown to discriminate between hypochondriacal patients, panic disorder patients and non-clinical controls, but had not been validated as a measure of health anxiety in the general population. The questionnaire was extended and refined so that it would be appropriate for use in both clinical and non-clinical populations. This questionnaire was then used in the bone density screening study.
- Chapter 3:** The method of the study into the psychological effects of bone density screening is described.
- Chapter 4:** The characteristics of the sample undergoing bone density screening for the first and second time are compared, and both groups are compared to women attending a GP clinic.
- Chapter 5:** Changes in levels of distress and illness beliefs are examined for women undergoing first and second scans. These changes are compared to changes shown by women undergoing a different medical consultation (seeing a GP).
- Chapter 6:** Women's interpretations of their bone scan are examined.
- Chapter 7:** Women with high and low bone density results (on their first scan) are compared with regard to feelings and beliefs, as are women with decreases or increases on their second scan.
- Chapter 8:** The reactions of women with high and low pre-scan scores on the Health Anxiety Questionnaire (which assesses symptoms of health anxiety over the past 6 months) are compared. Results from the 14-month follow-up are presented.
- Chapter 9:** Multiple regression analysis is used to examine predictors of anxiety, risk perceptions, reassurance/information-seeking and minimization of the seriousness of low bone density. Some of these analyses examine pre-scan predictors of distress 3 months after the scan.
- Chapter 10:** Final discussion.

Chapter 2: Development of a questionnaire to measure symptoms of health anxiety

2.1 Introduction

Hypochondriasis and health anxiety are usually assessed by interviews such as the SCID (Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorder III-R; Spitzer and Williams, 1986) although other methods include physician ratings and self-report questionnaires. The most widely used questionnaire measures which have previously attempted to assess health anxiety are Kellner's Illness Attitude Scale (IAS), Pilowsky's Whiteley Index or Illness Behaviour Questionnaire and the Hypochondriasis scale of the MMPI. I will briefly discuss these measures and some problems associated with them, before describing the development and validation of a new measure of health anxiety.

2.1.1 Illness Attitude Scales (Kellner, 1983, 1986)

The Illness Attitude Scales purport to measure "psychopathology which tends to be associated with hypochondriasis and which can be responsible for abnormal illness behaviour". The questions were constructed from statements made by patients who were either diagnosed as having hypochondriacal neurosis or who showed abnormal illness behaviour. The IAS consist of 7 scales which each contain 3 questions. The questions are self-rated on 5-point scales from "no" to "most of the time". The scales are as follows: 1) Worry about illness; 2) Concerns about pain; 3) Health habits; 4) Hypochondriacal beliefs; 5) Thanatophobia; 6) Disease phobia; 7) Bodily preoccupations. (A later version of the IAS contains two more scales which have not yet been adequately validated). The scales show adequate test-retest reliabilities.

Some of the items on the IAS do not relate to hypochondriasis, such as the ones assessing smoking and healthy eating. Two of the scales, Hypochondriacal Beliefs and Disease Conviction, have been shown to yield characteristic responses in hypochondriacal patients. Kellner suggests that a score of 3 or 4 on any of the six items in the Hypochondriacal beliefs and Disease Conviction scales may identify people who are clinically hypochondriacal although such scales "should not be used by themselves for the purpose of diagnosis" (Kellner, 1987). Kellner, Abbott, Winslow and Pathak (1987) found that hypochondriacal patients scored more highly on the IAS than other non-psychotic psychiatric patients. However, the hypochondriacal subjects were also more anxious in general than the control group so the group difference on the IAS may reflect general anxiety levels rather than health-related anxiety. The strictest test of the scale would be to compare hypochondriacal subjects with anxious controls who are matched for level of general anxiety.

2.1.2 Whiteley Index of Hypochondriasis (Pilowsky, 1967) and the Illness Behaviour Questionnaire (Pilowsky and Spence, 1981)

The **Whiteley Index** was devised in order to clarify the symptom clusters which are seen in clinical hypochondriasis, by using factor analysis. One hundred people were asked to write down their definition of hypochondriasis and these definitions were then used to form statements. These statements (together with a few added because they were of theoretical interest) were given to 100 hypochondriacal patients and 100 non-hypochondriacal psychiatric patients. Factor analysis of their responses gave rise to three factors- “bodily preoccupation”, “disease phobia” and “conviction of the presence of disease with non-response to reassurance”. The scale has adequate test-retest reliability.

The Whiteley Index includes some items which do not seem to be directly measuring hypochondriasis and are likely to be answered positively by some people who do not have the condition, such as, “Is it easy for you to forget yourself and think about all sorts of other things?”. Another item which does not seem to be consistent with the core features of hypochondriasis is: “If you are ill and someone tells you that you are looking better, are you annoyed?”.

The Whiteley Index does not include items concerning attitudes towards death, which it has been suggested play an important role in the problems of some hypochondriacal patients (e.g. Kellner, 1986). The questionnaire also does not include any measures of avoidance behaviour, reassurance-seeking, checking of bodily symptoms, the use of distraction and other behaviours which are prominent in hypochondriasis and which the cognitive-behavioural model suggests can be maintaining factors. There is no evidence that the Whiteley Index can discriminate between hypochondriacal patients and psychiatric patients who are matched for levels of anxiety.

The **Illness Behaviour Questionnaire** is an expansion of the Whiteley Index. The IBQ is not solely concerned with hypochondriasis- it was introduced as a way of measuring “abnormal illness behaviour” or inappropriate ways of responding to the state of one’s health. The IBQ has 7 scales- 1) general hypochondriasis; 2) disease conviction; 3) psychological versus somatic perception of illness; 4) affective inhibition; 5) affective disturbance; 6) denial; 7) irritability. The scales have been criticised for containing items which do not all measure the same aspect of illness behaviour (e.g. Kellner, 1987). (For example, the Disease Conviction scale contains an item about sleep disturbance, two items about the perception of somatic symptoms and only two which deal directly with disease conviction). The IBQ was developed with pain clinic patients and there have been no studies examining the extent to which the IBQ or scales from it can identify hypochondriacal patients.

2.1.3 Hypochondriasis scale of the Minnesota Multiphasic Personality Inventory (MMPI) (McKinley and Hathaway, 1940)

The original Hypochondriasis scale of the MMPI contains a number of items that are unrelated to hypochondriasis or somatization. A later version of the scale contains items related only to somatic complaints (Welsh, 1952) and does not mention hypochondriacal fears or beliefs. The MMPI scale therefore seems to be a scale of somatization rather than of hypochondriasis (Kellner, 1987).

2.2 The development of a new measure of health anxiety

The above discussion has highlighted that there are items on existing measures of health anxiety which assess aspects of abnormal illness behaviour that are not unique to hypochondriacal patients. Thus a new questionnaire, the Health Anxiety Questionnaire (HAQ) was devised as a measure of health anxiety and hypochondriasis.

The original HAQ was devised by Warwick and Salkovskis (1989). They produced a questionnaire which had 27 items assessing symptoms of hypochondriasis together with two further scales (one of which assessed reassurance-seeking about one's health and the other assessed avoidance of illness-related situations and stimuli). This original questionnaire successfully discriminated between hypochondriacal patients, patients with panic disorder and non-clinical controls (Salkovskis, Warwick and Rimes, in preparation).

The author and Paul Salkovskis then revised the original questionnaire. One of the reasons for doing this was to ensure that there were items which would not only discriminate between hypochondriacals and non-hypochondriacals but would also have neither a ceiling or floor effect in non-clinical populations. This is important since we wished to use the questionnaire in settings such as population health screening. Items which did not discriminate well between hypochondriasis and panic patients in the previous comparisons were also removed, as were items which had response options that were not all assessing exactly the same dimension. Items concerning missing concepts were added, resulting in a longer questionnaire of 47 questions for the main section of the questionnaire. There was also a new scale assessing beliefs about what it would be like to have a serious illness (the "Cost" scale), since the cognitive model of health anxiety suggests that these beliefs can play an important role in hypochondriasis. The avoidance and reassurance scale from the original questionnaire were not altered. The new questionnaire was piloted in a non-clinical population and items which had a ceiling or floor effect were altered as necessary.

Thus, in addition to the 47 questions in the main section of the HAQ, there are 17 questions

assessing beliefs about what it would be like to have a serious illness (the “Cost” section), 10 items assessing avoidance of illness-related situations and 9 items assessing reassurance-seeking. The main section of the questionnaire is itself made up of subscales assessing different aspects of health anxiety, which are described in section 2.3.5. See Appendix C for a copy of the HAQ.

2.3 Investigation of the validity and reliability of the HAQ

Overview: The reliability of the HAQ was investigated by examining the internal consistency of the scale and the test-retest reliability (over two weeks). The validity of the HAQ was investigated by comparing scores between 4 groups of subjects: hypochondriacal patients, GP attenders, non-clinical student controls and non-clinical / non-student controls. It was predicted that the hypochondriacal subjects would show much higher scores than the subjects in the other three groups. However, it was also predicted that the pattern of responses in the hypochondriacal subjects would not be significantly different from that in the other groups- in other words, that the differences in responding would be quantitative rather than qualitative. This was investigated using hierarchical cluster analysis.

The concurrent validity of the HAQ was investigated by asking 54 non-clinical subjects to complete both the HAQ and the Whiteley Index, and then correlating their two scores. The correlations between scores on the HAQ and other measures of psychological symptoms were also examined, to ensure that the HAQ did not correlate too highly with measures of depression, anxiety and obsessive-compulsive disorder (since this would indicate that it might not be measuring a different psychological dimension from these existing scales). There was also an examination of whether scales identified *a priori* as containing conceptually similar items would also be identified using factor analysis.

Subjects

In order to investigate the reliability and validity of the revised HAQ, the questionnaire was given to 11 hypochondriacal patients, 106 women attending a GP clinic, 86 students and 69 non-student control subjects. The patients had been previously diagnosed as having hypochondriasis by the SCID. They were only included if their hypochondriacal concerns were not secondary to any other psychiatric condition. They were given the HAQ before they had started receiving cognitive-behavioural treatment as part of a research trial.

The majority of the students were from Oxford University. In order to recruit non-students, acquaintances of the experimenter distributed questionnaires at their places of work. The method of

recruitment for the sample of women attending a GP clinic is described in the next chapter.

A one-way ANOVA, followed by a Tukey-B post-hoc test indicated that the student group were significantly younger than the other groups but there were no other group differences in age (see table 2.1).

Table 2.1 Ages of the subjects: means and standard deviations.

	Hypochondriacal patients	Non-clinical group (not students)	Non-clinical group- Students	Women attending GP clinic	
Age	37.9 [11.4]	36.4 [11.4]	22.9 [5.4]	38.4 [15.9]	$F_{(3,271)}=29.0^{***}$

2.3.1 Reliability of the HAQ

Test-retest reliability

Test-retest reliability was examined by giving the HAQ to 23 non-clinical subjects twice, two weeks apart. Pearson product-moment correlation coefficients were 0.76 for the main section of the HAQ, 0.73 for the Cost section, 0.76 for the Avoidance subscale and 0.64 for the Reassurance subscale.

Internal consistency

The internal consistency of the HAQ was assessed using the Spearman-Brown formula for split-half reliability and Cronbach's alpha. For the main section of the questionnaire, the split-half reliability of the HAQ was $r_{(263)} = 0.93$ and Cronbach's alpha was $\alpha_{(263)} = 0.95$. Both measures indicate that there is a satisfactory degree of internal consistency in the HAQ.

The internal consistency of the Cost, Reassurance and Avoidance scales are not investigated since these scales are simply assessing a range of specific beliefs or behaviours which are relevant to hypochondriasis, not all of which are expected to be present in each hypochondriacal patient - therefore the internal consistency will not necessarily to be very high. For example, in the "Cost" scale, it was predicted that hypochondriacal patients would show maladaptive views about what it would be like to have a serious illness but the negative beliefs may be reflected by a high scores on only a small number of items.

2.3.2 Validity of the HAQ

Concurrent validity

The concurrent validity of the test was assessed by asking 54 non-clinical subjects to complete both the Whiteley Index (see Appendix D) and the HAQ and comparing scores on each. The Pearson product-

moment correlation between the questionnaires was $r_{(54)}=0.78$.

Criterion validity

One of the purposes of the HAQ is to identify people who are suffering from severe health anxiety, so the criterion-related validity was assessed by comparing the scores of people who have been found to fulfil DSM-III-R criteria for hypochondriasis (American Psychiatric Association, 1987) with the scores of non-clinical control subjects. One-way ANOVAs were used to compare the scores on the HAQ of 11 hypochondriacal subjects, 69 non-student non-clinical controls, 86 students and 106 women attending a GP clinic. Scores on other psychological measures are also given in the table below, where available (not all the subjects were asked to complete each of the extra questionnaires). (These other psychological measures are the Beck Depression Inventory (BDI) by Beck, Ward, Mendelson, Mock and Erbaugh, 1961; the Beck Anxiety Inventory, Beck, Epstein, Brown and Steer, 1988; the State- Trait Anxiety Inventory (STAI) by Spielberger, 1983; the Padua Inventory- a measure of obsessions and compulsions by Sanavio, 1988; and the Anxiety Sensitivity Inventory (ASI) by Reiss, Peterson, Gursky and McNally, 1986. See Appendices D-H).

Table 2.2 Mean and standard deviations of the scores of hypochondriacal patients and control groups for the HAQ, other measures of psychopathology and age.

	Hypochondriacal patients		Non-clinical control group (not students)		Student control group		Women attending GP clinic		
HAQ	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Main section	86.1	[17.7]	28.2 ^a	[12.2]	31.9 ^{ab}	[12.3]	35.9 ^b	[12.7]	$F_{(3,268)}=68.2^{***}$
Cost section	20.4	[6.9]	12.2 ^a	[6.0]	14.5 ^a	[5.4]	14.1 ^a	[6.3]	$F_{(3,271)}=6.3^{***}$
Avoidance	18.6	[12.2]	10.7 ^a	[10.2]	10.8 ^a	[8.5]	10.0 ^a	[8.3]	$F_{(3,269)}=3.0^*$
Reassurance	22.5 ^a	[6.7]	13.1 ^b	[6.9]	14.2 ^b	[8.1]	18.9 ^a	[7.8]	$F_{(3,267)}=12.8^{***}$
BDI	20.9	[9.5]	6.4 ^a	[5.4]	7.9 ^{ab}	[6.7]	9.9 ^b	[9.1]	$F_{(2,223)}=10.4^{***}$
BAI	22.1	[6.2]	7.1 ^a	[7.2]	9.1 ^a	[6.9]	-----		$F_{(2,116)}=16.4^{***}$
STAI-state	48.9	[12.3]	34.9 ^a	[11.1]	35.3 ^a	[9.3]	-----		$F_{(2,119)}=7.9^{***}$
STAI-trait	53.5	[11.2]	40.6 ^a	[10.6]	41.1 ^a	[9.7]	43.7 ^a	[12.0]	$F_{(3,228)}=4.8^{**}$
Padua	-----		22.8	[20.2]	34.4	[23.3]	-----		$F_{(1,53)}=3.3, p=0.07$
ASI	-----		14.5	[7.8]	16.1	[1.6]	-----		$F_{(1,58)}=0.6$

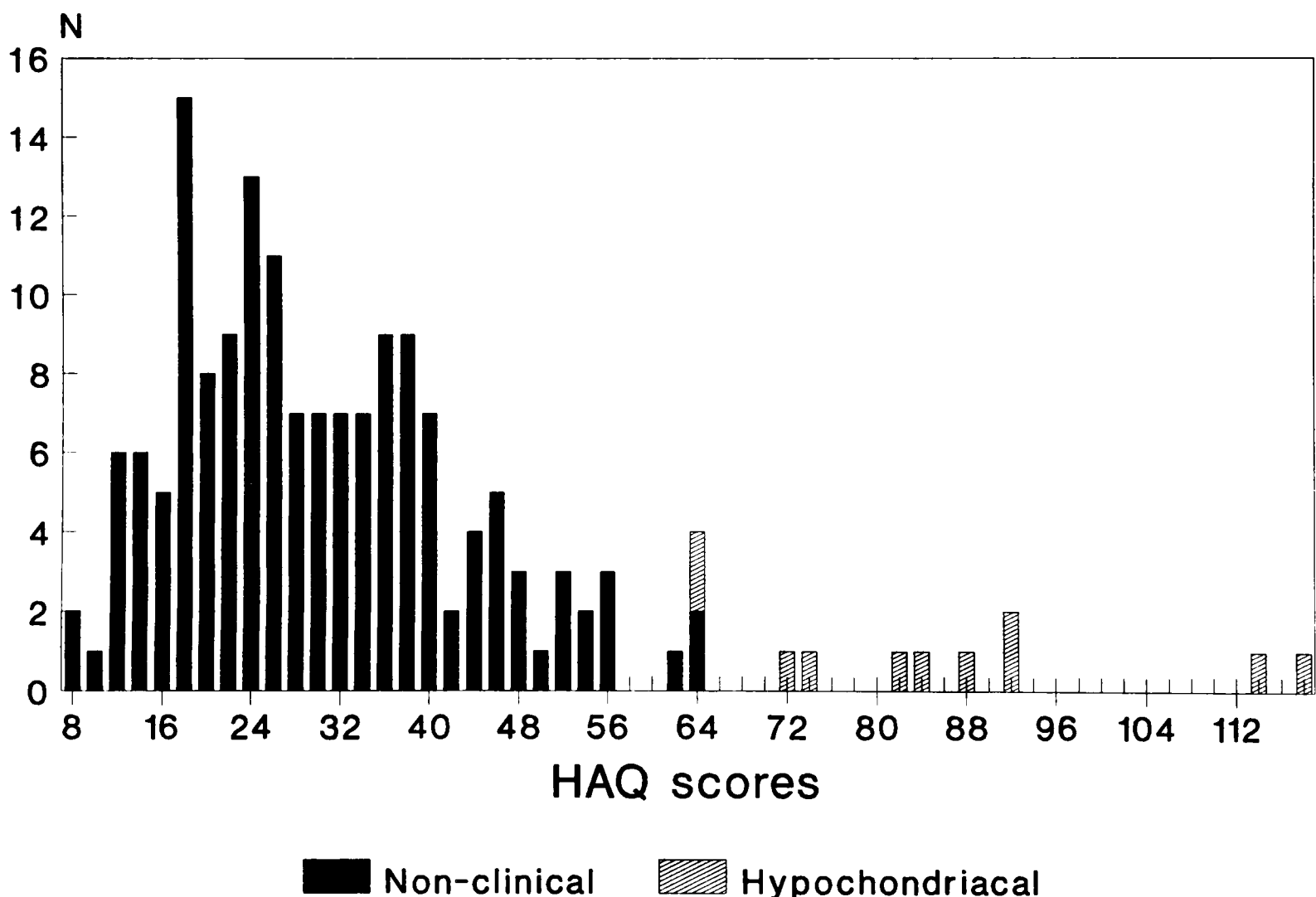
p<0.005 * p<0.0005

^a values on the same line which share a subscript are not significantly different from each other

Multiple comparisons (Tukey b-tests) indicated that hypochondriacal patients had significantly higher scores than the other three groups on the main scale of the HAQ, the Cost scale and the Avoidance scale; they did not differ significantly from the GP attenders on the Reassurance scale but had higher scores than the subjects in other two groups. The hypochondriacal patients also had significantly higher scores on the BDI and the STAI-trait than the other three groups and higher scores on the BAI and STAI-state than the non-clinical control groups (the latter two questionnaires weren't given to the GP attenders).

The extent to which the HAQ can distinguish between hypochondriacal patients and non-clinical control subjects can be readily seen when the scores of the two groups are plotted as a frequency distribution (see figure 2.1). (The scores of the students and non-student control subjects have been combined because there was no significant difference between their HAQ scores). Only 2 subjects of the 156 in the non-clinical group had scores in the same range as the hypochondriacal patients.

Figure 2.1 Scores on the Health Anxiety Questionnaire of hypochondriacal subjects and non-clinical controls



K-means cluster analysis was used to examine whether the hypochondriacal patients and the non-clinical control subjects would form separate groups if the program was instructed to find two clusters of

responses to the individual items on the HAQ. It was found that all of the hypochondriacal subjects clustered together, but three subjects from the non-clinical group also joined them in the same cluster. These were the non-clinical subjects with the three highest HAQ scores.

Item analyses

Inspection of the ranges of scores for the items in the main and Cost sections of the HAQ when completed by all the subjects showed that only one item had a response option which was never chosen: the item assessing the frequency that one has images of oneself being ill had no endorsement for the most severe item.

The scores for each item on the HAQ were compared between the groups of hypochondriacal patients, non-clinical controls and the women attending a GP clinic. There were only two items of the main HAQ on which the hypochondriacals did not have significantly higher scores than both of the other groups of subjects. These were items number 28 (avoidance of situations in which illness is prominent) and 42 (attempting to get rid of unexplained bodily sensations).

For the Cost section of the HAQ, hypochondriacals had significantly more *negative* ratings than both of the other two groups on only 5 items- the effects that serious illness would have on one's quality of life (item 47), the chance that one would be cured if one had a serious illness (item 53), the extent to which a serious illness would ruin one's life (item 56), the extent to which one would be able to tolerate the loss of independence caused by serious illness (item 60) and the extent to which one would be able to cope if one had a serious illness (item 64).

Hierarchical cluster analysis

The cognitive-behavioural model suggests that hypochondriacal patients are at the extreme end of a continuum of health anxiety, showing only quantitative differences in terms of health anxiety with the rest of the population. Thus it was predicted that hypochondriacal patients would not show a qualitatively different pattern of scores on the items of the HAQ than other subjects. Hierarchical cluster analyses was performed in order to examine this hypothesis, using the City Block Measure on SPSS (Statistical Package for the Social Sciences). Dendograms were produced using various different distance measures- nearest neighbour, furthest neighbour, centroid and median. Inspection of each of the dendograms confirmed that the hypochondriacal patients did not tend to cluster together but were interspersed between the other subjects, consistent with the notion of quantitative but not qualitative differences.

Relationship between the HAQ and other measures of psychological symptoms

It has previously been found that measures of health anxiety tend to be significantly correlated with measures of other types of psychopathology such as depression and anxiety (Kellner, Hernandez and Pathak, 1992). Thus it was predicted that scores on the HAQ would correlate significantly with scores on measures of depression (the Beck Depression Inventory- Appendix E), clinical anxiety (the Beck Anxiety Inventory - Appendix F), state and trait anxiety (the Spielberger State-Trait Anxiety Inventory - Appendix G) and obsessive-compulsive disorder (the Padua Inventory- see Appendix H). This prediction was confirmed (see table 2.3). However, since the correlations were only moderate, it does not seem that the HAQ is assessing exactly the same dimension as any of these measures.

It was also predicted that scores on the HAQ would correlate significantly with scores on the Anxiety Sensitivity Index (Reiss, Peterson, Gursky and McNally, 1986; see Appendix I). This scale assesses negative reactions to the experience of anxiety. Since some hypochondriacal patients misinterpret symptoms of anxiety (although the tendency is thought to be particularly characteristic of panic disorder) and because Reiss et al. (1986) suggest that “anxiety-sensitivity” is causally related to the development of anxiety disorders, the relationship between HAQ and ASI scores were examined. (Unfortunately it was not possible to give the ASI to the hypochondriacal patients or the GP attenders, so the relationship can only be investigated in the non-clinical groups). Pearson product-moment correlations indicate that there is indeed a relationship but it is only moderate, so the HAQ does not seem to be assessing the same dimension as the ASI.

Table 2.3 Correlations between scores on the HAQ and other measures of psychological symptoms.

	Health Anxiety Questionnaire			
	Main section	“Cost” section	Avoidance	Reassurance
Beck Depression Inventory	$r_{(225)} = 0.42^{***}$	$r_{(228)} = 0.33^{***}$	$r_{(227)} = 0.16^*$	$r_{(226)} = 0.18^*$
Beck Anxiety Inventory	$r_{(121)} = 0.61^{***}$	$r_{(121)} = 0.30^{**}$	$r_{(122)} = 0.12$	$r_{(122)} = 0.30^{**}$
Spielberger- state anxiety	$r_{(124)} = 0.55^{***}$	$r_{(124)} = 0.34^{***}$	$r_{(124)} = 0.34^{***}$	$r_{(124)} = 0.20^*$
Spielberger- trait anxiety	$r_{(229)} = 0.43^{***}$	$r_{(232)} = 0.43^{***}$	$r_{(229)} = 0.25^{***}$	$r_{(228)} = 0.14^*$
Anxiety Sensitivity Index	$r_{(59)} = 0.39^{**}$	$r_{(59)} = 0.27^*$	$r_{(60)} = -0.09$	$r_{(60)} = 0.46^{***}$
Padua Inventory -total score	$r_{(54)} = 0.47^{***}$	$r_{(54)} = 0.22$	$r_{(55)} = 0.06$	$r_{(55)} = 0.23$

* p<0.05, ** p<0.005, ***p<0.0005

The possibility that the HAQ is only tapping general anxiety rather than health anxiety was further explored by comparing the HAQ scores of hypochondriacal patients with those of a sub-sample of non-clinical subjects who have been matched for state anxiety or trait anxiety (see table 2.4). The hypochondriacal patients still had significantly higher scores on the main HAQ score and the Reassurance scale when compared to anxiety-matched controls, although they were not significantly higher for the Cost section of the HAQ. Scores on the Avoidance scale were higher in the hypochondriacals compared to controls matched for state anxiety but not when they were compared to people matched for trait anxiety.

Table 2.4 Comparison of HAQ scores between hypochondriacal patients and anxiety-matched controls

	Subjects matched on measures of <u>state</u> anxiety				
	Hypochondriacal (n=10)		Non-clinical (n=10)		
	Mean	SD	Mean	SD	
STAI-state	48.9	[12.3]	48.3	[11.6]	$t_{(18)}=0.1$
HAQ-main section	85.5	[18.5]	36.4	[10.0]	$t_{(18)}=7.4^{***}$
Cost section	19.2	[6.0]	15.8	[6.0]	$t_{(18)}=1.3$
Avoidance	19.5	[12.5]	9.1	[6.9]	$t_{(18)}=2.3^*$
Reassurance	22.2	[7.0]	14.9	[6.8]	$t_{(18)}=2.4^*$
	Subjects matched on measures of <u>trait</u> anxiety				
	Hypochondriacal (n=11)		Non-clinical (n=11)		
	Mean	SD	Mean	SD	
STAI-trait	53.5	[11.2]	53.5	[11.1]	$t_{(20)}=0.0$
HAQ-main section	86.1	[17.7]	31.6	[18.9]	$t_{(20)}=7.0^{***}$
Cost section	20.4	[6.9]	17.8	[7.0]	$t_{(20)}=0.9$
Avoidance	18.6	[12.2]	15.6	[15.8]	$t_{(20)}=0.5$
Reassurance	22.5	[6.7]	11.5	[6.9]	$t_{(20)}=3.8^{**}$

2.3.3 Gender and age differences in scores on the HAQ

There was no significant correlation between the main HAQ score and age ($r_{(267)}=0.04$), although younger people tended to have higher scores on the “Cost” section of the HAQ ($r_{(270)}=-0.16$, $p<0.05$). There were no significant differences between men and women for the main HAQ score ($t_{(162)}=-0.3$) or the “cost” section ($t_{(162)}=1.1$) ; the GP attenders were not included in these analyses since they were all female.

2.3.4 Relationship between the four main scales of the HAQ

In order to examine the relationship between the four main scales of the HAQ, correlations were calculated (see table 2.5). As predicted, these indicate a significant association between each of the scales. Stepwise multiple regression analysis was then used to examine the relationship between the Cost, Reassurance and Avoidance scales and the main section of the HAQ (see table 2.6). (For details of the methods used in

stepwise multiple regression in this thesis, see chapter 9, page 211). Each of the three scales entered significantly, indicating that each contributed unique variance in the prediction of the main HAQ scores.

Table 2.5 Pearson correlations between different parts of the Health Anxiety Questionnaire

HAQ	Main section	Cost section	Avoidance	Reassurance
Main section	-----	$r_{(274)}=0.41^{***}$	$r_{(271)}=0.18^{**}$	$r_{(270)}= 0.45^{***}$
Cost section	-----	-----	$r_{(274)}=0.26^{***}$	$r_{(273)}= 0.17^*$
Avoidance	-----	-----	-----	$r_{(274)}= -0.13^*$
Reassurance	-----	-----	-----	-----

Table 2.6 Results of multiple regression analysis examining the relative contribution of scores on the Cost, Avoidance and Reassurance subscales of the HAQ in the prediction of scores for the main section.

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F value
Reassurance scale	0.421	0.205	0.205	0.202	$F_{(1,267)}=68.7^{****}$
Cost scale	0.311	0.328	0.123	0.323	$F_{(2,266)}= 64.8^{****}$
Avoidance scale	0.155	0.349	0.021	0.342	$F_{(3,265)}=47.5^{****}$

2.3.5 Subscales of the main scales of the HAQ

The HAQ contains several subscales of factors which were composed of items which were felt to be conceptually similar to each other and theoretically relevant to hypochondriasis and health anxiety. These scales were: Disease conviction; Perceived vulnerability to illness; Fear and worry about illness; Preoccupation with health worries; Psychological reactions to bodily sensations; Deliberate actions on noticing bodily sensations; Attitude of self and others towards one’s health worries; Focusing on the body and Thanatophobia. The Cronbach’s alpha for these scales ranges from 0.70 to 0.82, indicating adequate internal consistency.

In order to compare these theoretically derived subscales with factors identified by factor analysis, principal components analysis was performed, followed by rotation of factors using the Varimax method. (Oblique rotation had been attempted first, under the hypothesis that the factors may be correlated, but the rotation failed to converge at 25 iterations). Only the non-hypochondriacal subjects (n=249) were used for the factor analysis: the factor analytic structure of the HAQ when given to hypochondriacal subjects will be examined at a later point in time, when the sample size is larger.

Results: Eleven factors were considered for interpretation because they had eigen values larger than one and two or more loadings greater than 0.4. Seven of these factors were easy to interpret and were broadly similar to those that had been identified theoretically; these factors were therefore chosen for extraction (following Hammond's (1995) recommendations regarding criteria for the number of factors to extract). Items with factor loadings larger than 0.4 on these seven factors are shown in the table below. The seven factors are 1) Disease conviction and perceived vulnerability to illness; 2) Reactions to bodily sensations; 3) Preoccupation with health worries; 4) Death anxiety; 5) Perceived vulnerability to illness and fear of developing an illness; 6) Opinion of self and others regarding one's health anxiety; 7) Bodily preoccupation. These seven factors accounted for 47.5% of the variance and fifteen items did not load strongly onto any one factor.

Table 2.7 Factor loadings of items from the HAQ

Factor 1. Disease conviction and perceived vulnerability	
Item from the HAQ (item number shown in brackets)	Factor loading
The idea that I have a serious illness is realistic (12)	0.77
The idea that I have a serious illness always seems sensible (25)	0.76
It is very likely that I have an undiagnosed serious illness (38)	0.60
I usually think that I am seriously ill (35)	0.59
I usually feel extremely vulnerable to serious illness (33)	0.53
I usually feel at high risk for developing a serious illness(29)	0.49
It usually feels likely that I will develop a serious illness in the near future (10)	0.42

Factor 2: Reactions to bodily sensations	
Item from the HAQ (item number shown in brackets)	Factor loading
If I notice an unexplained bodily sensation or change...I always try to find out the cause (19)	0.79
If I notice.... I constantly focus on it (14)	0.75
If I have.... I must know what it means (27)	0.72
If I notice I constantly check on it (11)	0.70
When I have an unexplained bodily sensation I always worry about it (4)	0.50
If I notice... I always try to get rid of it (42)	0.50
When I have... I always think that it is a sign of illness (7)	0.41

Factor 3: Preoccupation with health worries	
Item from the HAQ (item number shown in brackets)	Factor loading
I am unable to do anything because of my health worries (20)	0.79
I am so worried about my health that I can think of nothing else (23)	0.71
Nothing can take my mind off thoughts about my health (16)	0.60
I spend most of my time worrying about my health (1)	0.44

Factor 4: Death anxiety	
Item from the HAQ (item number shown in brackets)	Factor loading
I worry about dying most of the time (6)	0.74
I constantly believe that I am going to die soon (21)	0.68
I constantly have images of myself dying or dead (30)	0.68
It usually feels as though I am going to die soon (41)	0.54
(I always avoid situations which trigger thoughts of death or dying	0.38)

Factor 5: Fear of developing an illness and perceived vulnerability	
Item from the HAQ (item number shown in brackets)	Factor loading
I am afraid of developing a serious illness all the time (37)	0.67
I usually feel at high risk for developing a serious illness (29)	0.54
I constantly think about what it would be like if I were seriously ill (32)	0.49
I usually feel extremely vulnerable to serious illness (33)	0.49
I constantly have images of myself being ill(9)	0.49
It usually feels likely that I will develop a serious illness in the near future (10)	0.47

Factor 6: Opinion of self and others regarding one’s health anxiety	
Item from the HAQ (item number shown in brackets)	Factor loading
I think I am a hypochondriac (47)	0.76
My GP would say I am a hypochondriac (46)	0.74
My friends/family would say I am a hypochondriac (45)	0.69

Factor 7: Bodily preoccupation	
Item from the HAQ (item number shown in brackets)	Factor loading
I am constantly aware of bodily sensations or changes (3)	0.74
I examine my body constantly (15)	0.62
I am aware of aches/pains in my body all the time (2).	0.49

2.4 Summary and Discussion

Validity and reliability of the HAQ

Patients who fulfilled DSM-IIIR diagnostic criteria for hypochondriasis had significantly higher scores on all of the scales of the HAQ than non-clinical controls. A cluster analysis which was performed using the items in the main section of the HAQ indicated that the hypochondriacal patients formed a separate cluster from the non-clinical subjects except for the 3 non-clinical control subjects with the highest HAQ scores, who joined the same cluster as the hypochondriacal patients. It is not necessarily surprising or problematic that a few of the control subjects had HAQ scores similar to hypochondriacal patients, since they were not screened for psychiatric diagnoses - it is possible that some of this group may fulfil the diagnostic criterion for hypochondriasis. It should not necessarily be assumed that the HAQ will be as good at identifying people

with hypochondriasis if the sample were drawn from a different source - the hypochondriacal patients who had come for psychological treatment may differ from those with severe health anxiety and hypochondriasis who are not referred or who do not seek psychological help.

As predicted, scores on the HAQ correlated significantly with measures of symptoms of depression, trait anxiety, state anxiety and obsessionality to a moderate degree. Since the highest of these correlations is 0.61, the HAQ does seem to be measuring something different from these other measures. Furthermore, the higher scores on the main section of the HAQ in the hypochondriacal patients are not simply a reflection of their higher trait and state-anxiety levels- when they were compared with control subjects matched for anxiety levels, the hypochondriacal subjects still had significantly higher HAQ scores.

The HAQ showed adequate test-retest reliability and good internal consistency. Non-clinical control subjects showed an approximately normal distribution of scores on the HAQ and no items showed ceiling or floor effects. Hierarchical cluster analysis indicated that there did not seem to be a qualitatively different pattern of responses to the items of the HAQ in hypochondriacal patients, non-clinical controls and GP attenders. This is consistent with the notion that similar processes may be operating in the health anxiety seen in hypochondriacals, as in the health concern apparent in other populations.

Scores on the HAQ correlate quite highly with a questionnaire measure of health anxiety which has previously been widely used, the Whiteley Index, indicating good concurrent validity. The HAQ has advantages over existing measures such as the Whiteley Index and the IAS- for example, only including items which directly reflect health anxiety. The HAQ is also a more detailed assessment of the different types of symptoms of health anxiety than pre-existing measures.¹ Furthermore, in addition to the main scale, the HAQ contains scales assessing some of the beliefs and behaviours which the cognitive-behavioural model suggests may be important in health anxiety- beliefs about the “cost” of serious illness, reassurance-seeking and avoidance behaviours

It thus appears that the HAQ may be suitable for both identifying subjects with very severe health anxiety and for assessing individual differences in health anxiety in the normal population. The predictive validity of the HAQ will be investigated in chapters 8 and 9 where scores on the HAQ will be used to predict reactions to health screening. Previous research with a slightly different version indicated that the HAQ

1

Since the questionnaire may be too long for some situations, we have developed a shorter version (14 items in the main section, 3 items in the Cost section) which was not used in this thesis. For the hypochondriacal patients the correlations between the long and short versions of the HAQ are $r_{(11)}=0.93$ for the main section and 0.92 for the Cost section. For all the subjects in this chapter together, the correlations are $r_{(268)}=0.95$ for the main section and $r_{(276)}=0.88$ for the Cost section.

successfully discriminated between hypochondriacal patients, patients with panic disorder and non-clinical controls, but we are also currently recruiting anxious control subjects so that their scores on the revised HAQ can be compared with those of the hypochondriacal patients.

Are extremely negative beliefs about the effects of serious illness unique to hypochondriacals?

When compared to subjects matched for state anxiety, the hypochondriacals did not have significantly higher scores on the Cost section of the HAQ. Therefore there may be a “state” component to the Cost section of the HAQ, so that current distress will make people’s responses more negative. There was also a lack of significant difference between hypochondriacals and people matched for trait anxiety. It is thus possible that the negative beliefs about what it would be like to be seriously ill are not unique to hypochondriacal subjects. In theoretical terms this is not problematic since the cognitive-behavioural theory suggests that for people with disease conviction, extremely negative views of serious illness are not a necessary component. If a person believes that they are already seriously ill, they are likely to be very distressed, regardless of whether or not their beliefs about the consequences are more negative than the average person’s, because the average person views serious illness as a significant threat. According to the cognitive-behavioural model of health anxiety, extremely negative beliefs about illness will only be a necessary component in illness phobia. Thus the lack of difference between hypochondriacals and anxiety-matched controls may be partly the result of a predominance of disease conviction in these hypochondriacal patients (and perhaps a degree of illness phobia in the control group).

However, clinical evidence suggests that some patients showing disease conviction do also have especially negative views of serious illness. It is not clear whether these types of negative beliefs are also found in other anxious groups to the same extent, or whether the HAQ is not sensitive enough to detect differences between hypochondriacal patients and other anxious people. The HAQ is currently being given to patients with anxiety disorders so that further comparisons can be made.

Comparison between women attending a GP clinic and hypochondriacal patients

Compared to hypochondriacal patients, women attending a GP clinic had significantly lower scores on each scale of the HAQ except the Reassurance scale. The GP attenders had higher scores on the Reassurance scale than the subjects in the non-clinical control group, although did not have significantly different scores than the control group on the Main, Cost and Avoidance scales. This may indicate that women attending a GP clinic are characterised by an enduring tendency to seek reassurance about their health. However, the fairly

low test-retest reliabilities of the Reassurance scale ($r=0.64$) indicate that this scale may be more like a “state” rather than a “trait” measure and the higher scores of the GP sample may simply reflect their current illness concerns.

Factor analytic approach to sub-scales of the HAQ

A factor analysis produced factors which were largely similar to our conceptually-derived subscales. Both of these approaches had produced scales measuring preoccupation with health worries, death anxiety, focusing on the body and the attitudes of self and others regarding one’s health anxiety. There were two main differences between the two approaches. Firstly, the factor analytic approach produced one factor regarding reactions to bodily sensations while the theoretical approach had split this into two scales, one assessing psychological reactions to bodily sensations and another assessing deliberate responses to bodily sensations. (In retrospect, it would probably have made more sense to combine these two aspects into a single scale, since it would be expected that someone who takes deliberate action after noticing a bodily change is likely to have perceived some kind of threat). Secondly, the conceptual approach had separated disease conviction, perceived vulnerability and fear of developing an illness into separate scales; the factor analytic approach also produced separate factors regarding disease conviction and fear of developing an illness, but both of these scales also had moderately high loadings from items about perceived vulnerability. Previous research has produced similar results with regards to the distinction between disease conviction and illness phobia (e.g. Pilowsky, 1967) but questionnaires such as the IAS and the Whiteley have not included a scale assessing perceived vulnerability to developing an illness, so comparisons with regards to these beliefs cannot be made.

Not all of the items loaded strongly onto the seven main factors but this is not seen as problematic since some symptoms of health anxiety are assessed by one or two items. The primary purpose of the main section of the HAQ is to provide a single overall measure of health anxiety and the internal consistency for the scale as a whole is high.

For the research reported in chapter 9 of this thesis, the conceptually-derived subscales are used. The decision about whether to change the subscales in future research (i.e. so that they are closer to those factors identified by factor analysis) will be taken after further factor analyses have been performed using hypochondriacal patients and a new sample of non-clinical subjects.

Chapter 3: Investigation of the psychological effects of bone density screening:

Introduction and method

3.1 Introduction: Overview

Advances in medical technology are resulting in increasing numbers of different methods of health screening. Although health screening may have various benefits (for example, where disease is identified at an early stage where treatment is more likely to be successful), it can also have certain costs. For example, with regard to risk factor screening, it has been shown that a high risk result can result in severe distress (e.g. Palmer, Tucker, Warren and Adams, 1993). People who receive low risk results may also be more distressed afterwards (Stoate, 1989) or may erroneously assume that a low risk result endorses their current lifestyle (Tymstra and Bieleman, 1987). It is therefore important that the psychological effects of new health screening tests are evaluated.

In this thesis there will be an examination of the effects of bone densitometry, a technique which is gradually becoming available on the NHS as a means of screening for future risk of osteoporosis (and for diagnosing the condition). There has been very little research into the psychological and behavioural impact of this type of screening. A systematic, longitudinal examination of the impact of bone densitometry is presented in the following chapters.

Although it has been established that some people may experience adverse psychological effects as a result of health screening, little is known about whether it is possible to identify people who are particularly vulnerable to experiencing severe or persistent distress after screening. The research presented in this thesis investigates whether a general cognitive-behavioural model of health anxiety can be used to predict reactions to health screening. If this kind of prediction were possible, it would have important clinical implications: individuals likely to experience the most adverse reactions could be identified at an early stage and offered some kind of intervention in order to minimize their distress. Furthermore, if the types of pre-scan beliefs associated with post-scan distress were identified, it may be possible to address such beliefs in the information given to all women before they undergo screening. A successful treatment for severe health anxiety has been developed which is based on the cognitive-behavioural model, and it is possible that techniques used in this intervention could be adapted for use in the context of health screening. The cognitive-behavioural model also has the advantage that it is a general model which could potentially be adapted to different types of health screening, including new types of testing as they become available.

3.2 Bone density screening for osteoporosis

Osteoporosis is a condition characterised by low bone mass and increased risk of fracture. In people with osteoporosis, bone strength can become so low that even minor falls or events such as coughing can result in fracture. Osteoporotic fractures can lead to permanent disability, loss of independent living and depression (Cummings, Kelsey, Nevitt and O'Dowd, 1985). The prevention of osteoporosis is becoming a serious health concern because of its socioeconomic cost and rising incidence. The condition currently affects one in four women and one in twelve men over the age of sixty; it is more common in women than in men because of women's smaller skeletons, loss of oestrogen after the menopause and greater life expectancy. The total cost of osteoporotic fractures to the health services in the UK is an estimated £750 million per annum (Barlow, 1995).

Fracture risk approximately doubles for each standard deviation by which bone mineral density (BMD) is less than peak adult bone mass (Ross, Genant, Davis, Miller and Wesnich, 1993). Measurement of BMD using dual-energy x-ray absorptiometry (DXA) is currently the best method of assessing future fracture risk (Barlow, 1995). Results of bone density measurement can be used in decision-making about preventative measures such as hormone replacement therapy (HRT) and calcium supplements and the Department of Health recently recommended that bone scans should be available for people at high risk of developing osteoporosis. However, current purchasing for bone densitometry varies widely between different regions.

There is no widely agreed method for classifying and communicating the results of bone density screening. Fracture risk is inversely and proportionally related to bone density; the relationship is continuous - there does not appear to be a threshold below which the risk of fracture begins to rise. Misunderstandings of results seem to occur - Rubin and Cummings (1992) report that in a retrospective study of women who had undergone densitometry, only 85% of self-reported below-average results were confirmed by the densitometry results of the hospital. They do not report whether any women with above-average results mistakenly believed that they had low results. Bone density scans are difficult for even health professionals to interpret (Eastell and Peel, 1994). The degree of ambiguity involved makes it highly likely that the same numerical result will be interpreted (or misinterpreted) in a range of ways by people undergoing screening. The problems in the interpretation of bone scan results mean that the test is particularly interesting from the viewpoint of the cognitive-behavioural model of health anxiety. This model suggests that it is the individual's interpretation of ambiguous health-related information that will determine the level of anxiety experienced and that certain individuals are particularly prone to misinterpreting ambiguous health

information. The results of bone density screening appear to be particularly ambiguous and should therefore be liable to misinterpretation.

3.3 Psychological and behavioural effects of bone density screening

There has been little research into the psychological and behavioural effects of bone density screening. There is some evidence that women receiving low BMD results are more likely to begin or increase preventative measures such as HRT, calcium supplements, exercise and limiting activities to avoid falling than women with normal results (Rubin and Cummings, 1992; Ryan, Harrison, Blake and Fogelman, 1992). In terms of psychological responses, Rubin and Cummings (1992) found that women who reported a below-normal result were more likely to say that they have felt more worried about osteoporosis and more fearful of falling since the scan than women who had a normal result (55% vs 6%; 38% vs 2%). However, their study was retrospective, so estimates of change in anxiety after the scan may be affected by memory bias. They did not investigate any possible predictors of anxiety after bone density screening other than the result itself. They also do not report how the scan affected the women's perceptions of their risk of developing osteoporosis or other beliefs about osteoporosis.

3.4 Differences between bone density screening and other methods of screening for risk factors

As discussed in chapter 1, the cognitive-behavioural model of health anxiety proposes that anxiety about a particular condition will partly depend on factors such as how serious the condition is perceived to be and how likely it is that there will be possibilities for effective prevention and/or treatment. Thus it may be possible to anticipate some of the differences between reactions to different types of screening if one is aware how the sample screened perceives these factors. However, there have been no previous studies which have compared beliefs about these factors with regard to osteoporosis and the other diseases which are screened for, so anticipation of reactions to bone density screening on the basis of previous screening research is difficult. Anecdotal evidence suggests that most people do not judge osteoporosis to be as serious as diseases such as cancer and heart disease, since these conditions are much more likely to be judged as potentially fatal than osteoporosis. Thus it might be expected that reactions to a high risk result after bone density screening will be less severe, for the group as a whole, than reactions to a positive cervical smear test result, for example. (In addition, cervical screening is perceived by many as a means for detecting cancer rather than risk factors for its development (Wilkinson, Jones and McBride, 1990)). However, for some individuals who have seen relatives suffer greatly from osteoporosis, a positive test result may provoke very high levels

of anxiety, which highlights the importance of considering pre-existing individual differences in assumptions and beliefs about the condition.

3.5 Method

Overview : Women with an appointment to have a bone density scan were sent an invitation to take part in a study into their feelings about osteoporosis. If they replied, they were sent a questionnaire before the scan and given questionnaires on the day of the scan, a week later and three months later. A selected subgroup were sent a further follow-up questionnaire at approximately 14 months after the scan. A control group of GP attenders were given questionnaires assessing beliefs/feelings about osteoporosis.

Subjects : Subjects were female volunteers taking part in research into bone density measurement, aged 32-73 years (mean age 52). The majority were Caucasian and lived in or near to Oxford.

Return rates of the questionnaires: The pattern of questionnaire return rates for the 860 women invited to take part in the research are shown in figures 3.1a and 3.1b and tables 3.1, 3.2 and 3.3 below. The women who had an appointment in advance (n=703) and the women who came for the scan at short notice (n=157) are shown separately. The latter group could not be sent the initial questionnaire so were only asked whether they would like to complete the “on-the-day” and week follow-up questionnaires.

Figure 3.1a Pattern of questionnaire return rates for women who were contacted several weeks before the scan.

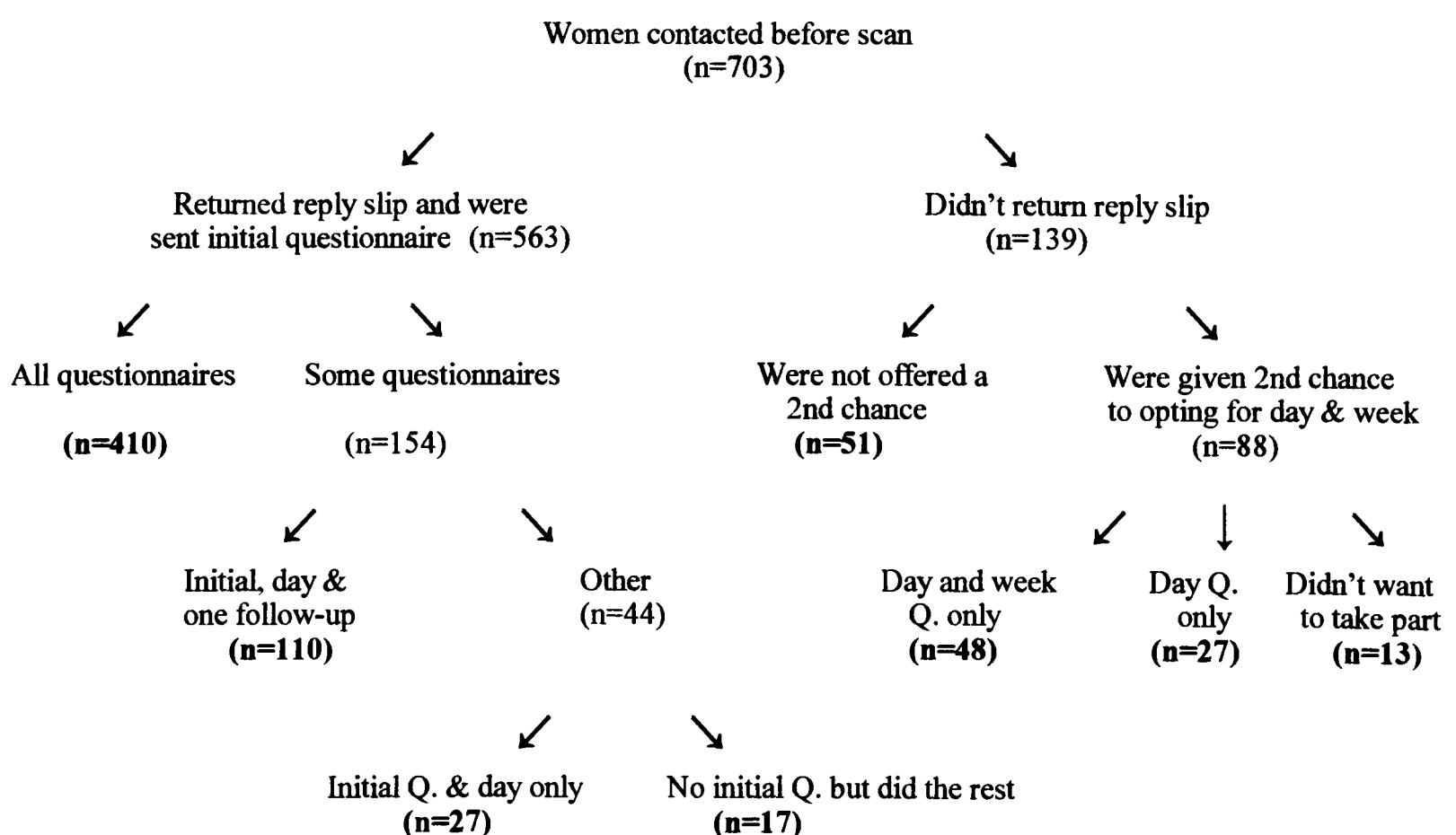


Figure 3.1b Pattern of response rates for women who came at short notice

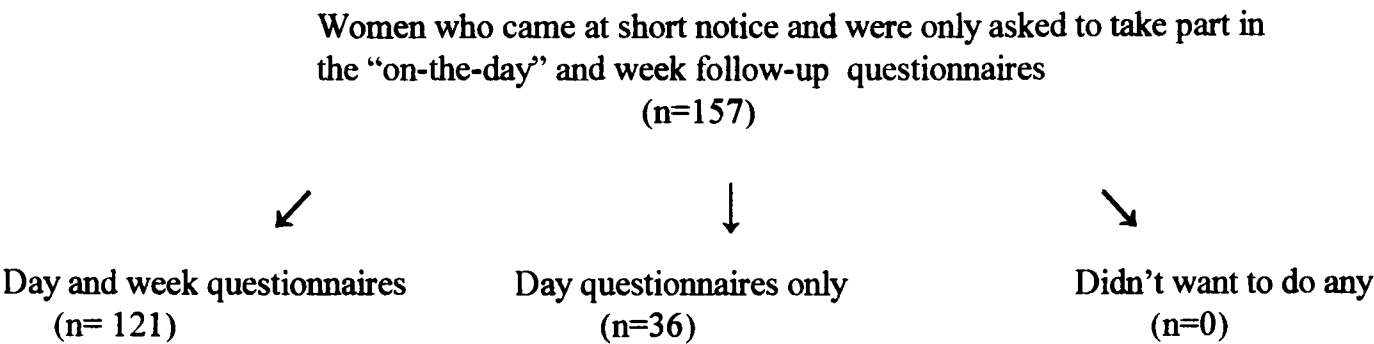


Table 3.1 Summary of compliance rates for the 703 women who were asked whether they would like to take part before the day of the scan.

Questionnaires completed	Number	%
At least one before the scan and one afterwards	639	98.0 ^a
Initial, day and at least one of the two follow-ups	520	74.0

^athe 51 women who weren't given a second chance to take part, weren't included in the calculation of this %

Table 3.2 Return rates of questionnaires, for the 703 women asked whether they would like to take part before the day of the scan.

Compliance	Number	%
<u>Returned initial reply slip</u>		
All questionnaires	410	58.3
No 3 month follow-up	58	8.3
No week follow-up	52	7.4
No week and no 3 month follow-up	27	3.8
Opted in, failed to complete initial Q. but completed subsequent ones	17	2.4
<u>Didn't initially opt in</u>		
Didn't initially opt in but then did the day and week questionnaires	48	6.8
Didn't initially opt in, did day Q. then failed to return week Q.	27	3.8
Didn't want to fill in any questionnaires	13	1.8
Didn't opt in and weren't given a second chance	51	7.3
Total	703	100.0

Table 3.3 Compliance rates of 157 women who came at short notice for a scan and so were only asked to take part in the “on-the-day” and week follow-up questionnaires

Questionnaires completed	N	%
Day and week	121	77.1
Day only	36	22.9
Didn't want to do any	0	0.0
Total	157	100.0

It should be noted that subjects occasionally missed out items within questionnaires, so the numbers of women responding to each individual question will vary slightly.

Questionnaire measures

Newly constructed questionnaires were piloted on volunteers in the Bone Densitometry Unit for a week, before the main data collection began, in order to evaluate any specific difficulties and to explore the possibility that there were ceiling effects. All questionnaires can be seen in Appendices J-N.

Core measures

A subset of 8 questions were included at each point in time; general anxiety, general sadness/low mood, anxiety about bone density, worry about developing osteoporosis, likelihood of developing osteoporosis in the near future, likelihood of developing osteoporosis at any point in the future, the seriousness of below-average bone density as a threat to health and need for reassurance about bone density. Visual analogue scales ranging from 0-100 were used; such scales have been shown to be a valid and reliable measure of subjective experience (McCormack, Horne and Sheather, 1988). They were anchored at each end, with “0” marked as (for example) “not at all [anxious]” or “no chance” and 100 marked as “extremely [anxious]” or “completely certain”. Every tenth point was marked with the corresponding number (10, 20, 30 etc).

Measures used in the initial questionnaire

The first section of the initial questionnaire contained questions about demographic details, reasons for having the scan, menopausal status, HRT usage, other health checks, current medical conditions, previous medical conditions relating to bone density, symptoms of low bone density, family history of osteoporosis, preventative behaviours relating to bone weakness, limiting of activities to avoid fracture and knowledge about osteoporosis. These were mainly open-ended questions.

The next section, called “Feelings about Osteoporosis” consisted of 17 visual-analogue scales and one multiple choice question. Eight of the questions were the “core” questions described above. There were additional risk questions (perceived vulnerability to osteoporosis and perceived risk compared to the “average” woman; the latter is multiple choice), “cost” questions (the effect that osteoporosis would have on her ability to enjoy life, how bad the consequences of osteoporosis would be for her), coping questions (anticipated coping ability if she found she had low bone density or osteoporosis; separate questions) and questions assessing worry about falls and fractures, expected ability to prevent osteoporosis if she had low bone density, and the likelihood that she will develop a serious illness other than osteoporosis, in the near future and at any point in the future.

Four multiple choice questions were included to assess interest in health issues in general and effort

to keep healthy. These questions were together called the “Health Interest Questionnaire” but the psychometric properties of this group of questions have not been investigated. The Health Anxiety Questionnaire (discussed in chapter 2) was used to assess symptoms of health anxiety and beliefs about serious illness. In addition, the Beck Depression Inventory (BDI; Beck Ward, Mendelson, Mock and Erbaugh, 1961) was used to provide a measure of depression and form Y-2 of the Spielberger State-Trait Anxiety Inventory (STAI; Spielberger, 1983) was used as a measure of trait anxiety.

Measures used on the day of the scan

The 8 core questions (described above) were given before immediately before the scan and after the results.

Measures used in the week follow-up questionnaire

In the week follow-up there was firstly a multiple choice question about how the subject would describe her result, from “much higher than average for my age” to “much lower than average for my age”. This was followed by 11 yes/no forced choice questions assessing whether the woman had sought further information or advice or had discussed her result with others. Preventative health behaviours regarding bone weakness were assessed with an open-ended question. Next there were multiple choice questions to assess frequency of thoughts about the result in day of and week after the scan, anxiety and concern about the result in the past week, the time taken to forget about the result, frequency of attempts to deliberately forget the result or distract herself from thinking about the result or reassure herself about the result, frequency of thoughts about whether she has had symptoms relating to bone density, frequency of thoughts about what it would be like to have osteoporosis and whether she is more or less worried about osteoporosis since the scan.

There were also open-ended questions about whether she has symptoms relating to bone weakness, what she thought her result means and whether there is anything she felt unclear about. Finally there was the “Feelings about Osteoporosis” group of questions that was given in the initial questionnaire.

Measures used in the three month follow-up questionnaire

The measures used in the three month follow-up were almost identical to those in the week follow-up. The only difference is the addition of the question “Do you have osteoporosis?” with five multiple choice answers ranging from “definitely” to “definitely not”.

Procedure

Bone density measurement research is currently being carried out at the Nuffield Orthopaedic Centre in Oxford. Women were originally recruited for bone density scans by advertisements in local newspapers, radio and a mention on a national television programme but the current main method of recruitment is word of mouth. Any woman over the age of 35 could have a bone scan. Women who phoned to volunteer were sent an information sheet about the scan (shown in Appendix O).

Women with appointments for bone density scans were also sent a letter and information sheet inviting them to participate in a questionnaire study looking at people's feelings about osteoporosis and bone density screening. They were given details of what this questionnaire study would involve. (The organisers at the bone density unit felt that an invitation regarding the questionnaire study should be sent separately so as not to overload the women with new information). If women wished to participate they could return a reply slip in the envelope provided. They would then be sent the first questionnaire and consent form, which they were asked to complete and bring along with them when they came for the scan.

Women were weighed and measured in height before their bone scan. When the current research began the women were given little (if any) explanation before their scan, although this changed so that now a receptionist gives a brief description of what to expect, in terms of the scan itself and the nature of the result. The experimenter would collect the initial questionnaire and ask the woman whether she would mind completing a brief questionnaire before her scan.

Dual-energy x-ray absorptiometry was used to assess bone mineral density in the lower back, which took about eight minutes. The woman simply had to lie on her back with her legs resting on a cushion. About five minutes after the scan the radiographer presented the woman with a piece of paper illustrating the result and usually gave a brief description of the graph. Most of the scans were carried out by one of a core of six radiographers from the main x-ray department.

The nature of the bone density scan result

A reproduction of a typical print-out is shown in figure 3.2 below. See Appendix P for a copy of the handout written by the project physician and given to all women to help them interpret their result.

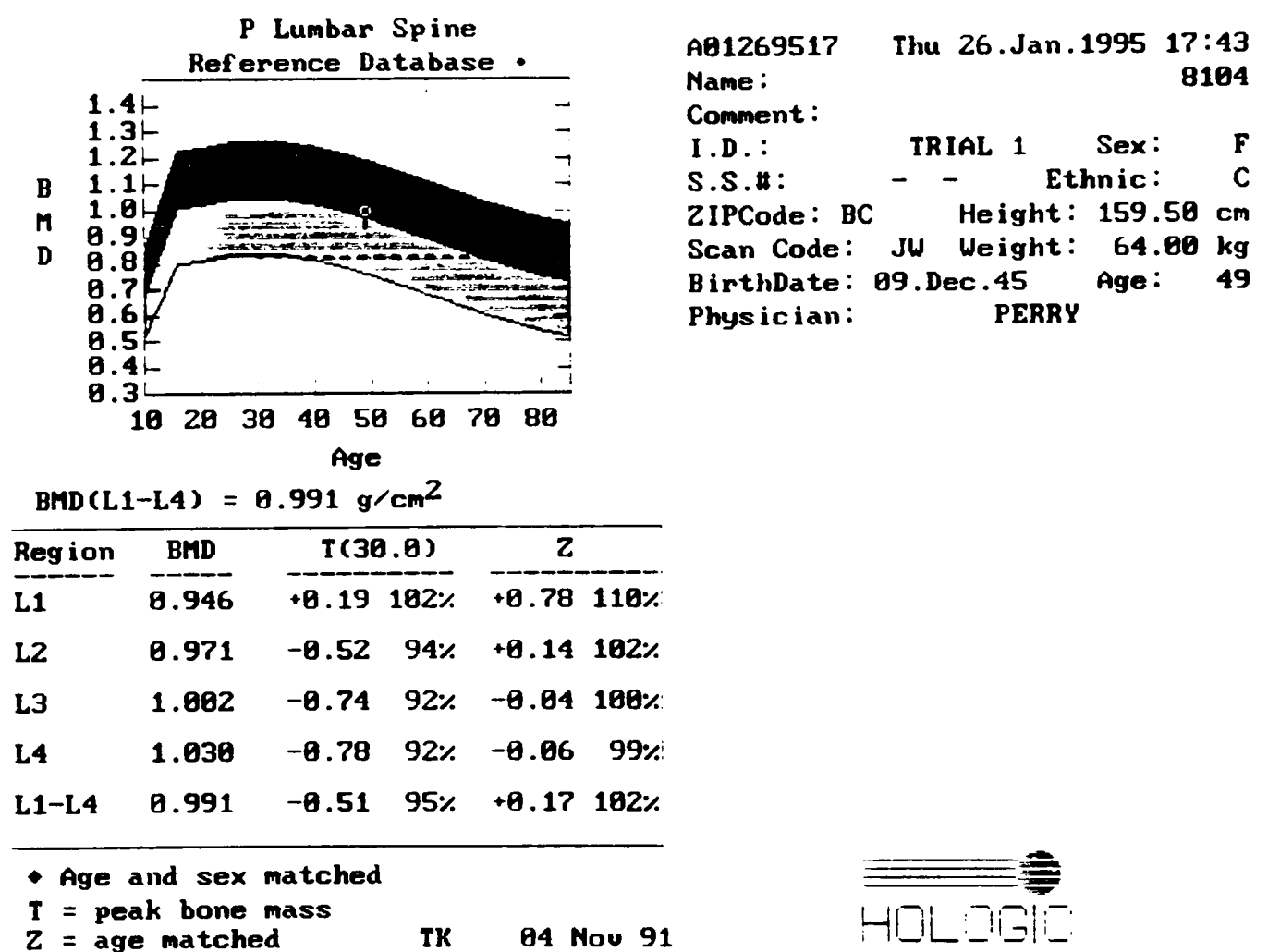
The result is represented both as a cross on a graph and by a set of numbers. The cross enables the volunteer to see where she lies relative to the reference range used by the bone densitometry machine. The x-axis represents age and the y-axis represents BMD. The reference range is illustrated in terms of the mean BMD together with lines indicating two standard deviations above and two standard deviations below the

mean. There is also a horizontal line on the graph (at around BMD=0.81) which is described in the hand-out as “the level below which women will probably have lost some bone and hence may suffer fractures in accidents more easily than women who have higher bone densities”.

The table underneath the graph - which is not usually mentioned by the radiographer when he or she presents the results to the volunteer - shows:

- the BMD measurements for each of the four lumbar vertebrae,
- the result for each vertebrae in relation to the mean value of a 30 year-old (since peak bone mass in the spine is probably reached at about 30 years of age).
- the result for each vertebrae in relation to expected results for a women of her age.

Figure 3.2 A copy of a print-out of a result from a bone density scan



It is important to note that the scanning machine has pre-set norms from a North American volunteer sample of 600 women in which the mean BMD is lower than the BMD in the thousands of women which constitute the Oxford sample. This difference means that more women than would be expected receive an above-average result at Oxford. This will obviously have implications for the level of distress shown by the group undergoing screening as a whole - one would expect it to be lower than if approximately equal number of women received above- or below-average results.

The project physician looks at all results at a later date and a letter is sent to each woman's GP. Occasionally GPs contact women about their result but usually it is up to the woman to contact her GP if she wishes to discuss anything.

After the woman had received her results, the experimenter would ask whether she would mind completing another brief questionnaire. The women were also given a further questionnaire which they were asked to complete a week after the scan and return in the envelope provided. Three months after the scan they were sent a further questionnaire and stamped addressed envelope.

It quickly became apparent that many women who had not returned the original reply slip were in fact happy to help with the questionnaire study, so everyone who did not return the reply slip was asked when they came for the scan whether they would like to fill out the "on the day" and "week after" questionnaires. These women were not sent the questionnaire at three months because there was little information from them before the scan.

Towards the end of the study the procedure had to be altered because there was a large increase in the number of scans performed each day. This meant that there was a very short waiting list for a while and the original system of reply slips would not work. Instead, women with appointments were sent the questionnaire, an information sheet and consent form and asked to fill in the questionnaire if they wished. Some women who did not complete the initial questionnaire offered to fill out the "on the day" and "week" questionnaires but otherwise such women were not usually asked to participate.

Unfortunately there was rarely enough time to pursue those who did not return their follow-up questionnaires so efforts were focused on those with the lowest results since they were relatively rare. The experimenter phoned 12 such women and sent another questionnaire if the original had been lost and they wished to participate. Each of the women said that they would return the questionnaire although only 10 questionnaires were actually received.

Women having their second bone density scan

For this psychological research, the procedure for women having second scans was identical to the procedure for women having their first scan. However, the methods for the recruitment of these women to attend a second scan were variable. At times, women with a low reading on the first scan were contacted and invited to return. At other times, it was only the women who actually contacted the unit themselves who came for second scans. Furthermore, sometimes only those with low readings or a family history of osteoporosis were encouraged to return while at other times all women were encouraged to attend for a second time.

Women having second scans were generally given a similar print-out of their results to those having first scans. (Occasionally they were given a graph showing both their original and new result). There was no standard way for the radiographer to discuss the second scans. All discussed it in terms of increase or decrease but some talked about absolute values while others looked at the percentage change. Some radiographers compared this change to the expected rate of change in that time period and many mentioned the fact that there was a certain amount of machine error which complicated interpretation of the result. When the present research began, women were being scanned six months after their first scan but this was found to be too short a time period and was increased to nine months and then a year.

Comments on the method

One of the main problems with the methodology of the present study concerns the variability in the procedure at the Bone Densitometry Unit, over which the investigator had no control. For example, the different recruitment methods for the follow-up scans will obviously cause difficulties in the interpretation of the results concerning women coming for a second scan. If these different methods had been known about from the beginning of the research, each woman coming for a second scan would have been questioned about exactly why she was coming for a second scan. A further problem is that different radiographers were observed to give different amounts and types of information. For this reason, where possible the radiographer was entered as a separate variable (as a number to ensure anonymity) so that volunteer anxiety associated with different radiographers could be assessed.

Although the return rate for the full set of questionnaires was about 60%, this was not surprising given that the initial questionnaire was very long- many women probably felt (quite rightly) that they had already been very helpful if they completed that one. The recruitment method which I was asked to use by the Bone Densitometry Unit may also have been a problem- a number of women forgot to return their reply slip so that they weren't sent an initial questionnaire even though they would have been happy to fill one in.

Ninety-eight percent of women filled in at least one questionnaire before the scan and one afterwards. This indicates that in clinical terms, it would definitely be feasible to give out questionnaires which could be used to predict which women are vulnerable to experiencing persistent distress after the scan. For clinical purposes the questionnaires could be brief, since only the items shown by this research to be the most useful would be included.

3.6 Method for the longer- term follow up study

Subjects

In order to investigate the longer-term effects of bone density screening, a follow-up questionnaire was sent to a selected sample of women. The mean length of time between the scan and this final questionnaire being returned was 14 months. Due to restricted time and resources only 100 women were sent the final questionnaire, with various subgroups being selected for this follow-up on the basis of their earlier questionnaire scores. There is insufficient space to present results from each of these different subgroups, so in this thesis only the comparison between the subgroup of women with the highest or lowest scores on the HAQ is discussed. For each group, women with similar types of results were selected - the groups were matched according to the area of the graph in which the results fell (using the areas shown in the graph in figure 3.2). Of the 43 women who were sent questionnaires for this part of the final follow-up, 41 (95.3%) returned them. A t-test indicated no significant difference in the length of time since the initial scan in the groups of women with high or low HAQ scores ($t_{(36)}=-0.6$, $p>0.1$).

Measures

Subjects were asked a subset of the questions given at the three month follow-up and two new questions: “How many scans have you had?” and “How depressed do you feel about osteoporosis” (using 0-100 visual-analogue scale ranging from “Not at all depressed” to “Extremely depressed”). This question was added because when subjects had been diagnosed as having osteoporosis they sometimes wrote (in earlier follow-ups) that they no longer felt anxious about it, although they did feel that osteoporosis was a considerable burden to them.

A copy of the final follow-up questionnaire can be seen in Appendix N.

Procedure

Subjects were sent the set of questions with a covering letter and stamped addressed envelope. They were asked to return the questionnaire blank if they did not wish to take part. Four women who did not return their questionnaires for some time were telephoned- all said that they would do the questionnaire but only two did actually return them.

3.7 Method for the Control group

Subjects: Subjects were women who had come to see a doctor or nurse at a health centre in Oxford. Of the women who were asked to if they would like to take part in the study, 165 (68.9%) agreed to take part. Of those who agreed to take part, 102 (61.8%) completed each of the three questionnaires and the rest failed to return the long questionnaire. Of the 102 women who had completed all questionnaires, 45 were of a similar age to women attending bone density scanning and these women were therefore used as the control group. (A further 4 women had been excluded because they had had a bone density scan).

Measures: The 8 core questions which were given throughout the osteoporosis study were also given here, before and after seeing the doctor (and in the longer questionnaire). The longer questionnaire was almost identical to the initial one given to women having bone scans although here they were asked whether they had ever heard of bone density screening.

Procedure

Women who had come to see a nurse or doctor at a health centre were approached in the waiting room. They were asked if they would like to take part in a questionnaire study looking at both how people feel when they come to see a doctor and attitudes towards osteoporosis. They were given an information sheet to read. If they wished to take part they were given a set of 11 questions before and after the consultation with the doctor (the 8 questions used in the bone density study and 3 extra questions which are not reported here since they are not relevant to the bone density study). Those who wished to help further were given a longer questionnaire to complete at home. They could return this questionnaire in the envelope provided.

3.8 Analysis of the data

Statistical analyses were performed using SPSS (Statistical Package for Social Sciences; PC version). Details of the analyses performed are given within each chapter.

3.9 Investigation of the characteristics of women who didn't take part in the full questionnaire study

Some of the analyses reported in later chapters only include women who have completed all of the questionnaires. Therefore it is important to know whether these women can be assumed to be representative of the group of women as a whole. Independent t-tests are used to compare the women who completed all

the questionnaires with a) the women who refused to take part at all and b) the women who completed the long initial questionnaire but returned neither of the follow-ups.

Women who hadn't initially "opted in" to the study were given a second chance to do so on the day of the bone scan, and most women did agree to take part at this point. However, a number of these women completed the questionnaires on the day of the scan but then failed to return the follow-up questionnaire. These women will also be compared to the women who did all the questionnaires.

Age and bone mineral density in women who refused to complete any of the questionnaires

Thirteen women did not wish to complete even the very short questionnaires on the day of the bone scan. The results of t-tests indicated that these women were not significantly different in terms of age or BMD from the women who completed all the questionnaires (see table below).

Table 3.4 Comparison of age and BMD in women who completed none or all of the questionnaires.

	Number of questionnaires completed:		
	No questionnaires	All questionnaires	
Age	Mean (SD) 52.8 (7.7)	Mean (SD) 55.9 (8.6)	$t_{(402)}=-1.4$
BMD	0.89 (0.16)	0.97 (0.16)	$t_{(402)}=1.6$

Comparison of women who completed questionnaires only on the day of the scan with women who completed all the questionnaires

Women who only completed the questionnaires on the day of the scan were not significantly different from those who did all the questionnaires in terms of BMD but there was a non-significant trend for them to be younger (see table below). Before the scan there were no significant differences between the two groups in terms of anxiety or sadness/low mood or perceived likelihood of developing osteoporosis at any point in the future. However, before the scan those who only completed the on-the-day questionnaires were more anxious/worried about osteoporosis, felt more at risk of developing osteoporosis in the near future, rated low bone density as more serious and felt more in need of reassurance about their bone density. Immediately after the scan, there were no significant differences between the two groups in terms of general anxiety, anxiety about bone density, worry about osteoporosis or perceived likelihood of developing osteoporosis; however, those who completed only the on-the-day questionnaires had higher ratings of the seriousness of below-average bone density and sadness/low mood than women who completed the full set of

questionnaires. There was also a non-significant trend for the former group to be more in need of reassurance about their bone density.

Table 3.5 Comparison of the age, BMD and feelings of women who only completed questionnaires on the day of the scan with those of women completed all the questionnaires.

	Questionnaires completed				
	On-the-day only		All		
	Mean	SD	Mean	SD	
BMD	0.97	[0.15]	0.96	[0.16]	$t_{(330)}=-0.4$
Age	50.0	[6.6]	52.9	[8.2]	$t_{(329)}=1.8, p=0.067$
Before the scan:					
General anxiety	16.4	[26.6]	12.0	[18.8]	$t_{(307)}=-0.8$
Sadness/ low mood	16.7	[22.4]	7.9	[16.0]	$t_{(305)}=-1.8, p=0.093$
Anxiety / worry about osteoporosis	41.8	[30.1]	25.8	[20.3]	$t_{(22.5)}=-3.4^*$
Perceived risk of ost: near future	39.1	[23.1]	25.7	[20.6]	$t_{(306)}=-2.9^{**}$

Higher scores indicate more distress or more negative beliefs.

Comparison of women who didn't return follow-up questionnaires with women who completed all questionnaires

See table 3.6 (below) for the mean age, BMD and ratings of feelings for women who did not return their follow-up questionnaires compared to those who completed all their questionnaires.

Independent t-tests indicated that women who completed the initial questionnaire but did not return the week or 3 month follow-up were no different from those who completed all the questionnaires in terms of BMD, perceived risk of developing osteoporosis, perceived cost/seriousness of osteoporosis or perceived ability to cope if one developed osteoporosis/low bone density. However, they were significantly younger, had higher scores on the Spielberger Trait-Anxiety Inventory, marginally lower ratings of the likelihood of developing osteoporosis immediately before the scan and marginally higher scores on the Reassurance scale of the Health Anxiety Questionnaire than women who completed all the questionnaires. They were not significantly different from the full-completers in their ratings immediately after the scan.

Table 3.6 Comparison of the BMD, age and psychological characteristics of women who didn't return any follow-up questionnaire with those of women who completed all questionnaires.

	Questionnaires completed		
	No follow-ups	All	
BMD	Mean [SD] 0.96 [0.16]	Mean [SD] 0.99 [0.15]	$t_{(330)}=0.3$
Age	45.8 [14.8]	52.9 [8.2]	$t_{(329)}=27.4^*$
Measures taken before the day of the scan:			
Anxiety/worry about osteoporosis	36.0 [28.1]	36.6 [25.7]	$t_{(322)}=0.1$
Perceived risk for osteoporosis	34.9 [22.1]	38.3 [23.9]	$t_{(318)}=0.7$
Perceived seriousness of osteoporosis	42.5 [19.5]	43.4 [19.5]	$t_{(319)}=0.2$
Anticipated ability to cope with osteoporosis	20.9 [12.2]	20.8 [13.0]	$t_{(323)}=0.0$
Perceived likelihood of preventing osteoporosis	53.5 [28.0]	63.6 [23.2]	$t_{(319)}=2.1^*$
Health Anxiety Questionnaire:			
Main section	32.9 [11.9]	30.2 [12.5]	$t_{(320)}=-1.0$
Cost section	10.8 [5.1]	12.0 [5.7]	$t_{(320)}=1.0$
Avoidance	7.4 [6.7]	7.8 [7.2]	$t_{(324)}=0.3$
Reassurance	17.7 [7.1]	15.1 [7.3]	$t_{(324)}=-1.7, p=0.09$
Depression (BDI)	7.8 [7.3]	6.5 [5.0]	$t_{(323)}=-1.2$
Trait anxiety (STAI-trait)	42.2 [10.5]	36.4 [9.2]	$t_{(326)}=-3.0^*$
Measures taken on the day of the scan:			
Before: Anxiety/worry about osteoporosis	25.3 [20.5]	25.8 [20.3]	$t_{(307)}=0.1$
Perceived risk for ost: near future	20.9 [17.3]	25.7 [20.6]	$t_{(307)}=1.1$
any point in future	28.7 [20.3]	37.8 [22.7]	$t_{(307)}=1.9, p=0.062$
Perceived seriousness of low BMD	45.2 [27.1]	49.9 [24.1]	$t_{(306)}=0.9$
Need for reassurance about BMD	38.7 [27.0]	40.0 [27.1]	$t_{(308)}=0.2$
After: Anxiety/worry about osteoporosis	16.0 [20.2]	20.3 [20.9]	$t_{(321)}=1.0$
Perceived risk for ost: near future	18.0 [23.1]	22.2 [21.1]	$t_{(322)}=1.0$
any point in future	24.8 [25.2]	32.6 [23.8]	$t_{(322)}=1.6$
Perceived seriousness of low BMD	44.8 [30.2]	49.2 [24.2]	$t_{(26.7)}=0.7$
Need for reassurance about bone density	23.2 [27.2]	27.0 [27.9]	$t_{(323)}=0.7$

Some of the measures are composites of two or three ratings. Higher scores indicated greater distress or more negative beliefs, except for the prevention beliefs where they indicate more positive beliefs.

Discussion: the characteristics of women who did not take part in the full questionnaire study

The small group of women who did not wish to fill in any questionnaires were not significantly different from those who did in terms of age or BMD. However, it is likely that there were psychological differences. This hypothesis is supported by the fact that women who only completed a minimal amount of questions, on the day of the scan, were more anxious about osteoporosis, felt more in need of reassurance, felt more at risk and felt that low bone density is more serious than women who completed all the questionnaires. These women may habitually attempt to cope with their anxiety by using avoidance, hence their unwillingness to complete questionnaires. Although the differences in anxiety and so on were mainly apparent only before the scan, it is possible that a week later women who had been more anxious beforehand would have experienced a return of some of the anxiety. The results suggest that the anxiety levels

shown in the women who completed all the questionnaires may be an underestimate of the anxiety felt by the group of women undergoing bone density screening as a whole. However, the number of women who completed only the on-the-day questionnaires, or no questionnaires at all, was small (approximately 6%).

In contrast, women who completed the initial long questionnaire and then returned no follow-ups were not significantly different from the women who completed all the questionnaires in anxiety and risk perceptions about osteoporosis (in fact, there was a non-significant trend for them to feel less at risk for osteoporosis), although they had higher scores on a measures of trait anxiety. This is consistent with the finding by Marteau et al. (1992) that women who completed only some of the questionnaires after prenatal screening had higher levels of trait anxiety than those who only completed all of the questionnaires.

Thus it is possible that there are at least two different types of women who did not return all the questionnaires. One group may be especially anxious about osteoporosis and uses avoidance to try to cope with their anxiety. The other is perhaps more anxious at a general trait level and their failure to return the follow-ups may reflect worry about other areas of life which are engaging their attention, rather than concern about osteoporosis. If so, it is the lack of responses from the former group which may result in an underestimate of anxiety felt about osteoporosis before and after bone density screening. Clearly the possibility of underestimation must be considered when interpreting the results presented in the following chapters.

Chapter 4: Characteristics of women undergoing bone density screening

4.1 Introduction

In this chapter, some of the pre-scan characteristics of the samples of women having bone density scans will be examined. It is important that the characteristics of the sample are specified for several reasons. For example, information about these characteristics is necessary if one wants to judge the extent to which the findings of the research may generalize to other populations and it may aid the interpretation of the findings. Furthermore, by investigating the type of women particularly likely to volunteer for bone density screening it may be possible to get an indication of which women will be the most likely to wish to have a scan in the NHS, where bone densitometry machines are becoming increasingly available.

There has been little previous research into the characteristics of women attending for bone densitometry. Torgerson et al. (1994) found that non-attenders were not significantly different from attenders in terms of smoking, previous hysterectomy, previous bilateral oophorectomy, menopausal status or the number of previous wrist fractures. Non-attenders were more likely to come from manual social groups, were significantly heavier, took less exercise and were less likely to have used hormone replacement therapy within the past 6 months than attenders. (However, exercise levels and HRT use were no longer significantly different between attenders and non-attenders if adjustment was made for weight and social class). Torgerson et al. conclude that non-attenders may be at lower risk for developing osteoporosis, because of their greater weight. Indeed, when 6 original non-attenders subsequently chose to attend screening, their bone density was higher (in some parts of the body) than non-attenders. In the present study, women were not sent invitations to attend screening so it is not possible to compare attenders and non-attenders in the same way. Instead, the characteristics of women volunteering for bone density screening are compared to women attending a GP clinic (for general, not osteoporosis-related advice).

In this chapter a comparison is also made between the characteristics of women having their first scan and those having their second scan. The differential effects of first and second scans will be examined in the next chapter and it is therefore important to establish whether there are pre-existing characteristics of the two groups of women. Due to the selection method for women having second scans (which at times was focused mainly on those with lower BMD), it was anticipated that women having second scans would have significantly lower BMD but that there may be psychological differences too, perhaps partly as a result of having had a previous scan.

4.2 Treatment of data

The data were derived from the initial questionnaire, which was sent to bone density volunteers two weeks before their bone scan (as described in the previous chapter). A similar questionnaire was given to a group of women attending a GP clinic, for them to take home with them and complete. Forty-six of the women who completed this questionnaire were of similar age to the bone densitometry volunteers and were therefore used as the control group.

The primary analysis was carried out using data from the 520 women who completed both the initial questionnaire and some or all of the follow-up questionnaires. There were 393 women having their first scan who fulfilled this criteria and 127 women having their second scan. In addition, the analyses were repeated for all women for whom the relevant information was available (which involved up to 855 women, for the analysis of age). These secondary analyses did not show different patterns of results to the main analysis.

Group comparisons were performed using one-way analyses of variance or chi-square analyses. Where there was a main effect of group using a one-way analysis of variance, post-hoc multiple comparisons were used using the Tukey B-test for which the criteria for significance was $p < 0.05$. The criteria for significance level when using partitioned chi-square analysis was $p < 0.05$.

Inter-rater reliability

For the open-ended questions regarding reasons for attending the bone scan, categories were devised on the basis of the answers of the first 70 subjects. Responses were written out and sorted into obvious groups and these groups were then amalgamated where possible to give a manageable number of categories. The final categories were chosen on the basis of discussion between the experimenter and her supervisor. All responses were coded into the eight derived categories by the experimenter.

For the questions about the nature of osteoporosis, answers were coded in terms of whether the subject mentioned a) bone loss or deterioration and b) bone fragility or susceptibility to fracture. This scoring was derived using a recent definition of osteoporosis as “a systemic skeletal disease characterised by low bone mass and microarchitectural deterioration of bone tissue, with a consequent increase in bone fragility and susceptibility to fracture” (Consensus Development Conference, 1993). For the other questions in the knowledge section, responses were simply counted - for example, the total number of (correct) preventative methods which the person mentions.

Data from the reasons for attendance question and the knowledge question was also rated by a second rater in order to assess inter-rater reliability (using the first 64 subjects). For several questions

correlations could be computed, which were all satisfactory (see table 4.1a)

Table 4.1a Inter-rater reliability: correlations between raters.

	Pearson correlation coefficients	p-value
Number of risk factors (reason 4)	0.940	p<0.0001
Knowledge: Causes	0.983	p<0.0001
Prevention methods	0.988	p<0.0001
Treatment methods	0.985	p<0.0001

For the categorical data, the percentage of subjects classified in the same way by both raters was calculated and phi-coefficients were used for statistical comparison (see table below).

Table 4.1b Inter-rater reliability: categorical data

	Percentage of identical classifications	Phi-coefficient*
<u>Reasons for attendance:</u>		
Confirmation of low bone density	98.4	0.810
HRT-related reasons	100.0	1.000
Prevention concerns	96.7	0.919
Symptoms of osteoporosis	96.7	0.918
Social reasons	98.4	0.968
Concern / anxiety	95.1	0.828
Description of osteoporosis	93.8	0.798

* where the variables were not dichotomous the contingency coefficient was given instead of the phi-coefficient.

The percentage of subjects classified in the same way by both raters ranged from 93.8% (for the description of osteoporosis) to 100% for HRT-related reasons for attendance, which (together with the phi-coefficients) indicates a satisfactory degree of inter-rater reliability.

4.3 Demographic characteristics

Some demographic characteristics of the sample of women attending first or second bone density scans (and the control group) are shown in table 4.2. Comparison between the three groups (using chi-square analyses and univariate analyses of variance) revealed no significant differences except regarding relationship status. Partitioned chi-square analyses showed that there was no significant difference in relationship status between women having their first or second scan, but women in each of these groups were significantly more likely to have a partner than women in the control group.

Table 4.2 Characteristics of the bone density sample and the control group in terms of age, relationship status, occupation, qualifications and number of children.

	Women having 1st scan		Women having 2nd scan		Women attending a GP clinic		F or χ^2 value
Age in years	Mean 52.6	SD [7.6]	Mean 53.0	SD [8.2]	Mean 52.0	SD [11.8]	$F_{(2,563)}=0.25$
Married or with partner (not including widows)	% 85.2 ^a	n (334)	% 79.5 ^a	n (101)	% 56.5	n (26)	$\chi^2_{(2)}=23.02^{***}$
Occupation (or previous occupation if stated by retired women):	%	n	%	n	%	n	$\chi^2_{(6)}=7.68$
1. not in paid employment / student	7.1	(28)	10.2	(13)	17.8	(8)	
2. unskilled / manual	51.8	(203)	53.5	(68)	46.7	(21)	
3 .professional / managerial	25.5	(100)	21.3	(27)	17.8	(8)	
4 .health professional	15.6	(61)	15.0	(19)	17.8	(8)	
Qualifications:	%	n	%	n	%	n	$\chi^2_{(2)}=1.28$
O level equivalent or less	48.2	(185)	46.0	(58)	56.4	(22)	
A levels/diploma/degree	51.8	(199)	54.0	(68)	43.6	(17)	
Number of children	Mean 1.95	SD [1.0]	Mean 1.87	SD [1.1]	Mean 2.1	SD [1.3]	$F_{(2,562)}=0.77$

^a On a given line, values sharing a superscript are not significantly different from each other.

*** p<0.0005

4.4 Depression, trait anxiety and health anxiety

Scores on the Health Anxiety Questionnaire (HAQ), Beck Depression Inventory (BDI) and Spielberger-trait anxiety inventory (STAI-trait) for women attending bone density screening and the GP control group are shown in table 4.3.

Table 4.3 Scores on questionnaires assessing pre-existing hypochondriacal symptoms, depression and trait anxiety of women attending bone density screening, the GP control group and a general population sample.

	Women having first scan	Women having a second scan	Women at GP clinic	F value	Previous findings for general population ¹
Health anxiety (HAQ): Main “Cost”	Mean SD 30.6 ^a [13.1] 12.4 [5.7]	Mean SD 31.0 ^{ab} [13.8] 11.7 [6.5]	Mean SD 36.0 ^b [13.4] 12.2 [5.4]	$F_{(2,547)}=3.13^*$ $F_{(2,548)}=0.66$	Mean SD 28.2 [12.2] 12.2 [6.0]
Avoidance	7.6 [7.5]	7.9 [7.4]	10.1 [8.2]	$F_{(2,554)}=2.00$	10.7 [10.2]
Reassurance-seeking	15.1 ^a [7.2]	15.4 ^a [7.3]	18.9 [7.4]	$F_{(2,550)}=5.22^*$	13.1 [6.9]
Depression (BDI)	7.1 ^a [5.5]	6.6 ^a [5.3]	9.8 [7.8]	$F_{(2,553)}=5.36^{**}$	6.4 [5.4]
Trait Anxiety (STAI)	37.4 [9.5]	35.1 [9.6]	42.2 [11.3]	$F_{(2,554)}=9.10^{***}$	40.6 [10.6]

¹ The general population sample from which these figures have been drawn has been previously described in chapter 2.

* p<0.05, ** p<0.005, *** p<0.0005

For each questionnaire, a higher score indicates a greater degree of distress.

^a or ^b On any line, figures sharing a superscript are not significantly different from each other.

Health Anxiety: Univariate analyses of variance indicated a significant main effect of group for the main section of the HAQ. Multiple comparisons indicated that the only difference which reached significance was that women having first bone scans had significantly lower scores than the women at the GP clinic.

There were no significant main effects of group for the Cost scale of the HAQ or the Avoidance scale. However, there was a significant main effect of group of the Reassurance scale. Multiple comparisons indicate that women having first and second bone scans were not significantly different from each other but both of these groups had significantly lower scores than the women at the GP clinic. In order to check that the Reassurance scale in the control group did not simply reflect the fact that they had just seen their GP, the ANOVA was repeated with the item about seeing one's family doctor removed from the scale: there was still a significant group effect with the GP group having a the higher score than the other two groups ($p < 0.05$).

Depression and Trait anxiety: Univariate analyses of variance indicated a significant effect of group on the BDI. Multiple comparisons revealed that both groups of women having a bone scan had significantly lower scores than woman at the GP clinic. There was also a main effect of group on the STAI-trait; multiple comparisons revealed that all groups were different from each other, with the control group showing the highest scores followed by the women having their first scan then women having their second scan.

BDI, STAI-trait and HAQ scores compared to scores found in general population samples

The scores on the STAI-trait and BDI of the women attending their first or second bone density scan were not significantly different from the sample of men and women recruited from the general population described in chapter 2, when controlling for age ($F < 1$ in all cases). The scores for the BDI were also not significantly different from the found in the general population sample described by Dent and Salkovskis (1986). (Their mean was 5.97, standard deviation was 5.07, which yielded Z scores for comparisons of the two means of -1.78 for the first-scan group compared to the general population sample and -1.28 for the second-scan group compared to the general population sample). Scores for the STAI-trait were not significantly different for the norms for females aged 50-59 published by Knight, Waal-Manning and Spears (1983). (Their mean was 36.7, standard deviation was 8.86, which yielded Z scores of -1.06 for the comparison with the first-scan group and 0.82 for the comparison with the second-scan group).

In contrast, the scores of the GP control group on the BDI and the STAI-trait were significantly higher than the scores of the general population sample described in chapter 2 ($p < 0.05$ in both cases).

Similarly the GP control group had significantly higher BDI scores than those of the sample reported by Dent and Salkovskis (1986) ($Z=2.92$) and significantly higher STAI-trait scores than those reported by a female sample age 50-59 reported by Knight et al. (1983) ($Z=6.05$).

The HAQ scores of women attending bone density screening (and the control group) were also compared to scores from the general population sample described in chapter 2. Analyses of variance, covarying for age, indicated that the women having their first bone density scan had significantly higher scores on the main part of the HAQ ($F_{(1, 450)}=5.0$, $p<0.05$) and the Reassurance scale ($F_{(1, 452)}=6.0$, $p<0.05$), but significantly lower scores on the Avoidance scale ($F_{(1, 453)}=8.0$, $p=0.005$) than the subjects from the general population. There was also a non-significant trend for the women having bone density scans to have higher scores on the Cost scale ($F_{(1, 449)}=2.84$, $p=0.093$). Women having their second bone scan also had higher scores than the sample from the general population on the main section of the HAQ ($F_{(1, 184)}=6.2$, $p<0.05$) and on the Reassurance scale ($F_{(1, 187)}=6.4$, $p<0.05$), but the scores on the Cost and Avoidance scales were not significantly different.

For the GP control group, scores on the main section of the HAQ were significantly higher than in the general population sample ($F_{(1, 107)}=9.7$, $p<0.005$), as were scores on the Reassurance scale ($F_{(1, 108)}=14.3$, $p<0.0005$); scores on the Cost and the Avoidance scale were not significantly different from the general population sample.

4.5 Current medical conditions, health screening behaviours and interest in health issues

Table 4.4 shows the proportion of women in the bone density and control groups who reported a current medical condition for which they were receiving treatment, together with details of their health screening behaviours over the past 5 years and their interest in health issues.

A chi-square analysis indicated that there was a group difference in the likelihood of being treated for a medical condition. Partitioned chi-square analyses showed that the only two groups which were significantly different were women coming for their first scan and women in the control group - the latter were more likely to be receiving treatment for a medical condition.

Univariate analyses of variance revealed an overall effect of group for the mean number of breast examinations, mammograms and mean total number of health checks over the past five years. Multiple

comparisons indicated that in each of these three cases, women having a bone density scan (first or second) reported more checks than the women in the control group.

There were significant main effects of group concerning the amount of effort made to keep healthy and interest in health issues. Multiple comparisons indicated that in both cases, the only significant difference was that women having their second scan reported more effort and interest than women having their first scan. There were no significant group differences regarding the extent to which one’s lifestyle was affected by efforts to keep healthy or regarding the frequency of reading books or magazines about health issues.

Table 4.4 The proportion of women having bone scans and women in the control group who have a current medical condition and a comparison of the level of health interest and the number of recent health checks in these groups.

	Women having 1st scan		Women having 2nd scan		Women attending a GP clinic		F or χ^2 value
Current medical condition for which receiving treatment	%	n	%	n	%	n	$\chi^2_{(2)}=8.48^*$
	40.7 ^a	(157)	49.2 ^{ab}	(62)	61.4 ^b	(27)	
Health checks (past five years)	%	n	%	n	%	n	$\chi^2_{(2)}=3.47$
Any	99.7	391	98.4	124	100	46	
	Mean	SD	Mean	SD	Mean	SD	
Cervical smear:	1.3	[1.1]	1.2	[0.9]	1.0	[0.6]	$F_{(2,560)}=1.54$
Breast examination	0.9 ^a	[1.4]	1.2 ^a	[2.2]	0.4	[0.6]	$F_{(2,560)}=4.43^*$
Mammogram	0.9 ^a	[0.9]	1.0 ^a	[0.9]	0.4	[0.6]	$F_{(2,560)}=7.99^{***}$
Blood pressure reading	2.2	[3.2]	2.6	[3.3]	1.7	[2.3]	$F_{(2,560)}=1.37$
Cholesterol test	0.7	[1.3]	0.8	[1.6]	0.3	[0.5]	$F_{(2,559)}=2.33$
Other	0.2	[0.5]	0.3	[0.5]	0.4	[1.0]	$F_{(2,559)}=2.07$
Total health checks	6.2 ^a	[4.9]	7.0 ^a	[5.2]	4.2	[3.1]	$F_{(2,558)}=5.59^{**}$
Health Interest							
Total	5.2	[1.9]	5.5	[1.9]	5.4	[2.1]	$F_{(2,557)}=1.58$
1. Effort to keep healthy	1.2 ^a	[0.5]	1.4 ^b	[0.6]	1.3 ^{ab}	[0.6]	$F_{(2,560)}=5.04^*$
2. Interest in health issues	1.8 ^a	[0.7]	1.9 ^b	[0.7]	1.7 ^{ab}	[0.7]	$F_{(2,558)}=3.96^*$
3. Lifestyle affected by efforts to keep healthy	1.0	[0.8]	1.0	[0.9]	1.2	[0.8]	$F_{(2,558)}=1.75$
4. Reads health magazines or books	1.2	[0.7]	1.2	[0.7]	1.2	[0.7]	$F_{(2,560)}=0.08$

* p<0.05, ** p<0.005, *** p<0.0005
^{a or b} On any line, figures sharing a superscript are not significantly different from each other.

4.6 Medical and family history related to osteoporosis

Table 4.5 shows details of the osteoporosis-related medical history and health behaviours of women undergoing bone density screening or attending a GP clinic.

Chi-square analyses revealed no significant group differences with regard to the proportion of

women with a medical condition affecting bone density (other than osteoporosis), symptoms relating to low bone density, menopausal status or HRT usage. A chi-square analysis revealed a significant group difference regarding a family history of osteoporosis. A partitioned chi-square analysis indicated that women coming for a second scan were significantly more likely to have a family history than women coming for a first scan and women in the control group. Women having a first scan were not significantly more likely than women in the control group to have a family history.

Table 4.5 Medical history and health behaviours relating to osteoporosis in women attending their first or second bone density scan and in the control group

	Women having 1st scan		Women having 2nd scan		Women attending a GP clinic		F or χ^2 value
Medical condition affecting bone density (present or past)	%	n	%	n	%	n	$\chi^2_{(2)}=3.60$
22.3	(85)	27.0	(33)	13.3	(6)		
Symptoms relating to weak bones:	%	n	%	n	%	n	
Any symptoms	19.1	(74)	19.8	(25)	8.9	(4)	$\chi^2_{(2)}=3.00$
Fracture(s)	10.1	(39)	12.7	(16)	4.5	(2)	$\chi^2_{(2)}=2.39$
Pain(s)	7.2	(28)	7.9	(10)	0.0	(0)	$\chi^2_{(2)}=3.57$
Other	6.5	(25)	8.7	(11)	2.3	(1)	$\chi^2_{(2)}=2.26$
	Mean	SD	Mean	SD	Mean	SD	
Total number of symptoms:	0.3	[0.6]	0.4	[0.8]	0.1	[0.5]	$F_{(2,554)}=2.2$
Family history of osteoporosis:	%	n	%	n	%	n	
Yes	22.8 ^a	(89)	41.6	(52)	15.9 ^a	(7)	$\chi^2_{(2)}=19.89^{***}$
No / don't know	77.2 ^a	(301)	58.4	(73)	84.1 ^a	(37)	
Menopausal status:	%	n	%	n	%	n	
pre-menopausal	20.8	(79)	16.9	(21)	27.3	(12)	$\chi^2_{(6)}=9.43$
currently menopausal	27.9	(106)	21.8	(27)	27.3	(12)	
post-menopausal	45.0	(171)	50.8	(63)	45.4	(20)	
hysterectomy	6.3	(24)	10.5	(13)	0	(0)	
H.R.T.: currently use	27.1	(106)	31.5	(40)	15.2	(7)	$\chi^2_{(2)}=4.53$
Previous H.R.T. use	20.9	(78)	24.8	(31)	13.3	(6)	$\chi^2_{(2)}=2.67$
Concerned about whether to take HRT	54.1	(206)	50.0	(61)	46.5	(20)	$\chi^2_{(2)}=1.30$

*** p<0.0005

^a On any line, values sharing a superscript are not significantly different from each other.

4.7 Osteoporosis prevention

Chi-square analyses indicate group differences regarding whether or not any preventive behaviour is undertaken (see table 4.6). Partitioned chi-square analyses showed that women who were coming for a second scan were more likely to perform some kind of preventive behaviour than women having their first scan and women in the control group. Women coming for their first scan showed only a marginally higher likelihood of preventive behaviours than women in the control group ($\chi^2_{(1)}=3.06$, p=0.08).

Chi-square analyses also indicated group differences regarding diet and calcium supplements. Partitioned chi-square analyses performed to investigate these differences further indicated a similar pattern to that shown for preventive behaviours as a whole: women coming for a second scan were significantly more likely make dietary changes and take supplements than women having their first scan or women in the GP clinic. These latter two groups did not significantly differ on preventive behaviours. In addition, 2 women having a second scan take Didronel, prescribed by their doctor for low bone density while no women from the other two groups take this.

Table 4.6 Pre-scan osteoporosis-preventive behaviours in women attending their first or second bone density scan and in the control group.

	Women having 1st scan		Women having 2nd scan		Women attending a GP clinic		F or χ^2 value
Osteoporosis prevention: any	%	n	%	n	%	n	$\chi^2_{(2)}=24.47^{***}$
Exercise	47.0 ^a	(183)	69.0	(87)	33.3 ^a	(15)	$\chi^2_{(2)}=5.16$
H.R.T.	21.0	(82)	27.0	(34)	11.1	(5)	$\chi^2_{(2)}=2.43$
Diet (e.g. calcium)	15.1	(59)	20.6	(26)	13.3	(6)	$\chi^2_{(2)}=20.94^{***}$
Calcium supplement	12.8 ^a	(50)	30.2	(38)	13.3 ^a	(6)	$\chi^2_{(2)}=11.5^{**}$
Other minerals or vitamins	14.6 ^a	(57)	25.4	(32)	6.7 ^a	(3)	$\chi^2_{(2)}=0.29$
Didronel or other prescribed drug	11.3	(44)	10.3	(13)	8.9	(4)	(numbers too small to analyse)
Other	0.0	(0)	1.6	(2)	0.0	(0)	
	1.0	(4)	3.2	(4)	2.2	(1)	
Limitation of activities to avoid falls and fractures	%	n	%	n	%	n	$\chi^2_{(2)}=3.08$
	9.0	(35)	14.4	(18)	9.1	(4)	

** p<0.005, **** p<0.00005, *** p<0.0005

^a On any line, values sharing a superscript are not significantly different from each other

4.8 Knowledge of osteoporosis

Analysis of variance regarding total scores for the knowledge questions indicated a main effect of group (see table 4.7). Multiple comparisons indicated that women having first and second scans did not differ significantly from each other, but both groups had higher total knowledge scores than women in the control group. The questions about knowledge were then analysed separately:

Firstly, a chi-square analysis indicated a significant group effect for the question asking “what the condition is”. Partitioned chi-square analyses were performed comparing the proportion of full, correct answers between the three groups. These revealed that women in the GP clinic were less likely to give a full description than women having first or second scans, with no significant difference between the latter two groups.

An analysis of variance indicated a main effect of group for the number of causes of osteoporosis

mentioned. Multiple comparisons revealed that the only significant difference was that women having their first scan mentioned more causes than the control group.

Table 4.7 Knowledge regarding osteoporosis in women having their first and second scan, and in GP attenders.

	Women having first scan		Women having a second scan		Women at GP clinic		F or χ^2 value
“What is osteoporosis?”	%	n	%	n	%	n	$\chi^2_{(4)}=18.1^{**}$
Full, correct description	46.7 ^a	(183)	49.6 ^a	(62)	26.7	(12)	
Partially correct description	47.2	(185)	41.6	(52)	51.1	(23)	
Incorrect / didn’t know	6.1	(24)	8.8	(11)	22.2	(10)	$F_{(2,559)}=6.99^{**}$
		SD		SD		SD	
Mean score (range is 0-2)	1.4 ^a	[0.6]	1.4 ^a	[0.6]	1.0	[0.7]	
Causes (mean correct)	1.6	[1.3]	1.7	[1.4]	1.1	[1.1]	$F_{(2,558)}=3.01, p=0.05$
Prevention methods (mean correct)	2.0 ^a	[1.3]	2.2 ^a	[1.3]	1.1	[1.4]	$F_{(2,559)}=12.0^{****}$
Treatment methods (mean correct)	1.3 ^a	[1.3]	1.5 ^a	[1.3]	0.6	[1.0]	$F_{(2,559)}=9.3^{***}$
Percentage stating that you can’t restore bone structure.	%	n	%	n	%	n	$\chi^2_{(2)}=11.79^{**}$
	9.2 ^a	(36)	19.2	(24)	4.4 ^a	(2)	
Effects of osteoporosis:	Mean	SD	Mean	SD	Mean	SD	$F_{(2,558)}=6.91^{**}$
Number described:	2.2 ^a	[1.3]	2.2 ^a	[1.4]	1.5	[1.4]	
Effects described:	%	n	%	n	%	n	$\chi^2_{(2)}=8.72^*$ $\chi^2_{(2)}=4.37$ $\chi^2_{(2)}=0.36$ $\chi^2_{(2)}=1.27$ $\chi^2_{(2)}=14.27^{**}$ $\chi^2_{(2)}=0.41$ (Numbers too small for chi-square analysis)
Fractures	68.6 ^a	(269)	65.6 ^a	(82)	46.7	(21)	
Pain	27.6	(108)	28.0	(35)	13.3	(6)	
Emotional	24.0	(94)	23.2	(29)	20.0	(9)	
Lifestyle/ activities	63.3	(248)	60.0	(75)	55.6	(25)	
Appearance	29.8 ^a	(117)	32.8 ^a	(41)	4.4	(2)	
Medical complications	6.6	(26)	7.2	(9)	4.4	(2)	
Increased mortality	2.6	(10)	7.2	(9)	2.2	(1)	
Other comments about osteoporosis (unclassified)	%	n	%	n	%	n	$\chi^2_{(2)}=3.5$
	12.8	(50)	18.4	(23)	8.9	(4)	
Total knowledge score	Mean	SD	Mean	SD	Mean	SD	$F_{(2,556)}=13.2^{****}$
	8.6 ^a	[4.4]	9.2 ^a	[4.6]	5.3	[4.6]	

* $p<0.05$, ** $p<0.005$, *** $p<0.0005$, **** $p<0.00005$

^a On any line, figures sharing a subscript are not significantly different from each other.

Analyses of variance indicated a main effect of group for questions concerning prevention methods, treatment and the number of different effects of osteoporosis that were mentioned. Multiple comparisons revealed that women having first and second scans were not significantly different from each other but both groups mentioned more methods of prevention and treatment and more effects of osteoporosis than women in the control group. When the different effects of osteoporosis were examined in turn, using chi-square analyses, there were overall group differences in the proportion of women mentioning fractures and effects

of osteoporosis on one's appearance. Partitioned chi-square analyses revealed that women in the control group were less likely to mention fractures or changes in appearance than women having a first or second scan, while there was no significant difference between the women in the two groups having a bone scan.

Chi-square analysis indicated that there was an overall difference between groups in the expression of the idea that you cannot restore bone structure. Partitioned chi-square analyses showed that women coming for a second scan were significantly more likely to express this knowledge than women coming for a first scan and women in the control group; there was no significant difference between these latter two groups. However, firm conclusions about differences in this knowledge cannot be drawn since it was only addressed indirectly, by response to the question "How can you treat osteoporosis?".

Knowledge and attitude towards bone density screening in the control group

Of the 46 women at the GP clinic, 43.5% (20) said that they had heard of bone density screening and 56.5% (26) had not. In their information sheet they were given a very brief description of what the scans involved; 65.2% (30) said that they would have a bone density scan if given the chance, 28.3% (13) said that they weren't sure, and 2.2% (1) said she wouldn't have a bone scan.

4.9 Beliefs and feelings about osteoporosis before the bone scan

One-way analyses of covariance were used to compare the three groups in terms of their beliefs and feelings about osteoporosis (see table 4.8). Trait anxiety (measured by Spielberger's trait anxiety inventory: STAI-trait) and depression (Beck Depression Inventory: BDI) were entered as covariates as the control group had higher scores on these questionnaires.

There were significant group effects for questions assessing anxiety about bone density, worry about developing osteoporosis, worry about falling and fracturing oneself, need for reassurance about bone density, likelihood of developing osteoporosis, risk of osteoporosis compared to other women, vulnerability to osteoporosis and the likelihood that one can prevent osteoporosis if one has low bone density. There were no significant main effects of group for questions concerning the "cost" of osteoporosis, anticipated ability to cope if one had osteoporosis, state anxiety or current sadness / low mood.

The significant effects were examined further using one-way ANCOVA (comparing two groups at a time) with the Spielberger and BDI scores as covariates. In all of these comparisons the criteria for significance were $p < 0.05$.

Table 4.8 Ratings of anxiety and beliefs about osteoporosis in women who were soon to have their first or second bone scan, and in GP attenders.

	Women having their 1st scan	Women having their 2nd scan	Women at GP clinic	F value
<u>Anxiety</u>	Mean SD	Mean SD	Mean SD	
Anxiety about her bone density	31.6 ^a [25.2]	41.7 [27.2]	31.3 ^a [25.0]	$F_{(2,540)}=9.31^{***}$
Worry about developing osteoporosis.	38.6 ^a [28.3]	45.8 [29.2]	34.0 ^a [26.5]	$F_{(2,540)}=6.01^{**}$
Worry about fractures	28.1 ^a [28.3]	36.9 [31.0]	31.8 ^a [24.9]	$F_{(2,541)}=5.12^*$
Need for reassurance about her bone density	44.9 [30.5]	51.5 [31.5]	34.5 [28.2]	$F_{(2,540)}=7.26^{**}$
<u>Probability of osteoporosis</u>				
Likelihood of developing ost., near future	28.11 ^a [23.4]	37.5 [25.2]	27.1 ^a [21.9]	$F_{(2,541)}=9.84^{***}$
Likelihood of developing ost. at any point in the future	41.6 ^a [24.7]	50.9 [27.0]	37.8 ^a [24.8]	$F_{(2,540)}=9.51^{***}$
Vulnerability to developing ost. in the future	38.5 ^a [26.3]	49.3 [29.7]	34.4 ^a [24.1]	$F_{(2,534)}=11.7^{***}$
How “at risk” she feels compared to the average woman of her age (<i>positive numbers indicate pessimism</i>)	0.05 [1.3]	0.88 [1.3]	-0.42 [1.1]	$F_{(2,534)}=28.4^{**}$
<u>Perceived “cost” of osteoporosis</u>				
Effect ost. would have on ability to enjoy life	36.9 [24.7]	38.2 [25.2]	44.9 [25.4]	$F_{(2,535)}=1.31$
How bad the consequences of ost. would be	48.1 [23.7]	50.9 [25.2]	52.3 [21.6]	$F_{(2,536)}=1.73$
How serious a threat to health is below average bone density?	47.6 [24.2]	48.3 [25.4]	52.5 [21.9]	$F_{(2,535)}=0.61$
<u>Coping</u>				
Anticipated coping ability if low BMD	28.5 [21.0]	28.2 [22.3]	36.0 [21.4]	$F_{(2,534)}=1.05$
Anticipated coping ability if developed ost.	35.7 [22.4]	34.4 [22.1]	43.3 [23.9]	$F_{(2,535)}=0.61$
<u>Prevention</u> : Likelihood that will be able to prevent ost. if have low bone density	64.6 ^a [23.6]	61.8 ^a [25.1]	48.9 [23.8]	$F_{(2,531)}=6.00^{**}$
General anxiety	25.9 [24.1]	27.0 [24.6]	32.0 [26.5]	$F_{(2,539)}=0.820$
Low mood / sadness	16.3 [21.8]	15.9 [24.5]	27.0 [27.8]	$F_{(2,538)}=0.266$

^a values on the same line sharing a superscript are not significantly different from each other.

* $p<0.05$, ** $p<0.0005$, *** $p<0.0005$.

Larger values indicated greater distress or higher risk perceptions except for prevention beliefs where higher values indicate a greater perceived likelihood of preventing osteoporosis.

Differences between women coming for a second scan and the other two groups

One-way analyses of covariance showed that women coming for a second scan had significantly higher scores than the other two groups on anxiety about bone density, worry about developing osteoporosis, worry about falling and fracturing herself, need for reassurance about her bone density, likelihood of developing osteoporosis in the near future or at any point in the future, vulnerability to developing osteoporosis and risk compared to other women. Women coming for a second scan also thought it more likely that you can prevent

osteoporosis than women in the control group but were no different in this measure than women coming for their first scan. (There was still a significant group difference in prevention beliefs if knowledge about prevention methods and general knowledge about osteoporosis were entered as covariates).

Differences between women coming for their first scan and the control group

One-way ANCOVA indicated that women coming for their first bone scan felt more in need of reassurance than women in the control group. They also felt at higher risk compared to others than the control group and felt it more likely that you can prevent osteoporosis.

Differences in beliefs about osteoporosis when controlling for state anxiety

The one-way analyses of covariance involving the three groups were repeated using state anxiety as a covariate in addition to the BDI and STAI-trait. The pattern of results was similar except that now the women coming for their first scan were more worried about osteoporosis than women in the control group.

4.10 Reasons for having the bone density scan

Results concerning reasons for having a bone density scan are shown in table 4.9.

Table 4.9 The proportion of women reporting different reasons for having first or second bone density scans

	Women having their first scan		Women having a second scan		F or χ^2 value
	%	n	%	n	
Already knows she has osteoporosis or low bone density (by previous scan or x-ray or on basis of symptoms)	1.6	(6)	9.9	(12)	$\chi^2_{(1)}=17.9$ ****
H.R.T.-related e.g. concerned about whether to start/stop H.R.T., can't take H.R.T	38.2	(142)	25.6	(31)	$\chi^2_{(1)}=6.32^*$
Prevention concerns (where not specifically related to H.R.T.)	21.2	(79)	17.4	(21)	$\chi^2_{(1)}=0.86$
Risk factors Proportion mentioning any risk factors:	44.1	(164)	55.0	(66)	$\chi^2_{(1)}=4.67^*$
Symptoms of osteoporosis	18.0	(65)	19.8	(24)	$\chi^2_{(1)}=0.20$
Social or "non-personal reason" e.g. friends coming for a scan, to help medical research.	37.4	(139)	33.9	(41)	$\chi^2_{(1)}=0.48$
Concern/anxiety	8.3	(31)	9.9	(12)	$\chi^2_{(1)}=0.29$
Other: Doctor/nurse advised	8.3	(31)	4.1	(5)	$\chi^2_{(1)}=4.3$
Miscellaneous	27.4	(102)	22.3	(27)	

* $p<0.05$, **** $p<0.00005$

Chi-square analyses indicated that women having their second scan were more likely to say that they were having a scan because they had already been diagnosed as having low bone density, were less likely to cite HRT concerns as a reason and were more likely to mention risk factors.

4.11 Comparison of bone mineral density between women having first and second scans

The mean bone mineral density (BMD) of the sample of women coming for first scan was 0.993 g/cm² (see table 4.10) or 5.3% above the age-related mean. Women having a second scan had a significantly lower BMD than women coming for a first scan and their mean result was 5.8% below the age-related mean.

Table 4.10 Bone mineral density in women having first and second scans

Result (alternative ways of describing)	First scan (n=393)		Second scan (n=127)		t-value
Bone mineral density (g/cm ²) (lumbar vertebrae 1-4)	Mean	SD	Mean	SD	$t_{(518)} = 7.53,$ $p < 0.0005$
Percentage above or below mean for woman of the same age (using the North American sample for comparison)	0.993	[0.162]	0.885	[0.134]	
	+ 5.3 %	[16.1]	-5.8%	[13.8]	

4.12 Numbers of women having BMD which is below average or below fracture threshold

In order to compare the numbers of women in each group having below average bone density two different cut-off points have been used. This is necessary because the print-out of the results was not detailed enough to show very small differences from the mean. The experimenter inspected many printouts where the result was close to the mean and decided that the figure at which the cross was always visibly below average was 0.023 below the mean. This figure has been used in a secondary analysis as the cutoff point for being below average bone density (labelled below average(2) in table 4.11).

Table 4.11 Comparison of the proportion of women having first and second scans whose BMD was below average for their age or were below fracture threshold

Bone Mineral Density	1st scans		2nd scans		χ^2 value
	%	n	%	n	
Below average	38.2	(150)	77.2	(98)	$\chi^2_{(1)} = 58.5^{***}$
Below average (2) ^a	33.1	(130)	73.2	(93)	$\chi^2_{(1)} = 63.1^{***}$
Below fracture threshold	13.5	(53)	22.0	(28)	$\chi^2_{(1)} = 5.34^*$
More than 2.5 SD below young adult mean (WHO classification for osteoporosis)	6.9	(27)	15.7	(20)	$\chi^2_{(1)} = 9.2^{**}$

*p<0.05, **p<0.005, *** p<0.0005

^a A value at which the result was clearly visible as being below the mean was used for the cut-off in this calculation (0.023 below the mean)

Only 38.2% of the sample of women attending first scans had below average BMD compared to 77.2% of women having second scans, a significant group difference. This number reduced to merely 33.1% if a cut-off was used at which the cross representing the woman's score was clearly below the mean on the graph. There were also significantly more women in the group having second scans with a BMD below the fracture threshold of 0.81 g/cm² and more who fulfilled World Health Organization (1994) criteria for osteoporosis.

4.13 Change in BMD between scans

Compared to their first scan result, 52.3% (58) of the women having a second scan showed an higher BMD result and 47.7% (53) showed a lower BMD result. At the Nuffield Orthopaedic Hospital the cut-off point for a significant change in BMD is 2.5%. If this criterion is used, 19.8% (22) of the women showed an increase, 15.3% (17) showed a decrease and 64.9% (72) showed no significant difference in BMD.

4.14 Summary and discussion

Some kind of bias in the uptake of health screening is likely to occur in most screening situations. If one wishes to examine the psychological effects of screening it seems preferable that pre-screening characteristics of the subjects are examined, so that the results can be considered within the context of these characteristics and there can be an estimation of the extent to which the results may generalize to other populations.

One of the most significant characteristics of this sample of women undergoing their first bone density screening is that their mean bone density is higher than the mean of the reference sample used by the machine, which were derived from a volunteer sample of 600 North American women. This means that the psychological effects of screening may be less adverse in the present sample than would otherwise have been observed, since fewer women than expected are receiving a below average results.

Regarding psychological characteristics, it was found that this sample of women undergoing bone densitometry had higher scores than a previously identified general population sample on the main section of the Health Anxiety Questionnaire, higher scores on the scale assessing reassurance-seeking behaviour but lower scores on the scale assessing avoidance of illness-related situations. It is therefore possible that some women may be attending bone density screening partly because of a general tendency to seek reassurance about their health while others may be avoiding screening because of a general tendency to avoid illness-related situations. (This latter finding is the only piece of evidence which could be seen as consistent with previous suggestions (e.g. Rudd et al. 1987) that people who chose not to be screened may be more

psychologically “vulnerable” to experiencing distress after health screening). There was also a non-significant trend for women volunteering for bone density screening to have higher ratings on the Cost scale of the HAQ, which indicates that they tend to rate the effects of serious illness in a more negative way than people in the general population. It would be interesting to see if the same pattern of characteristics concerning health anxiety is found in people who undergo different types of health screening.

Women who had an appointment to have a bone scan were also more in need of reassurance about their bone density and felt more at risk of osteoporosis (compared to others) than the control group (when controlling for depression and trait anxiety). These findings are consistent with the idea that heightened perceived risk and need for reassurance are motivating some of these women to volunteer for screening; indeed, some women cite risk factors as their reason for attending screening. However, it is also possible that the group differences are at least partly due to the appointment itself - the impending bone scan may create feelings of uncertainty and lead women to consider whether they have any risk factors. There were no differences between the bone densitometry volunteers and the control group in ratings about the perceived burden or seriousness of osteoporosis, so there is no evidence to support the idea that “cost” beliefs are a causal factor in the decision to volunteer for bone density screening. This is consistent with previous research such as studies into intentions to seek cervical screening, where it has been found that perceived seriousness was not associated with intentions to be screened (e.g. Hennig and Knowles, 1990).

Knowledge of osteoporosis (including aspects which weren’t mentioned in their appointment letters) was higher in the bone densitometry attenders than in women at the GP clinic. Thus it is possible that women who know more about osteoporosis are more likely to volunteer for screening. However, it is also possible that having made the appointment, women seek more information about osteoporosis or learn about it from friends who have already had a scan. A certain proportion of women will probably have learnt about the nature of osteoporosis at the same time as hearing about bone scans - for example in magazine articles or television coverage.

Women in the GP clinic reported having fewer health checks over the past five years than women having a first or second bone scan. The greater number of health checks does not simply represent greater reassurance-seeking in general in the bone density attenders, since the control group actually report the most reassurance-seeking. It may reflect a more positive attitude towards prevention, for women undergoing bone density screening have higher ratings of the likelihood of being able to prevent osteoporosis than women in the control group. This difference in prevention beliefs could not be accounted for by differences in knowledge and may reflect more positive views about prevention in general.

Women attending a GP clinic were less likely to have a family history of osteoporosis than women having a second bone scan but were no less likely to have a family history than women attending their first scan. Evidence regarding the relationship between family history and screening behaviour for other conditions is inconsistent, with some studies also finding no relationship (Vogel et al., 1990) while others find a positive or negative relationship (e.g. Lerman, Rimer, Trock, Balshem and Engstrom, 1993; Laville, Vernon, Jackson and Hughes, 1989).

There was no significant difference in the likelihood of having current medical treatment between second scan women and women at the GP clinic. This may be because some of those attending for second scans are receiving treatment for low bone density, or are being treated for a medical condition (such as a thyroid disorder) which has actually contributed to their low bone density. There is also the possibility that women who have current medical condition are more likely to return for second scans for reasons independent of their low bone density, such as a heightened attention to illness.

The finding that women attending a GP surgery had higher levels of depression, trait anxiety or health anxiety than the sample of women having bone scans or a general population sample is consistent with previous studies which have found higher levels of psychological distress among patients in primary care than in the normal population (e.g. Goldberg, Kay and Thompson, 1976; Kellner, Abbott, Pathak, Winslow and Umland, 1983-84).

Comparison between women coming for a first and second bone scan

Women coming for second scans had lower bone density than women having their first scans, consistent with biases towards low bone density in the recruitment policy for second scans at some points in time (e.g. at times, only women with low readings or a family history have been encouraged to return). However, it is also possible that women with a low result are more likely to seek a second scan for themselves and this possibility is investigated in chapter 7 by asking about intentions to have another scan.

Compared to women coming for their first scan, women having their second scan showed higher pre-scan ratings of pre-scan anxiety about osteoporosis and perceived vulnerability to osteoporosis, were more likely to report a family history of osteoporosis, had more interest in health issues and reported putting more effort into keeping healthy than women. These differences could be partly caused by their first scan result, and / or may be factors involved in their decision to have another scan.

The women coming for a second scan report more osteoporosis-preventative behaviours than women coming for their second scan. There could be various reasons for this, for example: 1) a proportion

found that they had low bone density on the previous scan and this prompted them to initiate preventive behaviours; 2) coming for the first scan could have made them more aware of the osteoporosis and had an effect independent of their own result; 3) they report more risk factors, which may have an additional effect in motivating preventive behaviours.

Women coming for second scans did not have significantly higher pre-scan scores on most of the questions assessing knowledge of osteoporosis than women having first scans. This is not unexpected with regard to information that might be gained through screening, since most of the information given to the women is sent before the bone scan appointment, although it might indicate that women who had already had one scan have made much effort to find out more about osteoporosis since their first scan.

Limitations of this examination into the characteristics of women attending bone density screening

GP attenders were chosen as the control group in order to compare the specific effects of bone density screening with another medical consultation (the comparison is described in the next chapter). This group was also used as a control group for attitudes, knowledge and behaviour regarding osteoporosis and illness, as described in this chapter. For practical purposes, the more detailed questionnaire had to be given to the control group to complete at home after they had seen the doctor, while in the bone density group the long questionnaire sent to them before the scan. This means that the situations in which questionnaires were completed are not directly comparable, so firm conclusion cannot be drawn about the differences between the two groups. Furthermore, one would ideally have a general population sample to act as an additional control group.

Chapter 5: Anxiety and beliefs about osteoporosis before and after a bone density scan

5.1 Introduction

In this chapter there will be an evaluation of changes in feelings and beliefs about osteoporosis after a bone density scan. There are two main comparisons: firstly between women having first and second scans and secondly between women having their first bone scan and a control group who are attending a GP clinic for a medical consultation not related to osteoporosis. The aim of this chapter is to present an overall picture of group changes, without separating groups on the basis of their scan result or psychological characteristics. (These comparisons will be made in subsequent chapters).

There has been no previous research evaluating whether first and second bone density scans have different psychological and behavioural effects. Both first and second bone density scans provide information about the absolute level of bone density, but since women having a second scan are already aware of their approximate level of bone density, it is possible that they will show a smaller degree of psychological reaction to this aspect of the information. However, unlike women having their first scan, women having a second scan also receive information about change in bone density between their two scans. The speed at which they are losing bone has implications for their future risk of osteoporosis and also provides some indication of the efficacy of any preventative behaviours which they may be undertaking. This information may have implications for emotional reactions to second scans: for example, if a woman who had previously had a low result on her first scan finds that she is losing bone quickly, despite taking preventative action, she may become distressed. Thus results from a second scan have a different type of meaning than results from a first scan. It is therefore important to evaluate the psychological and behavioural effects of first and second bone density scans. (There were not enough women having third scans to form a third group for comparison).

It is possible that when people are waiting for some kind of medical consultation, their feelings or attitudes about illness in general will be affected. Similarly, feelings about illness in general may change after one has had a medical consultation. Thus it is possible that any apparent psychological effect of bone density screening is actually a non-specific effect which might be detected after various types of medical consultation. In order to control for non-specific effects of imminent or recent medical contact, beliefs and feelings about osteoporosis will be assessed in a different sample of women before and after they have seen their GP. The change in beliefs in this sample will then be compared to the change in beliefs in the bone density sample.

5.2 Changes in feelings about osteoporosis over time, for women having their first or second bone density scan

In order to examine changes in feelings about osteoporosis over time, repeated measures analyses of variance were performed. In each of these analyses, the between-subjects factor is “group”, which refers first or second scan and the within-subjects factor is time. Analyses involving the variables which were used at each of the five assessment points (two before and three after the scan) will be presented first, followed by analyses of the measures which were only used at three points in time. Where significant effects were found, multiple comparisons were performed using paired t-tests or independent t-tests (using change scores where appropriate); only alpha levels of $p < 0.01$ were accepted as significant

Women were included in the first part of the analyses if they had completed each of the five questionnaires. There were 85 women in the second scan group and 273 in the first-scan group.

Table 5.1 shows the mean ratings for feelings about osteoporosis at each assessment point for women having their first or second scan.

Table 5.1 Feelings about osteoporosis at each assessment point: means and standard deviations.

	Scan	Initial Q		Before (day of scan)		After (day of scan)		Week after scan		3 months after scan	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Anxiety about bone density	First	26.1	[24.1]	12.9	[19.7]	11.4	[19.4]	14.7	[20.4]	15.4	[20.7]
	Second	24.1	[22.4]	8.4	[16.0]	12.2	[20.5]	19.5	[20.5]	18.8	[20.4]
Worry about developing ost.	First	37.1	[27.4]	30.1	[22.9]	22.0	[22.9]	24.3	[23.2]	23.5	[22.1]
	Second	42.8	[29.9]	33.6	[25.1]	30.8	[25.9]	33.3	[24.8]	31.7	[26.2]
Need for reassurance	First	43.1	[30.2]	38.0	[27.1]	24.1	[28.6]	20.7	[26.3]	21.2	[27.7]
	Second	48.0	[31.6]	42.8	[28.9]	31.8	[27.0]	31.7	[29.3]	27.8	[27.5]
Likelihood of ost. (near future)	First	26.9	[22.9]	23.8	[20.5]	18.9	[20.6]	16.8	[19.2]	18.6	[21.5]
	Second	35.2	[23.9]	29.4	[20.0]	26.9	[20.8]	25.4	[20.9]	23.9	[20.9]
Likelihood of ost. (at any time)	First	40.1	[24.7]	35.1	[21.9]	29.6	[22.7]	31.0	[22.0]	18.8	[21.5]
	Second	49.1	[27.6]	42.5	[23.5]	39.6	[25.3]	42.0	[25.4]	23.7	[21.0]
Seriousness of low BMD	First	46.0	[24.4]	49.3	[23.9]	48.3	[24.4]	47.5	[24.1]	38.3	[24.9]
	Second	48.2	[25.8]	49.6	[24.2]	48.4	[24.7]	50.9	[26.0]	37.4	[26.0]

Higher ratings indicate greater distress, higher risk perceptions or more negative beliefs.

Overview of results

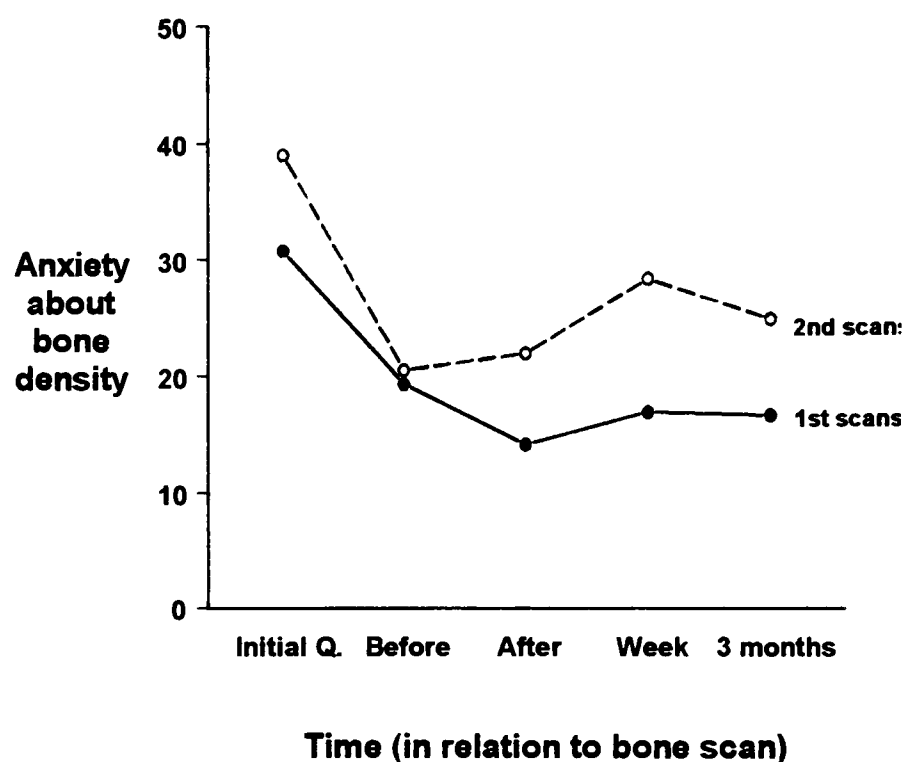
In general, women having second scans were more anxious and had felt at higher risk than women having first scans. Both groups showed significant decreases in both anxiety (general and osteoporosis-related) and

risk perceptions between the initial assessment and the three month follow-up, although if one used the assessment immediately before the scan as the baseline, the decreases were less marked or not apparent. There was little indication that first and second scans had differential effects in terms of anxiety about bone density, perceived risk or perceived seriousness.

Anxiety about bone density (See figure 5.1)

A repeated measures ANOVA showed a significant main effect of group ($F_{(1,353)}=11.17, p<0.005$) and a main effect of time ($F_{(4,1412)}=50.10, p<0.0005$). These effects were modified by a significant group by time interaction ($F_{(4,1412)}=3.88, p=0.005$).

Figure 5.1
Anxiety about bone density in
women having their first or second
scan.



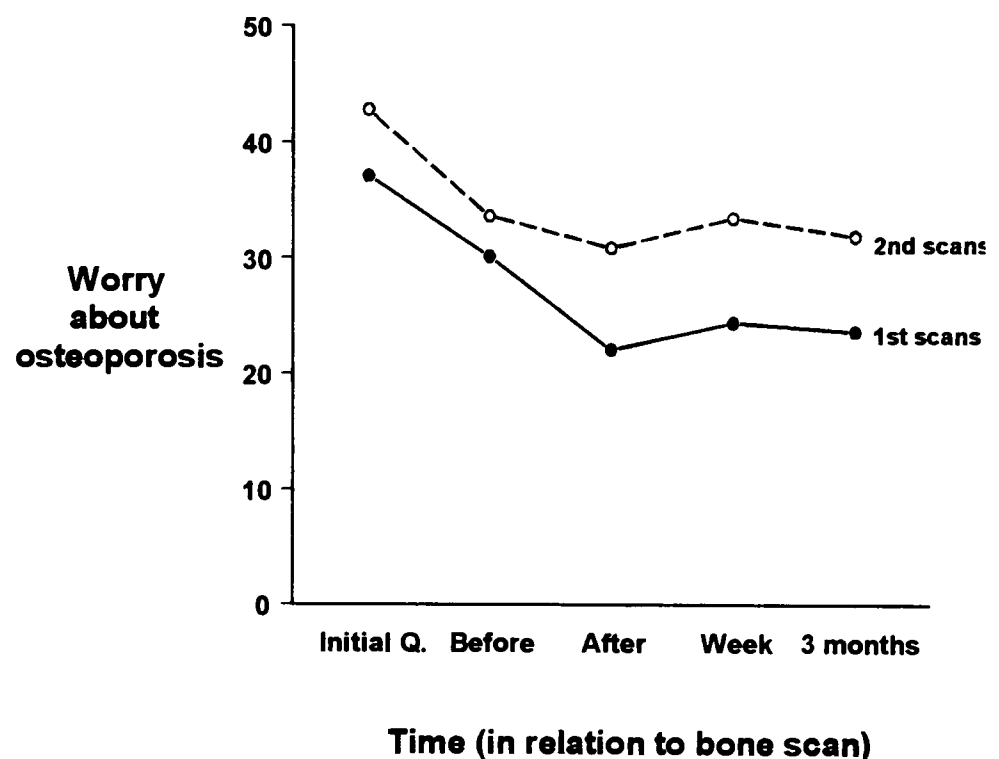
Multiple comparisons indicated that women having their second scan were significantly more anxious about their bone density than women having their first scan at every point in time except immediately before the scan, when there was no significant difference between the groups. Paired t-tests indicated that both groups showed a significant decrease in anxiety about bone density between the initial assessment and the one immediately before the scan, but t-tests using change scores showed that the second scan group showed a greater decrease in anxiety between these points. The first-scan group then showed a further significant decrease at the assessment immediately after the scan while the second scan group showed no significant change at this point. Both groups showed a significant increase in anxiety between the assessment immediately after the scan and the week follow-up and then no further significant change by the 3 month follow-up. Both groups showed significantly lower levels of anxiety at the 3 month follow-up than at the initial assessment and t-tests performed on change scores indicated no group difference in the amount of change between these two points. However, a t-test performed on change scores between the assessment

immediately before the scan and the 3 month follow-up showed a significant group effect, with the women having second scans showing a more negative reaction to the screening than women having first scans.

Worry about developing osteoporosis (See figure 5.2)

A repeated measures ANOVA showed a significant main effect of group ($F_{(1,350)}=7.48$, $p<0.05$), with the second scan group reporting more worry. There was also a significant main effect of time ($F_{(4,1400)}=31.24$, $p<0.0005$) but no significant group by time interaction ($F=1.55$). Paired t-tests indicated that there was a significant decrease in worry between the initial assessment and the assessment immediately before the scan, followed by a further decrease after the scan. There was no further change by the 3 month follow-up. At the 3 month follow-up, worry was significantly lower than it had been at the initial assessment and immediately before the scan.

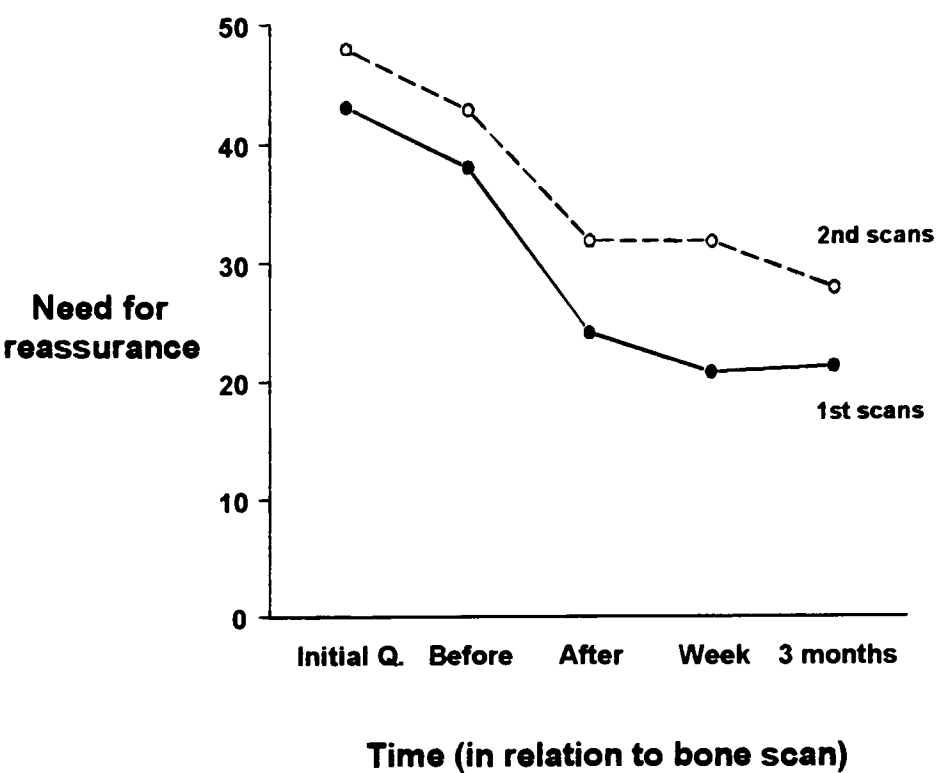
Figure 5.2
Worry about osteoporosis
in women having their first
or second scan.



Need for reassurance about her bone density (See figure 5.3)

A repeated measures ANOVA showed a significant main effect of group ($F_{(1,352)}=5.72$, $p<0.05$), with the second scan group feeling more in need of reassurance. There was a significant main effect of time ($F_{(4,1408)}=71.87$, $p<0.0005$) but no significant group by time interaction ($F=1.30$). Paired t-tests indicated that there was a significant decrease in need for reassurance between the initial assessment and the assessment immediately before the scan, followed by a further decrease after the scan and then no significant subsequent change by the 3 month follow-up. Ratings at the three month follow-up were significantly lower than at the initial assessment or the assessment immediately before the scan.

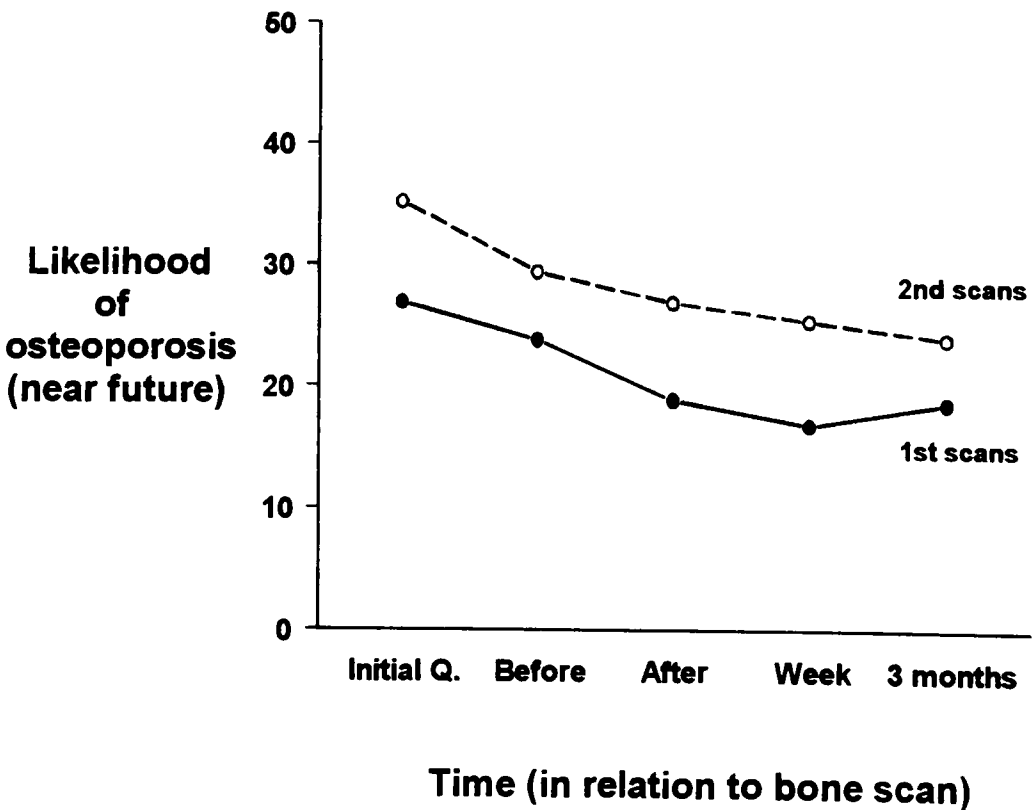
Figure 5.3
Need for reassurance about
one’s bone density in women
having their first or second scan.



Likelihood of developing osteoporosis in the near future (See figure 5.4)

A repeated measures ANOVA showed a significant main effect of group ($F_{(1,350)}=12.09, p<0.005$), with the second scan group having higher ratings. There was also a significant main effect of time ($F_{(4,1400)}=20.17, p<0.0005$). There was no significant group by time interaction ($F<1$). Paired t-tests indicated that there was a significant decrease in ratings between the initial assessment and the assessment immediately before the scan, followed by a further decrease after the scan and then no subsequent significant change by the 3 month follow-up. At the 3 month follow-up, ratings were significantly lower than they had been at the initial assessment and immediately before the scan.

Figure 5.4
Perceived likelihood of
developing osteoporosis
in the near future, for
women having their
first or second scans

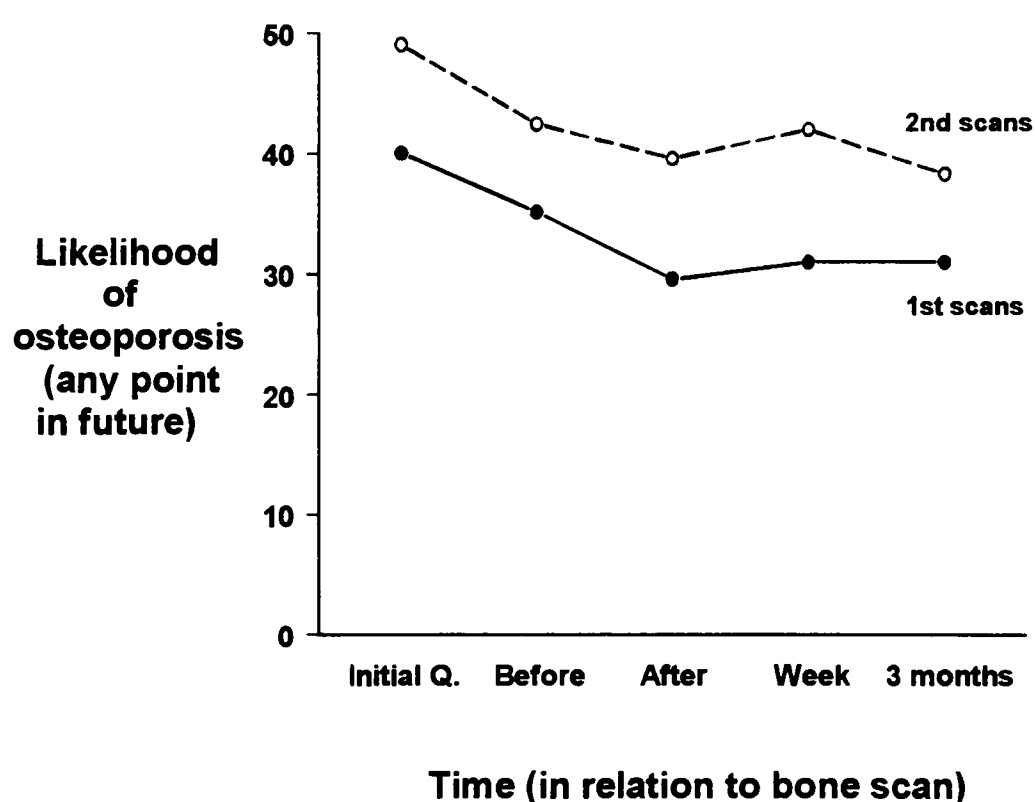


Likelihood of developing osteoporosis at any point in the future (See figure 5.5)

A repeated measures ANOVA showed a significant main effect of group ($F_{(1,350)}=13.27$, $p<0.0005$), with women having second scans having higher ratings. There was a significant main effect of time ($F_{(4,1400)}=19.71$, $p<0.0005$). There was no significant group by time interaction ($F<1$). Paired t-tests indicated that there was a decrease in ratings between the initial assessment and the assessment immediately before the scan, followed by a further decrease after the scan and then no subsequent significant change by the 3 month follow-up. At the 3 month follow-up, ratings were significantly lower than they had been at the initial assessment and immediately before the scan.

Figure 5.5

Perceived likelihood of developing osteoporosis at any point in the future, for women having their first or second scan.



Seriousness of below average bone density

A repeated measures ANOVA showed no significant main effect of group ($F_{(1,348)}<1$) or of time ($F_{(4,1392)}<1$) and there was no significant group by time interaction ($F_{(4,1392)}<1$).

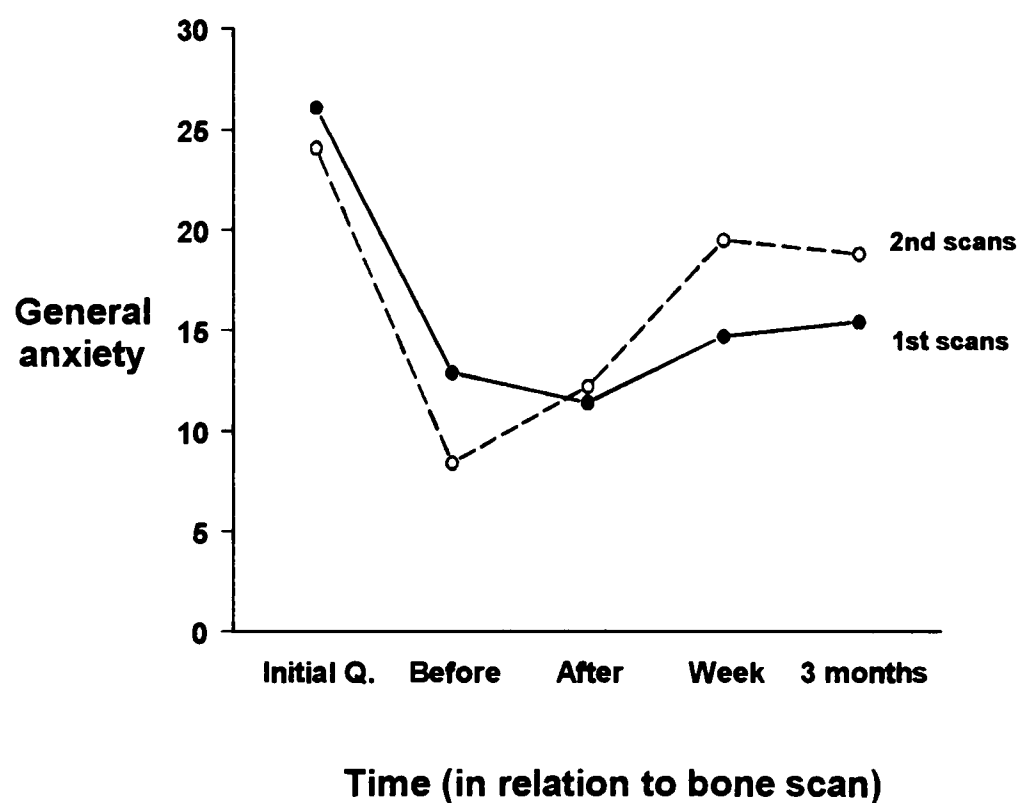
General anxiety (See figure 5.6)

A repeated measures ANOVA showed no significant main effect of group ($F_{(1,356)}<1$) but there was a significant main effect of time ($F_{(4,1424)}=36.44$, $p<0.0005$) and significant group by time interaction ($F_{(4,1424)}=4.05$, $p<0.005$). (See table 5.2 for means and standard deviations).

There were no significant differences in general anxiety between the two groups at any point in time. Paired t-tests indicated that both groups showed a significant decrease in anxiety between the initial assessment and the one immediately before the scan. Neither group showed a subsequent significant change

in anxiety at the assessment immediately after the scan, but then by the 3 month follow-up, anxiety had increased again for both groups. For both groups anxiety was significantly lower at the three month follow-up than at the initial assessment, although a t-test using change scores indicated that there was a non-significant trend for the women having second scans to show a smaller decrease in anxiety than women having first scans at the 3 month follow-up ($p=0.044$). Between the assessment immediately before the scan and the three month follow-up there was no significant change in anxiety for the first scan group but a significant increase for the second scan group.

Figure 5.6
General anxiety in women
having their first or second
scan.



Low mood and sadness (See figure 5.7)

A repeated measures analysis of variance showed a significant main effect of time ($F_{(4,1416)}=20.34$, $p<0.0005$) but there was no significant main effect of group ($F_{(1,354)}<1$) or group by time interaction ($F_{(4,1416)}=2.16$). Paired t-tests indicated that sadness was significantly lower on the day of the scan and a week later than at the initial ratings. By the 3 month follow-up, ratings were not significantly different from ratings at the initial assessment and were higher than they had been immediately before the scan. (See table 5.2 for means and standard deviations).

Figure 5.7
Sadness or low mood in
women having their first
or second scan.

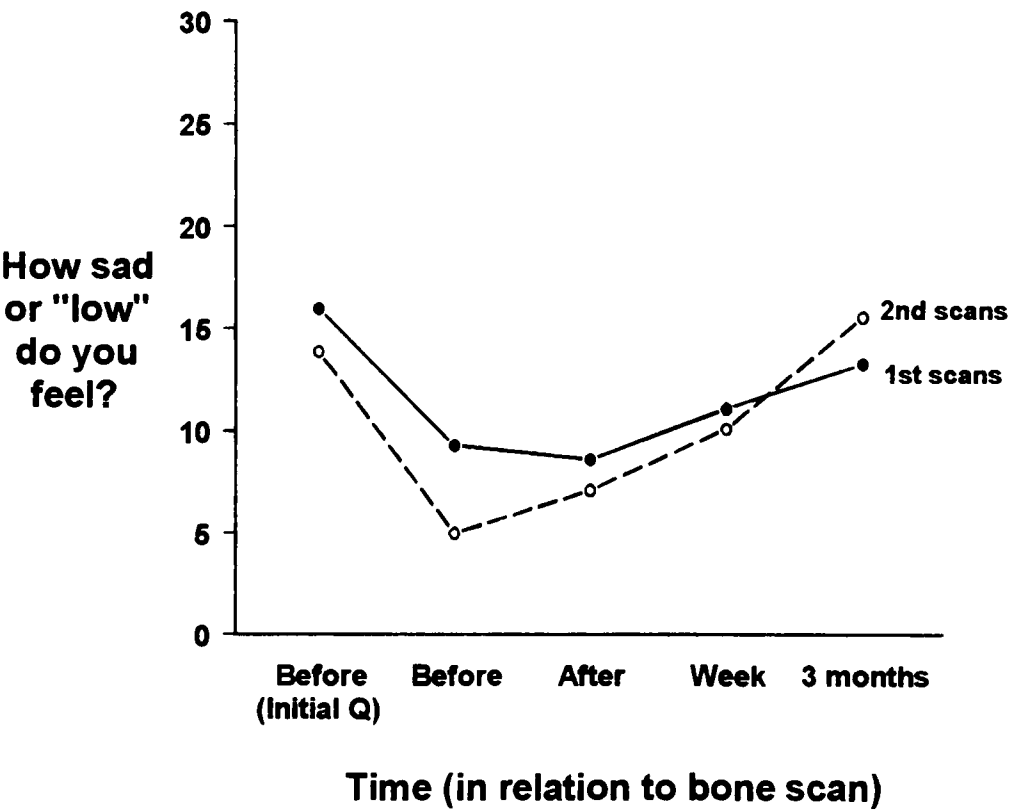


Table 5.2 : General anxiety and “low” mood at each assessment point: means and standard deviations

		Initial Q		Before (day of scan)		After (day of scan)		Week after scan		3 months after scan	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
General anxiety	1	26.1	[24.1]	12.9	[19.7]	11.4	[19.4]	14.7	[20.4]	15.4	[20.7]
	2	24.1	[22.4]	8.4	[16.0]	19.5	[20.5]	19.5	[20.5]	18.8	[20.4]
Feeling sad or “low”	1	16.0	[21.6]	9.3	[17.5]	8.6	[17.0]	11.1	[17.9]	15.4	[20.7]
	2	13.9	[18.6]	5.1	[11.0]	7.1	[14.9]	10.1	[16.8]	18.8	[20.4]

Change in beliefs about osteoporosis (Part Two): Variables used at three assessment points

Further variables assessing beliefs about osteoporosis were used in the initial questionnaire and follow-up questionnaires (a week and three months later) but not used on the day of the scan. Group changes on these variables were investigated using repeated measures analysis of variance for these three points in time. No significant group by time interactions were found. Where significant effects of time are found, paired t-tests are used to investigate them further; only alpha values of $p<0.01$ are accepted as significant. There were 291 women coming for their first scan who completed the three relevant questionnaires and 87 women coming for their second scan. Table 5.3 (overleaf) shows means and standard deviations for ratings of beliefs about osteoporosis, for women having their first or second scan.

Table 5.3 Ratings of beliefs about osteoporosis taken at only three points in time, for women having their first or second scan.

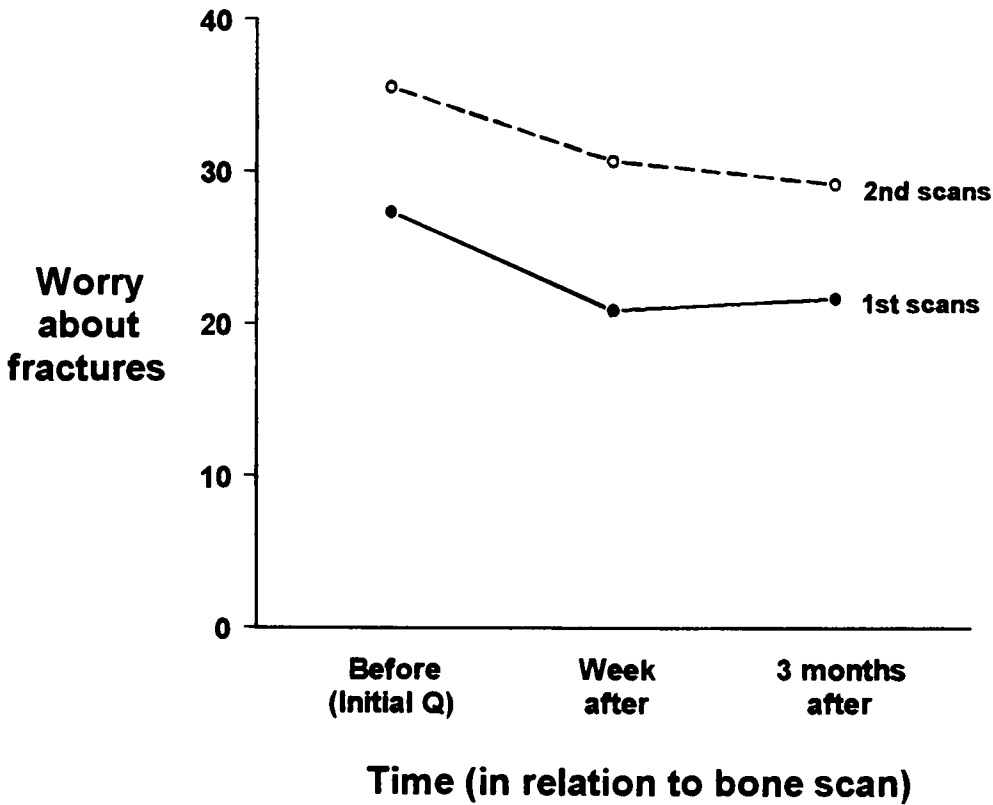
	Scan	Before: Initial Q		Week after		3 months after	
		Mean	SD	Mean	SD	Mean	SD
Worry about falling and fracturing her bones	First	27.3	[27.5]	20.8	[23.3]	21.6	[24.3]
	Second	35.5	[31.1]	30.6	[27.4]	29.1	[27.0]
Vulnerability to osteoporosis	First	38.0	[26.4]	26.8	[24.1]	26.7	[24.4]
	Second	46.7	[30.2]	41.6	[28.2]	38.2	[27.7]
Risk compared to other women of her age (scale of -3 to 3)	First	0.01	[1.34]	-0.44	[1.60]	-0.42	[1.52]
	Second	0.83	[1.41]	0.59	[1.59]	0.60	[1.44]
Likelihood of prevention of osteoporosis if have low BMD	First	62.5	[24.8]	57.0	[23.3]	55.1	[24.1]
	Second	64.8	[23.4]	59.0	[23.4]	55.7	[24.4]
Coping ability if developed osteoporosis	First	35.8	[22.9]	35.4	[21.4]	36.2	[23.4]
	Second	32.3	[22.5]	36.6	[21.6]	34.5	[21.9]
Cost 1: Effect osteoporosis would have on her ability to enjoy life	First	36.2	[24.5]	34.4	[22.5]	38.6	[25.0]
	Second	37.3	[26.2]	37.6	[26.4]	38.7	[26.0]
Cost 2: How bad the consequences of osteoporosis would be for her	First	46.5	[23.6]	41.3	[22.4]	42.7	[23.4]
	Second	49.3	[26.0]	46.8	[23.3]	43.2	[22.7]

Higher ratings indicate more negative beliefs except for prevention beliefs where high ratings indicate a greater perceived likelihood of preventing osteoporosis.

Worry about falling and fracturing one’s bones (See figure 5.8)

A repeated measures ANOVA showed a main effect of group ($F_{(1,376)}=9.15, p<0.005$), with the second scan group reporting more worry about falling and fracturing one’s bones. There was also a main effect of time ($F_{(2,752)}=14.46, p<0.00005$) but no group by time interaction. Paired t-tests indicated that there was significantly lower levels of worry about fracture at both of the follow-ups than at the initial assessment. There was no significant change between the week and 3 month follow-ups.

Figure 5.8
Worry about falling and fracturing one’s bones, in women having their first or second scan.

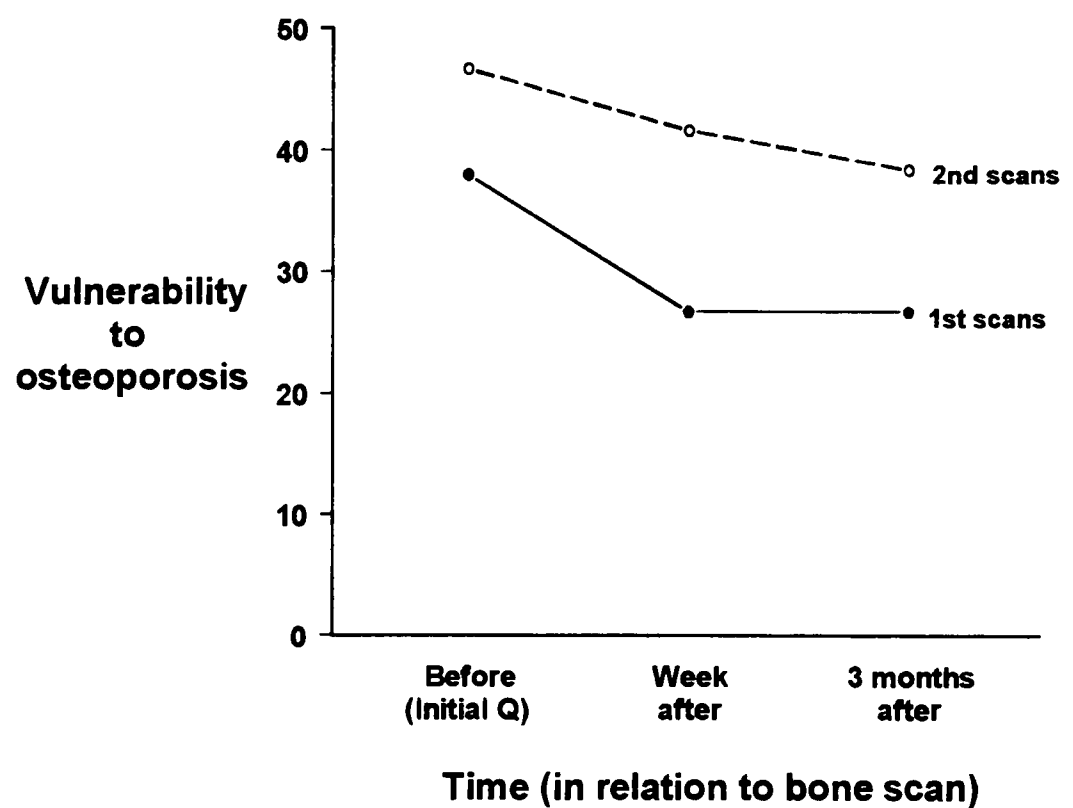


Vulnerability to osteoporosis (See figure 5.9)

A repeated measures ANOVA showed a main effect of group ($F_{(1,369)}=18.05$, $p<0.0005$), with the second scan group feeling more vulnerable to osteoporosis. There was also a main effect of time ($F_{(2,738)}=28.87$, $p<0.0005$) but no significant group by time interaction. Paired t-tests indicated that there were significantly lower levels of perceived vulnerability at both of the follow-ups than at the initial assessment. There was no significant change between the week and 3 month follow-ups.

Figure 5.9

Perceived vulnerability to developing osteoporosis in women having their first or second scan.

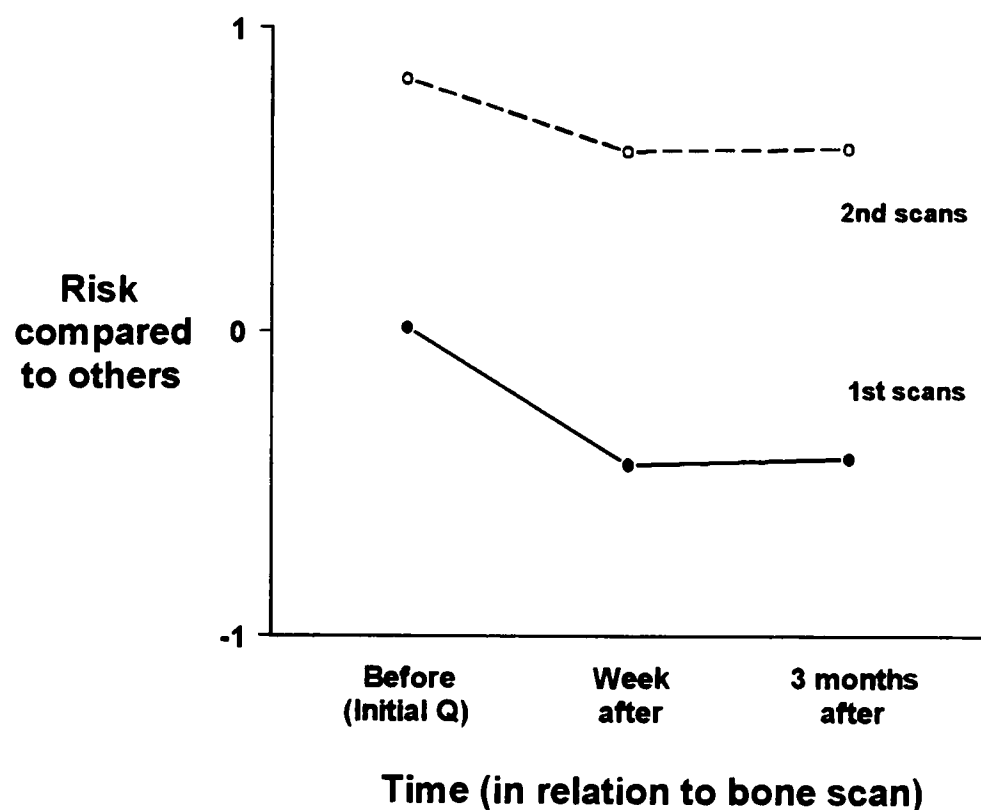


Risk compared to other women of the same age (See figure 5.10)

(See overleaf for details of the analyses).

Figure 5.10

Perceived risk for osteoporosis compared to "the average woman" of same age in women having their first or second scan
(Rating scale of -3 - much less at risk to +3- much more at risk.
 ± 1 =slightly more/less at risk)

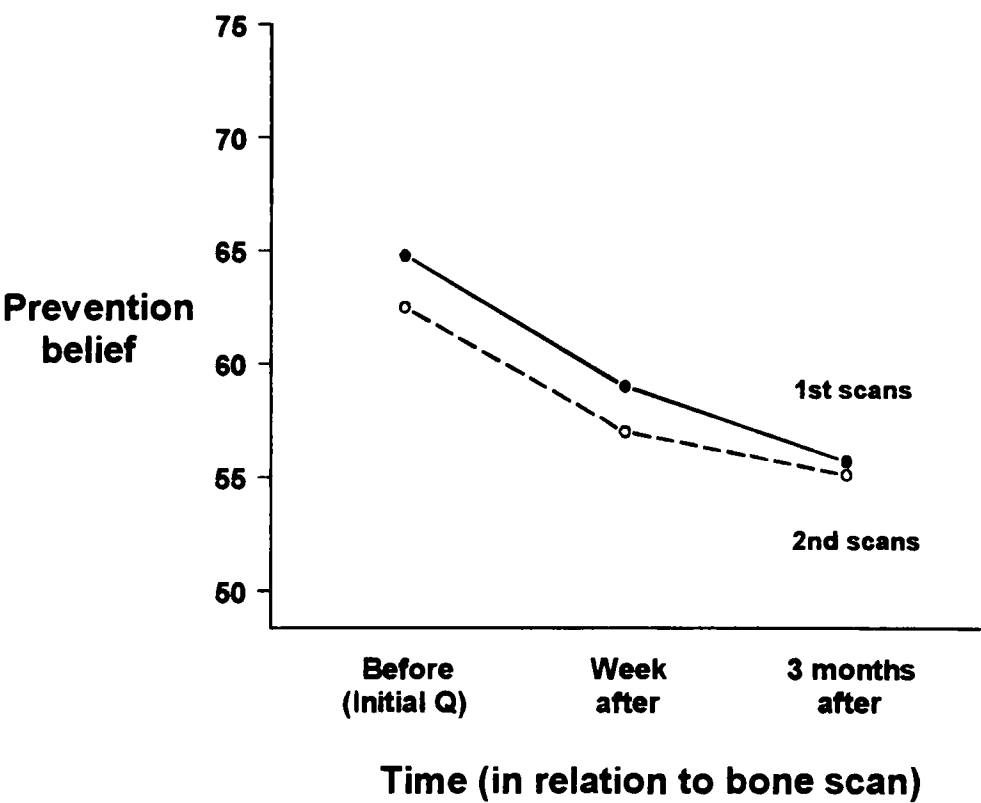


A repeated measures ANOVA for ratings of risk compared to the average woman of the same age showed a main effect of group ($F_{(1,370)}=37.71, p<0.0005$), with the second scan group having higher risk perceptions. There was also a main effect of time ($F_{(2,740)}=10.68, p<0.0005$), but there was no group by time interaction. Paired t-tests indicated that there was significantly lower levels of perceived risk at both of the follow-ups than at the initial assessment. There was no significant change between the week and 3 month follow-ups.

Perceived likelihood of preventing osteoporosis if you have low bone density (See figure 5.11)

Repeated measures showed a main effect of time ($F_{(2,682)}=13.16, p<0.0005$) but no main effect of group or group by time interaction. Paired t-tests indicated that there was significantly lower levels of prevention beliefs at both of the follow-ups than at the initial assessment. (In other words, after the scan, women felt that it was less likely that prevention was possible). There was a non-significant trend towards a decrease in ratings between the week and 3 month follow-ups.

Figure 5.11
Perceived likelihood of preventing symptoms of osteoporosis if one has low bone density.
(Higher values indicate greater perceived likelihood of prevention)



Anticipated ability to cope if she developed osteoporosis

A repeated measures ANOVA showed no significant main effects or interactions.

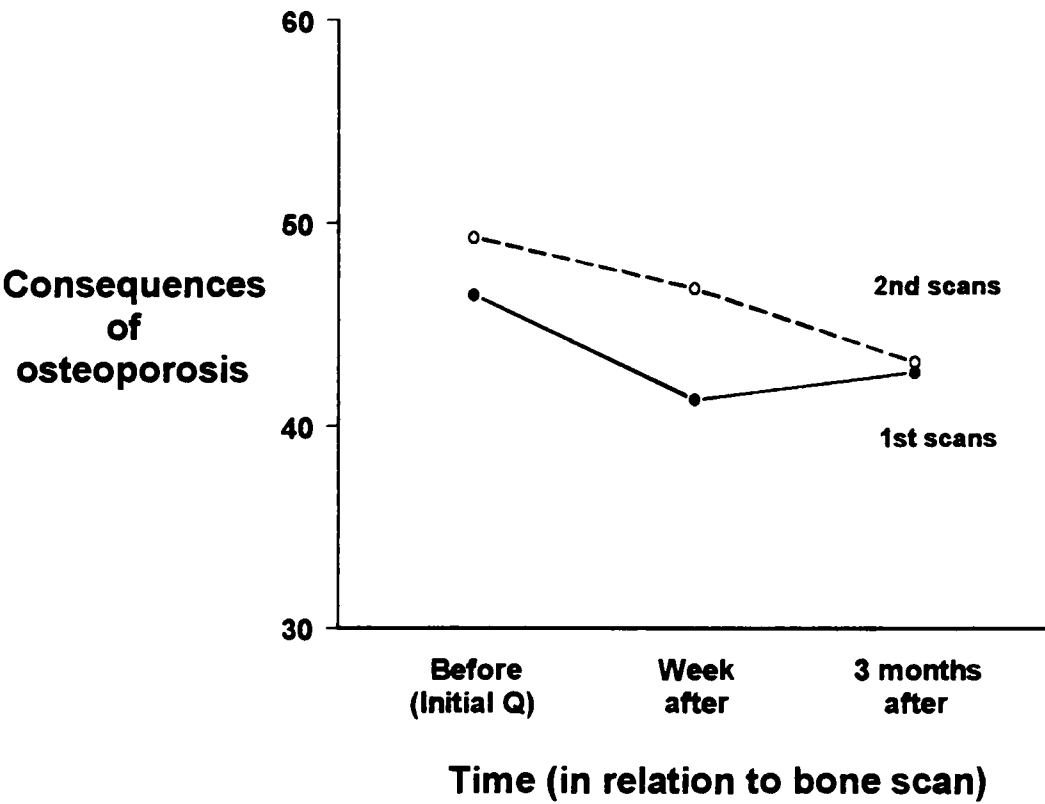
The effect of osteoporosis would have on her ability to enjoy life

A repeated measures ANOVA showed no significant main effects or interactions.

How bad the consequences of osteoporosis would be for her (See figure 5.12)

A repeated measures ANOVA showed a main effect of time ($F_{(2,746)}=8.73, p<0.0005$) but no significant main effect of group or group by time interaction. Paired t-test indicated that women rated the consequences of osteoporosis as being less “bad” at the follow-ups than at the initial assessment.

Figure 5.12
Perceived severity of the consequences of osteoporosis in women having their first or second bone scan



Likelihood of developing other serious illness

Repeated measures analyses of variance were performed on ratings of perceived likelihood of developing a serious illness other than osteoporosis, in the near future and at any point in the future. Neither showed significant main effects or interactions. (See table 5.4 for means and standard deviations).

Table 5.4 Ratings of perceived likelihood of developing any serious illness, for women having their first or second scan.

		Before scan		Week after		3 months	
		Mean	SD	Mean	SD	Mean	SD
Likelihood of developing a serious illness in the near future	1	19.3	[18.9]	18.8	[18.8]	18.2	[17.7]
	2	23.1	[21.1]	21.1	[19.0]	22.9	[20.5]
Likelihood of developing a serious illness at any point in the future	1	35.5	[24.7]	33.9	[22.6]	33.9	[23.1]
	2	36.3	[25.7]	33.1	[24.2]	33.7	[25.5]

Change in ratings before the scan

In order to examine the changes in ratings before the scan in more detail, specific correlational analyses were performed (using only women having first or second scans who had completed the questionnaires at each

point in time). It was hypothesized that if the decrease in ratings were due to social desirability effects on the day of the scan, then the changes may relate to scores on the Spielberger trait anxiety questionnaire (since people with high trait anxiety may show greater desire to present themselves in a positive light). It was found that change in ratings of general anxiety correlated significantly with score on the Spielberger trait anxiety questionnaire ($r_{(350)}=-0.165$, $p<0.005$) (the higher the score, the greater the decrease), and ratings of sadness showed a similar pattern ($r_{(348)}=-0.263$, $p<0.0005$). However, scores on the Spielberger trait anxiety questionnaire did not correlate significantly with changes in ratings of anxiety about bone density, worry about osteoporosis, perceived likelihood of osteoporosis, need for reassurance or perceived seriousness of below-average bone density.

Changes in ratings of general anxiety were also negatively correlated with scores on the Health Anxiety Questionnaire ($r_{(346)}=-0.144$), $p<0.05$), (the higher the HAQ score, the greater the decrease) as were ratings of sadness ($r_{(344)}=-0.11$, $p<0.05$). However, higher scores on the Health Anxiety Questionnaire were positively correlated with ratings of perceived likelihood of osteoporosis at any point in the future ($r_{(344)}=0.13$, $p<0.05$) (the higher the HAQ score, the smaller the decrease in ratings).

These patterns of correlations are not consistent with an explanation of pre-scan decreases in terms of a social desirability effect.

5.3 Changes in osteoporosis-related preventative behaviours

A repeated measures ANOVA for the total number of osteoporosis-preventative behaviours reported before the scan and 3 months later showed a main effect of group ($F_{(1, 446)}=11.1$, $p<0.005$) and time ($F_{(1, 446)}=136.3$, $p<0.0005$). There was also a non-significant trend towards a group by time interaction ($F_{(1, 446)}=3.6$, $p=0.057$). More preventative behaviours were reported at the 3 month follow-up than before the scan. Women having their second scan reported more osteoporosis-related preventative behaviours than women having their first scan (see table 5.5). (All women who had completed the relevant questionnaires were included in these analyses: 339 women having first scans and 109 women having second scans).

Table 5.5 Number of osteoporosis- preventative behaviours reported by women having their first or second scan

	Number of preventive behaviours			
	Before the scan		3 months after scan	
	Mean	SD	Mean	SD
Women having their first scan	0.76	[1.0]	1.6	[1.1]
Women having their second scan	1.21	[1.1]	1.8	[1.1]

A McNemar test performed on the first group indicated that there was a significant change in the proportion of women reporting preventative behaviours over time ($\chi^2_{(1)}=88.07, p<0.00005$) (see table 5.6). A binomial test indicated that there was a significant change in the proportion of women having a second scan who reported preventative behaviours over time ($p<0.00005$). The percentage of women having who reported at least one osteoporosis-preventative behaviour increased from 47.4% before the scan to 78.6% after the scan in the first group and from 68.6% to 87.4% in the second group. Chi-square analyses indicated that a higher proportion of the second group reported at least one preventative behaviours before the scan ($\chi^2_{(1)}=15.2, p<0.00005$) and afterwards ($\chi^2_{(1)}=4.2, p<0.05$).

At the 3 month follow-up, only 4.4% (15) of those having had a first scan and 3.6% (4) of those having had a second scan say that they intend to begin any other preventative measures in the future.

Table 5.6 Change in osteoporosis-preventative behaviours after the bone density scan.

Osteoporosis -preventative behaviours reported before and after the scan	First scans		Second scans	
	%	n	%	n
No change: Preventative behaviour(s)	44.0	(152)	67.6	(75)
No preventative behaviours	18.3	(63)	11.7	(13)
Started preventative behaviour(s)	34.5	(119)	19.8	(22)
Stopped preventative behaviour(s)	3.2	(11)	0.9	(1)

Changes in different types of osteoporosis-preventative behaviours after first scans

Table 5.7 shows the numbers of women having first scans who report the various different osteoporosis-preventative behaviours before and three months after their first bone density scan (n=339). Chi-square analyses and binomial tests indicated that there were significant increases in the numbers of women reporting all of the main types of behaviours: exercise, HRT, diet (e.g. high in calcium), calcium supplements, other minerals or vitamins and miscellaneous behaviours.

Table 5.7 The proportion of women reporting different preventative behaviours in an attempt to prevent osteoporosis before and after first scans.

	Before the scan		Three months after the scan		McNemar test
	%	N	%	N	
Exercise	20.4	(69)	46.0	(156)	$\chi^2=61.1, p<0.00005$
HRT	15.3	(52)	21.2	(72)	$\chi^2=6.7, p<0.05$
Diet	12.4	(42)	53.7	(182)	$\chi^2=123.8, p<0.00005$
Calcium supplements	15.3	(52)	27.1	(92)	$\chi^2=20.6, p<0.00005$
Other minerals or vitamins	12.1	(41)	5.6	(19)	$\chi^2=11.0, p<0.0005$
Didronel PMO	0	(0)	1.8	(6)	Binomial test $p<0.05$
Other	0.9	(3)	3.8	(13)	Binomial test $p<0.05$

Changes in different types of behaviours after second scans

Table 5.8 shows the numbers of women reporting different types of osteoporosis- preventative behaviours before and after a second bone density scan (n=109). Chi-square analyses indicated that there were significant increases in the numbers of women reporting exercise, dietary care, calcium supplements, other minerals or vitamins. Binomial tests indicated that there was no significant difference in the numbers of women reporting taking HRT, Didronel PMO or miscellaneous measures.

Table 5.8 The proportion of women reporting different preventative behaviours before and after **second** scans

	Before the scan		Three months after the scan		McNemar test
	%	N	%	N	
Exercise	27.5	(30)	51.4	(56)	$\chi^2=18.4$, $p<0.00005$
HRT	21.1	(23)	23.9	(26)	Binomial test not sig.
Diet	30.3	(33)	50.5	(55)	$\chi^2=11.0$, $p<0.0005$
Calcium supplements	26.6	(29)	39.4	(43)	$\chi^2=11.0$, $p<0.0005$
Other minerals or vitamins	10.1	(11)	9.2	(10)	$\chi^2=11.0$, $p<0.0005$
Didronel PMO	1.8	(2)	1.8	(2)	Binomial test not sig.
Other	3.7	(4)	4.6	(5)	Binomial test not sig.

Limiting actions to avoid fractures

A McNemar’s test indicated that there was no significant change after the scan in the proportion of women having first scans saying that they limited their activities to avoid fractures. A binomial test indicated that the same was true for women having second scans. Chi-square analyses showed that after the scans, women having second scans were more likely to limit their activities than women having first scans ($\chi^2_{(1)}=4.3$, $p<0.05$), although there was no group difference beforehand.

Other types of preventative behaviours

Miscellaneous osteoporosis-preventative behaviours mentioned by women before or after first and second scans are shown in table 5.9, overleaf . (For interest, responses from all women are reported, not only those who completed both initial and follow-up questionnaire). It should be noted that some of these have no proven effectiveness in preventing osteoporosis and some, such as losing weight, may even result in lower bone density.

Table 5.9 Miscellaneous behaviours reported as aimed at preventing osteoporosis by women having first and second scans

	1st	2nd
Before the scan	n	n
Taking a tincture from a herbalist	1	
Seeing a homeopath regularly to keep healthy	1	
“Having lots of interests”	1	
After the scan		
Joining the National Osteoporosis Society	2	
Fresh air (as separate from exercise)	2	
Not smoking (most women didn’t smoke but didn’t mention this)	2	
Trying to cut down and eventually stop smoking	1	
Reduced tea, coffee or caffeine consumption	1	1
Sun-bathing	1	1
Positive thinking (i.e. visualisation)	1	
GP has reduced dose of thyroxine (which can affect bone density)	1	
Not so concerned about losing weight	1	
Care not to become any weightier	1	1
Lose weight		1
“Watch out for changes in my physical health”	1	
“A think-ahead attitude- I always thought my bones were strong”	1	
Low or no alcohol consumption	2	1
Stopped taking progesterone-only pill		1
“Gaviscon and sol. Sulpherdine”		1
No additives. plenty of water		1

5.4 Beliefs and mood immediately before and after the scan; comparison with the control group

In the previous section it was reported that many of the ratings of beliefs about osteoporosis showed a decrease after the bone scan. It is possible that this effect would have been found with other types of medical consultation; for example, people might feel more negative about their health in general before seeing a doctor or having a test but will become more positive again afterwards. In order to examine whether the overall decrease in ratings were a result of the bone scan or would be found if women were asked the same questions before and after another medical consultation, a comparison is made between women having their first scan and women seeing their GP. It was predicted that for anxiety/worry about osteoporosis, need for reassurance about one’s bone density and risk perceptions, there would be a significant group by time interaction, due to greater changes in feelings in the bone density group than in the control group.

Treatment of data

Repeated measures analyses of variance were performed using the eight variables which were given before and after the scan or medical consultation. These analyses were also repeated using trait anxiety and depression as covariates since the control group have higher scores on the Spielberger trait anxiety inventory

and Beck Depression Inventory. Significant effects were investigated further using univariate analyses of covariance together with paired t-tests. In all cases with the effect or difference is judged significant if $p<0.05$.

The analyses presented in this section were performed using all women having first scans for whom data were available for the before and after “on the day” variables and BDI and STAI-T scores (345 women). The repeated measures analyses of variance were repeated using all the women for whom “before” and “after” scores were available (536 women), regardless of whether they completed the BDI and STAI-T. The pattern of significant effects was identical to the analysis reported below.

The means and standard deviations for the beliefs in the two groups are shown in the table below.

Table 5.10 Psychological assessments taken immediately before and after a bone scan or medical consultation; means and standard deviations.

		Before the bone scan or medical consultation		After the bone scan or medical consultation	
		Mean	SD	Mean	SD
General anxiety	A	13.4	[19.8]	11.7	[19.9]
	B	31.5	[27.5]	26.5	[26.5]
Sadness or ‘low’ mood	A	10.0	[18.8]	9.2	[17.4]
	B	29.5	[31.3]	25.7	[28.5]
Anxiety about bone density	A	19.9	[21.7]	14.1	[21.1]
	B	27.7	[22.2]	31.9	[23.0]
Worry about osteoporosis	A	30.5	[23.3]	21.2	[23.0]
	B	39.3	[26.5]	34.0	[24.3]
Likelihood of osteoporosis in the near future	A	24.2	[20.1]	18.2	[20.3]
	B	32.4	[24.7]	32.9	[21.3]
Likelihood of osteoporosis at any point in the future	A	35.2	[21.8]	28.5	[22.4]
	B	40.2	[23.9]	40.9	[24.6]
Seriousness of below-average bone density	A	49.5	[23.9]	49.5	[25.1]
	B	55.8	[26.7]	53.1	[26.8]
Need for reassurance	A	38.6	[26.9]	24.0	[28.5]
	B	38.4	[29.5]	40.2	[29.8]

A: women having their first bone scan, B: women seeing their GP

Overview of the results

Immediately before the scan / medical consultation, the bone density group’s ratings of anxiety about osteoporosis, perceived likelihood of developing osteoporosis and need for reassurance were not significantly different from those of the control group. Afterwards, the control group showed higher ratings for these feelings (when depression and trait anxiety are entered as covariates), due to a significant decrease in ratings

in the bone density group. Ratings concerning the seriousness of low bone density showed no group differences. The control group showed higher levels of general anxiety and sadness/low mood at both points in time, even when trait anxiety and depression were entered as covariates.

Anxiety about bone density: There was a main effect of group ($F_{(1,386)}=18.45$, $p<0.0005$) and a significant group by time interaction ($F_{(1,386)}=7.80$, $p=0.005$). When trait anxiety and depression were entered as covariates there was still a significant group effect ($F_{(1,384)}=12.98$, $p<0.0005$). Univariate analyses of covariance using trait anxiety and depression as covariates showed that there was no difference between groups beforehand but there was a significant differences afterwards ($F_{(1,384)}=21.9$, $p<0.0005$). Paired-t-tests showed that the control group showed no change over time whereas the women having their first bone scan showed a significant decrease after the scan ($t_{(345)}=4.72$, $p<0.0005$).

Worry about osteoporosis: There was a main effect of group ($F_{(1,385)}=10.06$, $p<0.005$), with the control group being more worried. There was also a significant main effect of time ($F_{(1,385)}=19.41$, $p<0.0005$), due to a decrease in worry over time. There was no significant group by time interaction ($F_{(1,385)}=1.4$). When trait anxiety and depression were entered as covariates there was still a main effect of group ($F_{(1,383)}=5.46$, $p<0.05$).

Despite the fact that there was no significant group by time interaction, the two groups were compared at the different points in time because there had been an *a priori* prediction about the differential effects of bone density scans and GP visits on worry about osteoporosis. Indeed, univariate analyses of covariance using trait anxiety and depression as covariates showed that there was no main effect of group beforehand but that there was the control group were significantly more worried afterwards ($F_{(1,383)}=7.94$, $p=0.005$).

Likelihood of osteoporosis in the near future: There was a significant main effect of group ($F_{(1,384)}=15.08$, $p<0.0005$) and a significant group by time interaction ($F_{(1,384)}=4.14$, $p<0.05$). When trait anxiety and depression were entered as covariates there was still a main effect of group ($F_{(1,382)}=9.42$, $p<0.005$). Univariate analyses of covariance using trait anxiety and depression as covariates showed that there was no main effect of group beforehand but there was a main effect afterwards ($F_{(1,382)}=14.35$, $p<0.0005$). Paired t-tests showed that the women having the bone scan showed a decrease in ratings ($t_{(344)}=8.14$, $p<0.0005$) while the control group showed no change.

Likelihood of osteoporosis at any point in the future: There was a significant main effect of group ($F_{(1,390)}=7.29$, $p<0.05$) and a significant group by time interaction ($F_{(1,386)}=5.21$, $p<0.05$). When trait anxiety and depression were entered as covariates a significant effect of group remained ($F_{(1,384)}=4.04$, $p<0.05$). Univariate analyses of covariance using trait anxiety and depression as covariates showed that there was no main effect of group beforehand but there was a main effect afterwards ($F_{(1,384)}=8.45$, $p<0.005$). Paired t-tests showed that this was due to the women having a bone scan showing a decrease ($t_{(345)}=6.02$, $p<0.0005$) while the control group showed no significant change.

Seriousness of below average bone density: There were no significant main effects or interactions, whether or not trait anxiety and depression were used as covariates.

Need for reassurance about bone density: There was a marginally significant main effect of group ($F_{(1,385)}=3.77$, $p=0.053$), a significant main effect of time ($F_{(1,385)}=11.34$, $p<0.005$) and a significant group by time interaction ($F_{(1,385)}=18.97$, $p<0.0005$). When trait anxiety and depression were entered as covariates there was no longer a main effect of group ($F=1.50$). Univariate analyses of covariance using trait anxiety and depression as covariates showed that there was no main effect of group beforehand but there was a main effect afterwards ($F_{(1,383)}=8.15$, $p<0.005$), with the control group reporting stronger need for reassurance. Paired t-tests showed that the women having the scan had decreased significantly ($t_{(344)}=11.27$, $p<0.0005$) while the control group showed no significant change.

General anxiety: There was a main effect of group ($F_{(1,386)}=32.31$, $p<0.0005$), with the control group reporting more anxiety. There was also a significant main effect of time ($F_{(1,386)}=4.0$, $p<0.05$), with anxiety decreasing over time. There was no group by time interaction ($F<1$). There was still a significant effect of group when depression and trait anxiety were used as covariates ($F_{(1,384)}=22.6$, $p<0.0005$).

Sadness/low mood: There was a significant main effect of group ($F_{(1,396)}=36.70$, $p<0.0005$), with the control group reporting higher levels of sadness. There was also a significant effect of time ($F_{(1,385)}=3.9$, $p<0.05$) with sadness decreasing over time. There was still a significant effect of group when depression and trait anxiety were used as covariates ($F_{(1,383)}=24.4$, $p<0.0005$).

5.5 Summary and discussion

Changes in feelings and beliefs between the two assessments *before* the scan

For these samples of women having their first or second bone scan, anxiety (general and osteoporosis-related), worry, need for reassurance and likelihood of osteoporosis were all significantly lower immediately before the scan than at the initial assessment (approximately two weeks before the scan). These decreases in ratings before the scan account for the fact that although in the previous chapter it was shown that women having their first bone scan felt more in need of reassurance about their bone density than the control group two weeks before the scan (covarying for BDI and STAI-trait), when the ratings made immediately before the scan / medical consultation were compared, there was no significant group difference. It is not possible to determine from this data which point in time gives the best representation of a “baseline” level for women. Anxiety ratings immediately before the scan may be lower than usual because the women are just about to find out their results and to have any uncertainty relieved. The decrease in risk perceptions may be caused by the reduction in anxiety. Alternatively, the decreases in likelihood perceptions could be due to some kind of minimization of the risk in order to manage anxiety before the scan. But these are only tentative suggestions and the present study does not provide evidence which can be used to test these possibilities.

It is possible that the initial ratings are higher than usual because the act of making an appointment heightens uncertainty and anxiety. This could explain the fact that at the initial assessment, the bone density group report more need for reassurance about their bone density and more worry about osteoporosis than the control group (if depression, trait and state anxiety are controlled for). Alternatively, these feelings may have existed before the appointment had been made and may have been a factor in these women volunteering for a scan. In order to examine these possibilities, a group of women could be asked to complete a similar initial questionnaire and then asked whether they would like to volunteer for a bone scan. It would then be possible to investigate the levels of anxiety and so on before and after the women had made their appointment and to examine whether pre-existing feelings affected the choice to be scanned. In addition, anxiety levels immediately before the scan could be compared to anxiety levels before the appointment had been offered.

An alternative explanation for the decrease in anxiety ratings on the day of the scan is that social desirability effects may have caused women to present a less anxious set of responses on the day of the scan. The initial questionnaire was completed in the women’s own home while the next questionnaire was completed in the waiting room and handed back to the experimenter. One might expect that the desire to present oneself in a positive light might correlate with trait anxiety, so to investigate the social desirability

hypothesis correlations were performed between the change in ratings before the scan and score on the Spielberger trait anxiety scale. This indicated that those with higher trait anxiety did show a larger decrease in anxiety and sadness on the day of the scan, but there was no correlation between trait anxiety and the variables specific to osteoporosis. Scores on the Health Anxiety Questionnaire also correlated with a greater decrease in general anxiety and sadness. However, scores on the Health Anxiety Questionnaire showed a correlation with an increase (or lesser decrease) in ratings for perceived likelihood of osteoporosis. Overall, the pattern of correlations is not consistent with a social desirability effect.

Whatever the reason is for the finding of a decrease in distress before the scan, it has important implications for research into health screening that involve measuring initial levels of anxiety, since the timing of the assessment may be very important. Obviously one also needs to take into account the nature of the procedure when assessing anxiety prior to a test- the fact that bone density screening is not intrinsically unpleasant for most people may be one reason why levels of anxiety are not very high immediately beforehand. (The women are informed about their method of screening in their initial appointment letter). The timing of the presentation of test results will also influence the temporal pattern of anxiety- in this bone density study, women receive their results just 5 minutes after their scan, hence the suggestion that the lower levels of anxiety seen immediately before the scan may be due to the anticipated relief of uncertainty.

Changes in feelings and beliefs about osteoporosis after a bone density scan

Anxiety about bone density and perceived risk

Anxiety and worry about osteoporosis, need for reassurance and perceptions of the likelihood of developing osteoporosis were significantly lower after a bone density scan for this sample of women having first or second scans. In contrast, perceptions of the likelihood of developing any serious illness in the near future did not change significantly over time and women who were questioned before and after seeing their GP did not show a decrease in anxiety or risk perceptions regarding osteoporosis. It thus seems that bone density screening may have specific effects on the subjects' beliefs and feelings about osteoporosis. However, since the women were not randomly assigned to these two groups (bone scan versus GP visit), firm conclusions cannot be drawn.

It is not appropriate to conclude that the effects of bone density screening are benign. The overall decrease in anxiety and risk perceptions may be partly due to the fact that most women having a first scan received above or near-average results and most women having a second scan did not show a decrease in

bone density. If norms representative of women in Oxford had been used, more women would have received “below-average” results and anxiety reductions may have been smaller for the group as a whole. It should also be noted that the apparent decrease in anxiety and risk perceptions occurs between post-scan ratings and pre-scan assessments made after the bone density appointment was made. It is possible that simply making the appointment for a bone scan caused an increase in anxiety and risk perceptions, so that the apparent reduction in anxiety is at least partly due to the result of initial levels of anxiety being higher than they would normally be. There are also indications that the results reported in this chapter may be an underestimate of distress after bone density screening. For example, women who only completed the very short questionnaires on the day of the scan had higher mean levels of worry about osteoporosis before the scan and may have experienced higher levels of distress at follow-up than those who completed all the questionnaires. Finally, it should be remembered that the sample of women undergoing bone densitometry who took part in this psychological study show certain characteristics such as more health anxiety and more reassurance-seeking than general population samples and more need of reassurance than the GP control group. Thus the reports described in this thesis may only apply to women with these characteristics.

Changes in beliefs about the effects of osteoporosis and anticipated ability to cope with it

Women having their first or second scan showed no change in their ratings of the seriousness of below-average bone density as a threat to health or to what extent osteoporosis would affect their ability to enjoy life or their anticipated ability to cope if one had osteoporosis. However, ratings of how bad the consequences of osteoporosis would be for them, were significantly lower at the three month follow up than at the initial assessment. The different effects for the “consequences” question might be partly because the other three questions are more influenced by the woman’s beliefs about how she thinks that she could react to and cope with the situation (e.g. preventive behaviours or emotion-focused coping).

It is possible that the information provided about osteoporosis to the women is partly responsible for the decrease in the ratings of how bad the consequences of osteoporosis would be. The information provided by the bone density unit described osteoporosis as a major health problem which causes about 45,000 fractured hips every year, but there was no information about other effects. Alternatively women may be taking their current bone density level into account when estimating how bad the consequences of osteoporosis would be for them (e.g. if one has good bone density now, then even if one develops osteoporosis much later it will not be as severe as for someone with low bone density now).

Comparison between women having their first and second scans

In general, there was little evidence of a differential effect of first and second scans. Thus, even though the women having second scans were receiving a different type of information (about their change in bone density), this did not seem to have a significantly different effect in terms of change in anxiety, risk perceptions and so on, between the initial assessment and the follow-ups. The only evidence of a differential effect concerned change in anxiety about bone density between the assessment immediately before the scan and the three month follow-up, with the women having second scans reacting more negatively than women having first scans.

There were significant overall group differences with regard to feelings relating to risk perceptions and anxiety about osteoporosis. Compared to women having their first scan, women having second scans were more anxious about their bone density, more worried about developing osteoporosis, more worried about fractures, more in need of reassurance, felt more vulnerable to osteoporosis, felt that it was more likely that they would develop osteoporosis and felt more at risk compared to other women of the same. The two groups were not significantly different at any point in time in terms of general anxiety or low mood. It is likely that the difference between women having first and second scans is at least partly due to the fact that the second scan group have lower bone density and therefore are at more risk than the first-scan group. It is also possible that women who are anxious about their bone density are more likely to return for a second scan.

Prevention beliefs and behaviours

Women having first or second bone density scans show a decrease in rated likelihood of preventing osteoporosis if you have low bone density. This may be due to information gained in the course of having the bone scan. For example, women are given a graph showing how bone density decreases with age, which may make it seem quite inevitable. Many would have been told that it is very difficult to increase bone density and that at the best one would usually hope for a halting of bone loss. Furthermore, some women with low results may be reacting in a similar way to the woman wrote “Why do I have a lower than average BMD despite doing all the things mentioned above- (calcium tablets, good diet, HRT, exercise..I feel I am already doing all I can”. (After the scan, this woman felt it was less likely that one could prevent osteoporosis). Thus investigation of the decrease will be continued in the next chapter where women with different types of result will be compared. It should also be noted that for the scale assessing prevention beliefs, higher numbers indicated a more positive attitude, unlike the other scales where higher numbers

indicated a more negative attitude, so it is possible that some women were simply not paying attention to the end-points of the prevention belief scale and assumed that higher numbers indicated a more negative attitude here too.

Despite the apparently increased pessimism about the possibility of preventing osteoporosis, women having first and second scans showed an increase in the number of preventative behaviours reported after the scan. This increase is consistent with a previous study which found that most women began some type of preventative measure against osteoporosis after their bone scan (Rubin and Cummings, 1992). The increase in preventative behaviour is encouraging, especially given the decrease in perceptions of vulnerability to osteoporosis, (although it is possible that the decrease in vulnerability perceptions were partly a result of planned or actual preventative behaviours). However, the apparent increase in preventative behaviours may be an overestimate of actual change in behaviour, since at follow-up women may be reporting behaviours which they were doing anyway but only now realise can contribute to osteoporosis prevention. This is unlikely to be a complete explanation of the change, since in the week follow-up questionnaire they had been asked whether they were intending to change their behaviour in any way because of the result; 41.8% of the first group and 52.8% of the second group had said “yes”, so much of the difference may be due to new behaviours.

The finding that women having second scans reported more preventative behaviours and more limitation of their activities than women having their first scan may be because women in the second scan group were more likely to have low BMD, and also because some of this group found that their bone density was decreasing.

After first scans there was a decrease in the proportion of women reporting that they restricted their activities in some way to avoid fractures, which is one of the positive effects of bone density screening (as long as women are interpreting their result correctly). One woman wrote “My life long ambition has been to do a parachute jump. Following my scan I decided to ‘go for it’. I completed a jump on 2nd July and it was wonderful- if I hadn’t had the scan, I probably wouldn’t have done it!”.

Chapter 6: The interpretation of results from bone density screening

6.1 Introduction

In this chapter, women’s interpretations and perceptions of bone density scan results will be described. It is important to investigate women’s understanding of the results because bone densitometry is a new type of health test, the results of which can inform decisions about preventative behaviours. Furthermore, anecdotal evidence suggests that the results of bone density screening are difficult to interpret, even for health professionals (Eastell and Peel, 1994). Another reason for examining interpretations is that misinterpretations of health-related information play a central role in health anxiety, according to cognitive-behavioural models of hypochondriasis (Warwick and Salkovskis, 1990).

One of the main problems in the interpretation of bone densitometry results is that there is no widely accepted level of BMD (bone mineral density) that warrants clinical concern (O’Neill and Silman, 1995). Some screening programmes use the recommendations of a recent World Health Organization Committee (1994) (see table 6.1). This committee proposed that osteoporosis is present when BMD or BMC (bone mineral content) is more than 2.5 SD below the young adult mean. Approximately 30% of post-menopausal women are below the WHO threshold and this figure is comparable to the lifetime risk of the major osteoporotic fractures from the age of fifty (O’Neill and Silman, 1995). The WHO committee also proposed that established or severe osteoporosis is present when BMD or BMC is more than 2.5 SD below the young adult mean and there is evidence of one or more fragility fractures. There is also another category, low bone mass, for cases where BMD/BMC is between 1 and 2.5 SD below the young adult mean. This category refers to about 15% of peri-menopausal women and the WHO suggests that individuals in this category are at moderately increased risk of fracture and should consider preventative measures.

Table 6.1 Classification of osteoporosis (World Health Organization, 1994)

Category	Criteria
Normal	BMD or BMC not more than 1 SD below young adult mean
Low bone mass (osteopaenia)	BMD or BMC between 1 and 2.5 SD below young adult mean
Osteoporosis	BMD or BMC > 2.5 SD below young adult mean
Established osteoporosis (severe)	BMD or BMC > 2.5 SD below young adult mean plus one or more fragility fractures

BMD=Bone mineral density; BMC= bone mineral content; SD=standard deviation

The research trial at the Nuffield Orthopaedic Centre began before the WHO report had been published. In this trial, instead of giving results in terms of a diagnosis of osteoporosis, they use the concept of a “fracture threshold” of 2 SD below the mean for women aged 30, “below which women will probably have lost some bone and hence may suffer bone fractures in accidents more easily than women who have higher bone densities”¹. (For a more detailed description of the way in which information was conveyed, see chapter 3, page 46). The fact that the screening information does not mention the diagnosis of osteoporosis may be confusing for some volunteers and the concept of a “fracture threshold” is likely to be new to most of the women. The results are also given in a form which shows the woman’s bone density in relation to the mean bone density in a population of women her age. This might be an easier concept to understand than fracture threshold, but it is not easy to convert this into one’s future risk for osteoporosis, since lifetime prevalence rates of osteoporosis for women with average levels of bone density are not provided. The interpretation is complicated by the fact that bone density decreases with age, so that one’s risk of fracture is constantly changing.

When examining the interpretations made of bone scans it may be important to consider not only the bone density information itself but pre-existing characteristics of the volunteers which may influence how interpretations are made. The cognitive-behavioural model of health anxiety asserts that pre-existing illness beliefs will influence how new illness information is interpreted. Thus someone who felt strongly at risk before the scan might require stronger evidence than someone who did not feel at risk if she is to conclude that she is not at risk after all. Beliefs influencing interpretations may be specific beliefs about the illness in question or general assumptions about illness. The CB model predicts that when illness information is ambiguous, people with a tendency to worry about their health will make more negative interpretations than people who don’t tend to worry about their health, because the former individuals will have more negative assumptions about illness. These predictions about pre-existing characteristics will be investigated using multiple regression analyses.

Overview of chapter six

The chapter begins with an evaluation of whether women who were seen by different radiographers give different interpretations of their result, since the radiographers say a few words to each woman as they hand over the scan result. Next, in the first of the three main sections, there is an examination of responses to a

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It should be noted that the threshold used in the present research of 2 standard deviations below the mean for subjects aged 30 and is slightly different from the WHO’s classification of osteoporosis which uses 2.5 SD.

multiple choice question asking “Which of the following best describes your result?” (with answers ranging from “Much higher than average for my age” to “Much lower than average for my age”). Then there is an examination of answers to the open-ended question “What did your result mean?”. Responses were rated in terms of perceived risk for osteoporosis, the emotional meaning of the result, implications for preventative action and miscellaneous responses. Thirdly there is an examination of whether women believe that they have osteoporosis, using a multiple-choice format in order to assess the certainty with which women believe that they have or don’t have osteoporosis. Finally there is a brief examination of how many women answer “yes” to the question “Is there anything important about your result that you feel unclear about?”. The general discussion includes a consideration of ways in which the information provided to women could be improved.

Due to space limitations, the results presented refer to the 3 month follow-up questionnaire, unless otherwise specified.

6.2 Comparison of the interpretations made by women x-rayed by different radiographers

In order to examine whether women who had seen different radiographers made significantly different interpretations, a one-way ANOVA was performed using the radiographer as the grouping variable and the interpretation as the dependent measure. (The scoring system for interpretations is shown in Appendix Q.) This revealed no main effect of group ($F < 1$), which indicates that there were no significant differences in the interpretations made by women x-rayed by different radiographers. There was also no significant difference between women x-rayed by different radiographers in responses to the question “Do you have osteoporosis?” or for “Which of the following best describes your result?” ($F < 1$ in both cases). Furthermore, chi-square analysis indicated that there was no difference between radiographers in the number of women they had seen who said that there was something that they were unclear about ($\chi^2_{(4)} = 4.0$).

In order to compare accuracy of interpretation between women who had seen different radiographers, correlational analyses involving the result and interpretation were performed separately for the patients associated with different radiographers. Only the three radiographers who had seen a moderately large number of women were used. The correlation coefficients were very similar: $r = -0.771$, $r = -0.795$ and $r = -0.795$ (all significant at $p < 0.0005$).

Thus for women seeing different radiographers there was no evidence of a differential bias towards positive or negative interpretations/perceptions, a difference in accuracy of interpretation or differences in whether there was something that the woman felt unclear about.

6.3 Perception of the result (multiple choice question)

The question, “Which of the following best describes your result”, was asked in order to investigate women’s perceptions of their result. The question had a choice of 7 answers ranging from “Much higher bone density than average for my age” to “much lower bone density than average for my age”. Only the results from women having their first scan will be presented in this section.

Table 6.2 shows the mean age-related result for women choosing each of the answers, and the range of results. If perceptions were all accurate, the women choosing the “higher than average” answers would all have age-related results which were larger than 0, and those choosing “below average” answers would all have results which were smaller than 0. Inspection of the minimum and maximum results for each response category indicates that for almost each category some women have made inaccurate descriptions of their result.

Table 6.2 Proportion of women endorsing different responses to a multiple choice question asking which description is the most appropriate for their result

	Proportion of women		Result (% above or below the mean for that age)		Minimum & maximum results	
	%	n	Mean	(SD)	Min.	Max.
Much higher <i>bone density than average for my age</i>	14.2	(49)	23.8	(12.9)	0.4	52.9
Moderately higher..	20.9	(72)	14.8	(10.9)	-20.7	52.0
Slightly higher...	16.8	(58)	10.0	(10.6)	-10.8	41.4
Average ...	18.8	(65)	2.9	(8.1)	-17.0	22.0
Slightly lower...	18.3	(63)	-9.2	(7.5)	-30.2	21.5
Moderately lower..	7.2	(25)	-11.7	(10.5)	-25.2	26.2
Much lower...	3.8	(13)	-14.3	(18.5)	-33.8	23.9

This table shows responses at 3 months for all subjects having a first scan who answered this question. The result is presented in terms of percentage above or below the mean for the sake of clarity.

Eight women with above average results ticked a choice indicating that they had below average bone density, three months after the scan. However, at the week follow up they had all correctly ticked an “above average” choice, and at the three month follow up gave an appropriate interpretation when asked to describe the meaning of their result in their own words.

Six women with below average bone density ticked a choice indicating above average bone density three months after the scan. However, four of these women gave appropriate descriptions when asked to describe their result in their own words. The other two women wrote that their result meant that they were at lower risk of osteoporosis, and although their results were only very slightly below average this was not an appropriate interpretation to make.

In order to examine accuracy of responses, correlational analyses were performed to determine the association between the women’s choice of response on the multiple-choice question and their scan result (in terms of distance from the mean for their age). The Pearson correlation coefficients indicate a fairly high degree of association: $r_{(256)}=0.82$ ($p<0.0005$) at the week follow-up and $r_{(256)}=0.75$ ($p<0.0005$) at three months.

A stepwise multiple regression analysis was performed to examine whether any pre-existing characteristics were associated with women’s responses to this question (see table 6.3). (For a detailed description of how all the multiple regression analyses have been performed throughout this bone density study, see chapter 9, page 211). The result entered first. In addition, higher initial levels of perceived risk predicted more negative descriptions of how the result compared to average and higher knowledge scores predicted more positive descriptions of the result. (See table below for details of the variables which didn’t enter).

Table 6.3 Results from a stepwise multiple regression analysis examining factors associated with description of the result.

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F value and sig. of F
Result (distance from mean for that age)	0.762	0.591	0.591	0.590	$F_{(1,293)}=424.1****$
Knowledge about osteoporosis	-0.087	0.598	0.007	0.595	$F_{(2, 292)}=217.1****$
Risk perceptions	0.082	0.605	0.007	0.600	$F_{(3, 291)}=148.0****$
Variables which didn’t enter the regression equation: fracture threshold, Health Anxiety Questionnaire (main section, “cost”, reassurance or avoidance), anxiety/worry about osteoporosis, seriousness beliefs, coping beliefs, prevention beliefs, symptoms of osteoporosis before the scan, family history of osteoporosis, BDI, STAI-trait, medical condition which may affect bone density .					

**** $p<0.00005$

For an indication of whether those with more knowledge were being more accurate, correlations were performed between the result and perceptions for two groups separately- the 50% with highest knowledge scores compared to the 50% with lowest knowledge scores. For those with higher knowledge the correlation coefficient was $r = 0.823$ and for the other group $r = 0.711$. Using the transformation specified by Kendall and Stuart (1961) (involving Fisher’s transformation) it was found that these two correlations were significantly different from one another ($Z=2.45$, $p<0.05$). This indicates that the association between the scan result and the perception of the result (as assessed using a multiple-choice 7-point scale) is stronger in those with more knowledge before the scan.

6.4 Interpretation of the result assessed by an open-ended question

Having examined women’s basic description of their result in terms of distance above or below the mean, interpretations and evaluations are next investigated, by looking at answers to an open-ended question: “What did your result mean?”.

6.4.1 Treatment of the data

The scoring system used for coding responses to “What did your result mean?” is shown in Appendix Q. The scoring categories were derived from an inspection of the type of answers given from the women and were as follows: meaning in terms of bone density or osteoporosis (positive and negative), emotional meaning, implications for action and miscellaneous. The scoring system was developed through discussion between the author and her supervisor. All ratings were made by the author. In order to investigate inter-rater reliability for the interpretation with regard to bone density, one of the radiographers who carried out bone density scans for this research also rated the interpretations (at three months) of the first 44 subjects who had answered this question. A psychology research assistant rated the interpretations for these 44 women in terms of emotional meaning, implications for action and miscellaneous aspects. Both the contingency coefficients and the percentages of answers classified in the same way indicate satisfactory inter-rater reliability (see table 6.4).

Table 6.4 Inter-rater reliability for the question “What does your result mean?”

Response category used for coding answers to the questions “what does your result mean?” ^a .	% classified the same by both raters	Contingency coefficient
Bone density / osteoporosis (positive)	90.9	0.92
(negative)	95.5	0.93
Emotional meaning	88.9	0.89
Implications for action e.g. (preventative measures)	95.6	0.85
Miscellaneous	93.3	0.82

^a The categories are not mutually exclusive.

6.4.2 Interpretation of first scans in terms of bone density and osteoporosis

Table 6.5 (overleaf) shows the numbers of women making different types of interpretations of the result (with regard to bone density or osteoporosis).

Positive or “average” interpretations were made by 70.8% of the women having first scans, negative or below average interpretations by 25.2% and the remainder (4%) gave answers which could not be classified in terms of the physical meaning of the result.

Table 6.5 The proportion of women giving different types of interpretation of the meaning of their first scans. in terms of their bone density and risk for osteoporosis

Description of the result	Proportion of women % n		Age-related result		
			Mean (SD)	Minimum & Maximum	
<u>Average or above average</u>					
Very good result ^a	3.8	(13)	26.4 (13.1)	2.1	46.7
Decreased likelihood of osteoporosis ^a	6.1	(21)	18.2 (15.9)	-4.7	52.0
Decreased likelihood of ost. <u>if I take care</u> etc.	1.5	(5)	17.4 (11.2)	1.5	31.1
Good result	33.6	(115)	12.8 (10.6)	-11.1	52.9
Good <u>now</u> but could change	15.2	(52)	11.2 (12.4)	-9.9	47.6
Above average (without positive interpretation)	5.3	(18)	12.1 (11.2)	-10.8	34.9
Normal, satisfactory	2.7	(9)	6.0 (10.5)	-3.7	28.3
Average (without positive interpretation)	3.2	(11)	-3.9 (5.0)	-15.3	1.2
<u>Below average</u>					
Below average but in the acceptable/normal range	0.9	(3)	-12.0 (3.9)	-16.4	-8.8
Below average bone density (without negative interpretation)	5.6	(19)	-8.9 (5.6)	-25.2	-2.5
Low bone density and/or negative interpretation without being specific	9.6	(33)	-12.7 (9.2)	-33.8	13.6
Increased risk of osteoporosis (in future)	1.8	(6)	-12.5 (7.6)	-24.5	-4.3
Lost bone (first scan only) ^b	4.1	(14)	-14.4 (5.9)	-22.4	-5.3
Bones brittle now ^b	3.2	(11)	-13.8 (8.0)	-29.3	-4.2
Will develop osteoporosis	0.0	(-)	0.0 (-)	-	-
Has got osteoporosis now	0.6	(2)	-27.5 (3.8)	-30.1	-24.8

Two subjects having first scans scored in both of the categories marked with ^a and one subject scored in both categories marked with ^b. Twelve women having a first scan gave answers which could not be classified in terms of physical interpretation of their result.

Of the women who interpreted their result as a good one, only 24.5% expressed caution, saying (or implying) that they realised that their bone density could change. Only one woman wrote that she would wait to have her second scan before drawing conclusions: “Difficult to know in just one scan. A second scan in nine months will be much more informative- it will show any variance.”

Examination of the mean age-related result obtained by women responding in each of the categories indicates that the interpretations are broadly accurate. However, in some cases quite large misinterpretations seem to have been occurring. Sometimes women were overly optimistic; for example, five (4.2%) of the women with below-average results concluded they are not likely to develop osteoporosis. No-one with an above-average result interpreted it in a strongly negative way and only two women were pessimistic about an average result. Sometimes comparison with other women’s results influenced such interpretations; one woman wrote “I had average bone density therefore need to be careful since other friends had high density”.

Some obvious misinterpretations occurred in the group who were below average but above the fracture threshold: for example, 6 women (8% of this group) interpreted their results as meaning that they had lost bone.

One woman showed an unusual pattern of misinterpretation and reaction. She had a slightly below-average result (3.5% below the mean), yet wrote, “ *Having imagined my bone density to be much higher, I was quite shocked to find it to be **just above** average for my age*” (my emphasis). Thus not only is she mistakenly believing that she is above average, she is interpreting her supposed above-average result in a negative way. Her responses to other questions confirm that she believes her result to be above average and indicate that although she thinks she is slightly less at risk than other women, she feels more worried about osteoporosis since the scan. At the week follow-up she scored 100 on 0-100 visual analogue scales assessing anxiety about bone density and 90 for perceived likelihood of developing osteoporosis. (Both scores had decreased to 50 by the three month follow up). In addition to her high expectations before the scan, her pre-existing beliefs about the seriousness of osteoporosis may help explain why she is so anxious. In response to the question concerning the effects that osteoporosis she wrote “*I shudder to think...Immobility would be the worst effect*” and said that coming for screening was of special importance for she lives alone and “cannot depend on anyone”. Her ratings of how bad the consequences of osteoporosis would be and of the seriousness of below average bone density were both 100 on a 1-100 rating scale. (Only 1.7% of women coming for first scans gave such high ratings). Since she believes that below-average bone density is extremely serious, then her perceived result (just above average) may seem alarmingly close to being a “bad” result.

6.4.3 Correlations between interpretations and the actual results

The categories for the coding of responses to the open-ended question “What does your result mean?” (shown in table 6.5) were next arranged into an scale (see Appendix Q, part 2). The new scale ranged from the most positive interpretations (e.g. “a very good result”, score of 1) to the most negative (e.g. “I have osteoporosis”, score 13). By examining the correlations between this scale and the scan results (in the form of distance above or below the mean for that age), a very approximate estimation of accuracy may be achieved; see table 6.6. (Only the 256 subjects who had completed the relevant questions in both of the follow up questionnaires are included, so that the correlations at both time-points can be compared). Since interpretations are expected to be influenced by the relation to the result to the fracture threshold, extremely high correlations were not expected.

The Pearson product-moment correlations between the age- related results (distance above/below mean for age) and the interpretations are moderately high ($r=-0.73$ at three months), suggesting that people with low scan results were generally making more negative interpretations than people with high scan results. Correlations between responses to the open-ended question and the multiple-choice question assessing description of the result (described in the previous sections) were also moderately high (-0.71 to -0.79 ; the correlations are negative simply because they are scored in different ways).

Table 6.6 Correlations between interpretations, descriptions and actual results

	Interpretation (week)	Interpretation (3 months)	Description ^a (week)	Description ^a (3 months)
Result	-0.74	-0.73	0.82	0.75
Interpretation (week)	-----	0.86	- 0.79	-0.74
Interpretation (3 months)		-----	- 0.79	-0.71
Description ^a - (week)			-----	0.83
Description ^a - (3 month)				-----

^a descriptions were assessed by multiple-choice questions

6.5 Predicting interpretations of bone scan results

A stepwise multiple regression analysis was used to examine whether variables assessed before the scan were significant predictors of interpretations, when entered as independent variables together with the result itself (see table 6.7).

Table 6.7 Results of a stepwise multiple regression analysis examining factors associated with responses to the question “What do you think that your result means?”

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Result of scan	0.560	0.541	0.541	0.539	$F_{(1, 278)}=327.8, p<0.0005$
Fracture threshold	0.228	0.580	0.039	0.577	$F_{(2, 277)}=191.4, p<0.0005$
Knowledge of osteoporosis (before the scan)	0.139	0.600	0.019	0.595	$F_{(3, 276)}=137.7, p<0.0005$
Variables which didn’t enter the regression equation (assessed prior to scan): Health Anxiety Questionnaire (main section, “cost”, reassurance or avoidance), anxiety/worry about osteoporosis, risk beliefs, seriousness beliefs, coping beliefs, prevention beliefs, perceived risk compared to other women, symptoms of osteoporosis, family history of osteoporosis, medical condition which may affect bone density, age, BDI, STAI-trait.					

The result itself entered first, followed by the position of the result in relation to the fracture threshold and lastly the amount of knowledge expressed before the scan. The greater the amount of knowledge before the scan, the less optimistic or more cautious the woman was in her interpretation. (See the table for details of which variables didn’t enter).

It is tempting to conclude that the women who know more are interpreting their results in more appropriate ways, especially since many women showed a lack of caution in interpreting their results (see section 6.4.2). However, it is difficult to examine this possibility further using the existing data, because accuracy would depend on not only the age-related result but the relation of the result to the fracture threshold. The relationship between knowledge and accuracy of interpretations requires further investigation in a future study.

6.6 Interpretation of second bone density scans

6.6.1 Introduction

The interpretation of second bone density scans is more complicated than the interpretation of first scans, because they provide information not only about the absolute level of bone density but also about change in bone density between the two scans. There is also the problem of machine error, which can be up to 1.5%. Some women in the present sample came for a second scan less than a year after the first, where changes seen are often within the range of machine error. (Now women are only advised to come back after at least a year). The Bone Density research group at the Nuffield Orthopaedic Hospital make a note of changes of more than 2.5% over a year. At the time of the present research, letters to GPs about second scans would say that the woman had shown a significant increase or decrease if the change was more than 2.5%, otherwise they wrote that there was no significant change. On the day of the scan, women having second scans would be presented with a graph showing their new BMD result. Usually the radiographer would say whether this is higher or lower than on the previous scan and often mentioned the possibility of machine error (although rarely gave a figure for this). The women were not given a figure representing their percentage change in BMD and were not given written information about how to interpret second scans.

6.6.2 Treatment of the data

Some women did not have their second scan at exactly a year since their last one, so for the purpose of this study an estimation was made of the expected change in bone density over a year, assuming a consistent rate of change. There are several reasons why this will not result in a perfect prediction of which people will show significant change over a year, in addition to the problem of machine error. For example, if preventative measures were initiated after the first scan one cannot assume that their action will be constant over the subsequent months. However, this estimated figure allows a more flexible assessment of accuracy in judgements of change, when used in conjunction with their actual bone density change.

6.6.3 Responses to the question “What did your result mean?” (See table 6.8, below)

Of the women who described the meaning of their second scan result at the three month follow up in terms of bone density, 46.5% (n=47) mentioned change or lack of change since the previous scan; the remainder mentioned the absolute level and/or an evaluative judgement. Increases or a lack of change in bone density tended to be given a positive interpretation.

Table 6.8 The proportion of women giving different types of interpretations of second scans, with regard to their level of bone density and risk for osteoporosis

Interpretation of second scans with regard to bone density and osteoporosis	Proportion of women		Age-related results			
			Mean (SD)		Maximum & minimum	
<u>Average or above average</u>	%	(n)				
Very good result	-	-	-	-	-	-
Decreased likelihood of osteoporosis	-	-	-	-	-	-
Good result	6.5	(6)	-2.6	(15.5)	-19.5	25.5
Decreased likelihood of ost. <u>if I take care</u> etc.	-	-	-	-	-	-
Above average (without positive interpret.)	2.2	(2)	19.9	(10.5)	12.4	27.3
Good <u>now</u> but could change	3.2	(3)	7.3	(12.2)	-6.6	16.2
Normal / satisfactory	3.2	(3)	18.0	(20.1)	-3.7	36.0
Average (without positive interpretation)	2.2	(2)	-3.2	(7.9)	-8.8	2.5
<u>Below average</u>						
Below average but in the normal range	7.5	(7)	-11.6	(6.8)	-20.2	-2.3
Below average bone density (without negative interpretation)	5.4	(5)	-8.4	(5.3)	-13.9	-2.6
Low bone density and/or negative interpretation without being specific	17.2	(16)	-15.9	(8.9)	-33.9	-4.2
Increased risk of osteoporosis (in future)	4.3	(4)	-13.2	(10.2)	-27.8	-5.4
Bones brittle now*	0.0	(0)	-	-	-	-
Will develop osteoporosis	1.1	(1)	-12.3	(0)	-	-
Has got osteoporosis now	2.2	(2)	-6.2	(8.8)	-12.4	0.0
<u>Changes in bone density</u>						
No change (without positive interpretation)	6.5	(6)	-9.3	(5.1)	-15.8	-2.5
No change (positive interpretation)	14.0	(13)	3.1	(17.9)	-25.9	38.8
Increase (without positive interp.)	3.2	(3)	-4.3	(7.0)	-11.8	2.2
Increase from last scan (positive interp.)	14.0	(13)	-8.7	(8.3)	-22.9	8.0
Decrease from last scan (no interpretation)	4.3	(4)	8.0	(18.1)	-10.7	31.5
Decrease from last scan <u>but</u> it could be machine error / is in the normal range etc.	3.2	(3)	-14.7	(5.6)	-18.8	-8.3
Decrease from last scan (negative interp.) ^c	5.4	(5)	-15.9	(9.7)	-34.3	-5.9

^c Two women scored in both of these categories. Two women having a second scan gave answers which could not be classified in terms of physical interpretation of their result

6.6.4 Accuracy of interpretations in terms of changes between scans

The mean changes in bone density associated with the different types of interpretations regarding change in bone density are shown in table 6.9.

Table 6.9 Mean changes in bone density associated with different interpretations

Interpretation at 3 months	n	Percentage change in bone density				Actual change in bone density (g/cm ²)			
		Mean	(SD)	Min.	Max.	Mean	(SD)	Min.	Max
No change	19	0.08	(1.75)	-3.3	4.8	0.00	(0.02)	-0.031	0.041
Increase	16	2.87	(3.96)	-7.2	9.1	0.02	(0.03)	-0.070	0.061
Decrease	8	-3.12	(1.67)	-6.6	-1.0	-0.05	(0.07)	-0.220	-0.011
Decrease (could be machine error)	4	-1.53	(1.78)	-2.9	0.9	-0.01	(0.01)	-0.026	0.007

Table 6.10 shows the actual change in bone density associated with different interpretations of change in more detail. The changes are shown in terms of whether they are more or less than 2.5% per year (which is the amount that the Bone Densitometry Unit considers to be a significant change) and whether the percentage change is less than 1.5%, which is the variability of the machine. (Obviously it is not correct to conclude that density has changed if the difference is within the error of the machine).

Table 6.10 Classification of women having second scans in terms of both their description of the change in their bone density (at 3 months after the scan) and their actual change in bone density.

Actual change	Interpretation			
	No change	Increase	Decrease	Decrease but could be machine error
Increase Increase > 2.5%	1	8	0	0
Increase> 2.5% only if multiplied up to a year	0	1	0	0
Increase < 2.5% even if multiplied up to a year <i>(The number of these which are <1.5% are shown in italics)</i>	9 <i>(7)</i>	5 <i>(1)</i>	0	1 <i>(1)</i>
Decrease Decrease > 2.5%	1	1	4	2
Decrease >2.5% only if multiply up to a year	1	1	2	0
Decrease <2.5% even if multiply up to a year <i>(The number of these which are <1.5% are shown in italics)</i>	7 <i>(6)</i>	0	2 <i>(0)</i>	1 <i>(1)</i>
Total	19	16	8	4

A detailed description of inaccuracies shown by women interpreting second scans is given in Appendix R. In summary, of the 47 women who had written about whether their bone density had changed between scans, a substantial minority gave inappropriate answers. Three women who described their result as showing no change had actually shown a change (or projected change) of more than 2.5%. Two women who described their result as a increase actually showed a decrease in bone density and five showed an increase (or projected increase) of less than 2.5%. Two women who described their result as a decrease had actually shown a projected decrease of less than 2.5% over a year. Two of the four women who said that their result had decreased but that this could be due to machine error, had actually shown a decrease of more than 2.5% and another of the four women had actually shown an increase in bone density. Thus if one uses 2.5% as the cut-off points (which was the figure used in the research trial), 15 (32%) of these 47 women were probably incorrect in their conclusions. Since only 46.5% of the women had mentioned change or lack of it between scans, one cannot make firm conclusion about the accuracy of the group as a whole. However, it is likely that some of the women didn't discuss the difference between scans because they were didn't know whether their change was significant.

6.7 Other responses to the question “What did your result mean?”

In addition to categorizing the responses to the question “What do you think that your result means?” in terms of bone density, emotional aspects, implications for action and miscellaneous responses were also coded. These are described briefly below. Clearly, since many women only answered in terms of bone density, responses showing other aspects of the meaning of the result cannot be taken as representative of the group as whole.

6.7.1 Emotional meaning of the result: results and discussion

The most commonly expressed emotional meanings of the result are shown in table 6.11. Positive emotions were most frequently mentioned: relief and reassurance (14.3% of women having their first scan) and pleasure (8.5%). Only 3 of the women (0.9%) having a first scan expressed negative feelings when asked about the meaning of her result e.g. “I am quite irrationally worried by being slightly below average which I know is stupid. I feel that I would like to have another test to assess the rate at which I am losing bone density in order to rationalise my feelings about this”.

Over-generalisations about overall state of health and lifestyle

Twenty-three (6.7%) of women having a first scan said that their result meant that their current lifestyle was satisfactory or that they do not need to start new preventative measures. A comparison using t-tests indicated that women who had concluded that their lifestyle was healthy showed no significant difference in the number of preventative behaviours (before or after the scan) than those with similar results who did not draw the same conclusions. Despite their conclusions, these women as a group were reporting more preventative behaviours after the scan than before it, although this may simply be due to discovery that some of their existing behaviours are helpful in osteoporosis prevention i.e. the change is due to change in reporting rather than change in behaviour. Of the 23 women who concluded that their lifestyle was satisfactory, five were less than 5% above average for their age and one was exactly average. At least six women expressed explicitly an over-generalisation regarding their overall state of health; comments included:

[the result meant that] *“I’m 100% healthy”*

 “reassurance that I’m as healthy as I feel”

 “I’m perfectly healthy for my age”.

6.7.4 Implications for action from a second scans

Women’s interpretations of second scans in terms of future action were usually consistent with their results (see table 6.13). For example, of those who said that they needed another scan, or needed to continue/begin preventative measures, all had average or below average bone density. None of those who felt that the result endorsed their current lifestyle had shown a significant decrease in bone density.

Table 6.13 The proportion of women reporting different implications for their health behaviours in the interpretation of their second scan

	Proportion % N		Mean SD	Min.	Max.
Need for preventative or treatment measures	10.8 (10)	Result ^a	-16.8 (10.0)	-29.3	0.0
		% change	-0.6 (3.2)	-3.3	5.9
Need or intention to have another scan	2.2 (2)	Result	-11.4 (1.0)	-12.0	-10.7
		% change	-4.5 (3.1)	-6.6	-2.2
Endorsement of current lifestyle	4.3 (4)	Result	-7.3 (12.0)	-21.7	6.8
		% change	4.5 (4.8)	-1.1	9.1
Wants to keep a check on her BMD, despite good result, because of family history of osteoporosis	1.1 (1)	Result	-15.4 -	-	-
		% change	-0.35 -	-	-

^a the result is reported in terms of % above or below the mean for the age of the woman scanned.

6.7.5 Miscellaneous answers to “what did your result mean?”

Some of the miscellaneous answers regarding the meaning of the result can be seen in table 6.14. Only three women correctly pointed out that their good spinal result may not be representative of the whole body. This did not seem to occur to many women and anecdotal evidence from hearing women discussing this point suggests that they assume that the result is representative otherwise they would be told, or more measurements taken. One factor which may cause large discrepancies between scan results from different areas of the body is osteoarthritis- the fact that this condition can artificially raise the apparent bone density in the back has led the bone density research group at the Nuffield Orthopaedic Centre to begin scanning the hips of some older women.

Two women (0.6%) wrote that they will get or have got arthritis, which is presumably due to the fact that osteoarthritis can show up as areas of high density on the scan. Another woman reported that she had come for screening in order to determine whether she had arthritis (although the scan should be not used as a way of screening for this condition); when she discovered that her very high result probably indicated osteoarthritis she became very distressed, saying that she was upset because her mother suffered from it very badly. On the 0-100 visual analogue scales given before and after the scan her anxiety rose from 0 to 40 and her feelings of sadness/low mood increased from 0 to 70. She did not return the follow up questionnaires and has not been used in the analyses. This highlights the problem that distress may be one of the reasons why people don't return their follow-up questionnaires, which could result in an underestimation of the distress associated with bone density screening.

Eight women (2.3%) concluded that their symptoms could not be due to osteoporosis e.g. *“..I feel back to square one with my pain. I think that I hoped it would have confirmed whatever, and maybe suggested treatment of some kind”*. Seven women (2.0%) expressed a causal attribution for their bone density level or wondered what the reason could be.

Five women (1.5%) with low results said that they were glad to know sooner rather than later. In contrast, two women expressed uncertainty about the value of knowing their low result:

“Discovering that I have already lost bone density has made me very aware of my bones generally. My joints are painful and I am concerned as to the long term effect. I am always very active so it does worry me. I think it may have been better not knowing” (woman aged 50)

“I am glad that I had the scan but because of my age (40) my low bone density will not have any effect for many years and therefore I am unsure of the value of knowing this fact at this present moment in time”
(my emphasis)

This latter figure may be an underestimation of the number of women questioning the worth of the test since most women were grateful to have had a free scan and may have found it difficult or inappropriate to express such views.

Table 6.14 Miscellaneous answers to “what does your result mean?”

	First scan		Second scan	
	%	n	%	n
Ok in the spine but might not be elsewhere	0.9	(3)	2.2	(2)
Pleased to know sooner rather than later	1.5	(5)	2.2	(2)
Causal attribution for her result (or search for)	2.0	(7)	6.5	(6)
Wished hadn't had the test, or wonders whether she should have had it	0.6	(2)	0	(0)
Back problems aren't due to osteoporosis	2.3	(8)	0	(0)
Will get or has got arthritis	0.6	(2)	0	(0)
Didn't understand result	0.6	(2)	2.2	(2)
Miscellaneous	7.0	(24)	8.6	(8)

6.8 Responses to the question “Do you have osteoporosis?”

Having examined interpretations using an open-ended question, it was felt that beliefs about whether or not osteoporosis was present should also be assessed in a more direct way, using a multiple choice question. Women were asked “Do you have osteoporosis?” with the following choice of responses: definitely / probably / don’t know / probably not / definitely not. Table 6.15 shows the proportion of women having first scans who chose each response to this question at the three month follow-up.

Table 6.15 Mean scan results for women endorsing different responses to the question “Do you have osteoporosis?”

	Proportion of women		Scan result (age-related)			
<u>Response</u>	%	n	Mean	SD	Minimum	Maximum
Definitely	3.7	(13)	-16.9	(6.4)	-30.1	-7.4
Probably	5.7	(20)	-9.6	(14.7)	-30.5	28.1
Don't know	8.6	(30)	-12.2	(9.4)	-33.8	11.6
Probably not	26.3	(92)	5.9	(13.4)	-20.8	38.0
Definitely not	55.7	(195)	11.5	(14.2)	-30.2	52.9

The result shown in table 6.15 indicate that each response category receives endorsement from women with

a very wide range of scan results. It is noteworthy that 40% of the women were not sure whether or not they had osteoporosis.

One way of examining the accuracy of the responses to this question in more detail is to take each response in turn and assess how many women endorsing that response had bone density below the fracture threshold used in study at the Nuffield Orthopaedic Centre or had osteoporosis as defined by the WHO (1994) classification. (See table below).

Table 6.16 The answers of women below fracture threshold and with osteoporosis to the question “Do you have osteoporosis”; the proportion of women in each group giving the different responses.

	Proportion giving each response who are below fracture threshold (including those with osteoporosis)	Proportion giving each response who have osteoporosis ^a
<u>Response</u>	%	%
Definitely	92.3	38.5
Probably	50.0	20.0
Don’t know	46.6	23.3
Probably not	4.3	2.2
Definitely not	3.6	1.5

^a According to WHO definition of more than 2.5 SD below the young adult mean
Note that those having osteoporosis will all be below fracture threshold and hence included in both of the columns.

An alternative way of examining the accuracy of responses is to take the group of women with osteoporosis or those below fracture threshold and examine what proportion of these women gave each type of response (see table below).

Table 6.17 Proportion of women who have osteoporosis or are below fracture threshold giving each response to the question “Do you have osteoporosis?”

	Of the women who are below fracture threshold, percentage giving each response		Of the women who have osteoporosis ^a , percentage giving each response	
<u>Response</u>	%	n	%	n
Definitely	25.5	(12)	23.8	(5)
Probably	21.3	(10)	19.0	(4)
Don’t know	29.8	(14)	33.3	(7)
Probably not	8.5	(4)	9.5	(2)
Definitely not	14.9	(7)	14.3	(3)

^a According to WHO definition of more than 2.5 SD below the young adult mean

6.8.1 Detailed examination of the women who endorse the different response option

A. Women who thought that they “definitely” had osteoporosis

Of those replying that they “definitely” had osteoporosis, two had been diagnosed as having osteoporosis before the scan (on the basis of fractures) and all but one (i.e. 92.3%) were below the fracture threshold (see table 6.16). However, according the WHO classification system, only 38.5% of the women who said that they had osteoporosis were correct. It was found that of the 22 women who did have osteoporosis according to this criteria, only 5 (23.8) said that they definitely had the condition.

One of the woman who said that she definitely had osteoporosis had a result which was not even below the fracture threshold and was only 13% below the mean for her age (47 years). This woman had had a hysterectomy and oophorectomy, was allergic to dairy products and had said that her reason for attending the scan was “increasing concern about osteoporosis” due to her risk factors. At three months she wrote “The scan confirmed what I thought was a possibility...”. She reported no symptoms so her conclusion that she has osteoporosis seems to be based on a misinterpretation of her result. She had a high score on the Health Anxiety Questionnaire (2 SD above the mean for the sample of non-clinical subjects described in chapter 2), which according to the cognitive-behavioural model of health anxiety indicates that she may have had a pre-existing tendency to misinterpret health-related information (see chapter 1).

B. Women who “probably” have osteoporosis

Of the twenty women who said that they probably had osteoporosis, only four (20%) were correct according to the WHO classification. Fifteen (75%) did not report any symptoms, ten (50%) were above the fracture threshold and 3 were above average. Possible contributory factors involved in misinterpretations might include high levels of pre-existing anxiety and perceived vulnerability regarding osteoporosis (due to family history and/or medical conditions) combined with an incomplete understanding of the nature of osteoporosis. The ways in which these factors could operate is illustrated by the cases of the three women with above average bone density who said that they probably have osteoporosis; see tables 6.18 and 6.19.(Each of these women was in her early fifties). These suggestions about factors which may be contributing to misinterpretations are purely speculative and similar combinations of these factors may be found in some women who did not misinterpret their result.

Table 6.18 Characteristics of three women with above average bone density who believe that they “probably” have osteoporosis.

	Women who thought that they probably had osteoporosis despite above average bone density			Other women with above-average bone density
	A	B	C	Mean rating
Anxiety about bone density ^a	100	50	80	30
Likelihood of osteoporosis in near future ^a	80	70	50	26
Need for reassurance ^a	100	70	90	43
Spielberger (Trait anxiety)	60	29	31	38.3
Health Anxiety Questionnaire	28	37	49	31.6
One of reasons for attending was anxiety	Yes	No	Yes	<u>% giving same answer</u> 9.1% said anxiety was a reason for attendance
Definition of osteoporosis	1	1	1	46.2% (range from 0-2, 1 being an inadequate description of the condition)
Family history	Adopted mother had it	Yes	Yes	29.5% had family history
Medical condition which may affect bone density	Yes	Yes	No	18.4% had medical condition affecting BMD

^a These pre-scan feelings were rated on 0-100 visual analogue scales

Table 6.19 Background details of three women who thought that they probably have osteoporosis, despite an above-average scan result (These are the same women included in table 6.18, above).
A. One woman reported that she had been “scared stiff” about osteoporosis prior to the scan, having seen her adoptive mother’s suffering with the condition. She feels herself to be at risk because of a lifetime of hormonal problems including a very early menopause. Although she says that she and her doctor were “surprised and delighted” at her high result, she believes that if she came off HRT she would experience severe loss of bone density. (Note that even if this were true, she would not be defined as having osteoporosis until it reached low levels).
B. Another woman had a very high result and osteoarthritis had been diagnosed. Areas of osteoarthritis will make the reading abnormally high so she is correct not to conclude that she is at low risk for osteoporosis. However, her scan does not give evidence to support the conclusion that she “probably” has osteoporosis. This view may be related to her beliefs about her bones in general, since she has had another bone disease (Sheuermann’s disease) in the past and says that her bones and joints ache a great deal.
C. A third woman had written before the scan, “My mother was very badly affected and having seen the way she suffered constantly ..made me realise the seriousness of osteoporosis”. She described osteoporosis as “a gradual thinning of the bones” and had a high score on the Health Anxiety Questionnaire (indicating higher than average number of symptoms of health anxiety). After the scan she wrote “ my bones are quite healthy for my age” although she felt more at risk for osteoporosis than other women. Her conclusion that she probably has osteoporosis may partly reflect beliefs that osteoporosis means <u>decreasing</u> bone density (rather than an existing low bone mass) and that the condition has a strong genetic base.

Other women who thought that they “probably” have osteoporosis seemed to be misinterpreting the result because of a misunderstanding of the information presented on the result print-out. For example, one woman (a nurse) noticed that her first lumbar vertebrae was less dense than the others and concluded that in addition to her overall result being slightly below average, that vertebrae was abnormally weak. She wondered whether her back pain related to that vertebrae. In fact a decrease in the level of bone density between vertebrae 4 and 1 is normal.

C. Women who didn’t know whether they had osteoporosis or thought that they probably didn’t have it

Of the women having first scans who answered the question, 30 (8.6%) said that they “don’t know” whether they have osteoporosis, 92 (26.3%) said that they “probably” don’t have it and 195 (55.7%) said that they definitely don’t have it. These three types of response were endorsed by over half of the 21 women who did actually have osteoporosis according to the WHO classification: seven (33.0%) said that they didn’t know whether they had it, two (9.5%) said that they probably didn’t have it and three (14.3%) said that they definitely didn’t have it.

6.8.2 Predicting responses to the question “Do you have osteoporosis?”

In order to investigate whether pre-existing characteristics of the women were associated with responses to the question “Do you have osteoporosis?”, a stepwise multiple regression analysis was performed (see table 6.20).

Table 6.20 Results of a stepwise multiple regression analysis examining factors associated with responses to the question “Do you have osteoporosis?”

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F value and sig. of F
Fracture threshold	0.453	0.386	0.386	0.384	F _(1, 298) =187.0****
Result of bone scan (age-related)	0.236	0.429	0.044	0.425	F _(2, 297) =111.6****
Risk perceptions before the scan	0.118	0.451	0.022	0.445	F _(3, 296) =80.9****
Medical condition affecting bone density	0.105	0.460	0.010	0.453	F _(4, 295) =62.9****
Variables which didn’t enter the regression equation: Health Anxiety Questionnaire (main section, “cost”, reassurance or avoidance), anxiety/worry about osteoporosis, knowledge of osteoporosis, seriousness beliefs, coping beliefs, prevention beliefs, symptoms of osteoporosis before the scan, family history of osteoporosis, BDI, STAI-trait.					

****p<0.00005

Women with lower bone densities and women whose result was below the fracture threshold line were more likely to give answers nearer to the “I definitely have osteoporosis” end of the options. As predicted by the cognitive-behavioural model, pre-existing beliefs also influenced responses: women who perceived themselves as more likely to develop osteoporosis before the scan or who have a medical condition which might affect their bone density were more likely to give answers near the “I definitely have osteoporosis” end of the scale.

6.9 Problems understanding the scan result

A chi-square analysis was performed to examine whether there was any difference between the first and second group in the number of women having problems understanding the scan. This revealed that 20.4% (n=22) of the second group answered “yes” to the question “is there anything important about your result that you feel unclear about?” compared to only 9.3% (n=31) of the first group, a significant difference ($\chi^2_{(1)}=9.58$, $p<0.005$).

One of the areas of confusion which has been highlighted earlier (section 6.9) concerns the diagnosis of osteoporosis, and is reflected in comments such as the following:

“I had hoped to find out whether or not I have osteoporosis. I would like to know what constitutes osteoporosis and how my bone density relates to it.”

“I am unsure when a person actually has osteoporosis. I know [my result is] below average but I do not understand when I would know if I have actually got osteoporosis.”

“I’m not really sure what the symptoms of osteoporosis are.”

In addition to problems understanding what constitutes a diagnosis of osteoporosis, there were a large range of other problems, from difficulties understanding the graph or table to questions about what they should do about their result in terms of prevention or treatment, whether their result generalised to other bones in their body, why their result had turned out as it did and why the different vertebrae scanned showed different densities. The comments were not presented here since the majority did not fall into clear categories.

Women interpreting second scans report a further set of problems, the most common being whether changes between scans were significant or not. One woman having a second scan wrote “although overall [there was] no change [I] am confused as some areas are improved but others worse..the results really proved nothing, especially not positive”.

6.10 Summary and general discussion

Interpretations and perceptions of first scans

The women in this sample described the meaning of their result in many different ways. The most common types of response were: an evaluative comment without being specific (e.g. “Good”), description of the bone density (high/low, above or below average), implications for preventative behaviours and emotional responses such as “relief”. Explicit descriptions of their risk for osteoporosis were more rare.

The correlation between women’s responses and their results was moderately high, which indicates that in general, people with lower BMD were correctly making more negative interpretations of their result than those with higher BMD. Obviously if the group as a whole were being either too optimistic or too pessimistic, a correlational analysis would not reveal this. There were some signs that some women were too optimistic in their conclusions: only a quarter of women who interpreted their result as a good one expressed caution or indicated that they knew that their result could change. Although the absolute level of bone density is important, it is possible that some women are not fully aware of the importance of the rate of bone loss, but firm conclusions cannot be drawn since the women were not asked directly about this.

Some obvious misinterpretations were occurring. For example, in the group who were below average but above the fracture threshold, 8% interpreted their results as meaning that they had lost bone, which is not necessarily the case. In some cases, this may be due to a misunderstanding of the concepts of means and standard deviations.

Predicting interpretations and perceptions of the result

The fact that there was a significant association between interpretations and both the distance of the result above or below the mean for their age and whether or not the result was below the fracture threshold, demonstrates that the women were able to utilise the information presented to them to some extent. However, as predicted by the CB model, pre-existing beliefs about osteoporosis were also significant predictors of interpretations and perceptions of the result. For example, high prior risk perceptions were associated with both a greater likelihood of thinking that one has or may have osteoporosis and a more negative perception of how the result compared to the result of other women of the same age. Believing that one had a medical condition (other than osteoporosis) which may affect one’s bone density was also associated with a greater likelihood of thinking that one may have osteoporosis. Greater knowledge about osteoporosis before the scan was associated with more positive perceptions of how the result compared to the average for women of the same age. This may be partly due to the fact that women with more knowledge

were being more accurate; these women showed a significantly higher correlation between their result and their perception of it than women with less knowledge. Greater knowledge about osteoporosis was associated with a more negative interpretation of the meaning of the result, but further research is needed to establish whether this reflects more accurate or overly pessimistic interpretations.

Pre-existing health anxiety and interpretations of the result

The cognitive-behavioural model of health anxiety would predict that people who tend to worry about their health will make more negative interpretations of a scan result, because they are likely to have negative beliefs about illness. However, multiple regression analysis using measures of health anxiety as independent variables did not support this hypothesis. One possible explanation is that the method used for assessing interpretations was not sufficiently sensitive to access the kinds of differences which might be found between people who do or do not tend to worry about their health. For example, most women described their result in a way which did not indicate their conclusions about their future risk for osteoporosis (e.g. “above-average bone density”). In future chapters, the reactions of women with high and low scores on a measure of pre-existing health anxiety will be compared on more sensitive measures.

Interpretation of second scans

Of the 47 women having a second scan who wrote about whether their bone density had changed, 15 (32%) gave answers which were probably inappropriate. However, since only 46.5% of the women had mentioned change or lack of it between scans, one cannot make firm conclusions about accuracy in the group as a whole. It is more likely that the figure of 32% is an underestimate of inaccuracy than an overestimate, since some women probably didn't mention change because they weren't sure whether the difference was significant or not. Women having their second scan were significantly more likely to report that there was something they felt unclear about than women having their first scan (20.4% versus 9.3%). One possible reason for the comprehension problems is that the volunteers were not given any written explanations for interpretation of change between scans and the radiographers did not seem to have been given a clear policy on how to explain second scan results to women.

One woman whose result showed an increase conceded that this could be machine error but still came to a positive conclusion about her result. In contrast, the three women with decreased bone density who mentioned machine error implied that this was a reason for not being concerned about their result. Although the numbers here are much too small to draw firm conclusions, the pattern of findings is consistent with

work by Cioffi (1991) and Jemmott, Ditto and Croyle (1986). For example, Jemmott et al. (1986) found that subjects who were told that their results were bad rated the test as less accurate as those whose test results were good.

Other aspects of the meaning of the scan result

The use of an open-ended question allowed a wider range of aspects of the meaning of the result to be revealed than could otherwise have been examined. For example, some women wrote that the main meaning of an above-average result was that their back pain was still undiagnosed. Others were seeking an indication of their risk for arthritis, which cannot be estimated using bone densitometry (this can sometimes show existing osteoarthritis but the trial is not designed to deal with this condition). A few of those with bad results commented on the value of the test: five said that they were glad to know sooner rather than later while two were unsure of the value of the early knowledge.

About a quarter of women described the meaning of their first scan in terms of implications for preventative behaviours: for example, that they need to continue with the behaviours or that they need to begin new ones. Some inappropriately concluded that their first scan result indicated that their lifestyle was satisfactory. This may be problematic since they could actually be losing bone quickly- only a second scan could show this. (Clearly even a second scan cannot tell you whether your lifestyle in general is adequate, which some women may have been thinking). These interpretations also indicate an over-emphasis on current lifestyle to the neglect of the many other factors (e.g. genetic influences) which affect the absolute level of bone density shown in their first scan. This “certificate of health” effect has been noted once before, by Tymstra and Bieleman (1987), who found that when they asked people whether their favourable result acted as proof that they did not need to change their way of life, 44% answered in the affirmative. Clearly the large difference in the proportion of people giving such a response between their study and the present one may be due to the fact that they asked a specific question rather than using an open-ended question.

An even more problematic conclusion was conveyed explicitly by several women who received satisfactory results, who wrote that their overall state of health must be good. This is a very inappropriate conclusion to make and could even lead to a delay in seeking help for symptoms of other illnesses or failure to perform general preventative health behaviours.

These types of misinterpretations could be addressed in written information given to women before their scan.

Answers to the question “Do you have osteoporosis?”

Much misunderstanding was apparent when the women were asked “Do you have osteoporosis?”. A substantial proportion (40%) of the women having their first scan were not sure whether or not they had osteoporosis. Only 42.8% (9) of those with osteoporosis (according to WHO classifications) said that they “definitely” or “probably” had the condition. Furthermore, of the thirteen women who said that they “definitely” had osteoporosis only 5 (38.5%) were correct, two of whom had been diagnosed before the scan, on the basis of fractures. Of the twenty who said that they “probably” had osteoporosis only 4 (20%) were correct. The lack of understanding demonstrated in these findings is a cause for concern.

A multiple regression analysis indicated that if a woman’s bone density was below the fracture threshold, she was more likely to say that she had osteoporosis, even after taking into account her absolute level of bone density. This use of the fracture threshold is not surprising since the women were not supplied with any information about how to interpret their result in terms of the diagnosis of osteoporosis. However, it may be problematic, since the fracture threshold would imply that more women have osteoporosis than would be diagnosed by the more recent WHO classification system for osteoporosis.

Implications for provision of information

The research described in this chapter highlights several areas in which women had problems understanding of their bone scan results. Some of the confusion or misinterpretation seemed to relate to lack of information rather than a misunderstanding of the information provided. I will briefly discuss how a modification of the type of information presented to the women may help to improve understanding.

There was an indication that women with greater general knowledge about osteoporosis before the scan (e.g. the nature of the condition, causes, treatment) were more accurate in their perception of how their result compared to the average for a woman of the same age. The women were given very few facts about osteoporosis before the scan (see Appendix O) and it would not be difficult to substantially improve the information that they are given.

The question “Do you have osteoporosis?” produced many obvious errors. It could be argued that discussing a diagnosis of osteoporosis after such screening would not provide any benefits and may produce harmful effects such as high levels of anxiety. Yet in the present situation many women still had opinions about whether or not they have osteoporosis and these ideas were usually wrong. This may be resulting in the wrong women becoming anxious and some women failing to seek treatment when they need it; anecdotal evidence from radiographers suggests that some women with very low results seem to fail to appreciate the

seriousness of the situation. It may be more appropriate to provide women with an actual diagnosis, perhaps using the WHO classification, which includes the classification of low bone density as well as osteoporosis. If it is not possible to provide each woman with her own diagnosis they could at least be given information about the relationship between bone density results and the diagnosis of osteoporosis.

Another problem area is the interpretation of second scans. After a second scan, the print-out only shows the absolute level of bone density again, rather than change from the previous scan. In order to improve understanding of second scans it might be useful to present change scores together with written information about how to interpret the change, which is also currently lacking. Although written information might have to address the fact that relatively little is known about the interpretation of change between scans, it may be preferable for women to come to no firm conclusion than come to the wrong one. They will be able to draw a more definite conclusion if they go for further scans.

Several women didn't understand that different vertebrae naturally vary in density; this point could be clarified, as could the meaning of the different figures on the print-out. (However, it should be noted that at least one radiographer mentions these points as a matter of course.) The information given to women could also perhaps discuss the relationship between density in the spine and density in other parts of the body, since it seemed that few women realised that different sites might differ quite widely in bone density. If this information is not conveyed some women could become inappropriately complacent.

One of the problems in providing more detailed information to women attending bone density screening is that it may heighten uncertainty and therefore perhaps raise anxiety levels. This must be weighed against the effects of a certainty which is inappropriate - such as complacency in those who mistakenly believe that their bones are strong throughout their whole body or who think that their bone density has improved when the change is not in fact significant, or who think that their current lifestyle must be good. Of course many would argue that women simply have the right to know the full implications of their bone scan result, including the problems of interpretation. This is especially important since women are having to make very difficult decisions about HRT, which can have both short-term side-effects and implications for their long-term health. Many women seemed highly motivated to take care of their health and keen for as much information as possible; one woman wrote: "Knowledge is always helpful and positive even if worrying!". Some of the women were very angry about not having been warned by their doctor of the effects of a hysterectomy or of certain drugs on their bone density and wanted to find out as much as possible, in order to make informed decisions in the future.

Some of the questions which women asked were highly idiosyncratic and it would be impossible

to address them all in the written information provided to women. Unfortunately many women reported that their GP had been uninterested or unhelpful after their scan result. This highlights the need for GP education and the importance of having a physician available to answer questions. Although the information sheet states that “You may make arrangements to consult the project physician if you have any cause for concern”, some women did not seem to be aware of this.

Research into interpretations

The research into interpretations described in this chapter was exploratory in nature because there had been no previous research in this area. The open-ended question “What do you think that your result means?” has indicated the kind of interpretations that women describe spontaneously. One advantage of this approach was that some interpretations emerged which one might not have expected. This method may also be the best way to access the essence of the meaning of the result which the woman actually remembers and acts on. In future research one could use the information gained from this study to create a list of interpretations which the woman would have to endorse or not endorse. This would allow a quantitative examination of interpretations and would permit a more accurate estimate of the extent of misinterpretations. This may also prove a more sensitive way of examining the prediction that people who tend to worry about their health will interpret ambiguous illness information in a more negative way than people who don't tend to worry about their health.

Chapter 7: Changes in beliefs, feelings and behaviours in women with a high or low BMD result from their first bone density scan, or an increased or decreased result from their second scan.

7.1 Introduction

This chapter begins with a comparison of women receiving high and low bone density results from their first scan, examining their feelings about osteoporosis, reassurance or information-seeking behaviours, preventative behaviours and symptom reporting after the result. Women with low BMD are more at risk for osteoporosis and are therefore expected to feel more vulnerable to developing this condition. Cognitive models of anxiety (e.g. Beck, 1976) would predict that increased perceived vulnerability will result in greater anxiety about osteoporosis. Clinical experience with patients who have severe health anxiety suggests that some women may react to the perceived health threat with attempts to forget about the result, distract themselves from thinking about it, or seeking reassurance. It was felt that these behaviours should be assessed since the CB model of health anxiety suggests that they have the potential to maintain anxiety in the long-term.

There has only been one previous study which has compared the psychological effects of high and low results from bone density measurement. Rubin and Cummings (1992) found that 55% of women in their sample who received a low result reported feeling more worried about osteoporosis after the test, compared to 6% of those with normal results. However, the study was retrospective, the degree of anxiety was not assessed, and changes in risk perceptions and other beliefs about osteoporosis are not reported. Studies comparing the effects of high and low risk results from other types of health risk screening have shown inconsistent results, with some detecting considerable distress in those who receive a high risk result and others finding no evidence of psychological effects (see chapter 1 and Appendix A). One of the possible reasons for the inconsistent findings concerns the types of measures which have been used. In the present study the measures mainly concern beliefs and feelings specific to osteoporosis, which may be more sensitive to changes than psychiatric diagnosis or “caseness”, which are sometimes used. However, it should be noted that much of the previous research has focused on testing for risk factors for conditions which are probably perceived to be more serious than osteoporosis (e.g. heart disease or cancer), so the level of psychological distress after a low bone density result may be lower than the levels that have been found in some previous work.

Preventative behaviours after high and low results will also be compared. An increase in

preventative behaviour in those at risk, leading to a reduction in later fractures, is the ultimate goal of the bone density screening. Indeed, Rubin and Cummings (1992) found that women who received low BMD results were more likely to begin preventative measures than women with normal results. However, in the present bone density research project there was fairly limited advice about preventative behaviours, so it is important to establish whether the women in this sample are actually changing their behaviour.

Symptom reporting and preoccupation with thoughts of symptoms are also compared in women with high and low results. Warwick and Salkovskis's (1990) model of health anxiety suggests that when people perceive a potential health threat they may show selective attention to possible symptoms. Leventhal (1986) has suggested that when people are given a verbal illness label (e.g. low bone density), they will search for symptoms consistent with the label. Both of these suggestions lead to the prediction that women who receive a low bone density result will show greater preoccupation with thoughts of symptoms and are more likely to report symptoms than women with a high result.

A further prediction was that women who have a low result would show lower ratings of the seriousness of below-average bone density and osteoporosis than women with a high result. This prediction arises from findings in laboratory studies by Jemmott, Ditto and Croyle (1986) where they examined the effects of telling subjects that they had an enzyme deficiency which was a risk factor for a fictional pancreatic disorder. They found that subjects who had previously been told that they had tested positive appraised the threat posed by this risk factor as less serious than those who tested negative.

The second part of the chapter looks at the effects of second scans, where women receive information about change in their bone density, rather than simply the absolute level. Women who have shown a decrease in bone density on their second scan are compared with those who have shown an increase. Those who have shown a decrease would be expected to show greater anxiety about their result and to be more likely to report intentions to start new preventative behaviours. The primary comparison will involve women who describe their change as a decrease or increase, regardless of whether their change is actually significant. This is necessary because difficulties in interpreting second scans meant that a substantial number of women were incorrect in their interpretations. Cognitive models of emotion such as by Beck (1976) suggest that it is the appraisal of the situation which is the key determinant of responses - in other words one would expect that women's appraisal of the change as a decrease or increase will be a more important determinant of emotional response than the actual change in bone density.

7.2 Treatment of the data

In order to compare women with high and low bone density, their scan results were calculated as a percentage of the mean for their age. In the first part of this chapter, women whose results were in the highest 30% of these age-related results were compared with women whose results were in the lowest 30%. This resulted in the “high” group having results between 11.6% and 52.9% above the mean for their age (BMDs were from 0.936 to 1.442 g/cm²). The “low” group had results between 4.2% and 33.8% below the mean for their age (BMDs were 0.629 to 0.984 g/cm²). There were 90 women in each group. Of the “low” group, 42 women were below the fracture threshold line (i.e. had BMDs of below 0.81 g/cm²).

Where significant effects were found using ANOVAs, these were investigated further using t-tests. Since there were *a priori* predictions about the pattern of results i.e. that those with a low BMD would show more anxiety and greater perceived vulnerability, only certain t-tests were performed and alpha levels of $p < 0.05$ were accepted as significant.

7.3 Pre-existing differences between women receiving high and low bone density results

Independent t-tests indicated that the women in the high and low BMD groups showed no pre-existing differences on the Health Anxiety Questionnaire ($t_{(175)} = 0.6$), the BDI ($t_{(175)} = 0.5$) the STAI-trait ($t_{(176)} = 0.2$), knowledge of osteoporosis ($t_{(177)} = -0.7$) or the number of osteoporosis-preventative behaviours reported ($t_{(176)} = -0.6$). Chi-square analysis indicated that there was no difference in the proportion taking HRT before the scan ($\chi^2_{(178)} = 0.7$) or in the proportion reporting a family history of osteoporosis ($\chi^2_{(178)} = 0.9$). However, those who subsequently received a low bone density result were more likely to report a medical condition which may affect bone density ($\chi^2_{(175)} = 8.4$, $p < 0.005$) and were more likely to report symptoms of osteoporosis ($\chi^2_{(178)} = 5.3$, $p < 0.05$).

7.4 Beliefs about osteoporosis and mood in women with high and low bone density results

In order to examine changes in feelings about osteoporosis over time, repeated measures ANOVAs were performed. The between subjects factor was result, which refers to a high or low BMD level; the within-subjects factor was time. The means and standard deviations for the ratings of feelings at different points in time are shown in table 7.1 (overleaf).

Table 7.1 Feelings about osteoporosis and general mood at each assessment point, for women with high and low results: Means and standard deviations

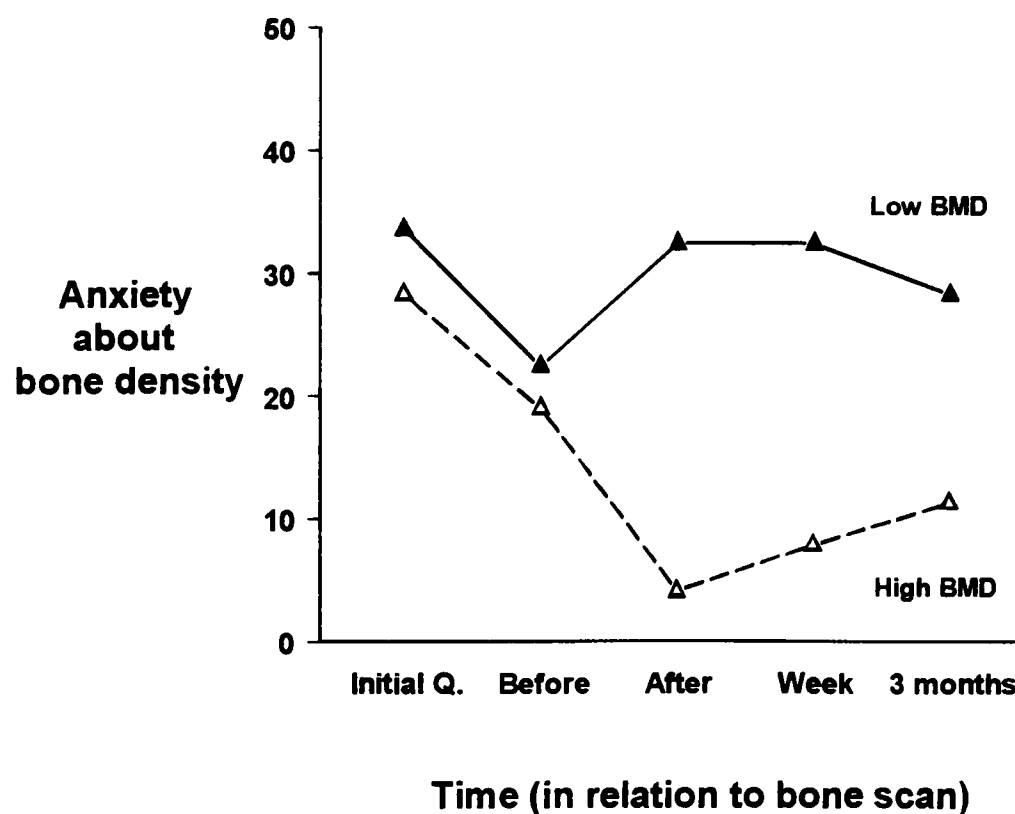
	Result	Initial Q	Before the scan	After the results	Week later	3 months later
Anxiety about bone density	High	Mean SD 28.3 (24.9)	Mean SD 19.0 (20.7)	Mean SD 4.1 (8.9)	Mean SD 7.9 (13.7)	Mean SD 11.3 (17.6)
	Low	33.6 (25.7)	22.4 (24.6)	32.3 (25.6)	32.3 (25.0)	28.2 (23.5)
Worry about osteoporosis	High	34.4 (25.4)	30.6 (23.3)	12.7 (17.4)	19.4 (21.6)	19.9 (21.7)
	Low	40.1 (29.0)	31.8 (25.3)	38.2 (25.7)	33.3 (25.3)	32.7 (23.4)
Need for reassurance	High	40.3 (29.9)	40.1 (27.6)	17.6 (25.4)	12.9 (21.2)	17.9 (25.7)
	Low	47.8 (32.8)	37.3 (29.4)	38.9 (28.4)	36.4 (29.8)	32.7 (32.2)
Likelihood of osteoporosis, in near future	High	27.9 (21.7)	26.9 (20.2)	12.1 (14.3)	11.4 (12.3)	13.7 (15.1)
	Low	31.5 (26.3)	24.0 (23.1)	31.4 (23.5)	29.0 (25.1)	29.3 (27.3)
Likelihood of ost, any point in future	High	35.7 (22.3)	35.7 (19.5)	20.6 (18.1)	23.0 (17.2)	24.8 (18.5)
	Low	46.2 (26.7)	36.0 (24.9)	45.1 (24.3)	44.9 (22.8)	43.4 (24.9)
Seriousness of below-average BMD	High	43.3 (23.5)	52.5 (22.6)	49.3 (24.2)	51.3 (22.0)	50.7 (23.0)
	Low	48.0 (25.5)	48.4 (25.6)	50.7 (25.5)	42.0 (25.9)	41.2 (25.6)
General anxiety	High	24.7 (23.4)	13.6 (19.8)	2.8 (7.4)	10.6 (16.1)	12.0 (16.2)
	Low	28.5 (26.8)	14.7 (23.0)	27.6 (25.2)	23.4 (24.0)	22.8 (24.7)
Sadness or low mood	High	16.9 (22.1)	9.5 (18.8)	4.8 (13.0)	10.5 (17.6)	12.9 (18.7)
	Low	14.9 (21.4)	8.6 (17.0)	14.9 (22.4)	14.2 (20.1)	16.4 (24.4)

All measures were 0 - 100 visual analogue scales. Higher scores indicate greater distress or more negative beliefs.

Anxiety about bone density (see figure 7.1, overleaf)

A repeated measures ANOVA showed main effects of result ($F_{(1,163)}=35.5$, $p<0.0005$) and time ($F_{(4,652)}=18.3$, $p<0.0005$) which were modified by a significant result by time interaction ($F_{(4, 652)}=21.6$, $p<0.0005$). Planned comparisons indicated that the two groups were not significantly different before the scan but afterwards those with a low result were more anxious about their bone density. Both groups showed a decrease between the initial assessment and the one immediately before the scan; after the results those with a high result showed a further decrease in anxiety after the scan while those with a low result showed an increase. For the low result group, the level of anxiety at the 3 month assessment was higher than it had been immediately before the scan but was not significantly different from the level at the initial assessment. For those with a high result there was a decrease in anxiety about bone density between the assessments before the scan and three month follow-up.

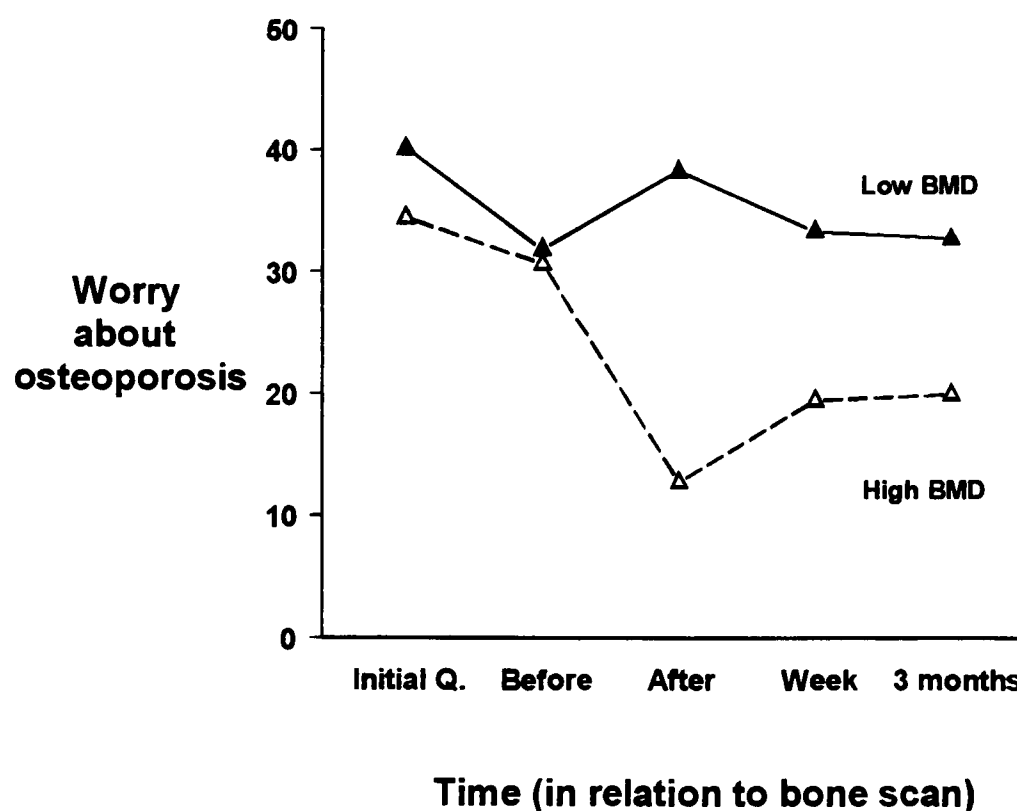
Figure 7.1
Anxiety about bone density
in women with high or low
scan results.



Worry about developing osteoporosis (see figure 7.2, below)

There was a main effects of result ($F_{(1,163)}=14.6, p<0.0005$) and time ($F_{(4,652)}=18.0, p<0.0005$) which were modified by a significant result by time interaction ($F_{(4, 652)}=15.44, p<0.0005$). Planned comparisons indicated that there was no significant difference between the two groups before the scan; afterwards those with a low result were more worried about their bone density. Those with a high result showed a significant decrease in worry immediately after the scan while those with a low result showed an immediate increase. For both groups worry about osteoporosis was lower the three month follow-up than at the initial assessment but a t-test on change scores indicated that the women with the low results showed significantly less decrease in worry than women with the high results.

Figure 7.2
Worry about osteoporosis
in women with high or low
scan results

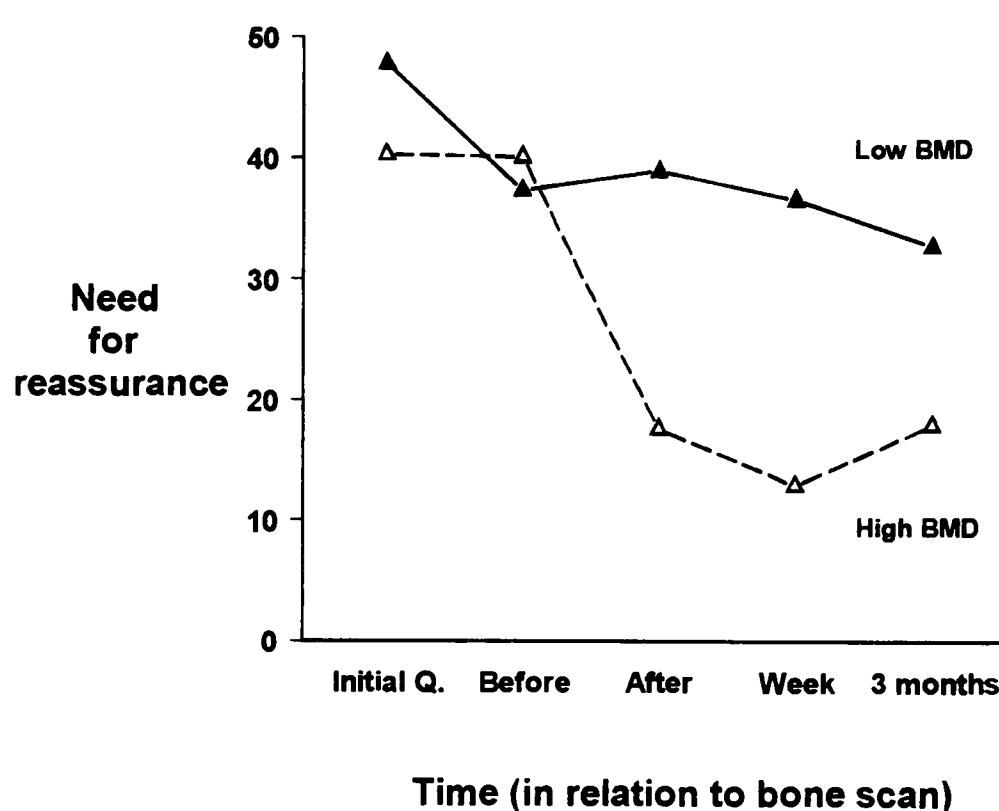


Need for reassurance (see figure 7.3)

A repeated measures ANOVA showed main effects of result ($F_{(1,164)}=12.3$, $p<0.005$) and time ($F_{(4,656)}=40.4$, $p<0.0005$) which were modified by a significant result by time interaction ($F_{(4,656)}=15.5$, $p<0.0005$). Planned comparisons indicated that although the two groups were not significantly different before the scan, afterwards those with a low result were more in need of reassurance. Both groups showed a decrease in need for reassurance between the initial assessment and three month follow-up; a t-test using change scores indicated that there was no significant difference between the amount of decrease in need for reassurance between the two groups.

Figure 7.3

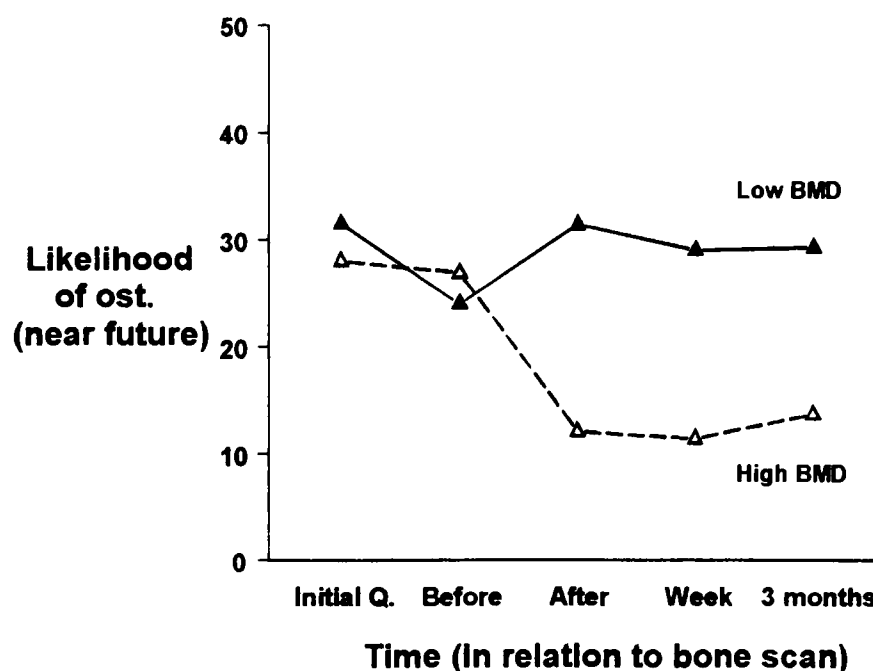
Need for reassurance about one's bone density in women with high or low scan results.



Likelihood of developing osteoporosis in the near future (see figure 7.4)

A repeated measures ANOVA showed main effects of result ($F_{(1,164)}=16.3$, $p<0.0005$) and time ($F_{(4,656)}=11.2$, $p<0.0005$) which were modified by a significant result by time interaction ($F_{(4,656)}=17.8$, $p<0.0005$). Planned comparisons indicated that there was no significant difference before the scan but afterwards those with a high result felt that they were more likely to develop osteoporosis in the near future. For those with a high result there was a significant decrease in perceived likelihood of osteoporosis in the near future after the scan. For those with a low result there was no significant difference between ratings at the initial assessment and the three month follow-up although there was a significant increase between the assessment immediately before the scan and the three month follow-up.

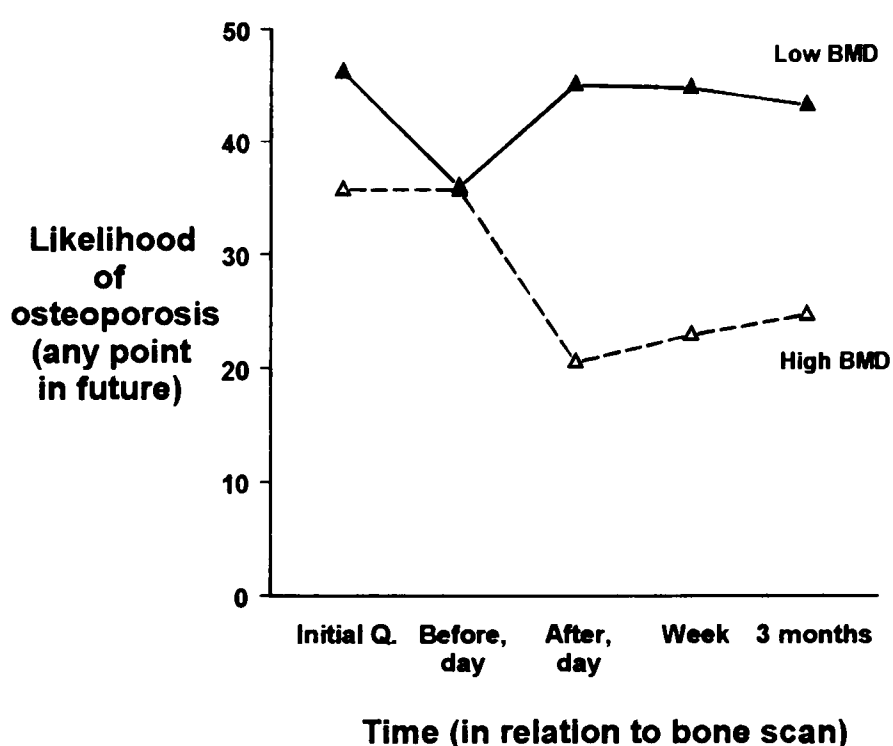
Figure 7.4
Perceived likelihood of
developing osteoporosis
(in the near future) in
women with high or low
scan results.



Likelihood of developing osteoporosis at any point in the future (see figure 7.5)

A repeated measures ANOVA showed main effects of result ($F_{(1,162)}=29.7$, $p<0.0005$) and time ($F_{(4,648)}=7.7$, $p<0.0005$) which were modified by a significant result by time interaction ($F_{(4,648)}=18.2$, $p<0.0005$). Planned comparisons indicated that at the initial assessment those who were going to receive a low result felt that they were significantly more likely to develop osteoporosis at any point in the future than those who were going to receive a high result. At the assessment immediately before the scan there was no longer any difference due to a decrease in ratings by those who were to receive low result. Immediately after the scan those with a low result rated osteoporosis as significantly more likely than those with a high result. This was due to a decrease in those with a high result and an increase in those with a low result. At the three month follow-up the ratings for the high result group were significantly lower than they had been at the initial assessment. In the low result group the ratings showed no significant change between the initial and three month assessment but there was an increase between the assessment immediately before the scan and the three month assessment.

Figure 7.5
Perceived likelihood of
developing osteoporosis
(at any point in the future)
in women with high or low
scan results.

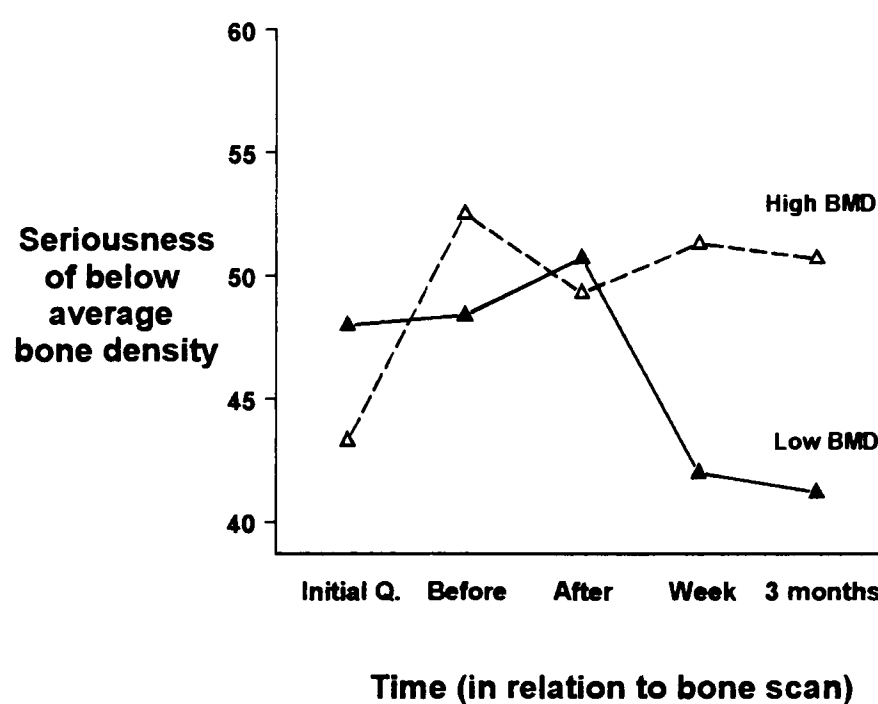


Perceived seriousness of below-average bone density (see figure 7.6)

A repeated measures ANOVA showed no main effect of result but there was a main effect of time ($F_{(4,644)}=3.4$, $p<0.05$) and a significant result by time interaction ($F_{(4,644)}=6.7$, $p<0.0005$). Planned comparisons indicated that before the scan there was no difference between the two groups; at the follow-ups those with a low result perceived below-average bone density as less serious than those with a high result. For those with a high result there was a significant increase in ratings of the seriousness of below average bone density between the two assessments prior to the scan and at the three month follow-up the ratings were still significantly higher than they had been in the initial assessment. For those with a low result there was a significant decrease in ratings between the initial assessment and the three month follow-up.

Figure 7.6

Perceived seriousness of below-average bone density in women with high or low scan results.



It is possible that judgements of seriousness will be associated with beliefs about how likely it is that one will be able to prevent symptoms osteoporosis if one has low bone density. (In other words, if the person believes that it is easy to prevent osteoporosis, below-average bone density will be perceived as being less serious than if the person believes that it is impossible to prevent the symptoms from occurring). In order to examine the relationship between these two sets of beliefs, correlations were performed. These indicated that before the scan there was not a significant correlation between ratings of seriousness and beliefs about how likely it is that one would be able to prevent osteoporosis if one had low bone density. Three months after the scan there was a significant correlation between these two ratings ($r_{(319)}=0.25$ ($p<0.0005$) for all those having first scans; $r_{(81)}=0.34$ ($p<0.005$) for those having a high result and $r_{(86)}=0.27$ ($p<0.05$) for those having a low result). These correlations show that higher seriousness ratings were

associated with higher ratings of the likelihood preventing osteoporosis (if one has low bone density). There were significant but small correlations between the changes in beliefs about prevention and changes in ratings of seriousness but only if one looked at all of those having first scans ($r_{(303)}=0.14$, $p<0.05$). This indicated that reductions in seriousness ratings were associated with a decrease in ratings of the likelihood of preventing osteoporosis (i.e. believing that it is less likely that osteoporosis can be prevented).

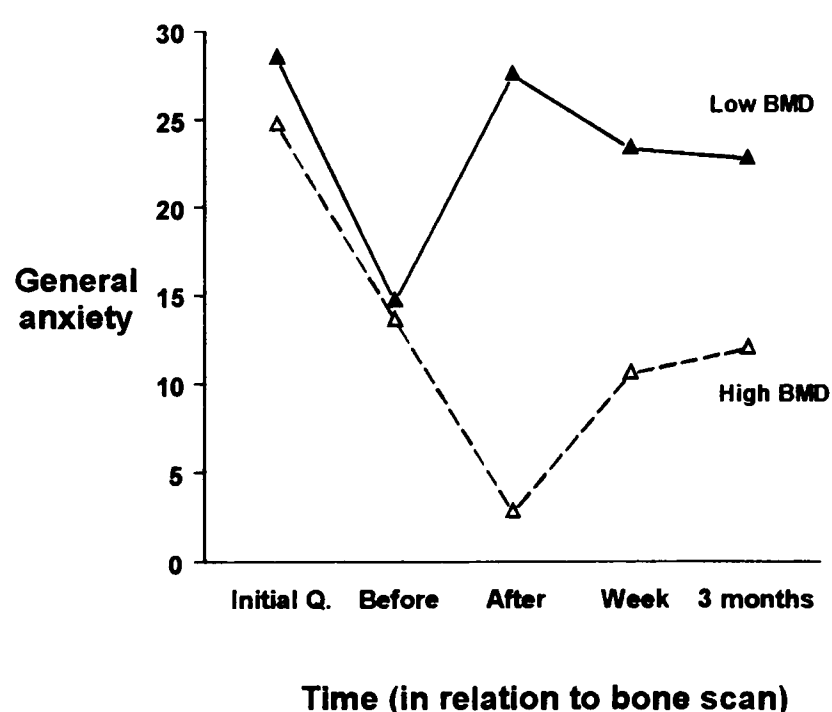
It was found that there were no significant correlations between ratings of seriousness or changes in ratings of seriousness and the number of preventative behaviours at three months or changes in the number of preventative behaviours after the scan; this was true if one looked at all those having first scans, just those with a low result or just those with a high result.

There was a non-significant tendency for a decrease in the rating of seriousness (between the initial assessment and the three month follow-up) in those who received a bad result, to be associated with a decrease in anxiety about bone density ($r_{(87)}=0.19$, $p=0.079$).

General anxiety (see figure 7.7)

A repeated measures ANOVA showed a main effect of result ($F_{(1,166)}=17.2$, $p<0.0005$), a main effect of time ($F_{(4,664)}=18.0$, $p<0.0005$) and a significant result by time interaction ($F_{(4, 664)}=15.8$, $p<0.0005$). Planned comparisons indicated that there were no differences between the groups before the scan but afterwards those who had a low result were significantly more anxious than those who received a high result. For both groups anxiety was lower at the three month follow-up than at the initial assessment although a t-test using change scores indicated that the group receiving low results showed a smaller decrease in anxiety than the group receiving high results.

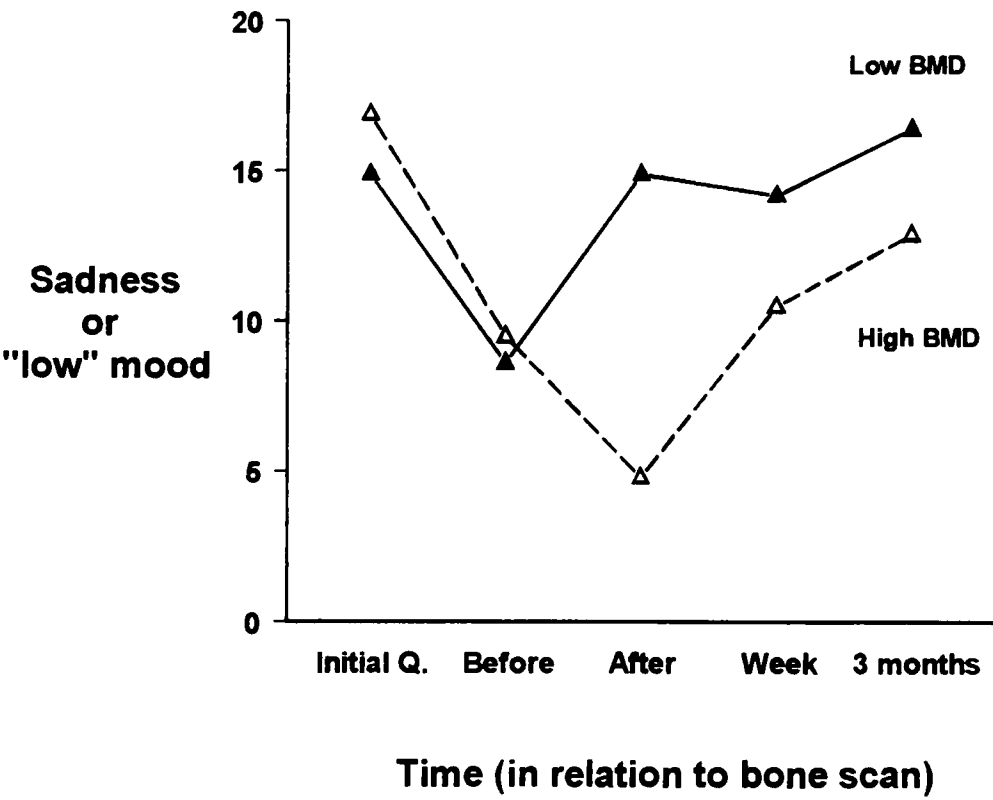
Figure 7.7
General anxiety in women with
high or low scan results.



Sadness or “low” mood (see figure 7.8)

A repeated measures ANOVA showed no main effect of result but there was a main effect of time ($F_{(4,660)}=8.4, p<0.0005$) and a significant result by time interaction ($F_{(4,660)}= 5.6, p<0.0005$). Planned comparisons indicated that immediately before the scan both groups showed less sadness than at the initial assessment and there were no differences between the groups. After the results those with a high result showed a decrease in sadness while those with a low result showed an increase so that the groups were significantly different. This difference was no longer significant at the week and 3 month follow-ups although a t-test using change scores between the initial and 3 month assessments indicated that there was a non-significant trend for the low-result group to show a smaller decrease in sadness than the high-result group ($t_{(165)}=-1.8, p=0.078$).

Figure 7.8
Sadness or low mood in women with high or low scan results.



Measures taken at three points in time

The means and standard deviations for ratings on measures which were only used at three points in time are shown in the table overleaf.

Table 7.2 Beliefs about osteoporosis which were assessed at three points in time: means and standard deviations

	Result	Initial Questionnaire		Week after scan		3 months after scan	
		Mean	SD	Mean	SD	Mean	SD
Worry about fractures	High	27.1	(28.0)	20.9	(22.7)	19.4	(22.5)
	Low	30.4	(30.2)	26.1	(26.5)	27.5	(27.6)
Perceived vulnerability	High	34.5	(25.2)	18.2	(18.6)	19.3	(20.2)
	Low	41.7	(28.4)	43.8	(26.0)	41.1	(27.3)
Risk compared to others ^a	High	-0.20	(1.3)	-1.52	(1.3)	-1.35	(1.4)
	Low	0.29	(1.3)	1.07	(1.1)	0.79	(1.1)
Prevention beliefs	High	64.2	(22.8)	56.4	(22.8)	53.3	(23.9)
	Low	64.8	(23.4)	61.8	(25.2)	58.5	(25.1)
Coping beliefs	High	33.4	(22.7)	34.8	(20.2)	37.4	(21.9)
	Low	38.1	(24.4)	36.8	(21.6)	39.9	(25.5)
Cost: ability to enjoy life if had osteoporosis	High	34.7	(25.1)	35.1	(21.2)	40.6	(25.5)
	Low	36.7	(24.1)	33.1	(23.7)	40.5	(26.3)
Cost: How bad the consequences of osteoporosis would be for her	High	46.4	(23.4)	43.4	(20.9)	43.6	(22.2)
	Low	48.1	(23.0)	40.0	(23.3)	44.2	(25.3)
Likelihood of developing serious illness other than osteoporosis (near future)	High	21.1	(18.7)	21.0	(17.5)	19.8	(16.1)
	Low	17.2	(18.7)	15.3	(18.3)	16.7	(19.1)
Likelihood of developing serious illness other than osteoporosis (any point in future)	High	37.2	(23.6)	36.7	(19.4)	36.9	(21.8)
	Low	33.8	(27.0)	30.4	(24.4)	32.3	(25.0)

^a this was a scale from -3 to 3.

High ratings indicate more negative beliefs except for prevention beliefs where they indicate more positive beliefs.

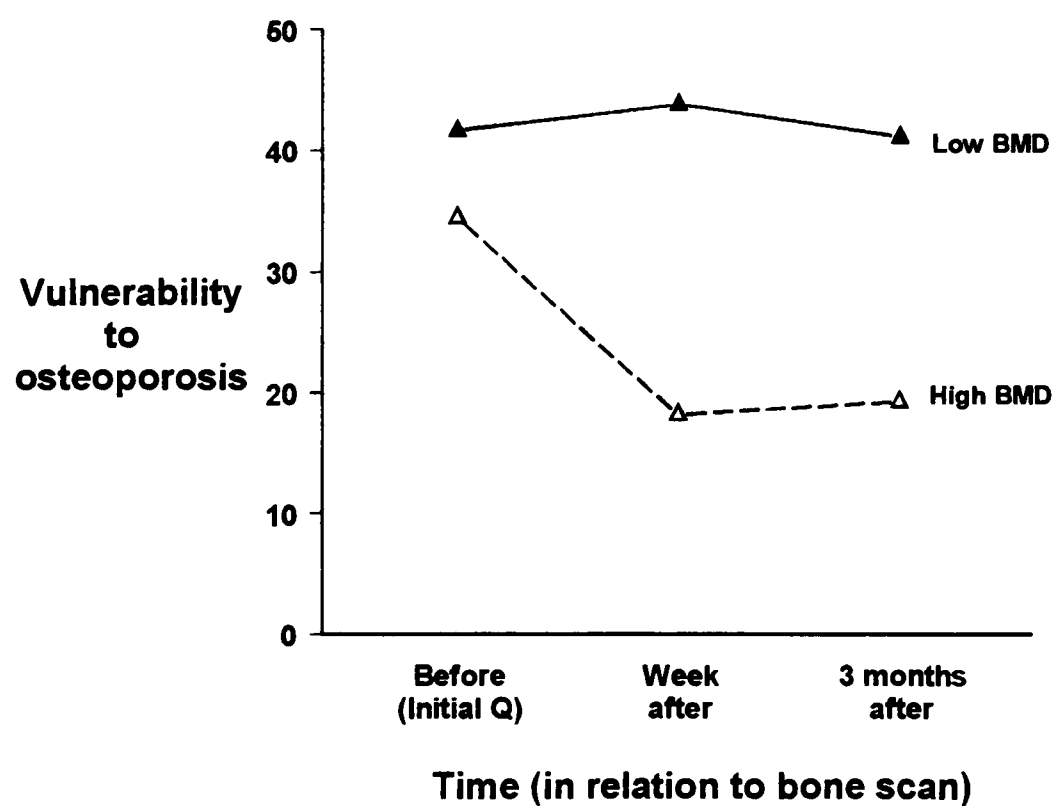
Worry about fractures

A repeated measures ANOVA showed no main effect of result although there was a main effect of time ($F_{(2,346)}=6.7$, $p<0.005$), indicating a decrease in worry about fracture over time. There was no significant result by time interaction.

Perceived vulnerability (see figure 7.9)

A repeated measures ANOVA showed main effects of result ($F_{(1,169)}=34.5$, $p<0.0005$) and time ($F_{(2,338)}=11.6$, $p<0.0005$) which were modified by a significant result by time interaction ($F_{(2,338)}=14.5$, $p<0.0005$). Planned comparisons indicated that there was a non-significant trend for those who were going to receive a low result to feel more vulnerable to osteoporosis before the scan ($t_{(169)}=0.08$). After the scan those with a low result felt significantly more vulnerable to osteoporosis than those with a high result. Those with a low result showed no significant change over time while those with a high result showed a significant decrease in perceived vulnerability after the scan.

Figure 7.9
Perceived vulnerability
to developing osteoporosis
in women with high or low
scan results.



Perceived risk compared to the “average” woman of the same age (see figure 7.10)

A repeated measures ANOVA showed main effects of result ($F_{(1,170)}=129.6$, $p<0.0005$) and time ($F_{(2,340)}=6.3$, $p<0.0005$) which were modified by a significant result by time interaction ($F_{(2,340)}=61.9$, $p<0.0005$). Planned comparisons indicated that both before and after the scan those with a low result felt more at risk compared to others. Those with a high result showed a decrease in perceived risk while those with a low result showed an increase in perceived risk.

Figure 7.10

Perceived risk compared to “the average woman” of the same age, in women with high or low scan results.

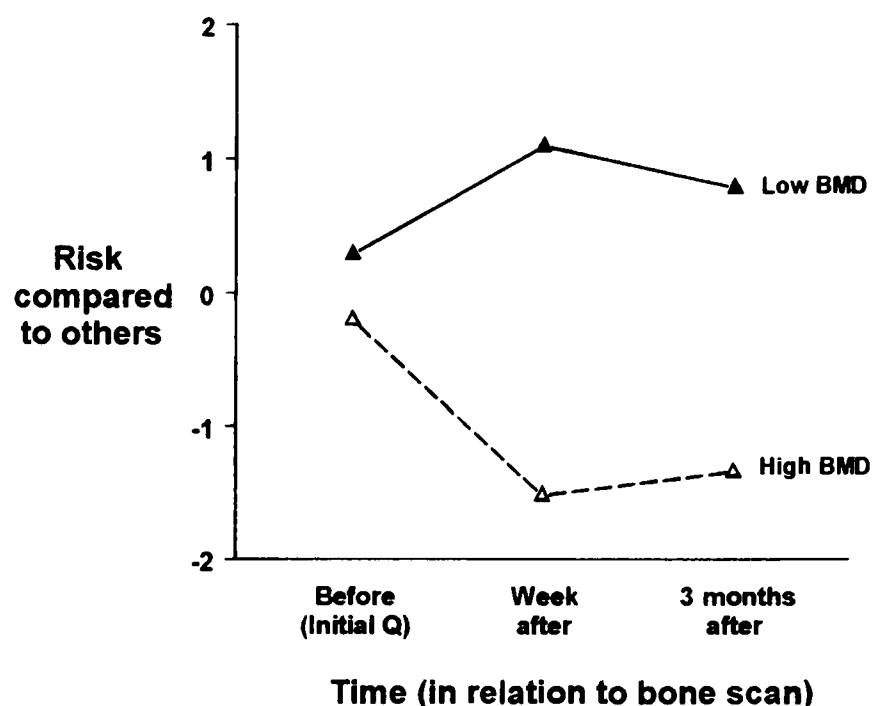
(Positive values indicate that the woman feels more at risk than the average woman of the same age.

2 = more at risk.

1 = slightly more at risk

-1 = slightly less at risk

-2 = less at risk).



Prevention beliefs: A repeated measures ANOVA showed no main effect of result and no significant result by time interaction. However, there was a main effect of time ($F_{(2,318)}=9.3$, $p<0.0005$), indicating that after the scan women believed that there was less chance of being able to prevent symptoms of osteoporosis if one has low bone density.

Anticipated ability to cope if one had osteoporosis: There were no significant main effects or interaction.

Anticipated ability to enjoy life if one had osteoporosis: There was no main effect of result and no significant result by time interaction, but there was a main effect of time ($F_{(2,340)}=7.8$, $p<0.0005$). After the scan, ratings of one's ability to enjoy life if one had osteoporosis became more negative.

Perceived severity of the consequences of osteoporosis: The only significant effect here was a main effect of time ($F_{(2,344)}=5.9$, $p<0.0005$) due to a decrease after the scan in ratings of how bad the consequences of osteoporosis would be.

Likelihood of developing a serious illness other than osteoporosis: There were no significant main effects or interactions.

7.5 Questions with multiple-choice answers

Treatment of the data

For the questions with multiple choice answers the numbers were usually too small to do chi-square analyses using the original five or six groupings. Instead, responses have been regrouped as “yes” or “no” rather than frequency data for the purpose of comparisons, although the raw data is presented in table form. For example, for the question “Did you try to forget yourself about your result” the responses were coded as “no” if the women ticked “Not at all” or “yes” if she ticked anything from “Once or twice” to “every day”.

7.5.1 Anxiety and Worry assessed using multiple-choice questions

How anxious have you felt about your result over the past few days? (See table 7.3)

Chi-square analyses indicated that those with a low result had been significantly more anxious about their result over the past few week than those with a high result, when assessed at the week ($\chi^2_{(1)}=85.1$, $p<0.00005$) and three month follow-ups ($\chi^2_{(1)}=34.2$, $p<0.0005$). In the week immediately after a low result, about three quarters of the women had felt at least slightly anxious about their result; at the three month follow-up this proportion had dropped significantly to 37.2% (McNemar’s test $\chi^2_{(1)}=26.3$, $p<0.0005$). However, for most women the level of anxiety is not very high: only 18.7% (16) said that they had been moderately, very or extremely anxious and by three months after the scan only 5.9% of the women were giving one of these three responses.

Table 7.3 Anxiety about the scan result, a week and three months after the scan, in women with a high or low result.

	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
	%	N	%	N	%	N	%	N
Not at all anxious	96.6	(86)	27.9	(24)	97.8	(87)	62.8	(54)
Very slightly anxious	2.2	(2)	30.2	(26)	1.0	(1)	17.4	(15)
Slightly anxious	-	-	23.3	(20)	1.0	(1)	14.0	(12)
Moderately anxious	1.1	(1)	12.8	(11)	-	-	3.5	(3)
Very anxious	-	-	4.7	(4)	-	-	1.2	(1)
Extremely anxious	-	-	1.2	(1)	-	-	1.2	(1)

Are you more, or less worried about osteoporosis since the scan? (See table 7.4).

A t-test used to compare answers to the question “Are you more or less worried about osteoporosis since the scan?” (which were scored on a scale from -3 to 3) indicated that those with a low result were more

worried (relative to before the scan) than those with a high result.

Table 7.4 Proportion of women with high and low results who feel less or more worried about osteoporosis since the scan.

	Week after the scan				Three months after the scan			
	High Result		Low result		High result		Low result	
	%	N	%	N	%	N	%	N
Much less worried	47.7	(42)	2.2	(2)	47.7	(42)	5.6	(5)
Less worried	29.5	(26)	6.7	(6)	19.3	(17)	3.3	(3)
A little less worried	4.5	(4)	7.8	(7)	9.1	(8)	2.2	(2)
Neither more or less worried	18.2	(16)	35.6	(32)	22.7	(20)	43.3	(39)
A little more worried	-	-	35.6	(32)	1.1	(1)	32.3	(29)
More worried	-	-	7.8	(7)	-	-	10.0	(9)
Much more worried	-	-	4.4	(4)	-	-	3.3	(3)

7.5.2 Preoccupation with thoughts of osteoporosis

How often have you thought about osteoporosis in the past week? (See table 7.5)

Chi-square analyses indicated that before the scan there was no difference between the two groups regarding the number of women who had thought about osteoporosis in the past week. After the scan those who had a low result were more likely to have thought about osteoporosis in the past week ($\chi^2_{(1)}=20.5$, $p<0.0005$). McNemar’s tests indicated that those with a high result showed a significant change over time, with fewer women reporting thinking about osteoporosis after the scan ($\chi^2_{(1)}=36.2$, $p<0.0005$) while those who received a low result showed no significant change over time.

Table 7.5 Frequency of thoughts about osteoporosis in the past week for women with high and low results, reported before and after the scan.

	Before the scan				Three months after the scan			
	High result		Low result		High result		Low result	
<u>Frequency</u>	%	N	%	N	%	N	%	N
Not at all	38.6	(34)	42.0	(37)	84.1	(74)	52.3	(46)
Once or twice	48.9	(43)	46.6	(41)	14.8	(13)	38.6	(34)
Several times	10.2	(9)	10.2	(9)	1.1	(1)	8.0	(7)
Every day	2.3	(2)	1.1	(1)	-	-	1.1	(1)
More than once a day	-	-	-	-	-	-	-	-

“When you received your result how long did it take you to forget about it?”(see table 7.6)

A chi-square analysis indicated that there was a significant difference in responses to this question between

those with high and low results both at the week follow-up ($\chi^2_{(1)}=10.7$, $p<0.05$) at the three month follow-up ($\chi^2_{(1)}=18.7$, $p<0.005$). Those with a low result reported that it took them longer to forget about their result than those with a high result and 27.9% still think about their result three months after the scan. (A transformation into a dichotomous variable did not have to be used for this question).

Table 7.6 The time taken to forget about the result, for women with a high or low result.

Time taken to forget about the result	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
	%	N	%	N	%	N	%	N
A few minutes	22.7	(20)	11.6	(10)	11.4	(10)	7.0	(6)
An hour or so	23.9	(21)	19.8	(17)	21.6	(19)	5.8	(5)
A day	20.5	(18)	15.1	(13)	17.0	(15)	8.1	(7)
Several days	18.2	(16)	19.8	(17)	30.7	(27)	39.5	(34)
Several weeks ^a	-	-	-	-	6.8	(6)	11.6	(10)
I still think about it	14.8	(13)	33.7	(29)	12.5	(11)	27.9	(24)

^a This response was only offered at the three month follow up

“Since the scan, how often have you thought about what it would be like if you developed the symptoms of osteoporosis (or developed more symptoms if you already have some)?” (See table 7.7).

A chi-square analysis indicated that those with a low result were more likely to say that they had thought about what it would be like to develop symptoms of osteoporosis (or more symptoms if they already had some), when asked a week after the scan ($\chi^2_{(1)}=5.3$, $p<0.05$) and three months after the scan ($\chi^2_{(1)}=11.2$, $p<0.005$).

Table 7.7 Frequency of thoughts about what it would be like if one developed symptoms of osteoporosis, for women with a high or low result.

	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
<u>Frequency</u>	%	N	%	N	%	N	%	N
Never	44.3	(39)	27.8	(25)	51.1	(45)	26.7	(24)
Once or twice	50.0	(44)	54.4	(49)	43.2	(38)	48.9	(44)
Several times	5.7	(5)	11.1	(10)	4.5	(4)	22.2	(20)
Many times	-	-	4.4	(4)	1.1	(1)	1.1	(1)
Every day	-	-	2.2	(2)	-	-	1.1	(1)

7.5.3 Cognitive coping responses which may act to maintain health anxiety

“Did you deliberately try to forget about your result?” (See table 7.8)

A chi-square analysis indicated that those with a low result were more likely to say that they had deliberately tried to forget about their result at the week follow-up ($\chi^2_{(1)}=15.0$, $p<0.0005$) and the three month follow-up ($\chi^2_{(1)}=26.6$, $p<0.0005$). Two women with a high result reported attempts to forget about their result at the week follow-up and a different two women report the same thing at the three month follow-up. Inspection of the questionnaires revealed that both of the women who reported deliberate forgetting at three months were worried that the result indicated arthritis, but there was no obvious explanation for the responses of other two women.

Table 7.8 Frequency of attempts to deliberately forget about the scan result in women with high and low results.

	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
<u>Frequency</u>	%	N	%	N	%	N	%	N
Never	97.7	(85)	76.5	(65)	97.7	(85)	68.2	(58)
Once or twice	2.3	(2)	12.9	(11)	1.1	(1)	22.4	(19)
Several times	-	-	8.2	(7)	1.1	(1)	4.7	(4)
Many times	-	-	2.4	(2)	-	-	3.5	(3)
Every day	-	-	-	-	-	-	1.2	(1)

“Did you do anything to distract yourself from thinking about it?” (See table 7.9)

A chi-square analysis indicated that those with a low result were more likely to say that they had done something to distract themselves from thinking about their result, when asked a week after the scan ($\chi^2_{(1)}=14.5$, $p<0.0005$) and three months after the scan ($\chi^2_{(1)}=19.4$, $p<0.0005$). As with the previous question, the two women with high results who reported attempts to distract themselves from thinking about their result (at three month follow-up) were both worried about arthritis.

Table 7.9 Frequency of attempts to distract oneself from the result, in women with high or low results.

	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
<u>Frequency</u>	%	N	%	N	%	N	%	N
Never	97.6	(83)	78.8	(67)	97.6	(84)	74.1	(63)
Once or twice	-	-	10.6	(9)	2.4	(2)	18.8	(16)
Several times	1.2	(1)	8.2	(7)	-	-	3.5	(3)
Many times	-	-	1.2	(1)	-	-	2.4	(2)
Every day	-	-	1.2	(1)	-	-	1.2	(1)

Did you try to reassure yourself about it? (See table 7.10)

A chi-square analysis indicated that those with a low result were more likely to say that they had tried to reassure themselves about their result when asked a week after the scan ($\chi^2_{(1)}=66.4$, $p<0.0005$) and three months after the scan ($\chi^2_{(1)}=66.4$, $p<0.0005$).

Table 7.10 Frequency of attempts to reassure oneself about the result, in women with high or low results.

	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
<u>Frequency</u>	%	N	%	N	%	N	%	N
Never	90.7	(78)	28.2	(24)	89.5	(77)	28.2	(24)
Once or twice	7.0	(6)	42.4	(36)	7.0	(6)	36.5	(31)
Several times	2.3	(2)	23.5	(20)	-	-	27.1	(23)
Many times	-	-	3.5	(3)	1.2	(1)	5.9	(5)
Every day	-	-	2.4	(2)	2.3	(2)	2.4	(2)

7.5.4 Thoughts and beliefs about symptoms in women with high or low results

Since the scan, how often have you wondered whether symptoms that you have now or have had in the past may be related to your bone density? (See table 7.11)

A chi-square analysis indicated that those with a low result were more likely to say that they had wondered whether symptoms that they had (or had had in the past) were related to their bone density, when asked a week after the scan ($\chi^2_{(1)}=13.6$, $p<0.0005$) and three months after the scan ($\chi^2_{(1)}=36.4$, $p<0.0005$).

Table 7.11 Frequency of thoughts about whether she has symptoms relating to her bone density since the scan, in women with high or low results.

	Week after the scan				Three months after the scan			
	High result		Low result		High result		Low result	
<u>Frequency</u>	%	N	%	N	%	N	%	N
Never	80.5	(70)	52.9	(46)	89.7	(78)	47.1	(41)
Once or twice	17.2	(15)	29.9	(26)	6.9	(6)	37.9	(33)
Several times	2.3	(2)	13.8	(12)	3.4	(3)	12.6	(11)
Many times	-	-	3.4	(3)	-	-	2.3	(2)
Every day	-	-	-	-	-	-	-	-

“Do you have, or have you had in the past, any symptoms / fractures that might be related to your bone density?”

Before the bone scan women who were to get a high result were significantly less likely to report symptoms ($\chi^2_{(1)}=5.8$, $p<0.05$). Afterwards the same pattern was true ($\chi^2_{(1)}=16.8$, $p<0.0005$) although the phi-coefficient was higher after the scan (0.31 compared to 0.18 before the scan) suggesting that the association between symptom reporting and bone density might be stronger after the scan result was known. Women with a high result were less likely to report symptoms after the scan ($p<0.05$ in binomial test) whereas for those with a low result there was no significant change over time. Table 7.12 shows the numbers of women in each group reporting symptoms before and after the scan and table 7.13 shows the types of symptoms reported.

Table 7.12 **Symptom reporting** in women with high and low scan results, before the scan and three months later.

Symptom reporting	High result		Low result	
	%	N	%	N
No change: symptoms at both	4.7	4	23.0	20
: no symptoms	80.2	69	58.6	51
Symptoms before only	12.8	11	10.3	9
Symptoms after only	2.3	2	8.0	7

Table 7.13 The number of women with high or low BMD reporting **different types of symptoms** 3 months after the scan

Symptoms of low bone density three months after scan	High result	Low result
Fracture(s)	4	18
Pain	2	12
<u>Other</u>		
Back injury (unspecified)	1	-
Slight humped back-scoliosis of the spine	1	-
Weakness in ankles and knees	1	-
Loss of weight and stature, general stamina	-	1
“Finding it a job to keep shoulders back, bad posture”	-	1

“How sure are you that you have/don’t have symptoms related to bone weakness?”

A chi-square analysis indicated that those with a low result were more likely to say that they had, or probably had, symptoms relating to bone weakness ($\chi^2_{(1)}=55.7$, $p<0.0005$) (see table 7.14). However, very few from either group were sure that they had symptoms.

Table 7.14 **Certainty about symptoms** three months after the scan in women with high or low BMD results

	High result		Low result	
	%	n	%	n
I am <u>sure</u> that I have symptoms related to bone weakness	2.3	(2)	5.6	(5)
I think that I <u>probably</u> have symptoms...	2.3	(2)	26.7	(24)
I have <u>no idea</u> whether I have symptoms...	6.9	(6)	30.0	(27)
I think that I <u>probably don't</u> have symptoms...	26.4	(23)	21.1	(19)
I am sure that I <u>don't</u> have symptoms....	62.1	(54)	16.7	(15)

7.5.5 Preventative behaviours reported by women having high and low results

A t-test indicated that before the scan there was no significant difference in the number of osteoporosis-preventative behaviours reported by women who were to receive a high or low result. After the scan there was a significant difference between the two groups ($t=-2.01$, $p<0.05$) with those who had received a low result reporting more preventative behaviours (the mean number was 1.8 compared to 1.5 in the other group). A chi-square analysis indicated that those with a low result were significantly more likely to report at least one preventative behaviour after the scan ($\chi^2_{(1)}=8.4$, $p<0.005$, 91% compared to 73.9%) whereas there had been no difference between the groups before the scan.

McNemar's tests showed that women in both groups were significantly more likely to report that they performed at least one osteoporosis-preventative behaviour after the scan than beforehand (see table 7.15). Preventative behaviours were reported after the scan but not beforehand by 42.7% of those with a low result and 34.1% of those with a high result. Only two women with results below the fracture threshold reported no preventative behaviours at follow-up. One of these had stopped taking HRT because of side-effects and was planning to see her doctor about it and the other woman said that she had discussed her result with her GP and intended to discuss it again in the future.

Table 7.15 **Changes in the reporting of preventative behaviours** in women with high and low results.

At least one osteoporosis -preventative health behaviour reported before and after the scan	High result		Low result	
	%	n	%	n
No change: preventative behaviour(s) before and after	39.8	(35)	48.3	(43)
no preventative behaviours before or after	20.5	(18)	9.0	(8)
Started preventative behaviour(s)	34.1	(30)	42.7	(38)
Stopped preventative behaviour(s)	5.7	(5)	0.0	(0)

A t-test indicated that after the scan women with a low result were significantly more likely to report taking

calcium supplements ($\chi^2_{(1)}=32.4$, $p<0.0005$) than those with a high result (see table 7.16). There was a non-significant trend for fewer of those with a low result to report eating calcium rich foods in order to prevent osteoporosis ($\chi^2_{(1)}=3.2$, $p=0.07$). There was no significant difference between the two groups in reports of exercise or HRT as osteoporosis-preventative behaviours. The numbers of people reporting taking other minerals or vitamins were too small to compare between groups. Six of those with low results reported taking Didronel PMO, a bisphosphonate which is only available on prescription.

Table 7.16 The types of preventative behaviours reported by women with high or low results, 3 months after the scan.

Type of preventative behaviour	High result		Low result		Chi-square analysis
	%	(N)	%	(N)	
Calcium supplements	13.5	(12)	54.0	(47)	$\chi^2_{(1)}=3.3$, $p<0.0005$
HRT	16.9	(15)	24.1	(21)	$\chi^2_{(1)}=0.231$, not sig.
Diet	59.6	(53)	46.0	(40)	$\chi^2_{(1)}=3.3$, $p=0.07$
Other minerals or vitamins	3.4	(3)	4.6	(4)	$\chi^2_{(1)}=0.17$, not sig.
Didronel	-	-	6.9	(6)	Comparison not applicable: prescribed treatment
Exercise	52.8	(47)	41.4	(36)	$\chi^2_{(1)}=2.3$, not sig.
Other	4.5	(4)	5.7	(5)	Fisher's exact test, not sig.

7.5.6 Information seeking and reassurance seeking

Those with a low result were significantly more likely than those with a high result to have discussed their result with their GP, to be intending to discuss their result with their GP in the future, to have contacted the project physician about their result, to have seen or be intending to see a specialist about their result, to have tried to find out more information about bone density or osteoporosis, to be intending to find out more information and to say that they will go for another scan in the next few months (see table 7.17 for χ^2 values and significance levels). There was a non-significant trend for more women with a low result to report talking to family or friends to get their opinion about their result than women with a high result (see table 7.18).

There was no significant difference between the two groups in the proportion of women reporting that they had discussed their result with another medically trained person (other than those mentioned above) or reporting that had discussed their feelings about their result with friends or family, or saying that they would have another scan at some point in the future.

Those who received a low result were significantly more likely to have already seen a health

professional about their result or sought further information about osteoporosis, since the scan. However, 25 (28.4%) of those with a low result hadn't yet sought reassurance or information and 12 of these were not intending to do so in the future.

Table 7.17 Proportion of women with high or low results who have discussed their result with health professionals or sought further information.

	Proportion saying "yes"		Results of chi-square analyses.
	High result	Low result	
	% (N)	% (N)	
Discussed result with GP	28.9 (26)	60.2 (53)	$\chi^2_{(1)}=17.7$ ***
Contacted project physician about result	1.1 (1)	12.5 (11)	$\chi^2_{(1)}=9.2$ **
Seen or intend to see specialist about result	2.2 (2)	16.7 (14)	$\chi^2_{(1)}=10.7$ **
Discussed result with any other medically trained person	19.1 (17)	28.1 (25)	$\chi^2_{(1)}=1.99$.
Tried to find out more about bone density or osteoporosis since the scan	24.7 (22)	51.1 (45)	$\chi^2_{(1)}=13.1$ ***
At least one of the above	42.2 (38)	71.6 (63)	$\chi^2_{(1)}=15.6$ ***

* p<0.05 ** p<0.005 *** p<0.0005

Table 7.18 The proportion of women with high or low BMD results who have discussed their result with family/ friends and the proportion who are intending to undergo further scans or seek more information.

	Proportion saying "yes"		Results of chi-square analyses.
	High result	Low result	
Intend to discuss result with GP in the future	26.8 (22)	67.5 (43)	$\chi^2_{(1)}=26.9$ ***
Intend to find out more information about BMD or osteoporosis	38.4 (33)	59.3 (51)	$\chi^2_{(1)}=7.5$, p<0.05
Talked to friends/family to get their opinion about result	61.1 (55)	73.0 (65)	$\chi^2_{(1)}=2.9$, p=0.09
Talked to friends/family about her feelings about result	71.1 (64)	71.9 (64)	$\chi^2_{(1)}=0.01$, not sig.
Intend to go for another scan in the next few months	30.6 (26)	56.8 (50)	$\chi^2_{(1)}=12.1$, p<0.005
Intending to go for another scan at any point in the future	93.2 (82)	96.5 (83)	$\chi^2_{(1)}=1.0$, not sig.

Part Two: Women having second scans

7.6 Comparison of women having second scans who have shown an increase or decrease

In order to examine the effects of an increase or decrease in bone density, two comparisons were performed. The first set of analyses involved those who wrote at the week follow-up that their bone density had increased or decreased when asked "What do you think that your result means?". The second set of analyses compared those who showed an actual change of at least 2.5%, which is the cut-off used at the Bone Densitometry Unit for significant change. This double analysis has been performed because a substantial

minority of women were wrong when they described their change as an increase or decrease or no significant change. It was predicted that the woman’s perceptions about the change will be the most important determinant of the psychological effects of a second scan. It was thus predicted that after the scan, those who perceived a decrease in BMD between scans would be more distressed about osteoporosis and will rate osteoporosis as more likely than those who perceived an increase; the effects for the group showing an “actual” decrease will be less pronounced. (In the description of the results, a change of 2.5% is referred to as an “actual” change in order to contrast with the group which described a change). Table 7.19 shows the number of women reporting different descriptions of change in bone density, compared to actual change in bone density.

Table 7.19 Descriptions of result in terms of change in BMD compared to actual change

	Actual change in bone density		
	Significant increase	Significant decrease	No significant change
Described as increase	11	-	7
Described as decrease ^a	-	6	5
Described as no change	1	1	<i>13</i>
Decrease attributed to machine error etc	-	2	2
Change not mentioned	20	17	<i>47</i>

^athose who said that their decrease could be machine error are not included
those shown in italics are not included in analyses in this chapter

Independent t-tests indicated that there was no significant differences in BMD, age-related result (percentage above or below the mean for their age) or age between the women who described an increase or decrease (or who showed an actual increase/decrease).

In order to examine differences in beliefs about osteoporosis between these two groups, repeated measures ANOVAs were performed using actual or perceived change as the grouping variable. Unfortunately some women did not describe their result in terms of a change and hence could not be used in these analyses. Since the numbers of subjects were thus reduced, only measures taken immediately before and after the scan and at the week follow-up were used, in order to maximise the number of subjects that could be included.

Anxiety about bone density (see figure 7.11 and table 7.20)

There was a main effect of group ($F_{(1,25)}=5.2, p<0.05$) and a group by time interaction ($F_{(2,50)}=7.1, p<0.005$), but no main effect of time. Planned comparisons indicated that those said that they had increased in bone density showed no significant change over time while those who said that they had decreased were more anxious about their bone density at the week follow-up than immediately before the scan. A week after the scan the Decreased group were more anxious than the Increased group.

If “actual” change was used as the grouping variable there were no main effects and the group by time interaction just failed to reach significance ($F_{(2,68)}=3.04, p=0.054$).

Figure 7.11
Anxiety about bone density
in women who described their
change in bone density as
an increase or decrease.

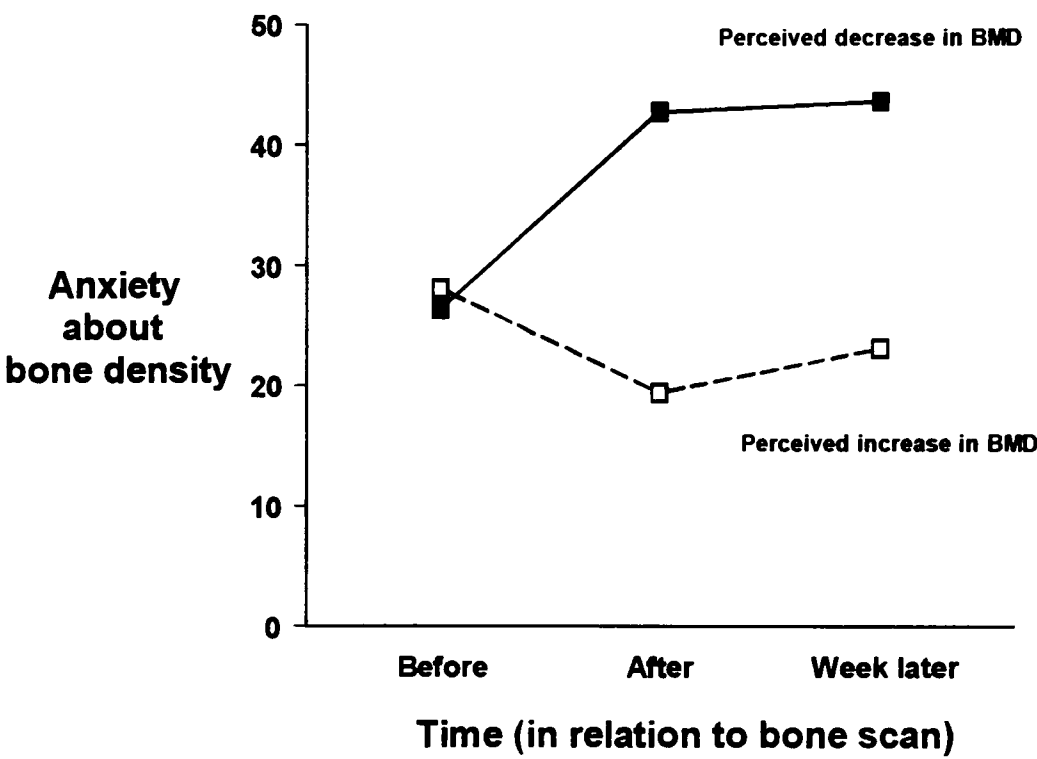


Table 7.20 Ratings of anxiety about bone density in women who showed / described an increase or decrease in BMD on their second scan.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	28.1	(19.1)	19.4	(12.9)	23.1	(20.2)
Described decrease	26.4	(18.0)	42.7	(22.0)	43.6	(22.0)
Increase >2.5%	30.0	(27.3)	20.0	(18.0)	26.3	(22.9)
Decrease >2.5%	26.5	(18.7)	34.7	(27.2)	40.0	(24.5)

Worry about developing osteoporosis (see figure 7.12 and table 7.21)

There was a main effect of group ($F_{(1,25)}=4.5, p<0.05$) and a significant group by time interaction ($F_{(2,50)}=3.8, p<0.05$) but no main effect of time. Planned comparisons indicated that before the scan the two groups were not significantly different in terms of worry about osteoporosis. The Decreased group were more worried than the Increased group immediately after the results due to the increased group showing a significant decrease in worry. The two groups were not significantly different at the week follow-up because the increase group showed a return of some of their worry.

In contrast, in the secondary analysis, using “actual” change as the grouping variable, there were no significant effects.

Figure 7.12
Worry about osteoporosis in women who described their change in bone density as an increase or decrease.

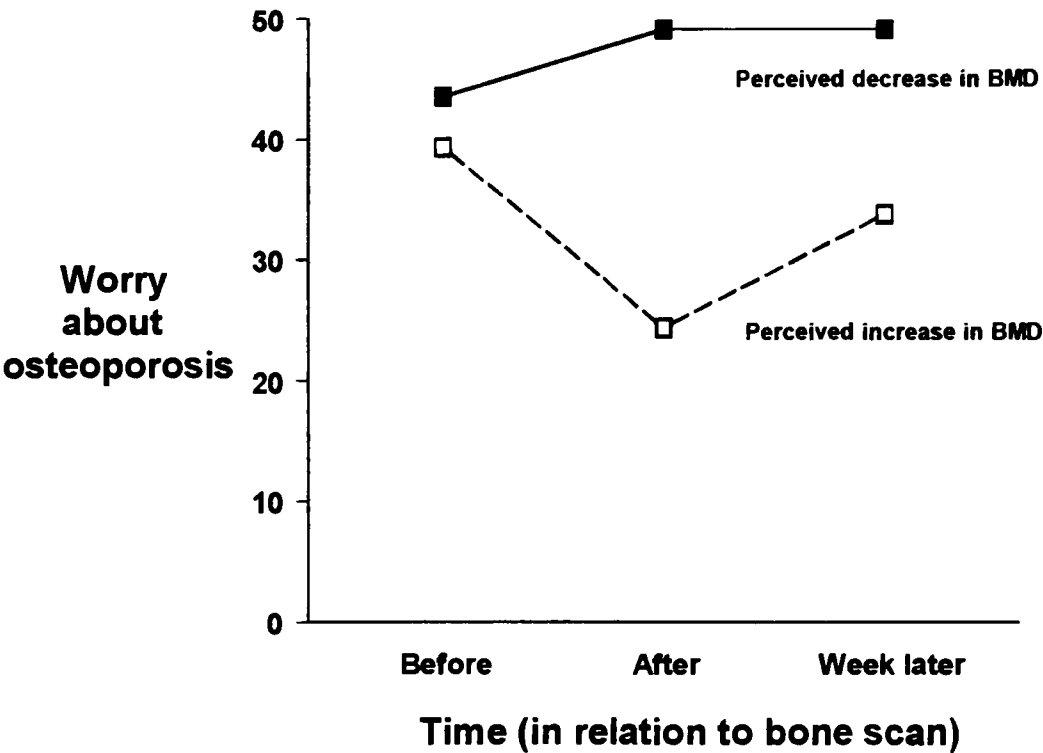


Table 7.21 Ratings of worry about developing osteoporosis in women who showed / described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	39.4	(18.8)	24.4	(18.6)	33.8	(23.3)
Described decrease	43.6	(15.0)	49.1	(20.2)	49.1	(27.7)
Increase >2.5%	37.4	(27.9)	27.4	(20.2)	34.7	(24.6)
Decrease >2.5%	40.6	(17.1)	45.9	(26.7)	42.4	(23.6)

Need for reassurance (see figure 7.13 and table 7.22)

The only significant effect was a main effect of group ($F_{(1,25)}=7.7$, $p<0.05$) with the Decreased group reporting greater need for reassurance. When “actual” change was used as the grouping variable there were no significant main effects or interactions.

Figure 7.13
Need for reassurance in women who describe their change in bone density as in increase or decrease.

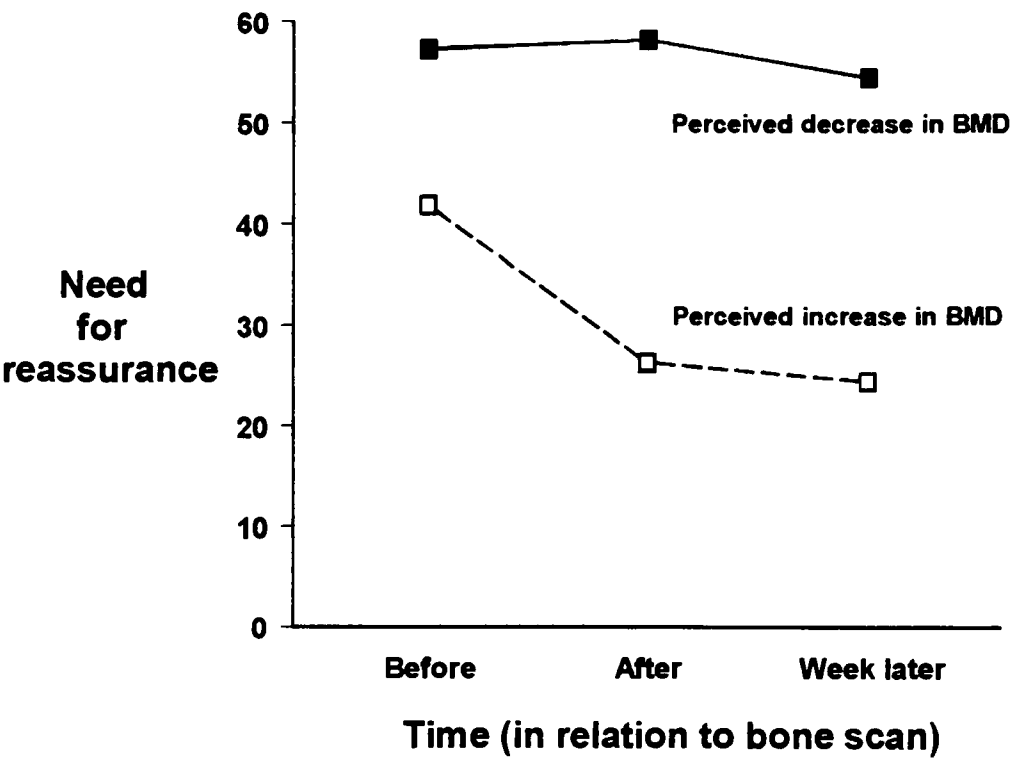


Table 7.22 Ratings of need for reassurance in women who showed / described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	41.8	(25.6)	26.3	(23.3)	24.3	(23.3)
Described decrease	57.3	(29.7)	58.2	(28.2)	54.5	(35.3)
Increase >2.5%	43.7	(28.9)	29.5	(24.8)	32.6	(24.6)
Decrease >2.5%	47.8	(26.1)	49.4	(32.7)	46.9	(28.0)

Perceived likelihood of developing osteoporosis in the near future (see figure 7.14 and table 7.23)

Here the only significant effect was a group by time interaction ($F_{(1,25)}=3.6, p<0.05$). Planned comparisons indicated that the two groups were not significantly different before the scan but at the week follow-up those who said that they had decreased to rated osteoporosis as more likely in the near future than those who said that they had increased. This difference was due to a decrease in perceived likelihood in the group who felt that they had increased in bone density.

Figure 7.14
Perceived likelihood of developing osteoporosis (in the near future) in women who described their result as an increase or decrease

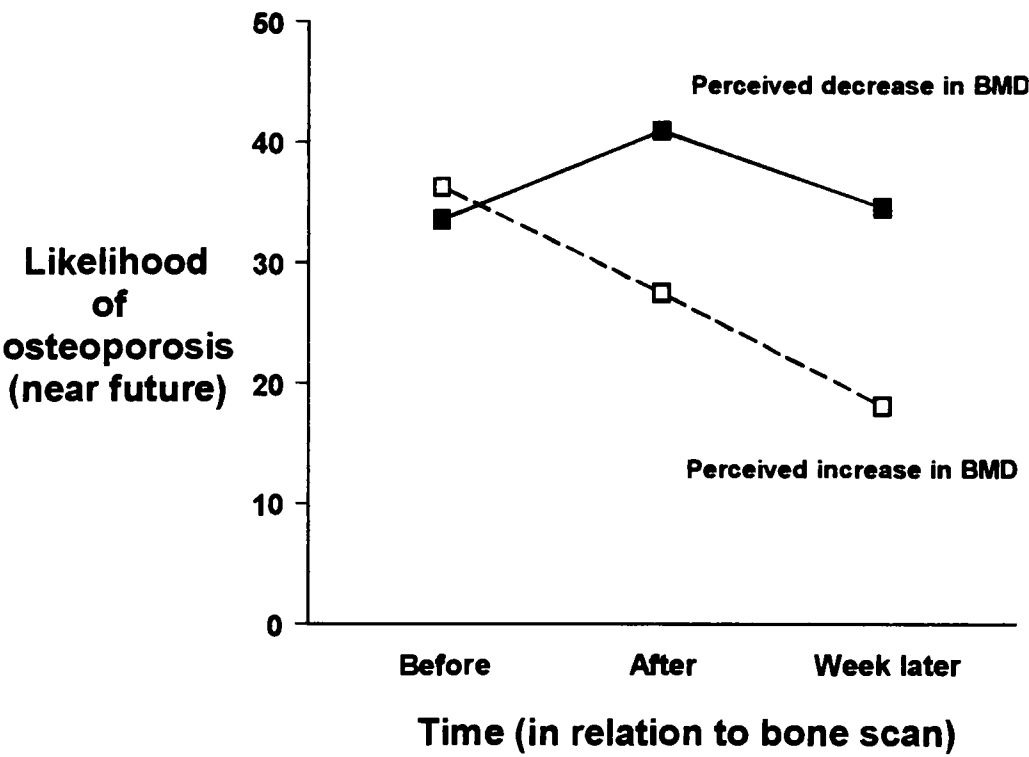


Table 7.23 Ratings of perceived likelihood of developing osteoporosis in the near future in women who showed / described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	36.3	(20.6)	27.5	(15.7)	18.1	(14.7)
Described decrease	33.6	(16.3)	40.9	(19.2)	34.5	(22.5)
Increase >2.5%	27.4	(19.4)	21.6	(14.2)	23.7	(16.7)
Decrease >2.5%	32.4	(13.0)	37.6	(23.1)	35.8	(15.8)

Perceived likelihood of developing osteoporosis at any point in the future

Repeated measures ANOVAs showed no significant main effects or interactions when either increase/decrease description or “actual” increase/decrease were used as the grouping variables.

Table 7.24 Ratings of perceived likelihood of developing osteoporosis at any point in the future, in women who showed or described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	46.9	(18.2)	38.8	(21.9)	38.8	(17.8)
Described decrease	50.0	(19.0)	51.8	(19.4)	51.8	(17.2)
Increase >2.5%	40.5	(21.5)	36.8	(24.5)	37.6	(18.9)
Decrease >2.5%	44.7	(16.2)	48.2	(19.1)	48.2	(21.0)

Perceived seriousness of below-average bone density (see table 7.25)

Repeated measures ANOVAs showed no significant main effects or interactions when either increase/decrease description or “actual” increase/decrease were used as the grouping variables.

Table 7.25 Ratings of perceived seriousness of below-average bone density in women who showed / described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	51.9	(25.1)	51.3	(26.3)	43.1	(25.5)
Described decrease	70.0	(21.9)	63.6	(20.1)	59.1	(25.9)
Increase >2.5%	45.0	(27.0)	45.0	(26.1)	52.0	(27.5)
Decrease >2.5%	54.1	(25.5)	57.1	(23.9)	58.2	(29.0)

General anxiety (see figure 7.15 and table 7.26)

Here there was a main effect of group ($F_{(1,25)}=13.3$, $p<0.005$) and of time ($F_{(1,25)}=12.8$, $p<0.0005$) although the interaction failed to reach significance ($F_{(1,25)}=2.4$, $p=0.10$). Those who described a decrease were more anxious than those who described an increase. Anxiety was greater at the week follow-up than on the day of the scan.

Using “actual” change as the grouping variable there was a similar pattern: a main effect of group ($F_{(1,35)}=8.01$, $p<0.05$) and of time ($F_{(2, 70)}=8.0$, $p<0.005$) and a non-significant trend towards a group by time interaction ($F_{(2,70)}=2.8$, $p=0.065$).

Figure 7.15
General anxiety in women
who described their change in
bone density as an increase or
decrease.

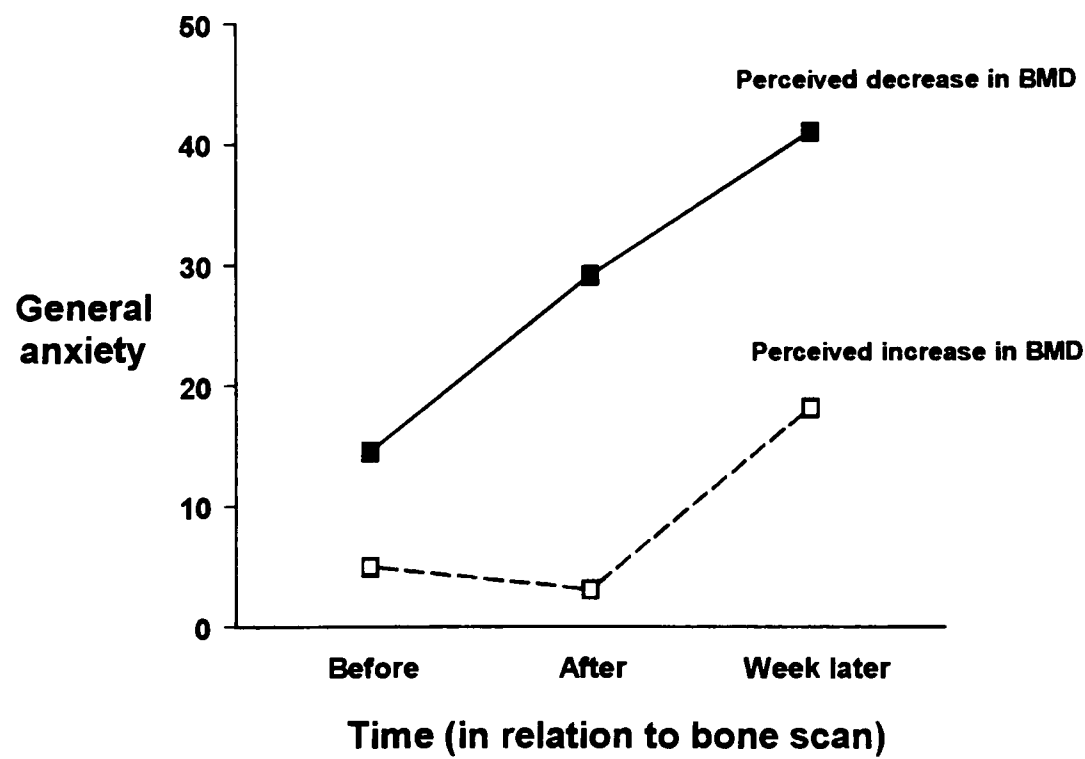


Table 7.26 Ratings of general anxiety in women who showed or described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	5.0	(8.9)	3.1	(4.8)	18.1	(17.2)
Described decrease	14.5	(24.2)	29.1	(25.9)	40.9	(23.9)
Increase >2.5%	8.0	(14.7)	5.0	(8.3)	17.0	(15.9)
Decrease >2.5%	12.9	(19.0)	25.3	(25.5)	58.2	(19.1)

Sadness or low mood (see figure 7.16 and table 7.27)

There was a significant group by time interaction ($F_{(2,50)}=3.4, p<0.05$). Planned comparisons indicated that immediately after the scan those who described a decrease in bone density showed a non-significant worsening in mood and a non-significant tendency to feel lower in mood than those who described an increase ($t_{(10.6)}=-2.1, p=0.059$). At other points in time there were no group differences.

In the secondary analysis, using actual change as the grouping variable, there were no significant effects.

Figure 7.16
Sadness or low mood
in women who describe
their result as an increase
or decrease

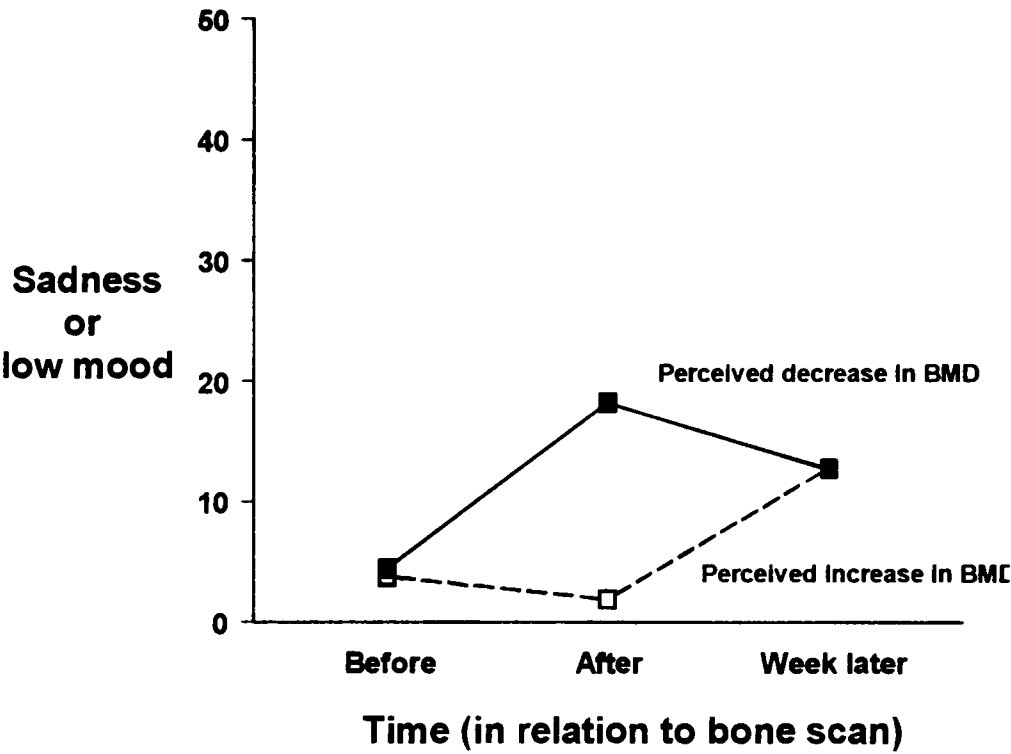


Table 7.27 Ratings of sadness or “low mood” in women who showed or described an increase or decrease in BMD.

Result	Before the scan		After the results		Week later	
	Mean	SD	Mean	SD	Mean	SD
Described increase	3.8	(8.1)	1.9	(5.4)	12.8	(19.0)
Described decrease	4.5	(8.2)	18.2	(25.2)	12.7	(19.0)
Increase >2.5%	6.0	(12.3)	4.0	(7.5)	12.8	(22.3)
Decrease >2.5%	7.6	(10.9)	14.1	(16.6)	12.9	(17.9)

Attempts to seek information or reassurance

In order to compare attempts to seek information or reassurance, the responses to six questions about such behaviours (listed in table 7.28) were added together and t-tests were performed on these totals. Those who described a decrease did not report more attempts to seek discuss the result or seek further information after the scan than those who described an increase. However, those who showed an actual decrease did report more types of information or advice-seeking than those who showed an actual increase.

Table 7.28 Frequency of different types of information- or reassurance-seeking

	Described an increase		Described a decrease		Increase >2.5%		Decrease >2.5%	
Total number of reassurance / information-seeking behaviours	Mean	SD	Mean	SD	Mean	SD	Mean	SD
	1.2	(1.4)	2.1	(1.9)	1.2	(1.2)	2.4	(1.6)
<u>Different types of behaviours</u>	%	n	%	n	%	n	%	n
Contacted GP about result	11.1	(2)	36.4	(4)	13.6	(3)	22.2	(4)
Spoke to project physician on day of scan	11.1	(2)	-	-	9.1	(2)	25.0	(4)
Phoned project physician since day of scan	5.6	(1)	9.1	(1)	-	-	-	-
Discussed result with another medically trained person	16.7	(3)	9.1	(1)	19.0	(4)	27.8	(5)
Tried to find out more information about osteoporosis since the scan.	16.7	(3)	27.3	(3)	28.6	(6)	66.7	(12)
Intend to find out more about osteoporosis	38.9	(7)	63.6	(7)	9.1	(2)	33.3	(6)

Intention to begin more preventative measures

At the week follow-up, those who described their result as a decrease were significantly more likely to say that they intended to change their behaviour in some way because of their result than those who described their result as an increase (Fisher's exact test, $p < 0.05$). Of the 11 women who described a decrease, 10 said that they intended to change their behaviour whereas 8 of the 18 women in the increase group reported these intentions. Similarly, those who showed an "actual" decrease were significantly more likely to say that they intended to change their behaviour than those who showed an increase ($\chi^2_{(1)} = 5.1$, $p < 0.05$). However in this comparison the group differences were slightly less marked: 13 of the 18 decreased group compared to 8 of

the 14 increased group reported intentions to start new behaviours. (Of the five women who did not intend to change their behaviour after a decreased in bone density, one had described her change as a decrease, one as “no change” and the other three did not mention their change in bone density).

Preoccupation with thoughts about osteoporosis or the result

Those who described their result as a decrease did not report thinking about their result more frequently over the past week than those who described an increase (see table 7.29). They were also no more likely to wonder whether they had symptoms of osteoporosis or to say that they had thought about what it would be like if they developed symptoms of osteoporosis (see tables 7.30 and 7.31). However, they were more likely to say that they had felt anxious about their result over the past week (Fisher’s exact test, one-tail $p<0.05$; see table 7.32). The same pattern of results was seen in those who showed an actual increase or decrease ($\chi^2_{(1)}=11.9, p<0.005$).

Table 7.29 **Frequency of thoughts about the scan result** in the week after the scan, in women who described or showed a decrease or increase in BMD.

	Described increase		Described decrease		Increase>2.5%		Decrease >2.5%	
	%	N	%	N	%	N	%	N
Not at all	11.1	(2)	9.1	(1)	18.2	(4)	16.7	(3)
Once or twice	61.1	(11)	36.4	(4)	63.6	(14)	28.9	(7)
Several times	22.2	(4)	36.4	(4)	18.1	(4)	44.4	(8)
Every day	5.6	(1)	18.2	(2)	-	-	-	-
More than once a day	-	-	-	-	-	-	-	-

Table 7.30 **Frequency of thoughts about whether one has symptoms of osteoporosis** in women who described or showed a decrease or increase in BMD. (Rated at week follow-up).

	Described increase		Described decrease		Increase>2.5%		Decrease >2.5%	
	%	n	%	n	%	n	%	n
Not at all	55.6	(10)	27.3	(3)	54.5	(12)	41.2	(7)
Once or twice	27.8	(5)	63.6	(7)	27.3	(6)	35.3	(6)
Several times	5.6	(1)	9.1	(1)	13.6	(3)	23.5	(4)
Many times	11.1	(2)	-	-	4.5	(1)	-	-
Every day	-	-	-	-	-	-	-	-

Table 7.31 **Frequency of thoughts about what it would be like to have symptoms of osteoporosis, in women who described or showed a decrease or increase in BMD. (Rated at week follow-up)**

	Described increase		Described decrease		Increase>2.5%		Decrease >2.5%	
	%	n	%	n	%	n	%	n
Not at all	44.4	(8)	27.3	(3)	40.9	(9)	17.6	(3)
Once or twice	27.8	(5)	36.4	(4)	40.9	(9)	41.2	(7)
Several times	22.2	(4)	27.3	(3)	9.1	(2)	35.3	(6)
Many times	5.6	(1)	9.1	(1)	9.1	(2)	5.9	(1)
Every day	-	-	-	-	-	-	-	-

Table 7.32 **Anxiety about the result over the past week in women who described or showed a decrease or increase in BMD. (Rated at week follow-up).**

Level of anxiety	Described increase		Described decrease		Increase>2.5%		Decrease >2.5%	
	%	n	%	n	%	n	%	n
Not at all anxious	82.4	(14)	27.3	(3)	86.4	(19)	33.3	(6)
Very slightly anxious	11.8	(2)	18.2	(2)	9.1	(2)	22.2	(4)
Slightly anxious	-	-	36.4	(4)	4.5	(1)	33.3	(6)
Moderately anxious	5.9	(1)	18.2	(2)	-	-	11.1	(2)
Very anxious	-	-	-	-	-	-	-	-
Extremely anxious	-	-	-	-	-	-	-	-

Cognitive coping responses which may contribute to the maintenance of health anxiety

Women who described their result as a decrease were no more likely to have tried to forget about their result or distract themselves from thinking about it (tables 7.33 and 7.34), but they were more likely to have tried to reassure themselves about it than women who described an increase (Fisher’s exact test, p<0.05; table 7.35).

The same pattern of results was seen in women who showed an actual increase or decrease in bone density ($\chi^2_{(1)}=9.4$, p<0.005).

Table 7.33 **Frequency of attempts to deliberately forget about the result in women who described or showed a decrease or increase in BMD.**

	Described increase		Described decrease		Increase > 2.5%		Decrease > 2.5%	
	%	n	%	n	%	n	%	n
Never	94.1	(16)	72.7	(8)	95.5	(21)	83.3	(15)
Once or twice	-	-	9.1	(1)	4.5	(1)	-	-
Several times	5.9	(1)	18.2	(2)	-	-	11.1	(2)
Many times	-	-	-	-	-	-	5.6	(1)
Every day	-	-	-	-	-	-	-	-

Table 7.34 Frequency of **attempts to distract oneself about the result** in women who described or showed a decrease or increase in BMD.

	Described increase		Described decrease		Increase > 2.5%		Decrease > 2.5%	
	%	n	%	n	%	n	%	n
Never	94.1	(16)	81.8	(9)	95.2	(20)	94.4	(17)
Once or twice	-	-	9.1	(1)	-	-	5.6	(1)
Several times	5.9	(1)	9.1	(1)	4.8	(1)	-	-
Many times	-	-	-	-	-	-	-	-
Every day	-	-	-	-	-	-	-	-

Table 7.35 Frequency of **attempts to deliberately forget about the result** in women who described or showed a decrease or increase in BMD.

	Described increase		Described decrease		Increase > 2.5%		Decrease > 2.5%	
	%	n	%	n	%	n	%	n
Never	82.4	(14)	27.3	(3)	71.4	(15)	22.2	(4)
Once or twice	11.8	(2)	36.4	(4)	28.6	(6)	44.4	(8)
Several times	-	-	18.2	(2)	-	-	22.2	(4)
Many times	5.9	(1)	9.1	(1)	-	-	11.1	(2)
Every day	-	-	9.1	(1)	-	-	-	-

Summary and discussion

Overview of results

Women who received a low result on their first bone density scan were more anxious about osteoporosis and more anxious in general than women who received a high result, three months after the bone scan. These differences were not apparent before the scan and were due to a decrease in the ratings of those with a high result. Before the scan, on some measures of risk perceptions, women who were subsequently to receive a low result rated themselves as more at risk than women who were subsequently to receive a high result. After the scan, risk perceptions decreased in those with a high result but generally showed no significant change in those with a low result. After the scan, women who received a low result were more likely to begin new preventative behaviours, report symptoms of osteoporosis, seek further information and try to use forgetting, distraction or self-reassurance than those with a high result. Those with a low result showed a decrease in perceived seriousness of below-average bone density while those with a high result showed an increase. There were no group differences in beliefs about prevention or in one’s ability to enjoy life or cope if one

had osteoporosis.

Women who described the result of their second scan as a decrease in BMD were more distressed and perceived osteoporosis as more likely than those who described their result as an increase. These group differences were only apparent after the scan. Those showing a decrease in BMD reported more information-seeking after the scan and were more likely to be intending to start new preventative measures than those showing an increase in BMD.

Summary and Discussion part 1: Women with high or low BMD results

Changes in perceived vulnerability to osteoporosis

Before the scan, the women who were to receive a low result perceived themselves as more at risk than others and rated it more likely that they would develop osteoporosis at any point in the future than women who were to receive a high result. This demonstrates that at least some of the women with low BMD had been able to use information gained their doctor, the mass media, a family history or from symptoms, to correctly conclude that they are at risk before they had the scan results.

After the scan, women with a high BMD result showed a decrease in perceived vulnerability to osteoporosis and perceived likelihood of developing the condition. Women with low results showed no significant change relative to ratings in the initial assessment point, although ratings of perceived likelihood were higher at the three month assessment than at the assessment immediately before the scan. (As discussed in the previous chapter, it is difficult to judge which of the pre-scan assessments should be used as the baseline). The only risk measure on which those with a low result showed an increase relative to the initial assessment was perceived risk compared to the average woman of the same age. This increase may be due to the fact that the scan results are presented in terms of BMD compared to the mean for their age and this information may convert fairly easily to risk compared to others. However, there were indications that although the group of women who had received low results showed an increase in their comparative risk judgement, they were still being overly optimistic about their risk. For example, at the 3 month follow-up their mean rating of risk compared to other women of the same age was 0.8 on a scale where 0 was “at the same risk as the average woman” and 1 was “slightly more at risk than the average woman”. The scale also

included the possible choices of “more at risk” and “much more at risk” which would have been a more accurate representation of the risk of women with a low result. The mechanism for this optimism is not clear, but it is possible that the women with a low result concentrate on reasons which mean that they are not as at risk as their result might suggest - such as the fact that they can begin preventative behaviours as a result of this early detection of low bone density, or have no family history, or are in general good health.

Perceptions of the likelihood of developing a serious illness other than osteoporosis, in the near or distant future, were not significantly different in the high and low-result groups. This indicates that bone density screening may have a specific effect on women’s beliefs about osteoporosis rather than illness in general.

Changes in beliefs about the seriousness of low bone mineral density

For ratings of the seriousness of below-average bone density, those with a low result show a significant decrease between initial and 3 month assessments and those with a high result show a significant increase. The finding of a post-test difference in seriousness ratings of people with high and low risk results is similar to findings from previous laboratory studies by Jemmott, Ditto and Croyle (1986) where they examined the effects of telling subjects that they had an enzyme deficiency which was a risk factor for a fictional pancreatic disorder. They found that subjects who had previously been told that they had tested positive appraised the threat posed by this risk factor as less serious than those who tested negative. Minimization of the seriousness of an condition is not only found after risk factor identification but can be seen in patients who have received diagnosis of an illness which is already present (e.g. Orr and Meyer, 1990).

Croyle, Jemmott, Ditto and colleagues characterize the minimization apparent in their studies as a form of defensive motivational process. Consistent with a motivational explanation, Ditto, Jemmott and Darley (1988) found that for subjects who were told that they had the deficiency, those who were also told that there was a “simple and painless” treatment, rated the threat as more serious than those who weren’t given treatment information. Similarly, in the present study there was a significant correlation between beliefs about how likely is it that one can prevent osteoporosis and seriousness ratings three months after the scan. (In other words people who felt it less likely that osteoporosis can be prevented tended to show

lower seriousness ratings). This would be consistent with an explanation in terms of some kind of cognitive coping response. However since the present data is correlational only, firm conclusions cannot be drawn.

Although Croyle, Jemmott, Ditto and colleagues characterize the minimization in their studies as a form defensive motivational process, they point out that the term “defensiveness” has negative connotations which may not be appropriate, since those who minimized the threat did not consequently desire less information about it (Ditto, Jemmott and Darley, 1988). Similarly, in this study preventative behaviours were undertaken by almost all those with a low result, so they were obviously not denying that a problem existed, just the seriousness of it. It has been suggested that minimizing a threat in this way may be adaptive in that it reduces emotional distress and thus allows cognitive resources to be focused on action or problem-oriented coping (Cohen and Lazarus, 1979). Indeed, there is evidence that minimization of the seriousness of symptoms can be associated with less delay in seeking medical care (Temoshok, 1985) and minimization of the seriousness of a diagnosed condition has been found to be associated with more favourable outcome (Greer, Morris and Pettingale, 1979).

Ditto, Jemmott and Darley (1988) found that the minimization in their study was evident immediately after testing, while in the present study it didn't appear until the week follow-up. Perhaps more cognitive restructuring is needed if the risk factor is associated with a real condition rather than the fictitious one which they used in the laboratory studies. With regard to those receiving a high BMD result, there was an increase in seriousness ratings before the scan, although at this point they were not significantly different from those who received a low result. It is possible that the increase is due to those who were at low risk learning more about osteoporosis in the two weeks before the scan- perhaps gaining knowledge already possessed by those at high risk.

It is interesting to note than in the previous chapter it was shown that women returning for their second scan were not significant different in their pre-scan seriousness ratings from women who were attending their first scan. Since the second-scan group tended to be lower in BMD than the first scan group, it might have been expected that seriousness ratings would be lower in this group, given the finding of a minimization effect after a first scan. The lack of evidence for a minimization effect in the second-scan group may be simply because the effect was not strong enough to be shown unless a group with very low BMD

was chosen. Alternatively, it is possible that women who do not show minimization are more likely to want to return for a second scan. A third possibility is that the minimization effect does not last much longer than a few months- this will be examined in chapter 8 when 14-month follow-up data is examined.

Anxiety, worry and need for reassurance in women receiving high and low results

a) Anxiety prior to the scan

Although before the scan, the women who were to receive a low result perceived themselves to be more at risk compared other women and more likely to develop osteoporosis than women who were to receive a high result, the two groups were not significantly different in terms of anxiety or worry about osteoporosis at this point. This is perhaps partly due to the fact that there is no difference in perceived likelihood of developing the condition in the near future: in other words, before the scan the threat may seem to be too far away to cause much higher anxiety in the group who were going to receive a low result. Also, before there is the evidence from the scan result, the increased risk may seem abstract and unproven.

b) Change in anxiety after a low BMD result

Between the initial assessment and 3 month follow-up, the group of women receiving a high BMD result showed a decrease in anxiety about bone density, worry about osteoporosis and need for reassurance while those receiving a low BMD result showed no significant change in these feelings. However, if one uses the ratings taken immediately before the scan as the baseline, the low-result group show an increase in anxiety about their bone density after the scan. As with the risk perceptions, it is not clear which is the more appropriate baseline to use and it is thus impossible to draw firm conclusions about the effects of receiving a low result. It could be argued that the ratings at the initial assessment are higher than they would have been before the appointment was made, for being reminded of the possibility of a problem, together with the knowledge that in a few days you will have a test, could have caused an increase in anxiety. If anxiety at the initial assessment has been heightened by the existence of the appointment, then one cannot rule out the possibility that a low result from bone density screening may in fact cause an increase in anxiety compared to how the woman felt before the appointment was made. As discussed in chapter 5, one could examine this

by giving women an initial questionnaire before asking whether they would like to volunteer for bone density screening. This problem with baselines may also have occurred in previous research into the psychological effects of health screening and may partly account for inconsistent results. If people are distressed by the invitation to be screened, (e.g. because of anxiety about the procedure or possible test result), then their distress at some points in time before the scan will be higher than usual and any adverse psychological effects of the scan may be missed or underestimated.

C) Severity of anxiety after a low result

With regard to absolute levels of anxiety about bone density, it appears that anxiety about bone density is not very high in those with a low result, at follow-up. For example, although 45.6% reported that they are more worried about osteoporosis since the scan (which is similar to the figure of 55% reported by Rubin and Cummings, 1992), most of the women were only “a little more worried”. Eleven percent said that they felt less worried since the scan. When asked about the level of anxiety about the result at the three month follow-up, only 6% said that they were moderately, very or extremely anxious about their result.

There are various reasons why women might not be very anxious after a low bone density scan result. Firstly, (as discussed above), it appears that after women receive a low result, some may be underestimating their risk of developing osteoporosis and minimizing the seriousness of having low bone density. According to the cognitive model of anxiety, minimization of either the likelihood or the seriousness would be sufficient to reduce anxiety. The fairly low levels of anxiety may also be partly because preventative measures are available and because osteoporosis is probably not perceived to be as serious as many other conditions. Furthermore, it is possible that for women who were aware of their risk beforehand, the uncertainty was aversive; receiving a low result would at least allow this uncertainty to be reduced (see Marteau, 1994) and would provide more information on which to base decisions about preventative measures such as HRT. Anecdotal evidence from discussions with the women undergoing bone densitometry also suggests that some of those with pre-existing worries felt that their GP would take their concern more seriously if they could take along evidence of low bone density.

Although levels of anxiety were not very high at the three month follow-up, it is possible that in the

future, anxiety will increase again for those with a low result, especially in response to certain triggers. Examples of potential triggers include pain or other symptoms which may be interpreted as signs of bone weakness, hearing information about osteoporosis in the mass media or becoming more negative in one's beliefs about how bad it is to have osteoporosis (perhaps due to seeing someone with osteoporosis). For women who have not yet reached the menopause, anxiety may increase when they have to consider whether or not to take HRT. For other women simply getting older and approaching the time of expected onset of osteoporosis may remind them that they are at risk. Clearly longer-term studies would be needed to assess the possibility that anxiety levels will increase in women with low results in the future.

Preoccupation with the result

As would be expected, at both the week and 3 month follow-ups, more women with a low result said that they had thought about osteoporosis in the past week and more had thought about what it would be like to have osteoporosis than women who received a high result. However, preoccupation does not seem to be severe - only 1 of those with a low result said that she had thought about osteoporosis every day of the past week. The women with a low result also said that it had taken them longer to forget about the result. At the three month follow-up women with high or low results tended to report a longer amount of time taken to forget the result than at the week follow-up. It is not clear if this is due to forgetting or whether thoughts of the scan returned after the week follow-up so that women who had previously thought that they had forgotten about it had to change their ratings.

Cognitive coping responses which may maintain health anxiety

Attempts to deliberately forget about the result or to distract oneself from thinking about it were reported by around a quarter to a third of women with a low result, but most did not use these strategies very frequently. These strategies were also reported at the three month follow-up by two women with a high result who were concerned about arthritis.

Attempts to reassure oneself were also significantly more common in those with a low result, although it is interesting that 10.5% of those with a high result say that have tried to reassure themselves

about their result, with 2 women saying that they do this every day. This indicates that a high result by itself was not fully reassuring for all of the women. In some cases, especially if the woman has not yet past the menopause, continuing awareness may be appropriate because they could experience rapid bone loss. Some women write that they are not sure whether their good result will be maintained e.g. “Although my results were very good and very reassuring, they did not explain if in another 10 years or so it is likely to develop”. This could perhaps be discussed in the written information given to women when they come for screening.

Preventative beliefs and behaviours

After the scan women were more pessimistic in their ratings of how likely it is that one can prevent osteoporosis if one has low bone density. In the previous chapter it was suggested that one possible explanation for this change is that some of those with a low result may have felt that they were already taking preventative measures before the scan and therefore concluded that such measures are not very successful. However, analyses in this chapter have shown that those with a low result show a smaller decrease than those with a high result, although the difference between the two groups at the follow-up is not significant. Instead, the decrease may relate to the information that many women receive during the course of the study, regarding expected rates of bone loss with age and the fact that it is difficult to prevent some loss.

Despite the slight decrease in ratings of the likelihood of being able to prevent the symptoms of osteoporosis, the numbers of women taking preventative action after a low result was encouraging: 91% reported at least one preventative behaviour. This is consistent with a study by Rubin and Cummings (1992) in which 94% of those with a low result reported taking some type of preventative measure after the scan. In both the present study and the one by Rubin and Cummings (1992), women with low results were significantly more likely to report preventative behaviours than women with high results. Of the 42 women with results below fracture threshold, only two reported no preventative behaviour and both of these had discussed their result with their GP. It is interesting that there is a non-significant trend for those with a low result to report less care to take dietary calcium than those with a high result; it is possible that allergies or dislike of dairy products (or other calcium rich foods) may be the reason for women with low results

reporting less intake and this may have also been a causal factor in their lower bone density.

Symptoms of osteoporosis

Women who were to receive a low result reported significantly more symptoms of osteoporosis before the scan than women who were to receive a high result. This could indicate that some accurate symptom-labelling may have been occurring before the confirmation of the scan result. However, even after the results of the scan were known, very few women were sure that they had symptoms of osteoporosis and it's possible that knowing that one is at risk leads to a misinterpretation of aches, pains and even fractures. There was no significant change in symptom reporting in women having a low result after the scan, but 46 (52.8%) of this group said that they had wondered whether they had symptoms of osteoporosis (compared to 10.3% in the high-result group). These results are consistent with the CB model of health anxiety which proposes that heightened risk perceptions and the resulting anxiety can cause heightened attention to possible symptoms. The results are also consistent with Leventhal's idea that if people are given a diagnosis, they will search for symptoms consistent with the diagnosis.

The decrease in symptom reporting shown by the group of women with high results is likely to be due to a reattribution of the causes of their symptoms. Some of these women said that they had come for screening in order to try to find out the cause of their pain and that their high result simply meant that osteoporosis was one explanation to rule out. It is not clear why six women with a high result feel that they have symptoms of bone weakness after the scan. It may be due to a belief (which is correct) that high density in the back does not mean that other bones in the body also have high bone density, or to a misinterpretation of the meaning of the result.

Information and reassurance-seeking

Women receiving a low reading were more likely to report having discussed their result with a health professional or having tried to find out more information about osteoporosis than women having a high result. However, 25 (about a quarter) of those with a low result had not yet sought further help or information and 12 were not intending to do so in the future. These women may have felt that they already

knew a lot about osteoporosis and preventative measures, or they may have felt that the result was not serious enough to warrant further attention, or they may have been deliberately avoiding the issue. Thus it is possible that some women with low results are not receiving information which could be helpful to them.

The vast majority of women in both groups said that they intend to have another scan at some point in the future. It is possible that in a screening situation in the NHS, second scans would only be available for those with very low scores or would not be available at all. If women are given one scan but not allowed another, the experience may result in an increased anxiety about bone density for some women. Indeed, the fact that anxiety did not increase for the group of women with low results may be partly because they knew that their bone density would be monitored in the future.

Discussion (part 2): Differences between women who have increased or decreased BMD

Distress and perceived vulnerability

Results from the comparison of women who showed an increase or decrease in BMD are consistent with the hypothesis that receiving a “increased” result will result in greater distress and perceived risk than receiving a “decreased” result. Group differences occurred more frequently when one compared groups on the basis of the women’s descriptions of change rather than their actual change, despite the larger numbers of subjects in the latter comparisons. For example, there was only an interaction between group and time (i.e. before or after scan) for ratings of anxiety about bone density, worry about osteoporosis and sadness/low mood if one selected the groups on the basis of their description of change in bone density. This is consistent with the hypothesis that the appraisal of the result that will be more important in determining responses than the actual result, as suggested by cognitive models of anxiety by Beck (1976) and others. However, firm conclusions cannot be drawn about this point since not all women explicitly described their result in terms of change in bone density, so only a subset of the women could be included in these analyses.

It should be noted that since some of the perceptions of change were incorrect, some women are experiencing unnecessary anxiety while others are feeling unwarranted reassurance. It is possible that if women were provided information about how to interpret second scans, these effects would be reduced.

Perceived seriousness of below-average bone density in women having second scans

There were no group differences for ratings of perceived seriousness of below-average bone density: the lack of a minimization effect is not surprising since there was no difference in BMD between the two groups.

Preventative behaviours

Those showing a decreased BMD were more likely to say that they intended to start new preventative behaviours than those with increased BMD. Only 1 of the 11 who described their result as a decrease said that she wasn't intending to change her behaviour and this woman hadn't actually shown a significant change. However, 5 of the 18 women who showed an actual decrease said that they weren't intending to change their behaviour, which may be because some did not realise that they had shown a significant decrease.

Chapter 8

Reactions to bone density screening in women with high and low levels of pre-existing health anxiety

8.1 Introduction

The ability to predict which individuals are likely to experience distress after bone density screening (or any type of health screening) would be invaluable, because it would allow interventions to be targeted at vulnerable individuals, in an attempt to prevent or minimize distress after the health test. Alternatively, (or additionally), if pre-scan beliefs or behaviours associated with post-scan distress could be identified, it may be possible to address such factors in the information given to everyone before they undergo screening. Identification of predictors of reactions to health screening, could be done on an *ad hoc* basis, perhaps by testing a wide range of possible predictors and seeing which perform best in that screening situation. Another option is that possible predictors could be derived from general psychological models. This has the advantage that the model could be continually tested and refined over time, for different types of test, and could be applied to new tests as they become available. A possible candidate for such a model is the cognitive-behavioural (CB) model of health anxiety (described in chapter 1). This model suggests that emotional reactions to health information are a result of the person's interpretation or appraisal of the situation, and that this interpretation will be guided by the person's pre-existing beliefs and assumptions about health and illness. The CB model suggests that some people have "maladaptive" assumptions about their health which result in these people being particularly likely to interpret health threats in a very negative way and hence experience high levels of distress. So applying the CB model of health anxiety to health screening, one would predict that people who have a pre-existing tendency to worry about their health will react more negatively (or less positively) to a health test, because these people are likely to have negative assumptions about illness.

The primary prediction examined in this chapter is that women who report high levels of health anxiety in the six months prior to the scan will be more likely to show distress after a low scan result and are likely to interpret the new risk information in a more negative way than women who didn't have a pre-existing tendency to worry about their health. However, the predictions derived from the cognitive-behavioural formulation of hypochondriasis do not only concern the effects of bad news about one's health, they also concern the effects of good news or reassurance. Two single case experiments by Salkovskis and Warwick (1986) indicated that for two hypochondriacal patients, reassurance about their health produced an immediate but transient reduction in anxiety, followed by enhanced anxiety and increased urge to seek

reassurance over the ensuing 24 hours. There are several ways in which “good news” or reassurance might increase anxiety in the long-term. For example, some aspect of the “reassurance” may in fact be anxiety-provoking (e.g. after medical tests, a doctor may tell the patient that “the results indicate that cancer is at the very bottom of the list”; the patient then interprets this to mean that cancer is in fact a possibility). Alternatively, there may be conflicting statements within a consultation or different doctors may give conflicting medical opinions. Terminology or explanations may not be understood. Furthermore, the patient may begin think of reasons why the test may not have been valid or may go over the consultation repeatedly in their mind, creating doubts about what was said. Salkovskis and Warwick (1986) suggest that reassurance-seeking in hypochondriacal patients is functionally similar to compulsive behaviour in patients with obsessive-compulsive disorder - reassurance seeking can also seen as a form of avoidance behaviour which maintains the preoccupation with health in the same way as avoidance seems to operate in other anxiety disorders (Rachman, 1976). With regard to bone density screening, it was therefore predicted that women who tend to worry about their health and who receive a high scan result will be temporarily reassured, but will then show a subsequent return of anxiety and a return of the perceived need for reassurance. One reason why this might happen in bone density screening is that the first scan can only tell the woman about her absolute level of bone density - only a second scan can provide information about the rate of change of bone density. Therefore, after initial relief that her current bone density level is good, a woman may begin to wonder about how quickly she is losing bone and her anxiety may return. In this chapter the longer-term psychological effects of a high scan result for women who tend to worry about their health will be examined.

Overview of chapter 8

In this chapter, individual differences in reactions to bone density screening will be explored, by comparing groups which have been selected on the basis of pre-screening symptoms of health anxiety. In the first section of the chapter, the groups of women with high and low bone-density results which were used in the previous chapter are further subdivided on the basis of pre-existing health anxiety. In the second part of the chapter the results of a longer-term follow-up are presented. This follow-up (at approximately 14 months after the scan) involved a comparison of the women who before the scan had extremely high or extremely low scores on measures of health anxiety.

8.2 Treatment of the data

In the previous chapter, the two groups of interest had been the women with the highest and lowest scan results. In this chapter, these two groups have each been subdivided further, to result in four groups in all. For the 90 women with highest results, two groups were formed, using cutoff values which gave approximately 20 women in each group- those with the highest or lowest scores on the Health Anxiety Questionnaire (n=21 and n=24). Of the 90 women with the lowest results, two groups were selected in a similar way (n=22 and n=21). The mean scan results in each of the four new groups are shown in the table below.

Table 8.1 Scan results (as a percentage above/below mean for women of the same age) in the high and low HAQ groups

	Low HAQ		High HAQ		
	Mean	SD	Mean	SD	
High result	27.2	(10.5)	23.5	(8.9)	$t_{(43)} = 0.7, \text{ n.s.}$
Low result	-13.6	(7.6)	-15.1	(7.1)	$t_{(41)} = 0.5, \text{ n.s.}$

Multiple comparisons were Tukey-B tests for between-group comparisons. For within-subjects comparisons (i.e. across time), paired t-tests were used, with alpha-levels of $p < 0.01$ accepted as significant. Since this study is exploratory in nature, if the significance levels are found to be between $p = 0.01$ and $p = 0.1$, these are reported as non-significant trends, so that potentially interesting trends are not missed. Where partitioned chi-square analyses are used to investigate significant effects, alpha levels of $p < 0.05$ are accepted as significant.

8.3 Pre-existing differences between women with high and low scores on the Health Anxiety Questionnaire and high and low bone density results (See table 8.2)

One-way ANOVAs were used to examine whether there were any significant pre-scan differences in terms of age, BDI scores and STAI-trait scores between the women in the four groups being examined in the following section. These indicated that there were significant group effects for the BDI and STAI-trait but not for age. Multiple comparisons indicated that for both the BDI and the STAI-trait, the two low-HAQ groups (i.e. low and high BMD) were not significantly different from each but were both lower than the two high-HAQ groups, who in turn were not significantly different from each other.

Kruskal-Wallis tests were used to compare the 4 groups with regard to pre-scan ratings of whether or not the women had a medical condition which they thought may affect bone density, whether they had a current medical condition and whether they had a family history of osteoporosis. These indicated that there

were main group effects regarding the medical condition which may affect bone density and the family history of osteoporosis, but not for a current medical condition. Partitioned chi-square analyses were performed to investigate the significant effects further. These indicated that women in the low HAQ / high result group were less likely to report a medical condition which may affect bone density than women in the other three groups. Women in the high HAQ / low result group were more likely to report a medical condition which may affect bone density than women in the other three groups. Women in the low HAQ / low result group were significantly more likely to report a family history of osteoporosis than women in the low HAQ / high result group or the women in the high HAQ / low result group.

Table 8.2 Pre-scan characteristics of the four different groups (formed on the basis of result and HAQ scores)

	Low HAQ				High HAQ				
	High result		Low result		High result		Low result		
Age (years)	Mean 53.4	SD (7.4)	Mean 53.1	SD (7.7)	Mean 54.7	SD (6.0)	Mean 53.8	SD (7.9)	$F_{(3, 87)}=0.2$
BDI	4.6 ^a	(4)	5.0 ^a	(4.8)	9.3 ^b	(6.1)	9.4 ^b	(4.6)	$F_{(3, 86)}=6.3^{**}$
STAI-trait	32.8 ^a	(7.8)	33.3 ^a	(8.7)	44.0 ^b	(10.5)	41.6 ^b	(7.6)	$F_{(3,87)}=9.5^{****}$
Medical condition which may affect bone density	% 4.2 ^b	n (1)	% 20.0 ^{ab}	n (4)	% 25.0 ^{ab}	n (5)	% 45.5 ^a	n (10)	<u>Kruskal-Wallis</u> $\chi^2_{(3)}=11.0^*$
Current medical condition	23.8	(5)	45.5	(10)	42.9	(9)	54.5	(12)	$\chi^2_{(3)}=4.3$
Family history of osteoporosis	8.3 ^a	(2)	42.9 ^b	(9)	19.0 ^{ab}	(4)	9.1 ^a	(2)	$\chi^2_{(3)}=10.7^*$

^avalues which share a superscript are not significantly different from one another

*p<0.05 **p<0.005 *** p<0.0005 n.s.= not significant

8.4 Changes in feelings and beliefs about osteoporosis in women with high or low HAQ scores

Due to space limitations, results will presented for all the variables which were included at each of the five assessment points but for only a selection of those included at three points. A composite of the two variables assessing anxiety about bone density and worry about developing osteoporosis has also been used. This composite variable is referred to as “anxiety/worry about osteoporosis”.

Feelings about osteoporosis were analysed using repeated measures analyses of variance. The scan result (high or low) and HAQ score are the two between-subjects factors and time is the within-subjects factor. It should be noted that in order to save space, only significant main effects and interactions are mentioned.

Anxiety and worry about osteoporosis (See figure 8.1 and table 8.3)

There were main effects of HAQ ($F_{(1,76)}=19.7$, $p<0.0005$), result ($F_{(1,76)}=15.5$, $p<0.0005$) and time ($F_{(4,304)}=11.0$, $p<0.0005$). These results were modified by a significant result by time interaction ($F_{(4,304)}=10.1$, $p<0.0005$) and HAQ by result by time interaction ($F_{(4,304)}=2.7$, $p<0.05$).

Multiple comparisons indicated that at the initial assessment there were no significant differences between the four groups. Immediately before the scan, the women with low results / high HAQ scores had significantly higher anxiety levels than the low result / low HAQ group and the high result / low HAQ group. After the results had been given, both groups who received a low result were more anxious than the two groups who had a high result, although the low result / high HAQ group were significantly more anxious than the other three groups and were still more anxious than the others at the 3 month follow-up. At the three month follow-up the high result / high HAQ group were significantly more anxious than the high result / low HAQ group. With regard to change over time, the groups with high results showed a decrease in anxiety about osteoporosis between the initial and final assessment and the women with a low result / low HAQ show a non-significant trend in the same direction ($t_{(18)}=2.0$, $p=0.067$). In contrast, for the low result / high HAQ group there was no significant difference in anxiety levels between the initial and 3 month assessment. The high result / high HAQ group showed a significant increase in anxiety between the assessment immediately after the scan and the three month follow-up.

Summary: These findings indicate that those with high levels of pre-existing health anxiety who received a low result were more anxious about osteoporosis than the other groups at each of the assessments after the scan. Those with high health anxiety and a high result showed immediate reassurance which was short-lived- at the week and three month follow-up they were not significantly different in anxiety than the group with low health anxiety and a low result.

Figure 8.1
Anxiety and worry about
osteoporosis in women with high or low scan
results and high or low HAQ scores.

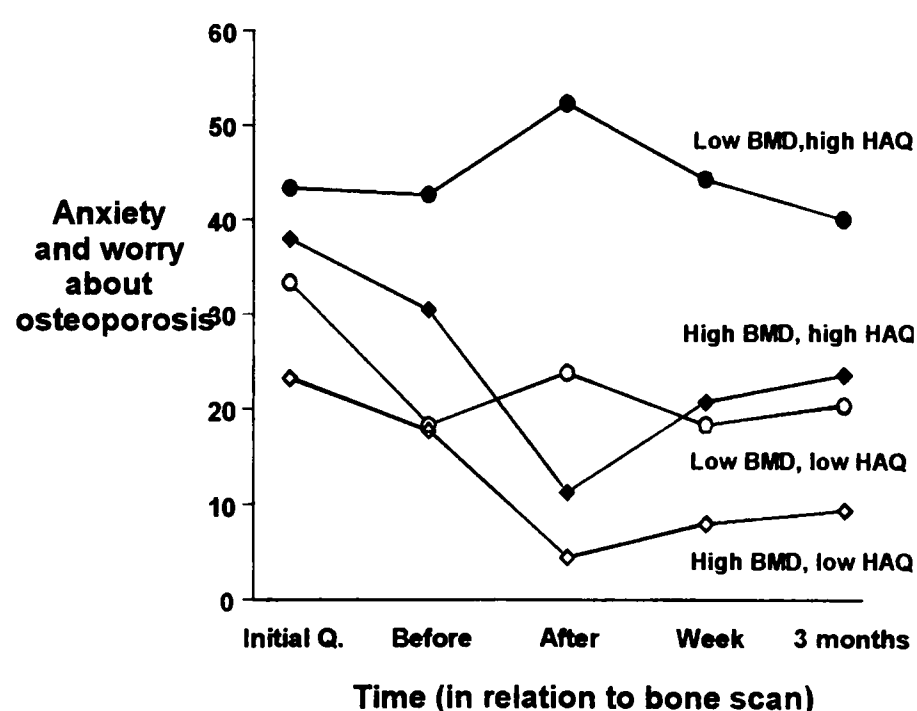


Table 8.3 Ratings of anxiety and worry about osteoporosis in women with high and low HAQ scores

	Initial Q		Before (day of scan)		After (day of scan)		Week after scan		3 months after scan	
<u>High result</u>	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Low HAQ	23.3	(21.9)	17.8	(15.5)	4.5	(7.6)	8.0	(14.5)	9.4	(7.6)
High HAQ	38.0	(27.1)	30.5	(25.1)	11.3	(13.5)	20.8	(18.7)	20.8	(18.7)
<u>Low result</u>										
Low HAQ	33.4	(30.5)	18.4	(23.9)	23.9	(24.6)	18.3	(18.3)	20.4	(18.7)
High HAQ	43.3	(18.2)	42.7	(24.1)	52.4	(25.5)	44.4	(22.2)	40.1	(15.9)

Likelihood of developing osteoporosis in the near future (See figure 8.2 and table 8.4)

There were main effects of HAQ ($F_{(1,77)}=15.2$, $p<0.0005$), result ($F_{(1,77)}=11.7$, $p<0.005$) and time ($F_{(4,308)}=10.2$, $p<0.0005$). These effects were modified by an HAQ by time interaction ($F_{(4,308)}=2.8$, $p<0.05$), a result by time interaction ($F_{(4,308)}=4.9$, $p<0.005$) and an HAQ by result by time interaction ($F_{(4,308)}=2.4$, $p=0.050$).

Multiple comparisons indicated that at the initial assessment there were no significant group differences. At all the other assessments, those with low results / high HAQ scores had significantly higher ratings than the other three groups. In addition, immediately after the scan, those with a low result / low HAQ had significantly higher ratings than those with a high result / low HAQ. At the three month follow-up those with a high result and high HAQ rated osteoporosis as more likely than those with a high result and low HAQ score.

Paired t-tests indicated that the groups with a high result / low HAQ score showed a significant decrease in ratings of the likelihood of developing osteoporosis between the initial and 3 month assessment. The low result / low HAQ group showed a non-significant trend in the same direction ($t_{(18)}=2.7$, $p=0.016$). Those with a high HAQ scores (both high and low result groups) showed no significant change between the first and 3 month assessments.

Summary: Those with high levels of pre-existing health anxiety who received a low result rated osteoporosis as more likely in the near future than the other groups and did not show the decrease in ratings shown by everyone else. As with measures of anxiety, after the scan those with high health anxiety and a high result were not significantly different in their ratings of likelihood from those with low health anxiety and a low result.

Figure 8.2
Perceived likelihood
of developing osteoporosis
in the near future, in women
with high or low results and
high or low HAQ scores.

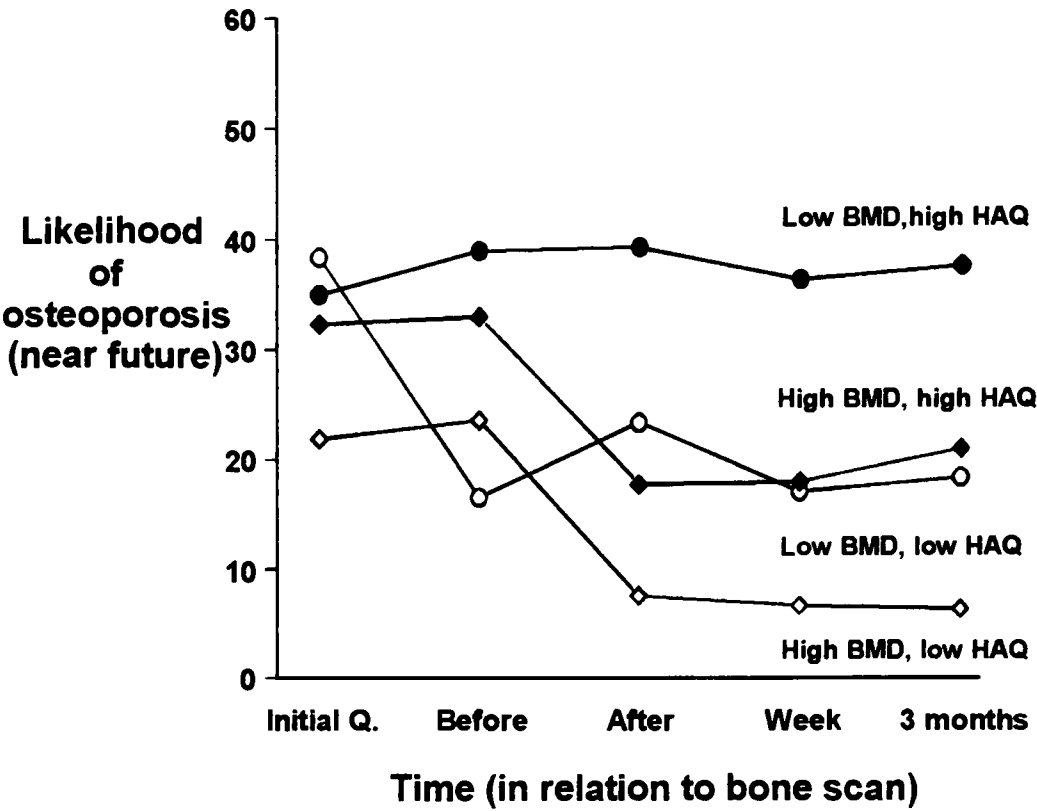


Table 8.4 Ratings of the likelihood of developing osteoporosis in the near future in women with high/low HAQ scores

	Initial Q		Before (day of scan)		After (day of scan)		Week after scan		3 months after scan	
<u>High result</u>	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Low HAQ	21.9	[16.6]	23.6	[17.5]	7.6	[12.2]	6.7	[7.3]	6.4	[6.5]
High HAQ	32.3	[21.2]	33.0	[22.5]	17.8	[18.7]	18.0	[16.4]	21.0	[20.5]
<u>Low result</u>										
Low HAQ	38.4	[32.2]	16.6	[19.6]	23.4	[23.3]	17.1	[15.8]	18.4	[18.9]
High HAQ	35.0	[17.6]	39.0	[23.2]	39.3	[23.1]	36.4	[23.3]	37.6	[26.3]

Likelihood of developing osteoporosis at any point in the future (See figure 8.3 and table 8.5)

There were main effects of HAQ ($F_{(1,76)}=14.5, p<0.0005$), result ($F_{(1,76)}=18.1, p<0.0005$) and time ($F_{(4,304)}=6.7, p<0.0005$). These effects were modified by a significant result by time interaction ($F_{(4,304)}=6.7, p<0.0005$) and an HAQ by result by time interaction ($F_{(4,304)}=2.5, p<0.05$).

Multiple comparisons indicated that at the initial assessment those who were to receive a low result and who had high HAQ scores had higher ratings than women who were to receive a high result and who had low HAQ scores. Immediately before the scan this was still true; in addition, those who were to receive a low result and who had high HAQ scores had higher ratings than those who were to receive a low result and who had low HAQ scores. Immediately after the results, both groups with low results had higher likelihood ratings than the group with high results / low HAQ. At the week follow-up, those with low results / high HAQ still had significantly higher ratings than the other three groups while those with a high result / low HAQ had significantly lower ratings than the other groups. At the three month follow-up, the only significant difference was that those with a high result / low HAQ had significantly lower ratings than the

other three groups.

The two groups with low results showed no significant change in their ratings between the initial and three month assessments. In contrast, those with high results and low HAQ scores showed a decrease in ratings between the initial and final assessments. In the group with high results / high HAQ scores, there was a significant decrease in ratings immediately after the scan but the ratings had increased significantly by the three month follow-up; for this group, ratings of likelihood were not significantly different at three months than they had been at the initial assessment.

Summary: Those who had high levels of pre-existing health anxiety and a low result had higher ratings of likelihood immediately after the scan and at the week follow-up. Those with high health anxiety and a high result showed an initial decrease in ratings followed by a increase by the three month follow-up - at the follow-ups they did not differ from the group with low health anxiety and a low result.

Figure 8.3
Perceived likelihood of developing osteoporosis at any point in the future in women with high or low scan results and high or low HAQ scores.

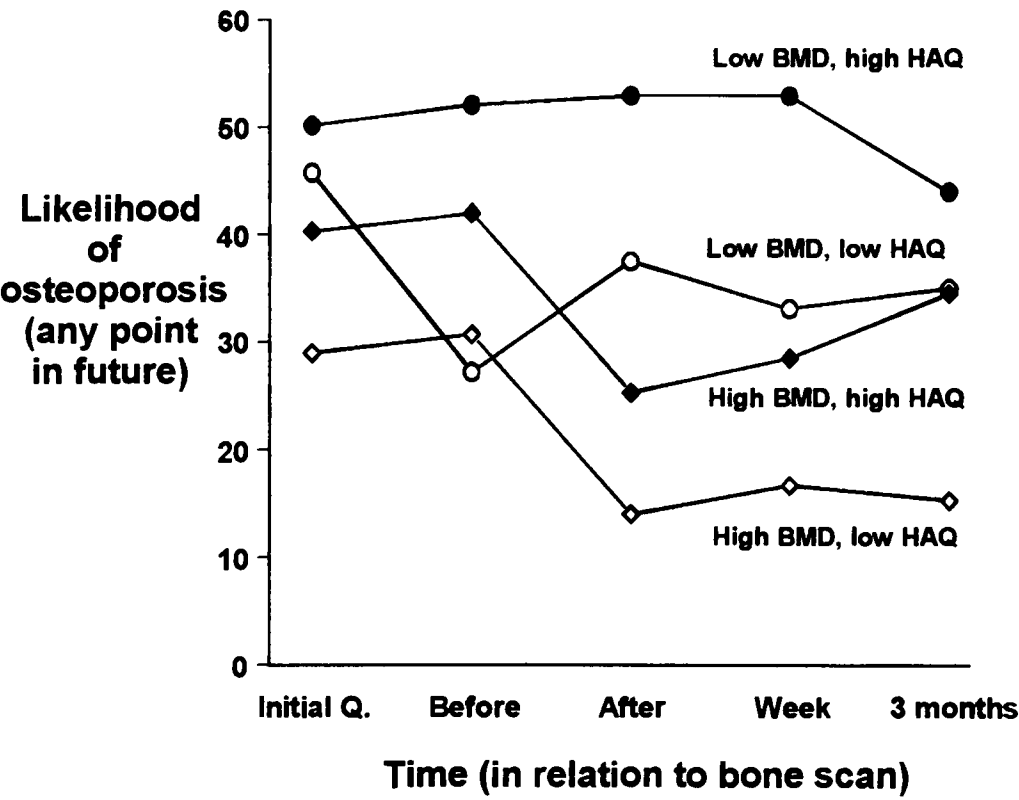


Table 8.5 Ratings of the likelihood of developing osteoporosis at any point in the future in women with high / low HAQ scores.

	Initial Q		Before (day of scan)		After (day of scan)		Week after scan		3 months after scan	
<u>High result</u>	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Low HAQ	29.0	[17.6]	30.7	[13.3]	14.0	[14.4]	16.7	[10.6]	15.2	[12.5]
High HAQ	40.3	[21.2]	42.0	[19.6]	25.3	[17.6]	28.5	[19.3]	34.5	[20.6]
<u>Low result</u>										
Low HAQ	45.8	[27.3]	27.2	[25.4]	37.5	[27.7]	33.1	[22.8]	35.0	[27.3]
High HAQ	50.2	[22.7]	52.1	[24.0]	52.9	[23.5]	52.9	[18.5]	44.0	[18.9]

Need for reassurance about one's bone density (See figure 8.4 and table 8.6)

There was a main effect of HAQ ($F_{(1,77)}=24.9, p<0.0005$)- women with high HAQ scores were more in need of reassurance than women with low HAQ scores. There was also a main effect of time ($F_{(4,304)}=17.3, p<0.0005$) and a main effect of result ($F_{(1,77)}=8.9, p<0.005$); these results were modified by a significant result by time interaction ($F_{(4,304)}5.4, p<0.0005$).

Multiple comparisons indicated that those with a low result were more in need of reassurance at the initial assessment, immediately after the scan and at the follow-ups. Paired t-tests indicated that the women who subsequently received a low result showed a significant decrease in need for reassurance immediately before the scan whereas those who subsequently received a high result showed no significant change. The groups with high and low results both showed a significant decrease in need for reassurance between the initial assessment and 3 month follow-up. There was a non-significant tendency for those with a high result to show an increase in need for reassurance between the week follow-up and the three month follow-up ($p=0.039$).

Figure 8.4
Need for reassurance
in women with high or low
scan results and high or low
HAQ scores.

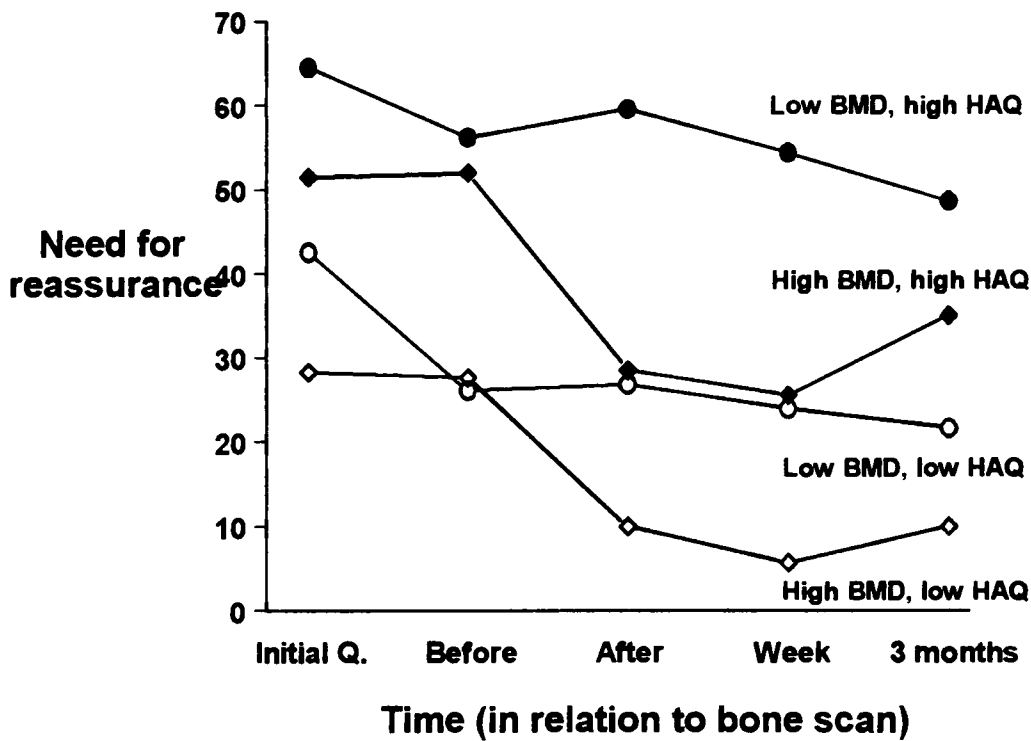


Table 8.6 Ratings of need for reassurance about one's bone density in women with high / low HAQ scores

	Initial Q	Before (day of scan)	After (day of scan)	Week after scan	3 months after scan
<u>High result</u>	Mean SD	Mean SD	Mean SD	Mean SD	Mean SD
Low HAQ	28.3 [25.4]	27.6 [20.5]	10.0 [21.9]	5.7 [17.8]	10.0 [17.8]
High HAQ	51.5 [33.1]	52.0 [30.5]	28.5 [34.8]	25.5 [32.4]	35.0 [36.1]
<u>Low result</u>					
Low HAQ	42.6 [30.5]	26.1 [27.1]	26.8 [25.3]	23.9 [26.5]	21.6 [28.7]
High HAQ	64.5 [31.9]	56.2 [30.7]	59.5 [27.8]	54.3 [25.2]	48.6 [26.9]

General anxiety (See figure 8.5 and table 8.7)

There were main effects of HAQ, ($F_{(1,77)}=27.0$, $p<0.0005$), result ($F_{(1,77)}$, $p<0.0005$) and time ($F_{(3,308)}=10.9$, $p<0.0005$). These effects were modified by a significant result by time interaction ($F_{(4,308)}=6.3$, $p<0.0005$) and a significant interaction between HAQ, result and time ($F_{(4,308)}=2.6$, $p<0.05$).

Multiple comparisons indicated that at the initial assessment, women with high HAQ scores were more anxious than women with low HAQ scores. Immediately before the scan, both groups of women with high HAQ scores were more anxious than the high result / low HAQ group. Immediately after the scan, the low result / high HAQ group showed a significant increase in anxiety and were significantly more anxious than the other groups. The women in this group was still more anxious than the others at the week and three month follow-ups, although they showed a non-significant decrease in anxiety between the initial and final assessment ($t_{(20)}=2.0$, $p=0.06$). The low result / low HAQ group showed no significant change in general anxiety over time, while both groups of women with high results showed a significant decrease in anxiety between the initial and final assessments.

Summary: Those with high levels of pre-existing health anxiety and a low result showed an increase in general anxiety immediately after the results and at follow-up were still more anxious than the other groups.

Figure 8.5
General anxiety in women
with high or low scan
results and high or low
HAQ scores.

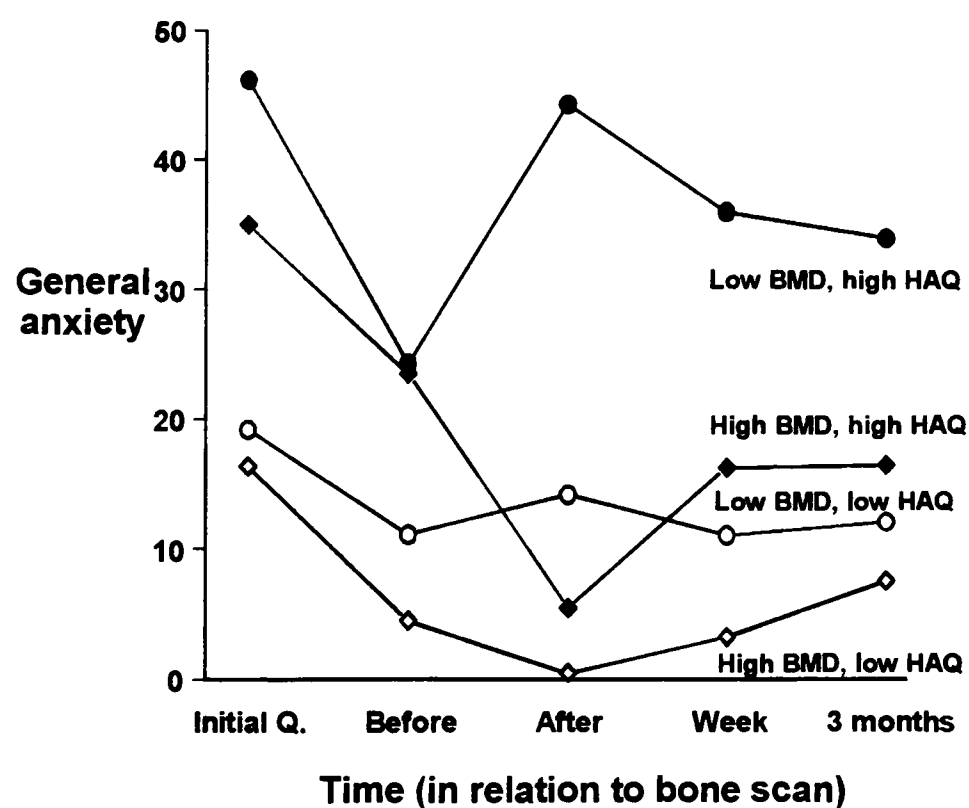


Table 8.7 Ratings of general anxiety in women with high and low HAQ scores

	Initial Q	Before (day of scan)	After (day of scan)	Week after scan	3 months after scan
<u>High result</u>	Mean SD	Mean SD	Mean SD	Mean SD	Mean SD
Low HAQ	16.4 [19.8]	4.5 [8.6]	0.5 [2.2]	3.3 [9.1]	7.6 [12.6]
High HAQ	35.0 [26.4]	23.5 [29.2]	5.5 [11.0]	16.3 [18.8]	16.5 [22.5]
<u>Low result</u>					
Low HAQ	19.2 [25.6]	11.1 [26.2]	14.2 [23.9]	11.1 [17.0]	12.1 [14.4]
High HAQ	46.1 [24.1]	24.3 [25.0]	44.3 [25.8]	36.0 [23.5]	34.0 [27.2]

Sadness or low mood (See figure 8.6 and table 8.8)

There were significant main effects of HAQ ($F_{(1,77)}=20.8, p<0.0005$) - those with high HAQ scores had higher sadness ratings. There was also a main effect of time ($F_{(4,308)}=3.8, p=0.005$) due to a significant decrease in ratings of sadness between the initial assessment and the assessment immediately before the scan.

Figure 8.6
Sadness or low mood
in women with high
or low scan results
and high or low HAQ
scores.

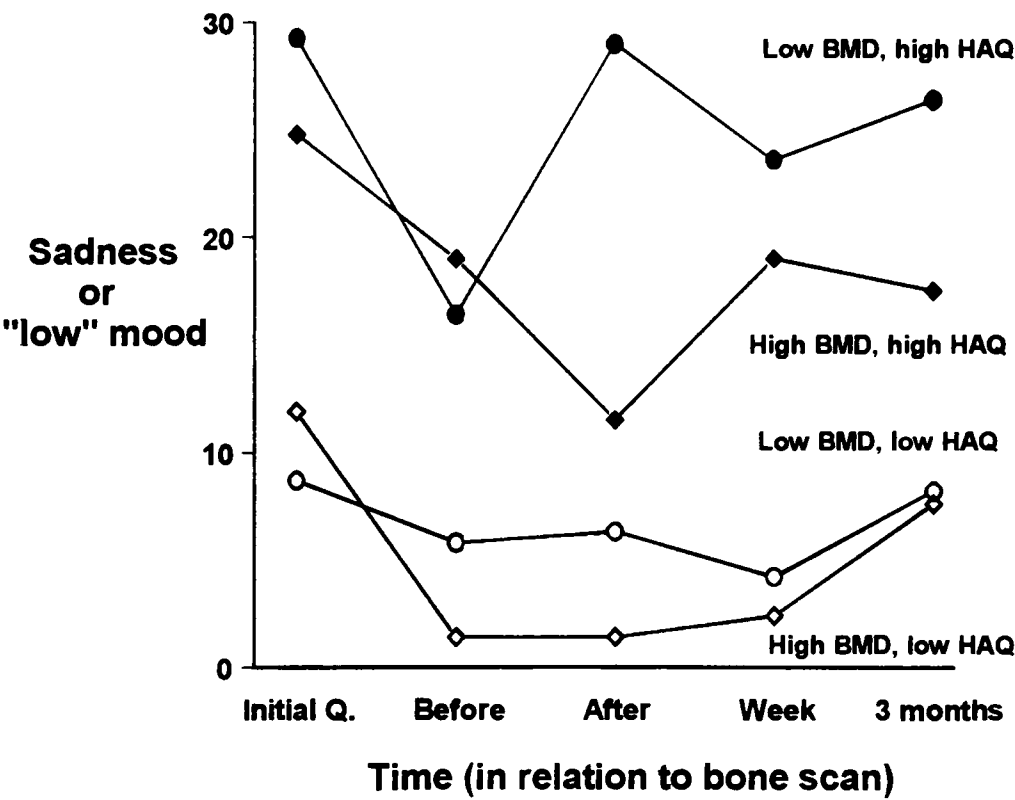


Table 8.8 Ratings of sadness or “low” mood in women with high and low HAQ scores

	Initial Q	Before (day of scan)	After (day of scan)	Week after scan	3 months after scan
<u>High result</u>	Mean SD	Mean SD	Mean SD	Mean SD	Mean SD
Low HAQ	11.9 [23.8]	1.4 [4.8]	1.4 [4.8]	2.4 [7.0]	7.6 [13.4]
High HAQ	24.8 [24.1]	19.0 [27.7]	11.5 [22.1]	19.0 [21.7]	17.5 [24.5]
<u>Low result</u>					
Low HAQ	8.7 [17.6]	5.8 [20.6]	6.3 [18.3]	4.2 [9.6]	8.2 [16.8]
High HAQ	29.3 [24.9]	16.4 [18.2]	29.0 [25.9]	23.6 [21.5]	26.4 [31.7]

Seriousness of below-average bone density (See figure 8.7 and table 8.9)

There was a significant main effect of HAQ ($F_{(1,74)}=8.4, p<0.05$) and a significant result by time interaction ($F_{(4,296)}=3.2, p<0.05$). There was no significant result by time by HAQ interaction ($F<1$).

Those with high HAQ scores rated below-average bone density as more serious than women with low HAQ scores. Multiple comparisons indicated that those with a low result showed a significant decrease in ratings of seriousness between the assessment immediately after the scan and the longer term follow-ups; there was a non-significant trend towards a decrease between the initial and final follow-ups ($t_{(37)}=1.9, p=0.08$). In contrast, those who received a high result showed a non-significant trend towards an increase in ratings of seriousness between the initial and final assessment ($t_{(39)}=-1.8, p=0.08$).

Given that there had been a specific prior prediction that minimization after a low result would occur in the low health anxious group but not in the high health anxious group (or to a lesser degree), planned comparisons were carried out, even though there was no significant result by HAQ by time interaction in the repeated measures ANOVA. Paired t-tests indicated that the group of women with low results and low health anxiety showed a significant decrease in ratings of seriousness between the initial and final assessments ($t_{(19)}=2.2, p<0.05$), while the group with low results and high health anxiety did not show a significant change.

Summary: A minimization effect was observed in those who received a low result, with regard to the seriousness of below-average bone density. There was an indication that this effect may be less strong in those with high levels of pre-existing health anxiety, although since the result by time by HAQ interaction was not significant, any difference in the pattern of responses of high and low HAQ groups was not large.

Figure 8.7
Perceived seriousness of below-average bone density in women with high or low scan results and high or low HAQ scores.

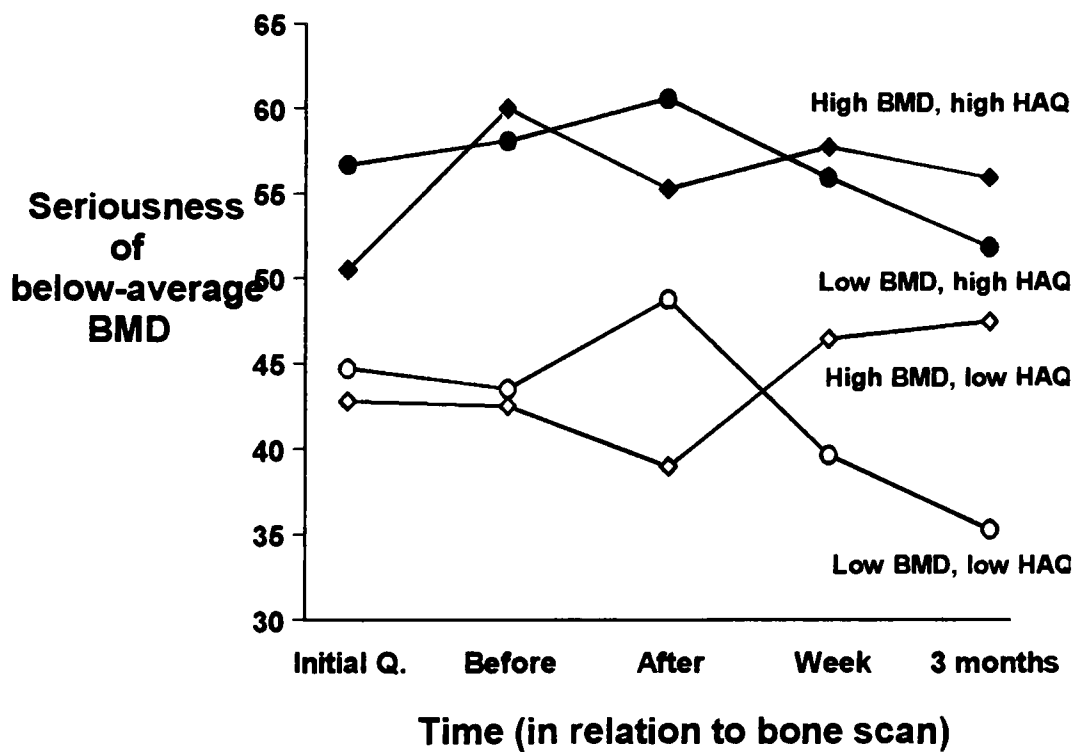


Table 8.9 Ratings of the seriousness of below average bone density in women with high / low HAQ scores

	Initial Q		Before (day of scan)		After (day of scan)		Week after scan		3 months after scan	
<u>High result</u>	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Low HAQ	42.8	[22.4]	42.5	[15.5]	39.0	[22.7]	46.5	[19.5]	47.5	[22.0]
High HAQ	50.5	[24.8]	60.0	[22.9]	55.3	[25.2]	57.8	[23.3]	56.0	[23.7]
<u>Low result</u>										
Low HAQ	44.7	[25.8]	43.5	[32.2]	48.8	[30.6]	39.7	[27.1]	35.3	[22.9]
High HAQ	56.7	[24.4]	58.1	[23.8]	59.8	[25.6]	56.0	[22.0]	51.9	[25.0]

Measures used at only three points in time

Risk of developing osteoporosis compared to other women (See figure 8.8 and table 8.10)

There were main effects of HAQ ($F_{(1,81)}=4.9$, $p<0.05$), result ($F_{(1,81)}=76.1$, $p<0.0005$) and time ($F_{(2,162)}=7.2$, $p<0.005$) and a result by time interaction ($F_{(2,162)}=25.5$, $p<0.0005$). Multiple comparisons indicated that those who received a high result showed a significant decrease in their comparative risk perceptions after the scan. In contrast, those who received a low result showed a significant increase by the week follow-up, although due to a subsequent non-significant decrease by the three month follow-up, the difference between the initial and three-month ratings was not significant for those with a low result.

Figure 8.8
Perceived risk compared to the “average” woman of the same age, in women with high or low results and high or low HAQ scores.
Positive scores indicate that the woman feels more at risk than the average woman her age.
2= more at risk
1= slightly more at risk
-2= less at risk
-1= slightly less at risk

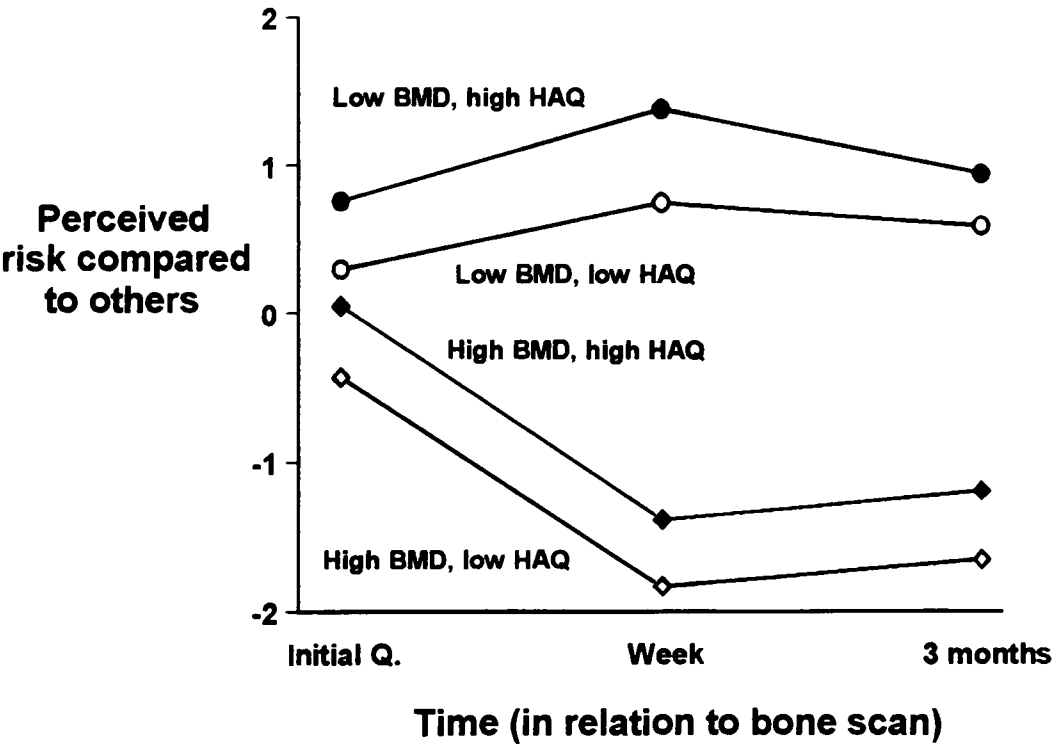


Table 8.10 Ratings of one’s risk compared to the “average” woman, in women with high or low HAQ scores

		Initial Q		Week after scan		3 months after scan	
		Mean	SD	Mean	SD	Mean	SD
<u>High result</u>	Low HAQ	-0.43	(1.3)	-1.83	(1.2)	-1.65	(1.4)
	High HAQ	0.05	(1.4)	-1.38	(1.2)	-1.19	(1.5)
<u>Low result</u>	Low HAQ	0.30	(1.3)	0.75	(1.2)	0.60	(1.4)
	High HAQ	0.76	(1.2)	1.38	(0.9)	0.95	(0.7)

Comparative risk was assessed on a scale from -3 (“Much less at risk than the average woman of the same age) to 3 (much more at risk).

Prevention beliefs (See figure 8.9 and table 8.11)

There was a significant main effect of time ($F_{(2,148)}=4.0, p<0.05$)- after the scan women felt that it was less likely that one would be able to prevent osteoporosis if one had low bone density. There was also a non-significant trend towards an effect of result, which would indicate that those with a low result felt it more likely that prevention is possible ($F_{(1,74)}=3.4, p=0.068$).

Figure 8.9
Perceived likelihood of preventing osteoporosis if one has low bone density in women. (Low scores are more pessimistic).

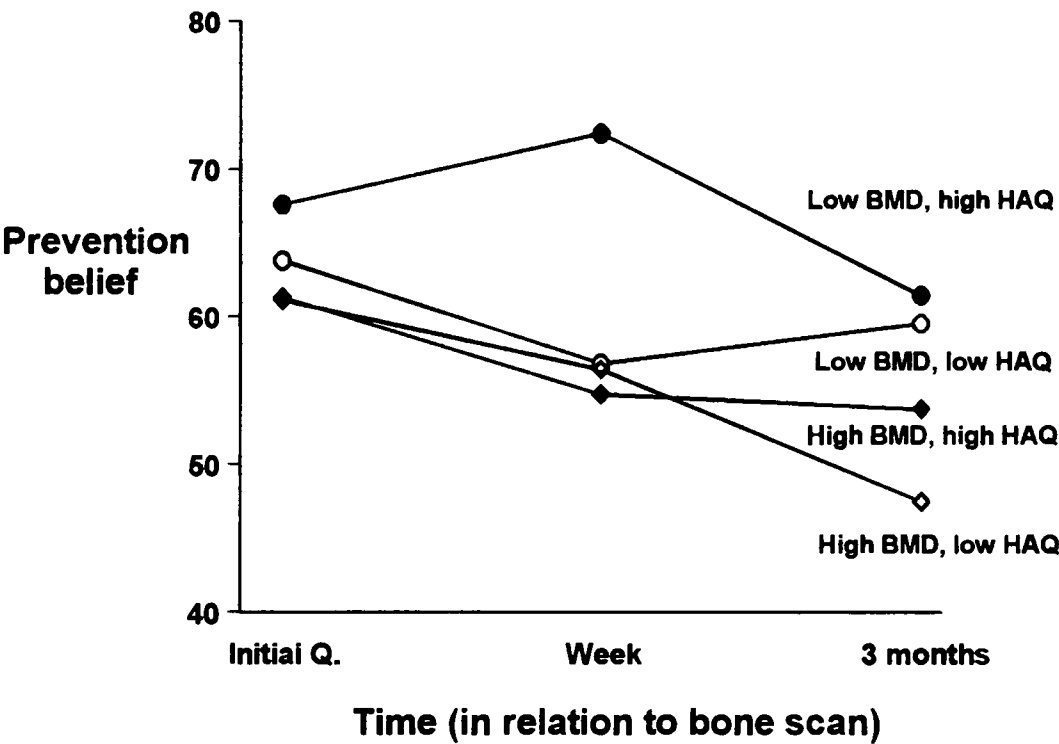


Table 8.11 Ratings of the likelihood of being able to prevent the symptoms of osteoporosis, in women with high and low HAQ scores

		Initial Q		Week after scan		3 months after scan	
		Mean	SD	Mean	SD	Mean	SD
<u>High result</u>	Low HAQ	61.1	(23.3)	56.4	(21.4)	47.5	(25.6)
	High HAQ	61.3	(24.4)	54.7	(24.8)	53.7	(24.8)
<u>Low result</u>	Low HAQ	63.8	(21.8)	56.8	(24.5)	59.5	(24.4)
	High HAQ	67.6	(25.7)	72.4	(17.6)	61.4	(22.0)

The higher the score, the greater the likelihood of being able to do something to prevent symptoms of osteoporosis.

Ability to cope if one had osteoporosis (See table 8.12)

There was a main effect of HAQ ($F_{(1,81)}=21.2, p<0.0005$) - those with higher HAQ scores felt that they would be less able to cope if they developed osteoporosis than women with low HAQ scores.

Table 8.12 Ratings of anticipated ability to cope if one had osteoporosis in women with high and low HAQ scores.

	Initial Q		Week after scan		3 months after scan	
	Mean	SD	Mean	SD	Mean	SD
<u>High result</u>	Low HAQ	26.5 (19.7)	31.1 (21.2)		27.4 (20.4)	
	High HAQ	46.9 (26.0)	42.9 (20.5)		49.0 (24.7)	
<u>Low result</u>	Low HAQ	32.5 (20.7)	28.5 (20.8)		31.3 (24.4)	
	High HAQ	51.4 (24.8)	47.9 (22.5)		48.8 (24.4)	

The higher the score, the less well the woman feels that she would be able to cope.

Likelihood of developing a serious illness in the near future (See table 8.13)

There was a main effects of HAQ ($F_{(1,81)}=37.5, p<0.0005$) - those with higher HAQ scores felt that they were more likely to develop a serious illness (other than osteoporosis) in the near future than women with low HAQ scores.

Table 8.13 Ratings of the likelihood of developing a serious illness (other than osteoporosis) in the near future, in women with high and low HAQ scores.

	Initial Q		Week after scan		3 months after scan	
	Mean	SD	Mean	SD	Mean	SD
<u>High result</u>	Low HAQ	10.7 (11.1)	14.8 (14.4)		12.6 (12.1)	
	High HAQ	33.5 (16.3)	29.0 (18.3)		26.0 (16.4)	
<u>Low result</u>	Low HAQ	10.0 (15.2)	9.0 (12.9)		7.8 (13.2)	
	High HAQ	25.2 (18.2)	27.0 (24.9)		26.1 (22.1)	

8.5 Further investigations of reductions in seriousness and likelihood beliefs

It is possible that those who minimize the risk of below-average bone density may as a result fail to perform as many preventative behaviours; alternatively women may be using knowledge of their preventative behaviours in order to minimize the threat. In order to examine the relationship between preventative behaviours and minimization, correlations were performed (see table 8.14). Correlations were also performed in order to see whether minimization was associated with a pre-existing tendency to use coping strategies of avoidance or reassurance-seeking. These results indicated that for people with low HAQ scores there was a non-significant trend ($p=0.055$) for reductions in seriousness ratings to be associated with higher levels

of preventative behaviours 3 months after the scan. For people with low HAQ scores there was also a significant correlation between a reduction in seriousness ratings and lower scores on the scale assessing avoidance of illness-related situations in the 6 months prior to the scan.

For people with high HAQ scores there was a significant correlation between an increase in seriousness ratings and increase in number of preventative behaviours after the scan. There were also non-significant trends for reductions in seriousness and likelihood ratings to be associated with a higher score on a scale assessing reassurance-seeking in the 6 months prior to the scan. None of the other correlations were significant or near-significant.

Table 8.14 Correlations between changes in perceived likelihood of osteoporosis and seriousness of below-average bone density and preventative, avoidance and reassurance-seeking behaviours.

Change in ratings of:	Number of preventative behaviours at 3 months	Change in no. of preventative behaviours	Avoidance of illness-related situations (in 6 months before scan)	Reassurance-seeking (in 6 months before scan)
<u>Seriousness</u>				
Low HAQ	$r_{(20)}=-0.44, p=0.055$	$r_{(20)}= -0.32, \text{ n.s.}$	$r_{(20)}=0.52^*$	$r_{(20)}=0.11, \text{ n.s.}$
High HAQ	$r_{(22)}= 0.33, \text{ n.s.}$	$r_{(22)}= 0.44 ^*$	$r_{(22)}=0.34, \text{ n.s.}$	$r_{(22)}= - 0.37, p=0.095$
<u>Likelihood</u>				
Low HAQ	$r_{(20)}=0.09, \text{ n.s.}$	$r_{(20)}=-0.02, \text{ n.s.}$	$r_{(20)}=-0.07, \text{ n.s.}$	$r_{(20)}=-0.00, \text{ n.s.}$
High HAQ	$r_{(21)}=0.28, \text{ n.s.}$	$r_{(21)}=0.35, \text{ n.s.}$	$r_{(22)}=0.34, \text{ n.s.}$	$r_{(22)}= - 0.37, p=0.094$

* $p<0.05$. n.s.= not significant

In order to investigate whether changes in ratings of seriousness or of perceived likelihood were related to changes in anxiety, correlations were carried out for all the subjects who received a low result. Changes in perceived likelihood correlated quite highly with changes in anxiety ($r_{(42)}=0.70, p<0.0005$) while there was a non-significant tendency towards a correlation between changes in ratings of seriousness and changes in ratings of worry ($r_{(42)}=0.27, p=0.089$).

Since the low health anxious group were more likely to report at family history of osteoporosis, it could be argued that this is mediating the group differences, because those with a family history are more motivated to minimize the threat. However, a t-test between women with or without a family history, from the low health anxious/ low result group indicated no significant difference with regard to change in preventative beliefs ($t_{(18)}=1.6$).

8.6 Preventative behaviours and symptoms reporting in women with high and low HAQ scores

Chi-square analyses indicated that there were no significant differences in the proportion of women with high and low HAQ scores who reported the different types of preventative behaviours 3 months after the scan, except with regard to calcium supplements. After a low result a greater proportion of women with high HAQ scores took calcium supplements than women with low HAQ scores (table 8.15). In order to investigate this difference further, pre-scan reports of calcium supplements were examined in women who received a low result. Before the scan, 6 of the low health anxious group reported calcium supplements while only 2 of the high health anxious group did so- the former group showed non-significant increase to 7 people after the scan (binomial test, $p=1.0$) while the latter group increased significantly to 14 people (binomial test $p=0.0005$)

There were no significant differences between women with high or low HAQ scores in terms of their total number of preventative behaviours, before or after the scan; this was the case both in the group with high results and the group with low results. However, there was a non-significant trend for those with a high HAQ score to report more preventative behaviours before the scan than those with a low HAQ score, in the group receiving a high result. (In those with a low result the pattern of results is in the opposite direction but the difference is not significant).

There were no significant differences between women with high or low HAQ scores in terms of symptom reporting, before or after the scan (table 8.16).

Table 8.15 The proportion of women with high or low HAQ scores reporting different types of preventative behaviour

<u>Behaviours 3 months after scan</u>		Low HAQ		High HAQ		
		%	N	%	N	
Exercise	High result	50.0	(12)	61.9	(13)	$\chi^2(1)=0.6$, n.s. $\chi^2(1)=0.4$, n.s.
	Low result	38.1	(8)	47.6	(10)	
HRT	High result	12.5	(3)	23.8	(5)	$\chi^2(1)=1.0$, n.s. $\chi^2(1)=0.1$, n.s.
	Low result	28.6	(6)	33.3	(7)	
Diet	High result	50.0	(12)	57.1	(12)	$\chi^2(1)=0.2$, n.s. $\chi^2(1)=0.0$, n.s.
	Low result	47.6	(10)	47.6	(10)	
Calcium supplements	High result	12.5	(3)	23.8	(5)	$\chi^2(1)=1.0$, n.s. $\chi^2(1)=4.7$, $p<0.05$
	Low result	33.3	(7)	66.7	(14)	
Other vitamins or minerals	High result	-	-	4.8	(1)	$\chi^2(1)=1.2$, n.s. $\chi^2(1)=0.4$, n.s.
	Low result	4.8	(1)	9.5	(2)	
Didronel or other prescribed drug	High result	-	-	-	-	$\chi^2(1)=1.1$, n.s.
	Low result	14.3	(3)	4.8	(1)	
Other	High result	4.2	(1)	4.8	(1)	$\chi^2(1)=0.0$, n.s. $\chi^2(1)=0.4$, n.s.
	Low result	9.5	(2)	4.8	(1)	

Table 8.16 The number of preventative behaviours and symptoms reported by women with high or low HAQ scores

		Low HAQ		High HAQ		
<u>Preventative behaviours</u>		Mean	SD	Mean	SD	
	High result	0.7	(0.9)	1.2	(1.0)	$t_{(43)}=-1.9, p=0.06$ $t_{(33)}=1.1, n.s.$
- before the scan	Low result	1.2	(1.0)	0.8	(0.8)	
- after the scan	High result	1.3	(1.0)	1.8	(1.2)	$t_{(43)}=-1.4, n.s.$ $t_{(40)}=-1.1, n.s.$
	Low result	1.8	(1.2)	2.1	(1.1)	
<u>Symptoms</u>		%	N	%	N	
	High result	13.0	(3)	30.0	(6)	Fisher's test n.s. $\chi^2_{(1)}=1.3, n.s.$
- before scan	Low result	28.6	(6)	45.5	(10)	
- after scan	High result	4.3	(1)	10.0	(2)	Fisher's test, n.s. $\chi^2_{(1)}=0.3, n.s.$
	Low result	33.3	(7)	40.9	(9)	

8.7 Attempts to reassure self,distract oneself, forget result and seek more information (table 8.17)

Chi-square analyses indicated that there were no significant differences between women with high or low HAQ scores with regard to whether or not they attempted to distract themselves from thinking about the result or to forget about it. (This was the case for women with high or low results). There was a non-significant trend for women with high HAQ scores to be more likely to try to reassure themselves after a low result but there was no significant group difference after a high result. After a low result women with high HAQ scores were more likely to have sought further information than women with low HAQ scores- there was no significant difference after a high result.

Table 8.17 The proportion of women with high or low HAQ scores reporting information-seeking and different cognitive responses after the scan.

Responses to the result	Scan result	Low HAQ		High HAQ		
		%	N	%	N	
Attempted to reassure herself about the result	High result	9.1	(2)	19.0	(4)	$\chi^2_{(1)}=0.9, n.s.$ $\chi^2_{(1)}=3.4, p=0.07$
	Low result	61.9	(13)	86.4	(19)	
Attempted to distract herself from the result	High result	-	-	5.0	(1)	$\chi^2_{(1)}=1.1, n.s.$ $\chi^2_{(1)}=1.4, n.s.$
	Low result	20.0	(4)	36.4	(8)	
Attempted to forget about the result	High result	-	-	5.0	(1)	$\chi^2_{(1)}=1.2, n.s.$ $\chi^2_{(1)}=0.0, n.s.$
	Low result	28.6	(6)	45.5	(10)	
Attempted to find out more information about osteo. since the scan	High result	12.5	(3)	28.6	(6)	Fisher's exact test not significant. $\chi^2_{(1)}=8.4^{**}$
	Low result	28.6	(6)	72.7	(16)	

**p<0.005 n.s.= not significant

PART TWO: Longer-term follow-up

8.8 Introduction

As a preliminary study into the longer-term effects of bone density screening, a further questionnaire was sent to women approximately 14 months after their initial scan (see chapter 3 for description of method and Appendix N for a copy of the questionnaire). In this chapter, the results from only a sub-group of the women - those selected for their very high or very low scores on the Health Anxiety Questionnaire- are presented.

Three main hypotheses were tested with regard to the longer-term follow-up:

- 1) - after a low scan result, women with a pre-existing tendency to worry about their health (as indicated by high HAQ scores) would still show greater distress 14 months after the scan than women who did not tend to worry about their health.
- 2) - women with a pre-existing tendency to worry about their health who received a high result would show a return of anxiety and need for reassurance over time (after the initial decrease shown immediately after the results, discussed earlier in the chapter).
- 3) - a “minimization” effect in seriousness ratings after a low result would occur most prominently (or only) in those who don’t tend to worry about their health.

8.9 Pre-existing differences between women with extremely high or extremely low HAQ scores

There was no significant difference between the high and low HAQ groups in terms of age, scan result or in the proportion reporting a medical condition related to bone density, a current medical condition or a family history of osteoporosis. The high HAQ group had significantly higher scores on the Beck Depression Inventory and Spielberger Trait Anxiety Inventory (see table 8.18).

Table 8.18 Characteristics of women with very high and very low scores on the HAQ

	Low HAQ		High HAQ		
	Mean	SD	Mean	SD	
Age (years	55.2	(8.5)	48.6	(14.0)	$t_{(37)} = 1.8$, not sig.
Result (% above or below mean for that age)	1.4	(11.2)	0.6	(13.4)	$t_{(37)} = 0.2$, not sig.
Beck Depression Inventory	2.0	(2.5)	16.3	(8.0)	$t_{(37)} = -7.4$, $p < 0.0005$
STAI- trait	29.0	(5.8)	51.4	(8.5)	$t_{(37)} = -9.4$, $p < 0.0005$
Medical condition which may be related to bone density	16.7%	(n=3)	30.0%	(N=6)	$\chi^2_{(1)} = 0.9$, not sig.
Current medical condition	21.1%	(n=4)	44.4%	(N=8)	$\chi^2_{(1)} = 2.3$, not sig.
Family history of osteoporosis	26.3%	(n=5)	25.0%	(N=5)	$\chi^2_{(1)} = 0.0$, not sig.

Second scans

The numbers of women saying that they have had a second scan are shown in table 8.19. A chi-square analysis indicated that there was no significant difference between the proportion of women with high and low HAQ scores who had had a further scan for the sample as a whole (Fisher’s exact test, $p=0.5$) or amongst those with a low result (Fisher’s exact test, $p=0.6$).

Table 8.19 The numbers of women in the longer-term follow-up who have now had another scan (grouped by scan result and HAQ score)

	Result of bone scan	
	Above average	Below-average
Low HAQ	1 (10)	3 (9)
High HAQ	1 (10)	4 (7)

(number in brackets refers to total number in each group)

8.10 Reactions to below-average results in women with high or low HAQ scores

It was predicted was that 14 months after a below-average scan result, the high HAQ group would still be more anxious about their bone density, feel more likely to develop osteoporosis and report more need of reassurance than the low HAQ group (after adjusting for initial levels). In order to test this hypotheses, analyses of covariance were performed between the two groups, using the longer-term follow-up measures as the dependent variables and the initial measures as the covariates.

Analyses of covariance were also performed using measures assessing general anxiety and sadness/low mood to investigate whether bone density screening would have any impact on these measures 14 months after the scan.

Results

Analyses of covariance indicated that at approximately 14 months after a low result, the women with high pre-scan scores on the HAQ were more anxious about their bone density, worried about developing osteoporosis, in need for reassurance, had higher ratings for the likelihood of osteoporosis in the near future or at any point in the future and more anxious in general than the women with low scores on the HAQ, after adjusting for initial ratings on the measures.

There were non-significant trends for the high HAQ group to rate their likelihood of developing

other serious illnesses more highly ($F_{(1,13)}=4.6, p=0.051$) and to feel more sad/low ($F_{(1,13)}=3.1, p=0.103$) than the low HAQ group, after adjusting for initial ratings.

See table 8.20 (below). The figures 8.10 - 8.17 show ratings for women who completed measures at each of the three points in time.

Table 8.20 Women with high and low levels of health anxiety who receive below-average results- Means, standard deviations and results from ANCOVA.

	Health anxiety	Initial ratings		14 month		Adjusted 14 month	
		Mean	SD	Mean	SD	Mean	
Anxiety about bone density	Low	45.0	(35.9)	16.9	(18.7)	18.1	$F_{(1,13)}=8.2^*$
	High	53.8	(22.0)	51.3	(26.4)	50.0	
Worry about developing ost.	Low	48.8	(34.8)	10.1	(13.0)	9.8	$F_{(1,13)}=13.6^{**}$
	High	66.3	(27.2)	52.5	(27.6)	52.9	
Need for reassurance	Low	43.8	(38.9)	12.6	(18.2)	13.5	$F_{(1,12)}=6.6^*$
	High	58.6	(24.1)	45.7	(26.4)	44.9	
Likelihood of osteoporosis (1)	Low	32.5	(28.2)	11.3	(8.3)	29.2	$F_{(1,13)}=7.8^*$
	High	50.0	(28.8)	51.3	(33.6)	13.3	
Likelihood of osteoporosis (2)	Low	42.5	(28.2)	18.8	(9.9)	18.4	$F_{(1,13)}=18.0^{**}$
	High	66.3	(27.2)	65.0	(25.6)	65.4	
General anxiety	Low	25.0	(33.4)	1.3	(3.5)	2.5	$F_{(1,13)}=8.7^*$
	High	65.0	(29.8)	42.5	(29.6)	41.3	
Sadness/ low mood	Low	7.5	(17.5)	0.0	(0.0)	5.5	$F_{(1,13)}=3.1, p=0.103$
	High	42.5	(36.2)	36.3	(35.0)	30.7	
Likelihood of developing other serious illness	Low	11.3	(16.4)	15.0	(16.0)	23.3	$F_{(1,13)}=4.6, p=0.051$
	High	42.5	(25.5)	48.8	(17.3)	40.6	

Women who had not completed the 3 month follow-up were included in this analysis to maximise the sample size
* $p<0.05$ ** $p<0.005$

Figure 8.10
Anxiety about bone density before, 3 months and 14 months after a bone scan, in women with very high or low HAQ scores and above or below-average bone density.

The means and standard deviations for anxiety and other ratings these 3 points in time (initial assessment, 3 month follow-up and 14 month follow-up) are give in table 8.24

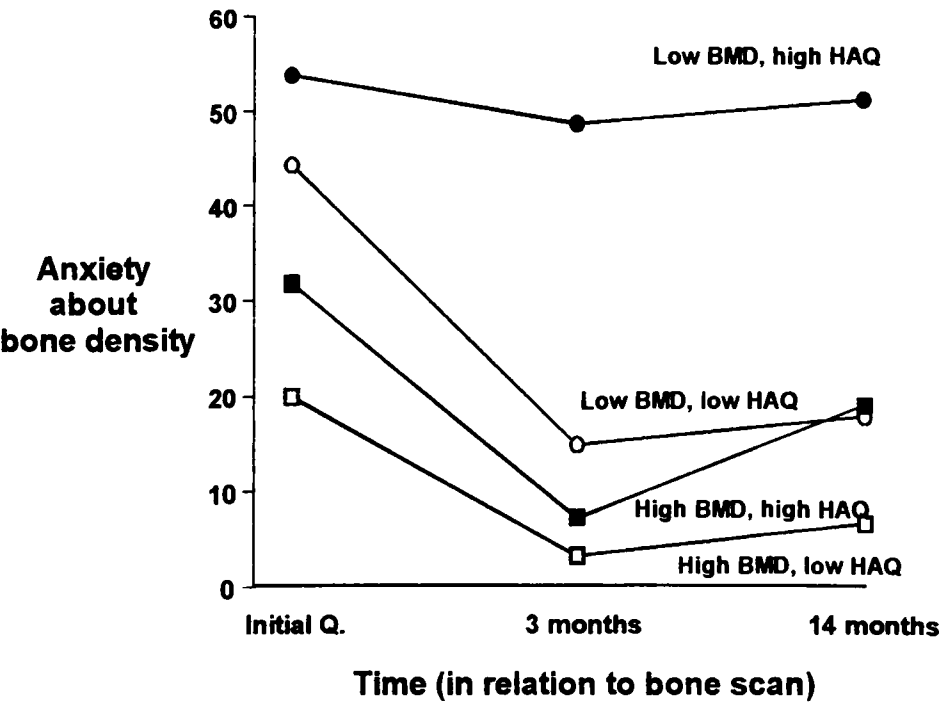


Figure 8.11
Worry about osteoporosis
before, 3 months and 14 months
after a bone scan, in women with
very high or low HAQ scores and
above or below-average bone density.

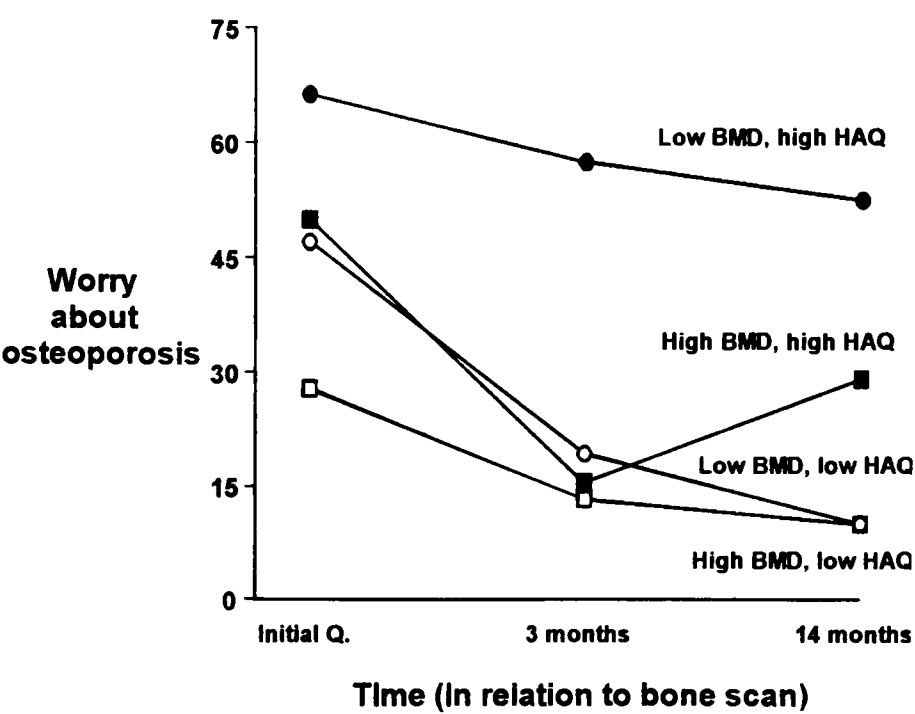


Figure 8.12
Need for reassurance,
before, 3 months and 14 months after
a bone scan in women with very high
or low HAQ scores and above or
below-average bone density.

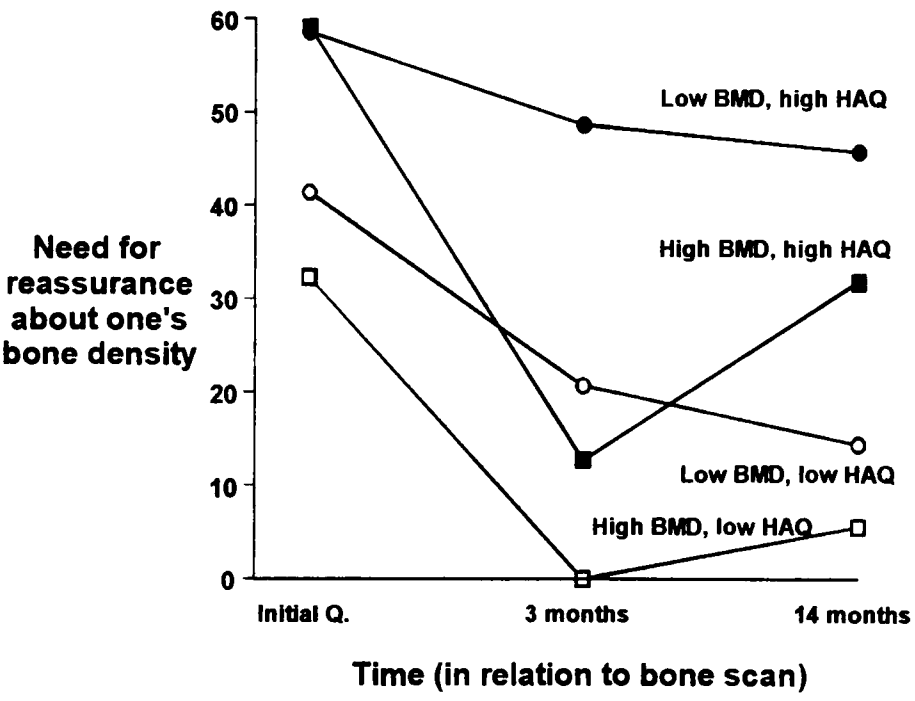


Figure 8.13
Perceived likelihood of
developing osteoporosis
(in the near future), before, 3 months
and 14 months after a bone scan in
women with very high or low HAQ
scores and above or below-average
bone density.

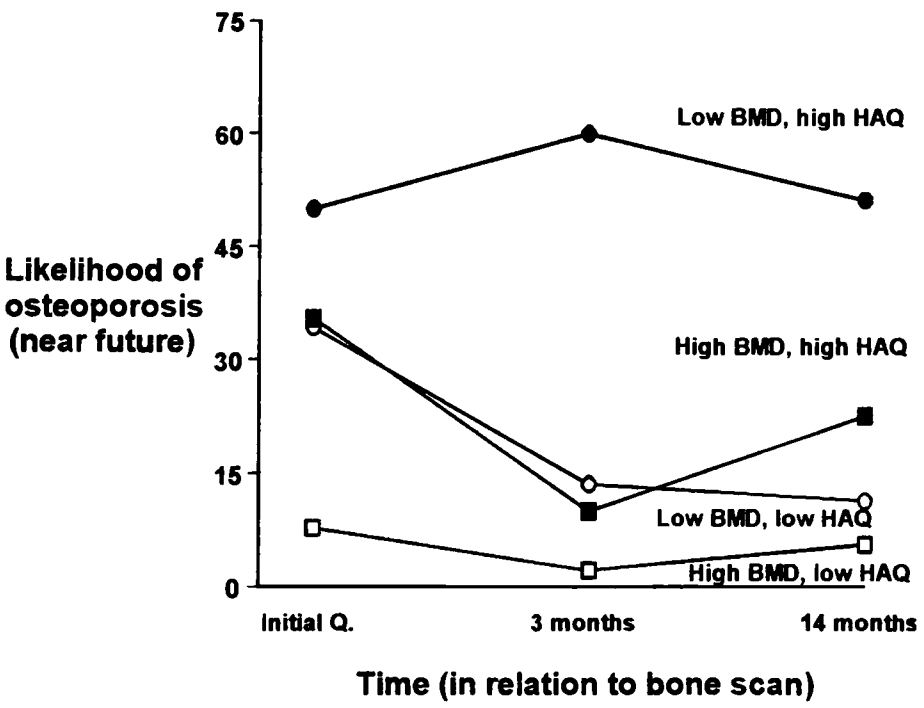


Figure 8.14
Perceived likelihood of developing osteoporosis (at any point in the future), 14 months after a bone scan in women with very high or low HAQ scores and above or below-average bone density.

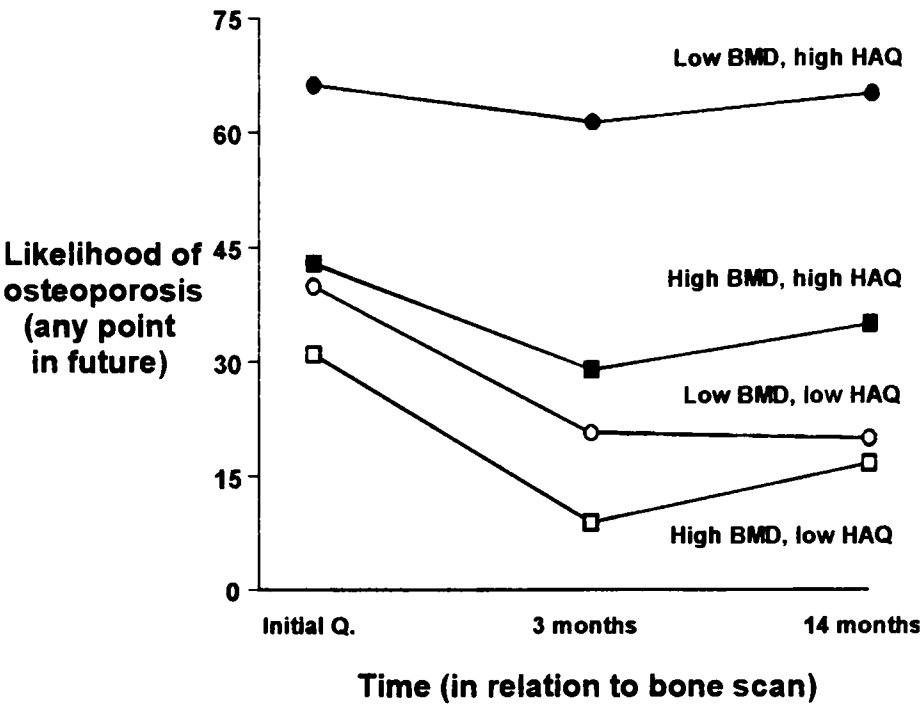


Figure 8.15
General anxiety, before, 3 months and 14 months after a bone scan in women with very high or low HAQ scores and above- or below-average bone density.

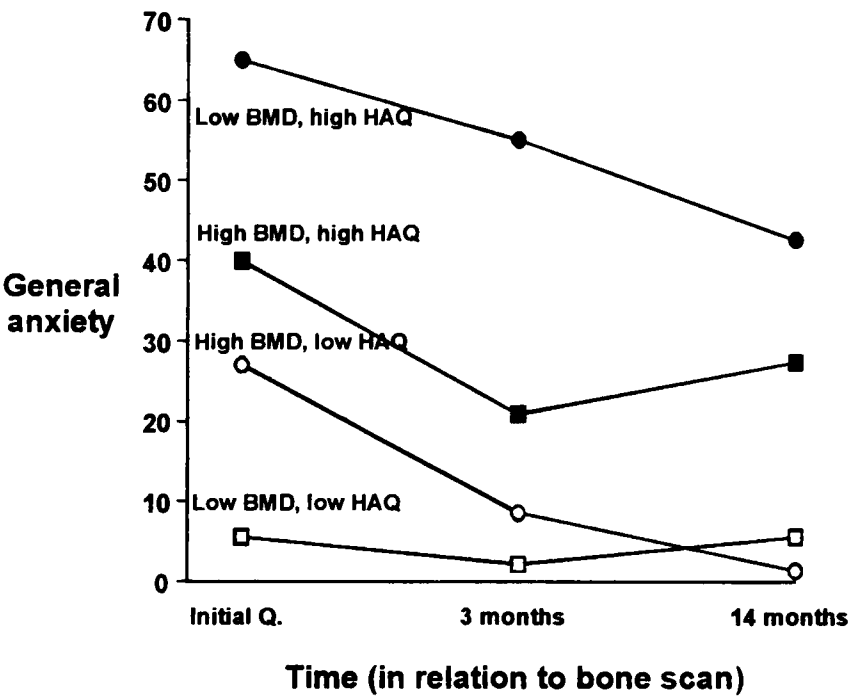


Figure 8.16
Sadness or low mood, before, 3 months and 14 months after a bone scan in women with very high or low HAQ scores and above or below-average bone density.

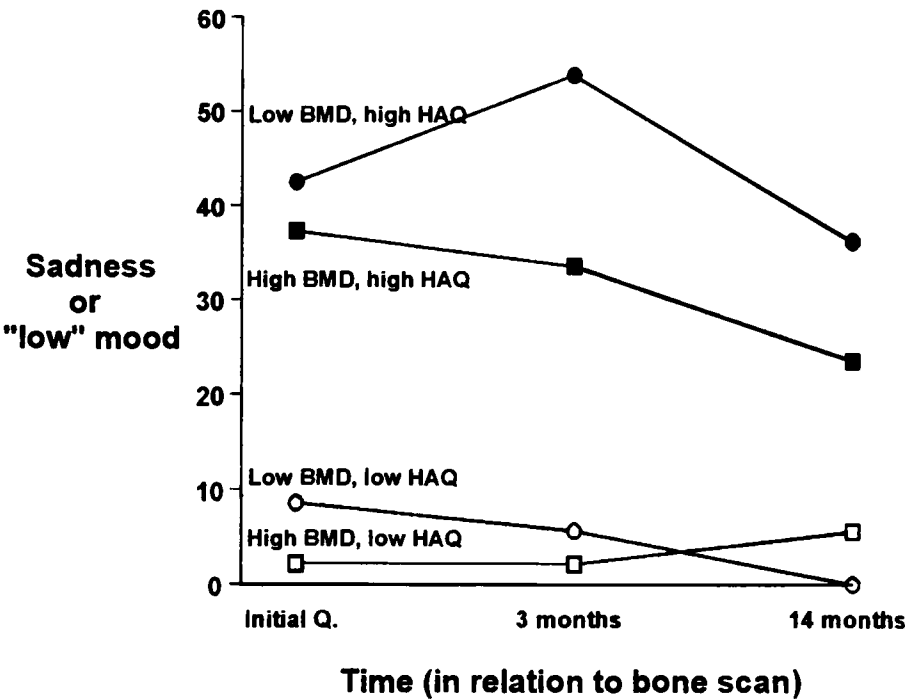
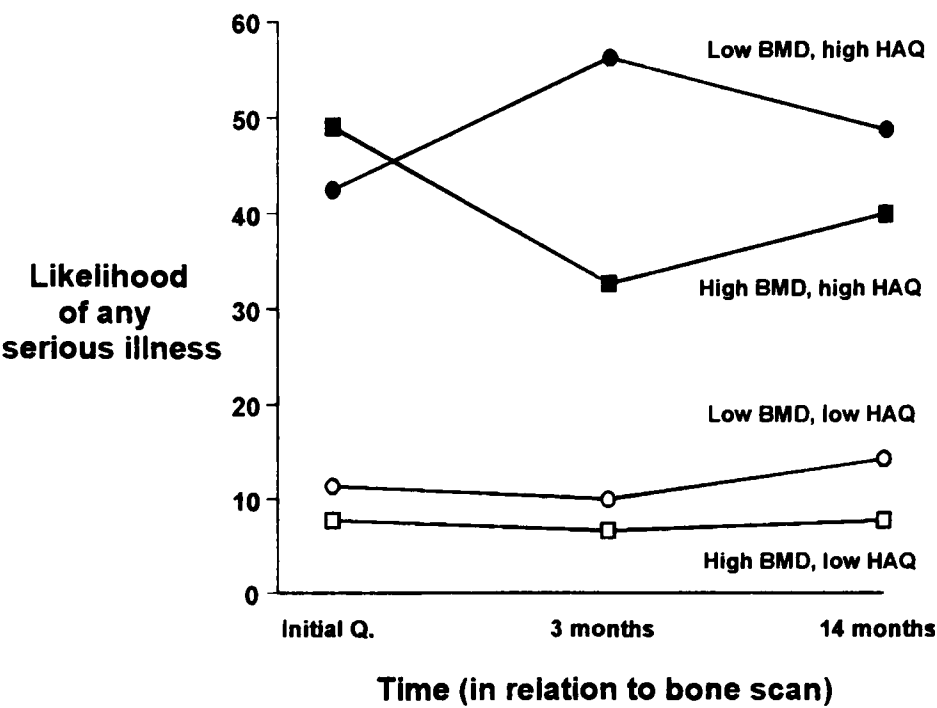


Figure 8.17
Perceived likelihood of developing a serious illness other than osteoporosis in the near future; before, 3 months and 14 months after a bone scan in women with very high or low HAQ scores and above or below-average bone density.



Depression about osteoporosis

The question “How depressed do you feel about osteoporosis?” was asked only at the final follow-up, so t-tests were used to compared high and low HAQ groups (see table 8.21). For those who had received a low result the difference between the high and low HAQ groups was not significant but for the sample as a whole the high HAQ group were significantly more depressed about osteoporosis than the low HAQ group.

Table 8.21 Depression about osteoporosis in women with high and low levels of pre-existing health anxiety

	Low result			All results		
	Mean	SD	$t_{(15)}=1.6$ not sig.	Mean	SD	$t_{(37)}=-2.1, p<0.05$
Low health anxiety	3.4	(7.0)		2.2	(5.3)	
High health anxiety	23.8	(35.8)		14.0	(24.8)	

8.11 Longer-term effects of an above-average scan result in women with high HAQ scores

Hypochondriacal patients often show initial feelings of reassurance after a negative health test result, followed by a subsequent increase in need for reassurance over time (e.g. Salkovskis and Warwick, 1986). Thus it was predicted that women with high levels of pre-existing health anxiety who received an above-average result would show an increase in need for reassurance, perceived likelihood of osteoporosis and anxiety between earlier and later follow-ups; it was expected that those with low health anxiety would show no increase or a much smaller one. In order to investigate this possibility, analyses of covariance were performed using only subjects who received an above-average result, comparing those with high and low HAQ scores with regard to need for reassurance, anxiety about bone density and worry about osteoporosis at the final assessment. The three month measure was used as the covariate. The analyses have been

performed twice: the second time, the two subjects who had had a further scan (one in each group) were eliminated, since this would be expected to affect their need for reassurance and anxiety. (See table 8.22 for the means, standard deviations and F-values and also the previous figures 8.10 to 8.14).

Anxiety about bone density: There was no significant group effect.

Worry about developing osteoporosis: An ANCOVA using all subjects showed a significant effect of group ($F_{(1,17)}=5.0$, $p<0.05$) as did the one using only subjects who had had one scan ($F_{(1,15)}=6.4$, $p<0.05$). Paired t-tests indicated that for all those with high HAQ scores there was a non-significant trend towards an increase in worry about osteoporosis between the three month and 14 month assessment ($t_{(10)}=-2.1$, $p=0.062$). For women who had had only one scan, the increase was significant ($t_{(9)}=-2.4$, $p<0.05$). Paired t-tests comparing ratings before the scan and 14 months later indicated that there was no significant difference in worry about osteoporosis for women with high HAQ scores ($t_{(10)}=1.8$ for all the women, $t_{(9)}=1.6$ for those who had had only one scan).

Those with low levels of health anxiety who received a high result showed no significant change in worry about osteoporosis between the 3 and 14 month assessments.

Need for reassurance: An ANCOVA using all subjects showed a non-significant trend towards a group effect ($F_{(1,17)}=3.3$, $p=0.089$) as did the ANCOVA using only subjects who hadn't had another scan ($F_{(1,15)}=3.8$, $p=0.070$). Given the strong *a priori* prediction, these non-significant effects were investigated further. Paired t-tests showed that those with high HAQ scores showed a significant increase in need for reassurance between the three month and 14 month assessments (all subjects: $t_{(10)}=-2.3$, $p<0.05$; subjects who had had only one scan: $t_{(9)}=-3.7$, $p=0.005$). Despite the significant increases between the 3 and 14 month assessments, the ratings at the final assessment were not as high as they had been before the scan ($t_{(10)}=3.7$, $p<0.005$ for all women, $t_{(9)}=3.2$, $p<0.05$ for those who had had only one scan).

Those with low HAQ scores showed no significant change in need for reassurance between the 3 and 14 month assessments.

Likelihood of osteoporosis in the near future: An ANCOVA using all subjects showed a non-significant trend towards a group effect ($F_{(1,18)}=3.3$, $p=0.086$) as did the one using only women who had had one scan ($F_{(1,16)}=3.0$, $p=0.101$). Because of the possibility of a floor effect in the ratings of the low HAQ group, the differences were examined in more detail. Paired t-tests indicated that for the high HAQ group there was a

significant increase in perceived likelihood between the 3 and 14 month assessments for those who had had only one scan ($t_{(9)}=-2.4$, $p<0.05$) and a non-significant trend in the same direction for the group as a whole ($t_{(10)}=-2.1$, $p=0.061$). This increase was so large that ratings at the 14 month follow-up were not significantly different than they had been at the initial assessments, for women with high HAQ scores ($t_{(10)}=1.5$ for the whole group, $t_{(9)}=1.3$ for those who had had only one scan).

Those with low HAQ scores showed no significant change in anxiety between the 3 and 14 month assessments.

Likelihood of osteoporosis at any point in the future: An ANCOVA using all the subjects showed no significant group effect ($F_{(1,17)}=1.8$); neither did the one using only women who had not had a further scan ($F_{(1,15)}=1.4$).

Table 8.22 Feelings about osteoporosis in women with high and low HAQ scores who received a high result: results of analyses of covariance investigating differences at 14 month follow-up after adjusting for 3 month follow-up.

	HAQ score	3 months		14 months		Adjusted 14 month	
<u>Need for reassurance</u>		Mean	SD	Mean	SD	Mean	
All subjects	Low	0.0	(0.0)	5.6	(8.8)	9.1	$F_{(1,17)}=3.3$, $p=0.089$
	High	12.7	(19.5)	31.8	(28.9)	28.2	
Subjects who hadn't had another scan	Low	0.0	(0.0)	5.0	(9.3)	11.0	$F_{(1,15)}=3.8$, $p=0.080$
	High	9.0	(16.0)	34.0	(29.5)	28.0	
<u>Anxiety about bone density</u>							
All subjects	Low	3.3	(7.1)	6.7	(11.2)	7.7	$F_{(1,17)}=2.1$, not sig.
	High	7.3	(11.9)	19.1	(21.2)	11.6	
Subjects who hadn't had another scan	Low	3.8	(7.4)	6.3	(11.9)	6.5	$F_{(1,17)}=2.6$, not sig.
	High	7.0	(12.5)	21.0	(21.3)	20.8	
<u>Worry about osteoporosis</u>							
All subjects	Low	13.3	(26.0)	10.0	(13.2)	10.5	$F_{(1,17)}=5.0$ *
	High	15.5	(12.9)	29.1	(24.3)	28.6	
Subjects who hadn't had another scan	Low	13.8	(27.7)	8.9	(13.6)	9.1	$F_{(1,15)}=6.4$ *
	High	15.0	(13.5)	31.0	(13.6)	30.7	
<u>Likelihood of osteoporosis (1)</u>							
All subjects	Low	7.8	(19.9)	5.6	(5.3)	8.9	$F_{(1,18)}=3.3$, $p=0.086$
	High	10.0	(13.4)	22.7	(18.5)	21.9	
Subjects who hadn't had another scan	Low	2.5	(4.6)	5.0	(5.3)	8.7	$F_{(1,16)}=3.0$, $P=0.101$
	High	8.0	(12.3)	23.0	(19.5)	22.0	
<u>Likelihood of osteoporosis (2)</u>							
All subjects	Low	8.9	(6.0)	16.7	(7.1)	19.9	$F_{(1,17)}=1.8$, not sig.
	High	29.0	(16.6)	35.0	(20.7)	21.1	
Subjects who hadn't had another scan	Low	8.8	(6.4)	16.3	(7.4)	21.1	$F_{(1,15)}=1.4$, not sig
	High	26.7	(15.8)	36.7	(21.2)	32.1	

* $p<0.05$

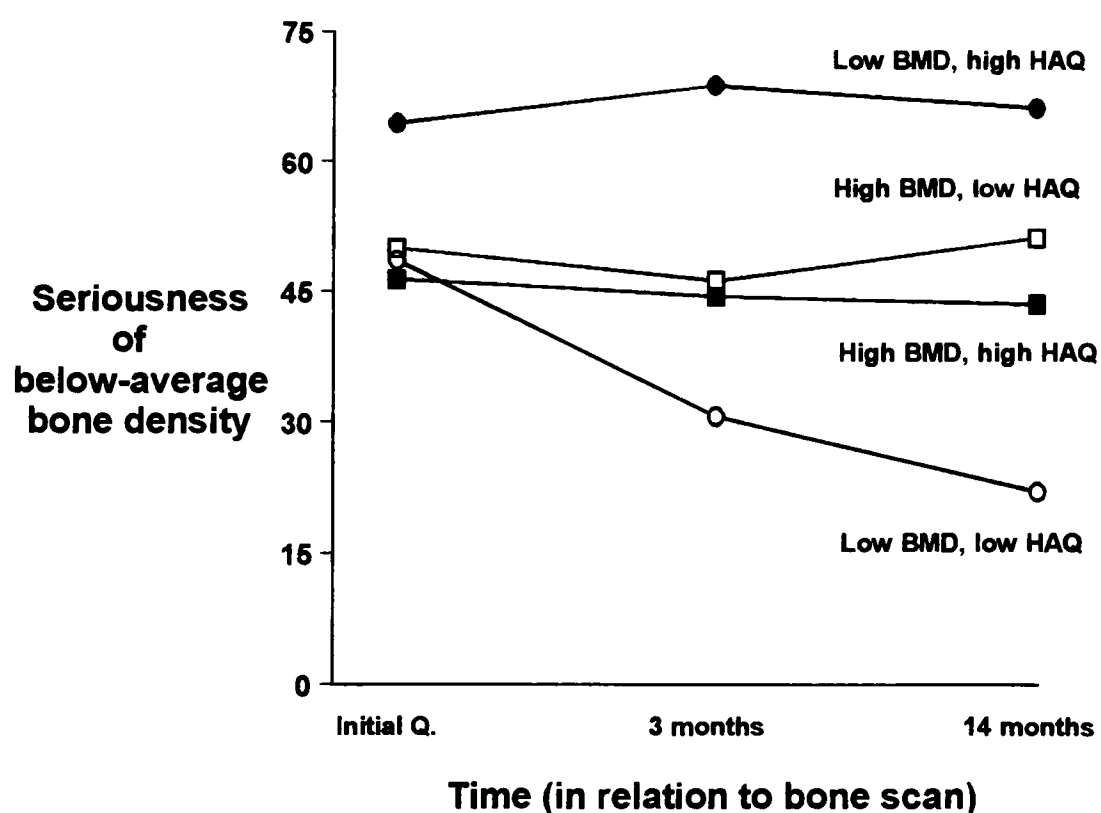
8.12 Beliefs about the seriousness of osteoporosis at the longer-term follow-up

In the first part of this chapter it was seen that after low BMD results there was a minimization effect for ratings of the seriousness of below-average bone density. In order to examine whether this sample of women with high or low results and very high or very low HAQ scores reacted differently with regard to changes in seriousness beliefs, repeated measures analyses of covariance were performed using the initial (pre-scan) ratings as the covariate and the 3 month and 14 month measures as the dependent variables. Other variables concerning “cost” beliefs were also analysed to examine whether any minimization effect was apparent for these measures at the 14-month follow-up. It was predicted that minimization effects would be less strong, or not apparent, in women with very high HAQ scores who received a below-average result. Since there were *a priori* predictions, significant effects are investigated further using only selected comparisons and alpha levels of $p < 0.05$ were accepted as significant.

Seriousness of below-average bone density: (See figure 8.18 and table 8.23)

There was a significant effect of HAQ ($F_{(1,29)} = 5.5$, $p < 0.05$), with the high HAQ group rating below-average bone density as more serious than the low HAQ group after the scan (after adjusting for initial ratings). There was also a result by HAQ group interaction ($F_{(1,29)} = 8.0$, $p < 0.05$). The *a priori* prediction had been that the low HAQ group, but not the high HAQ group would show a minimization effect after a low result. An ANCOVA using only those with a low result and the 14 month rating as the dependent variable confirmed that there was a significant group effect ($F_{(1,13)} = 6.2$, $p < 0.05$), indicating that the low HAQ group had significantly lower ratings than the high HAQ group at the final follow-up, after controlling for initial ratings.

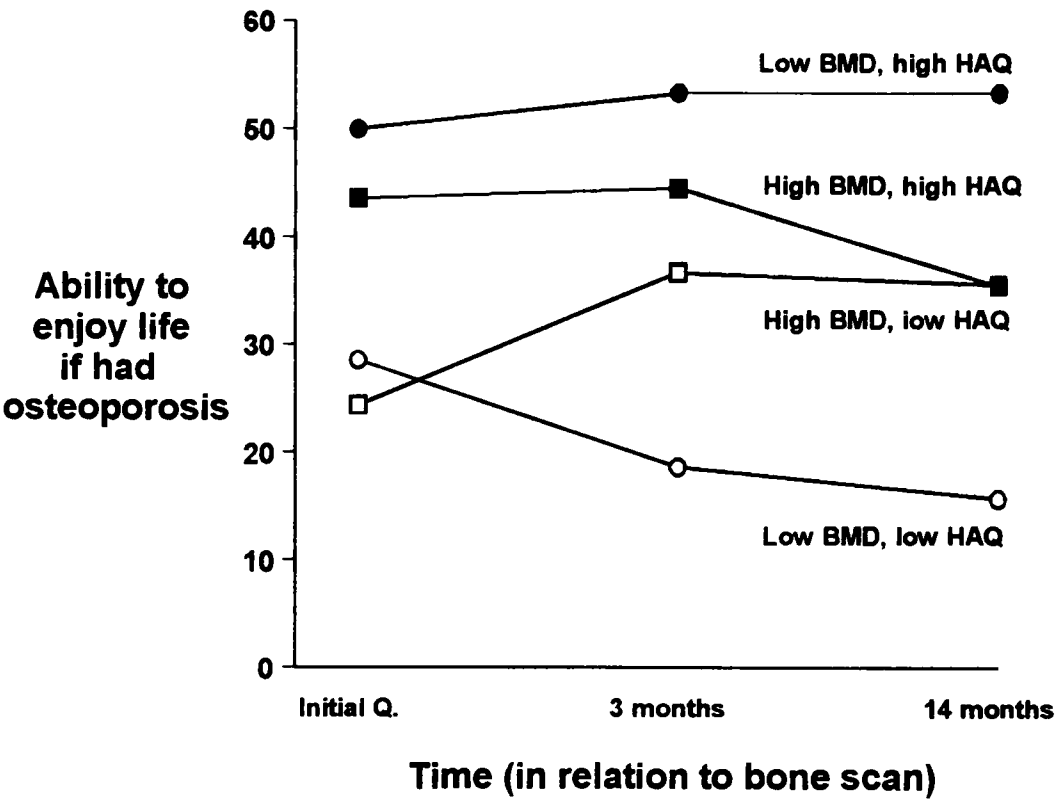
Figure 8.18
Perceived seriousness of below-average bone density before, 3 months after and 14 months after a scan, in women with very high or low HAQ scores and above- or below-average bone density.



Ability to enjoy life if one had osteoporosis (See figure 8.19 and table 8.23)

The only significant effect was a result by HAQ interaction ($F_{(1,28)}=9.6, p<0.005$). The *a priori* prediction was that only the low result / low HAQ group would show a “minimization effect” on these ratings. An ANCOVA comparing high and low HAQ groups who received a low result showed a non-significant trend towards a group effect ($F_{(1,11)}=3.4, p=0.092$), indicating a non-significant tendency for the low result / low HAQ group were more optimistic in their ratings after the scan even after adjusting for initial ratings.

Figure 8.19
Anticipated ability to enjoy life if one had osteoporosis in women with very high or low HAQ scores and above- or below-average bone density.



Severity of the consequences of osteoporosis (See table 8.23)

There were no significant effects.

Table 8.23: Means for “cost” ratings after the scan, adjusted for initial ratings from repeated measures ANCOVA.

	Health anxiety	3 months after the scan		14 months after the scan	
		High result	Low result	High result	Low result
Seriousness of below-average bone density	Low	69.8	38.8	73.3	32.8
	High	64.6	90.8	64.0	89.0
Ability to enjoy life if one had osteoporosis	Low	65.0	33.4	64.2	31.4
	High	48.6	60.3	42.2	60.3
Consequences of osteoporosis	Low	62.3	44.9	61.5	43.9
	High	62.3	72.8	61.0	71.0

See table 8.24 for observed means and standard deviations

Table 8.24 Means and standard deviations for ratings of beliefs and feelings at the initial assessment, 3 months after the scan and 14 months after the scan

	HAQ	Initial assessment		3 months after scan		14 months after scan	
		High BMD	Low BMD	High BMD	Low BMD	High BMD	Low BMD
Anxiety about bone density	Low High	Mean SD 20.0 (25.0) 31.8 (20.9)	Mean SD 44.3 (38.7) 53.8 (22.0)	Mean SD 3.3 (7.1) 7.3 (11.9)	Mean SD 15.0 (18.5) 48.8 (34.8)	Mean SD 6.7 (11.2) 19.1 (21.2)	Mean SD 17.9 (20.0) 51.3 (26.4)
Worry about osteoporosis	Low High	27.8 (34.6) 50.0 (31.6)	47.1 (37.3) 66.3 (27.2)	13.3 (26.0) 15.5 (12.9)	19.3 (21.3) 57.5 (26.0)	10.0 (13.2) 29.1 (24.3)	10.1 (14.0) 52.5 (27.6)
Need for reassurance.	Low High	32.3 (28.2) 59.1 (28.4)	41.4 (41.4) 58.6 (24.1)	0.0 (0.0) 12.7 (19.5)	20.7 (35.6) 48.6 (36.3)	5.6 (8.8) 31.8 (28.9)	14.4 (18.9) 45.7 (26.4)
Likelihood near future	Low High	7.8 (19.9) 35.5 (27.0)	34.3 (29.9) 50.0 (28.8)	2.2 (4.4) 10.0 (13.4)	13.6 (17.5) 60.0 (32.1)	5.6 (5.3) 22.7 (18.5)	11.4 (9.0) 51.3 (33.6)
Likelihood any point	Low High	31.1 (32.6) 43.0 (21.1)	40.0 (29.4) 66.3 (27.2)	8.9 (6.0) 29.0 (16.6)	20.7 (20.1) 61.3 (24.2)	16.7 (7.1) 35.0 (20.7)	20.0 (10.0) 65.0 (25.6)
General anxiety	Low High	5.6 (10.1) 40.0 (24.5)	27.1 (35.5) 65.0 (29.8)	2.2 (4.4) 20.9 (23.4)	8.6 (18.6) 55.0 (33.0)	5.6 (7.3) 27.3 (29.0)	1.4 (3.8) 42.5 (29.6)
Sadness / low mood	Low High	2.2 (4.4) 37.3 (35.5)	8.6 (18.6) 42.5 (36.2)	2.2 (4.4) 33.6 (33.2)	5.7 (15.1) 53.8 (33.4)	5.6 (7.3) 23.6 (22.5)	0.0 (0.0) 36.3 (12.4)
Coping beliefs	Low High	24.4 (24.6) 43.6 (21.1)	25.7 (23.7) 51.7 (17.2)	31.1 (31.4) 49.1 (21.7)	12.9 (18.0) 41.7 (17.2)	34.4 (30.0) 39.1 (18.1)	14.3 (17.2) 36.7 (15.1)
Ability to enjoy life	Low High	24.4 (30.5) 43.6 (20.1)	28.6 (21.9) 50.0 (10.6)	36.7 (32.4) 44.5 (25.0)	18.6 (15.7) 53.3 (13.7)	35.6 (29.2) 35.5 (23.4)	15.7 (21.5) 53.3 (16.3)
Conseq. of osteoporosis	Low High	30.0 (30.4) 53.6 (23.4)	40.0 (16.3) 66.3 (26.2)	35.6 (29.2) 48.2 (23.1)	28.6 (33.3) 62.5 (24.9)	34.4 (28.3) 46.4 (24.6)	27.1 (17.0) 60.0 (27.3)
Seriousness of low b.d.	Low High	50.0 (32.1) 46.4 (22.9)	48.6 (18.6) 64.4 (22.3)	46.3 (22.0) 44.5 (24.2)	30.7 (27.5) 68.8 (21.0)	51.3 (12.4) 43.6 (33.2)	22.1 (25.1) 66.3 (26.2)
Likelihood of serious illness	Low High	7.8 (16.4) 49.1 (22.1)	11.4 (17.8) 42.5 (25.5)	6.7 (7.1) 32.7 (21.5)	10.0 (19.1) 56.3 (32.0)	7.8 (6.7) 40.0 (24.9)	14.3 (17.2) 48.8 (17.3)

All measures were 0 - 100 visual analogue scales on which the higher the rating, the greater the distress or risk perception or the more negative the response.

8.13 Preventative behaviours

Looking at the longer-term follow-up sample as a whole, there is a significant increase in the proportion of women reporting preventative behaviour(s) between the initial and 3 month assessments (Binomial test, $p < 0.05$) and between the initial and 14 month assessments (Binomial test, $p < 0.05$) but no significant change between the 3 month and 14 month assessments (Binomial test, $p = 1.0$).

Chi-square analyses indicated no significant difference in the proportion of women reporting at least one preventative behaviour in the low and high HAQ groups at the initial assessment ($\chi^2_{(1)}=1.1$), 3 month follow-up (Fisher’s exact test, $p=0.45$) or at 14 month follow-up (Fisher’s exact test, $p=0.24$). However, t-tests indicated that although there had been no significant difference between the two groups in the number of preventative behaviours reported before the scan ($t_{(32)}=1.5$), a year later those with high HAQ scores reported fewer preventative behaviours than those with low HAQ scores ($t_{(32)}=2.1$, $p<0.05$) (see table 8.25).

Table 8.25 Mean numbers of preventative behaviours reported by women with high and low levels of health anxiety

	Number of preventative behaviours				
	Low HAQ		High HAQ		
	Mean	SD	Mean	SD	
Before scan	1.2	(1.1)	0.6	(0.9)	t ₍₃₂₎ =1.5
3 months later	1.8	(1.2)	1.3	(1.2)	t ₍₃₂₎ =1.3
14 months later	1.9	(1.1)	1.2	(1.0)	t ₍₃₂₎ =2.1, p<0.05

Analyses were not performed on the four groups of women (derived by dividing in terms of result and HAQ score) because the numbers of women in each group were so small. However, the numbers reporting preventative behaviour in each group are shown in table 8.26 (only those answering this question at each point in time have been included).

Table 8.26 Number of women with high or low HAQ scores reporting preventative behaviours at different points in time

	High result			Low result		
	Low HAQ	High HAQ	Total	Low HAQ	High HAQ	Total
Number saying that they acted to prevent bone loss or fractures						
Before the scan	5 (9) ^a	3 (11)	8	6 (8)	6 (8)	12
3 months after the scan	6 (9)	6 (11)	12	8 (8)	7 (8)	15
14 months after the scan	8 (9)	6 (11)	14	7 (8)	7 (8)	15

^a the number in brackets is the total number in each group.

8.14 Discussion

Summary of results from the main comparison of women with high and low HAQ scores

As predicted, women with a pre-existing tendency to worry about their health showed a more negative reaction to a low result than women who don't tend to worry about their health, in terms of anxiety and perceived likelihood of developing osteoporosis. In addition, the highly health anxious women who received a high result showed immediate decreases in anxiety after the result but their ratings had increased significantly again by the 3 month follow-up.

Anxiety and perceived likelihood of developing osteoporosis after a low result

After a low bone density result, women who reported high levels of pre-existing health anxiety showed higher levels of anxiety about osteoporosis and perceived likelihood of developing osteoporosis in the near future than women with lower levels of pre-existing health anxiety, even though the two groups did not differ significantly in these ratings at the initial assessment. These results indicate that the Health Anxiety Questionnaire given to assess pre-existing health anxiety may be useful in helping to identify those who will react more negatively to a low bone density scan result. However, it should be noted that it may be possible to improve prediction by also assessing specific illness beliefs about the condition in question. In the next chapter there will be an examination of the extent to which distress after testing can be predicted by general and specific measures of health anxiety and health beliefs.

In previous chapters it has been noted that decreases in anxiety about bone density and risk perceptions occur between the initial assessment and the assessment immediately before the scan. Analyses in this chapter indicate that women who had a pre-existing tendency to worry about their health do not show this reduction in their ratings and it is not clear why the other group do show the decrease. Results presented in chapter 7 suggest that women who subsequently receive low scan results have higher risk perceptions before the scan, and it is possible that the low health anxiety group are minimizing their risk immediately before the scan in order to manage their anxiety. Those who tend to worry about their health may not be able to (or may not try to) reduce their anxiety about their bone density in the same way. Both high and low HAQ groups show a significant decrease in general anxiety before the scan, which is perhaps because uncertainty is about to be relieved or because it is perceived that help will be given if the news is bad. However, these are only tentative suggestions and the matter requires further investigation in future studies.

“Cost” beliefs in women with high and low levels of pre-existing health anxiety

Women with a pre-existing tendency to worry about their health felt that they would be less able to cope if they had osteoporosis and rated below-average bone density to be a more serious threat to health than women who didn't have a tendency to worry about their health. (These differences were apparent before the scan, unlike differences in the perceived likelihood of developing osteoporosis, which only appeared afterwards). According to the cognitive-behavioural model of health anxiety, the more negative beliefs in the highly health anxious group before the scan may be one of the reasons that these women were more likely to experience anxiety if they found that they were risk for developing osteoporosis.

Minimization shown by women with low levels of pre-existing health anxiety

After a low result, the women who had low levels of pre-existing health anxiety showed a decrease (relative to initial ratings) in their ratings of perceived likelihood of developing osteoporosis and of the seriousness of below-average bone density (and there was also a tendency to show a decrease in anxiety and worry). The mean values of ratings for risk compared to others and the perceived likelihood of developing osteoporosis indicated that the low health anxious group were underestimating their comparative risk and their chances of developing osteoporosis. In contrast, those with high levels of pre-existing health anxiety did not show a significant change in their ratings of likelihood for developing osteoporosis or the seriousness of a below-average result between the first and last assessments. It should be noted that the group difference for minimization of seriousness was not a strong one, since it was only apparent if one compared the results of paired t-tests, not if one used repeated measures analyses of covariance. Furthermore, the mean values for the ratings of "risk compared to other women" indicate that underestimation of risk may be occurring in some of the more highly health anxious group as well as in the less health anxious group. However, overall it seems that women with low levels of pre-existing health anxiety may be minimizing the likelihood of osteoporosis and the seriousness of below-average bone density, while the more health anxious group are not showing such tendencies, or showing them to a much smaller degree.

Cognitive models of anxiety such as that by Beck (1976) would predict that a reduction in perceived seriousness or perceived likelihood of osteoporosis would result in a reduction in anxiety about osteoporosis. Consistent with this prediction, there was a moderately high correlation for changes in worry about osteoporosis and changes in perceived likelihood, and a trend in the right direction regarding perceived seriousness. It should be noted that minimization only need to occur in one of the crucial beliefs (i.e. beliefs about “seriousness”, likelihood, coping and rescue factors) in order for anxiety to reduce, so one would not

necessarily expect very high correlations between changes in anxiety and changes in any one of the particular beliefs. Obviously firm conclusions cannot be drawn from this correlational data but the findings are consistent with the notion that minimization may be adaptive in terms of anxiety.

The low HAQ group, (who show minimization of seriousness) do not seem to be simply denying that they have a problem, since their reductions in seriousness ratings tended to be associated with higher levels of preventative behaviours 3 months after the scan. Furthermore, within the low health anxiety group the degree of minimization of seriousness was inversely related to a tendency to use a generally maladaptive coping strategy- avoidance of stimuli / situations which remind one of illness (assessed prior to the scan). Thus the low health anxious group show minimization of the risk and seriousness accompanied by decreases in anxiety but increases in preventative behaviours. Although the relationship between these changes is not clear, it is possible that minimization may be a useful strategy for these women.

The possibility that minimization may be adaptive is consistent with the views of Shelley Taylor and her colleagues. Taylor and Brown (1988) suggest that normal human thought is skewed in a positive direction and characterised by positive biases; these biases guide the processing of information such that mildly negative or ambiguous information is distorted to be more positive than is in fact the case. They argue that these biases are adaptive because they facilitate positive emotional well-being and effective functioning. Their suggestion that minimization allows anxiety to reduce and resources to be allocated to more action-oriented coping is consistent with the finding that the number of preventative behaviours at the 3 month follow-up tends to correlate with minimization in the low health anxious group.

However, there is also the possibility that the minimization effect is partly the result of women's plans or actual behaviour change. Croyle (1992) has suggested that the minimization process is a case of "motivated reasoning". (There is evidence to support the notion that people are more likely to arrive at conclusions that they want to arrive at, although they are constrained by their ability to construct seemingly reasonable justifications for these conclusions (Kunda, 1990)). But Croyle does not discuss the information that people may use in their motivated reasoning about their health. Work by Weinstein (e.g. 1984) looking at unrealistic optimism may be relevant here. His work indicates that one reason why people in general are optimistic about their risk for illness (or other negative events) may be that they tend to focus on their own risk-reducing attributes, fail to take into account all their risk-increasing ones and fail to acknowledge the amount of risk-reducing attributes of other people. There is also evidence that people who consider the particular event to be particularly undesirable, show these biases more strongly (Gerrard, Gibbons and Warner (1991)). It is possible that these tendencies regarding perceived vulnerability may also apply to

minimization of the seriousness of a health threat and are accentuated when one is particularly motivated to believe that one is not at a health risk, such as after a bad test result. If this were the case in the present study, it is possible that when women were asked to judge how serious a threat to health a low scan result might be, they focus on reasons why it is a mild risk rather than a serious one (e.g. they think about the preventative measures they are taking or plan to take). This might explain the finding that in the low health anxious group, minimization tended to positively correlated with the number of preventative behaviours reported after the scan.¹ There are of course various factors which different women may focus on to justify their conclusion that the threat is not severe, for example: the hope that one may be low in bone density but not actually currently losing bone. In minimizing one's likelihood of developing osteoporosis one could concentrate on a lack of family history of osteoporosis (or differences between oneself and the affected relative if there is a history), the possibility that new preventative measures will be available in the future, the belief that one is generally a healthy person and so on.

Of course it is also possible that minimization is a dynamic process which involves both of the elements discussed above: in other words, plans for behaviour change allow some minimization, which reduces anxiety and allows resources to be focused on behaviour change rather than on emotional distress; the actual performance of these behaviours allows further minimization because the woman has evidence that she is able to maintain preventative behaviours. This would be consistent with the finding that there tends to be a decrease in ratings of seriousness both between the assessment immediately following the result and the week follow-up, and between the week and 3 month follow-up.

Possible explanations for the lack of minimization in the health anxious group

Previously the cognitive model of health anxiety has addressed reasons why health anxious individuals feel particularly anxious about symptoms or health information, and why this anxiety persists. It has not explicitly described how these cognitive biases, processing styles and behaviours relate to normal ways of coping with a health threat such as minimization. Using the cognitive model of health anxiety proposed by Warwick and Salkovskis (1990), it is possible to identify several reasons why women high and low in pre-existing health anxiety may differ in minimization after a health threat. These ideas are based on the assumption that minimization is a form of motivated reasoning and are purely speculative:

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It should be noted that although this process may be occurring in some women with low levels of pre-existing health anxiety, the opposite appears to be the case in those with high levels of health anxiety, in whom there is a significant positive correlation between change in seriousness ratings and change in the number of preventative behaviours performed.

1) Beliefs about illness and health: The health anxious women will have certain maladaptive beliefs which will probably be activated by the health threat so that they are more likely to experience negative thoughts about the situation. These thoughts may be so negative that the woman does not believe that there can be any positive ways of looking at the situation or may be so overwhelming that the woman has no cognitive resources with which to attempt to minimize the threat. Furthermore, the low health anxious group will probably have a number of positive beliefs about themselves and their health which they can use in the process of minimization of the threat, such as “I’m hardly ever ill”: health anxious women may have many fewer positive beliefs which they could use.

2) Selective attention: Those who tend to worry about their health will probably have shown a cognitive response to the health threat which acts against minimization: selective attention to the more threatening aspects of the situation. This will directly oppose minimization, if the minimization effects are indeed mediated by focusing on reasons why the problem is not serious.

3) Biases in risk perceptions caused by anxiety: The immediate anxiety felt by the health anxious group after a low result was greater than in the low health anxious group. Anxiety itself tends to be associated with increased perceptions of one’s risk for negative events (Butler and Mathews, 1987), which would act against a minimization of the likelihood of developing osteoporosis in the more anxious group.

4) Coping responses: Health anxious women may be more likely to use coping strategies which will act against minimization. For example, clinical observation suggests that hypochondriacal patients often use avoidant cognitive or behavioural responses which prevent disconfirmation of maladaptive beliefs and maintain anxiety (Salkovskis and Clark, 1993). Obviously avoidance would not allow the woman to focus on any positive aspects of the situation and hence she will not re-evaluate or minimize the threat. (This is consistent with the finding that in the low health anxious group a tendency to avoid illness-related situations (assessed prior to the scan) was associated with less minimization). Although not all means of avoidance were assessed, women were asked whether they had tried to forget the result or distract themselves from thinking about it. The proportions of high and low health anxious women reporting deliberate distraction or forgetting did not differ significantly, but it is possible that the two groups used different methods for distraction or forgetting. For example, the health anxious women may have been more likely to have tried to suppress thoughts in an attempt to forget about them (which has been shown to result in an increase in

such thoughts in the long term; Trinder and Salkovskis, 1994) while the low health anxious group may be trying to convince themselves that it's not worth worrying about. This needs to be investigated in future research.

A further explanation for the lack of group differences in distraction or forgetting is that although health anxiety is higher in women who attend bone density screening than in the general population, these women have a lower than expected tendency to avoid illness-related situations than people in the general population (see chapter 4); it is possible that these strategies would be more prevalent in health anxious individuals who show report higher levels of pre-scan avoidance. It is likely that the health anxious women who volunteer to take part in a screening study are those who prefer to seek reassurance and indeed more of the highly health anxious group report seeking further information about osteoporosis since the scan than the group with low levels of health anxiety. There was a non-significant trend for a tendency to seek reassurance (assessed prior to the scan) to be associated with minimization of seriousness and likelihood in the health anxious group so it may be that reassurance-seeking in this situation is actually helpful for some women. This could be because the reassurance that a woman will receive after a low bone density result is often not the kind of reassurance that has been identified as problematic for hypochondriacal patients (Warwick and Salkovskis, 1985) where the doctor tries to convince the patient that there is no serious health problem but provides no new information. After a low bone scan, reassurance from health professionals or written information is probably likely to emphasize things that can be done to prevent fractures. In other words, in some cases the health professional may be helping the woman to focus on a more positive interpretation of the situation and hence minimize the problem in a way that the low health anxious women were more able to do for themselves. Indeed, anecdotal evidence from conversations with some women at the Bone Density Unit suggests that women who were simply told by their GP that a low result is not a problem, are often not convinced and remain anxious.

5) Meta-cognitive beliefs: It is possible that one of the reasons that the health anxious group fail to show minimization is because they have certain beliefs about using this kind of coping strategy. For example, they may believe that to minimize a threat to health can be very dangerous because then one would not take proper care of oneself. Meta-cognitive beliefs about minimization and other strategies such as focusing on / attending to a health threat could be explored in a future questionnaire study.

Return of concern in highly health anxious women who received high scan results

There was support for the prediction that women with high levels of pre-existing health anxiety who received a high result would show only temporary reassurance. Anxiety and worry about osteoporosis and perceived likelihood of developing osteoporosis at any point in the future increased significantly in this group between the assessment immediately after the results and the three month follow-up. Ratings of need for reassurance also showed an increase although this change didn't begin to appear until later- at some point between the week and three month follow-up.

At the three month follow-up the levels of anxiety and need for reassurance had not returned to the levels seen at the initial assessments. However, at the initial assessments, ratings may have been higher than usual due to the impending scan, so it impossible to assess from the present data how the post-scan ratings compare to how the women felt before they knew that the scan was available. Thus one cannot rule out the possibility that for women who tend to worry about their health, having a high result may have caused no long term reduction in anxiety or may have even increased anxiety.

Prevention beliefs and behaviour: There was no significant difference in prevention beliefs in women with high or low levels of pre-existing health anxiety. However, it is possible that this is because the question ("If you have low bone density, how likely is it that you will be able to do something about it to prevent the symptoms of osteoporosis?") may have been answered for people in general rather than oneself (this is especially likely to be true for women with high bone density) so firm conclusions cannot be drawn from responses to this question.

There were no group differences in terms of the number of preventative behaviours performed, except that after a low result women with high levels of pre-existing health anxiety were more likely to report taking calcium supplements than women with low levels of health anxiety. Although one might expect that the greater risk perceptions in the health anxious group would lead to more preventative behaviours, some in the health anxious group may try to deal with their anxiety by avoidance of the topic and some may feel that the situation is too hopeless to merit much effort. It may be noteworthy that the only behaviour which was reported by more of the highly health anxious women was the taking of calcium supplements, which for many is probably the easiest change to make. Furthermore, taking HRT increases the risk of developing diseases such as breast cancer which may be of particular concern to some of the health anxious women.

Symptom reporting: The proportions of low and high health anxious patients reporting symptoms of low bone density did not differ significantly, either before or after the scan. This is perhaps not surprising- although anxiety about health can lead to a focusing on bodily sensations and a perceived or real worsening of symptoms (see Salkovskis, 1989), the most well-known symptoms of osteoporosis - fractures, cannot be increased by heightened attention or anxiety in the same way as symptoms such as palpitations can be.

8.15 Discussion: Longer-term follow-up

Overview

The results from the longer-term follow-up were broadly consistent with the cognitive-behavioural model of health anxiety. At about 14 months after a below-average result from their first bone scan, women with high levels of pre-existing health anxiety were still more distressed and perceived osteoporosis as more likely than women with low levels of health anxiety. The low health anxious group who received a low result showed a decrease in their ratings of anxiety, perceived likelihood of osteoporosis and seriousness of below-average bone density between the assessment before the scan and the 14 month follow-up.

Of the women who received an above-average result, those with high levels of pre-existing health anxiety showed an increase in worry about osteoporosis, perceived likelihood and need for reassurance between the 3 and 14 month follow-ups, unlike those with low levels of pre-existing health anxiety.

Limitations of the 14 month follow-up study: It should be noted that a quarter of the women in the longer-term follow-up sample had had a further scan and this will have affected their feelings. Although the analyses looking at just women with a high result have been performed twice (with and without women who have had a further scan) in other cases the sample sizes would have been too small. For this reason, and the small sample sizes involved, firm conclusions cannot be made about the long-term effects of bone density scans.

Distress and risk perceptions: Fourteen months after a below-average bone scan result, women with a pre-existing tendency to worry about their health were more anxious about their bone density, worried about developing osteoporosis, in need of reassurance about their bone density, had higher ratings for perceived likelihood of osteoporosis in the near future or at any point in the future and were more anxious in general than women who didn't tend to worry about their health (after adjusting for initial ratings). This confirmed prior predictions derived from the cognitive model of health anxiety and was consistent with the findings

from the 3 month follow-up.

Minimization effects: There was support for the prediction that after a below-average result, those with low levels of pre-existing health anxiety would show significantly lower ratings of the seriousness of such a result than women with high levels of health anxiety, after adjusting for initial ratings. (There was a non-significant trend in the same direction for ratings of how much having osteoporosis would affect one's ability to enjoy life). The group differences in the minimization of seriousness ratings are stronger in this longer-term follow-up than at the 3 month follow-up reported in the first part of this chapter (where there were only slight indications of a group difference in minimization). This may be partly because the groups at the 14 month follow-up are more extreme in terms of scores on the HAQ than the groups reported in the 3 month follow-up analyses.

Temporary reassurance for health-anxious women who receive an above-average result

There was confirmation of the prediction that for some women with high levels of pre-existing health anxiety, the reassurance of an above-average result would not be permanent: it was found that for women who had only had one scan there was an increase in worry about osteoporosis, need for reassurance and perceived likelihood of osteoporosis between the 3 month and 14 month assessment. (If the person who had had a subsequent scan was added to the analyses, the effects are not as strong, which indicates that this second scan may have been reassuring, at least temporarily). The low health anxious group showed no significant change over this time period. At the 14 month follow-up the ratings of worry and likelihood of developing osteoporosis had increased so much in the high health anxiety group that the ratings were not significantly different to the levels seen at the initial assessments. Furthermore, since these initial ratings may have been higher than usual due to the impending scan, one cannot rule out the possibility that for women who tend to worry about their health, having a scan may have left them feeling more worried and vulnerable than they had been before they heard of the scans- even if they receive an above-average result.

Perceived likelihood of developing other serious illness: For those receiving a low result, there was a marginally significant trend for the high health anxious group to rate their likelihood of developing serious illness other than osteoporosis more highly than the low health anxious group, after adjusting for initial ratings. It is thus possible the scan result reinforced or even enhanced some of the health anxious women's maladaptive beliefs about illness in general. Having a bad result from a bone scan can mean that you have

been diagnosed as “not healthy” in the absence of any symptoms and it is easy to see how this could be disconcerting. Although the differential group effect is not a strong one, it may be important to investigate in more detail the effects that one piece of bad news about one’s health can have on one’s beliefs one’s health in general, particularly in women who already hold maladaptive views about illness.

Maintenance of preventative behaviours

There was no significant change between the 3 and 14 month assessments in the proportion of women reporting preventative action: it is reassuring to see that the behaviour changes have been maintained. There was also no significant difference in the proportion of women with high or low levels of pre-existing health anxiety reporting some kind of preventative behaviour 14 months after the bone scans. However, those with high levels of health anxiety reported a significantly smaller number of preventative behaviours at the 14 month assessment than women with low levels of health anxiety. There are several possible reasons for this difference, which could be investigated in future studies. For example, women with higher levels of health anxiety may be using avoidance as a coping strategy or perhaps their higher ratings of depression about osteoporosis reflects hopelessness about their chances of preventing the onset of osteoporosis and hence lack of motivation to change their behaviour in many ways.

Chapter 9: The prediction of reactions to bone density screening

9.1 Introduction

Overview

In this chapter there is an evaluation of the hypothesis that measures derived from the cognitive-behavioural model of health anxiety can help predict which women will be vulnerable to experiencing anxiety after bone density screening. The relative contribution of measures derived from the model and the scan result itself are investigated using multiple regression analyses. There is also an examination of factors which are associated with other reactions to bone density screening (including information/reassurance-seeking, attempts to forget about the result, changes in risk and seriousness ratings) and which factors are associated with risk perceptions before the scan.

Test of the basic cognitive model of anxiety

The cognitive model of anxiety (e.g. Beck, 1976) states that appraisals of threat, and hence anxiety, are the product of perceptions of the likelihood of a threatening event and perceptions of how bad the consequences of the event would be; the reaction is further modified by beliefs about how the individual feels that they would be able to cope if the danger materialised and whether there are external factors such as medical treatment which could “rescue” the person from the danger. Thus the first prediction examined in this chapter is the degree of anxiety about one’s bone density after screening will be associated with the nature of these beliefs about osteoporosis.

Predicting longer-term distress after bone density screening

The cognitive-behavioural model of health anxiety (e.g. Warwick and Salkovskis, 1990) predicts that certain pre-existing beliefs about health and illness increase the likelihood of negative interpretations of a result and therefore increase the likelihood of high levels of distress after health screening; furthermore, certain behavioural and cognitive responses are likely to help to maintain anxiety. These predictions will be evaluated and there will be an examination of the relative contributions of general illness beliefs or behaviours and specific beliefs concerning osteoporosis.

Clinical considerations

Long-term distress: In clinical terms, the value of being able to predict at an early stage which women are

likely to be vulnerable to adverse psychological reactions after health screening, is the prospect of being able to intervene to prevent or minimize long-term distress. However, in some health screening situations it may not be possible to get patients to complete questionnaires before attending, or to complete lengthy questionnaires. Thus the extent to which brief “on-the-day” measures can predict persistent distress will be examined. Analyses will also be performed to examine whether more detailed pre-scan measures can make a significant contribution to the prediction of persistent distress, if they are used in addition to the “on-the-day” measures.

Reassurance or information-seeking: It was expected that women who were more anxious about their health would be more likely to seek further medical consultations after a bone scan. However, the CB model would also predict that people who have a relatively enduring tendency to react to health anxiety with reassurance-seeking will be particularly likely to seek further advice or information after a bone scan. Thus there will be an examination of whether advice or information-seeking behaviours after a bone density scan are associated with reassurance-seeking over the past 6 months prior to the scan.

Depression and trait anxiety as predictors of reactions to bone density screening

The cognitive model of health anxiety predicts that beliefs and behaviours concerning health threats will be more important predictors of reactions to bone density screening than less focused measures of depression levels or trait anxiety. This prediction will be examined using stepwise multiple regression analyses.

Other variables which may affect long-term distress after bone density screening

Other factors which may influence whether women experience persistent distress or seek further medical consultations include a family history of osteoporosis, symptoms which may be related to osteoporosis and the belief that one has a medical condition (other than osteoporosis) which may be affecting one’s bone density. Such factors may be frequent reminders about osteoporosis and hence act as triggers for anxiety or reassurance/information-seeking. Factors such as a family history may also make the problem seem less abstract, less controllable, and so on. Therefore, these types of factors have been included in some of the multiple regression analyses reported in this chapter.

9.2 Method and treatment of the data

Statistical analyses

Stepwise multiple regression analyses have been performed using questionnaire measures from women

having their first bone density scan. A variable was entered if the significance level of it's F was less than 0.05 and was removed if the significance level of F was greater than 0.1.

In order to test the assumptions of multiple regression analysis, standardised residuals were plotted against standardised predicted values for each analysis. In a few cases, assumptions of normality seemed to have been violated (where the dependent variables were anxiety and worry about osteoporosis after the scan, change in levels of anxiety and worry about osteoporosis and attempts to forget the result or distract oneself from it). In these cases, the dependent variable was transformed using the Blom method in SPSS to approximate the normal distribution; after this, the residuals plot did not indicate a violation of the normality assumption. In another case it appeared that there might be some outliers, but inspection of Cook's distances indicated that there were no points with undue influence on the regression. In order to test for collinearity, variance inflation factors were examined: in no cases were they large enough to indicate a problem with collinearity.

Beliefs about treatment

Beliefs about possible treatments for osteoporosis were not assessed in the same way as other beliefs derived from the cognitive model, since at the time of designing the questionnaires there was no treatment which could be said to "cure" the condition; it was anticipated that the women would learn this fact when undergoing the study. However, some women wrote that osteoporosis could not be cured in response to open-ended questions about their knowledge before the scan. In some analyses a dichotomous variable, based on whether or not the woman wrote that osteoporosis could not be cured, was used as an independent variable.

9.3 Testing a basic cognitive model of anxiety

In order to test the cognitive model of anxiety, stepwise multiple regression analysis was used to examine the extent to which beliefs about osteoporosis derived from the model (i.e. perceived risk, cost and coping ability) were associated with anxiety and worry about osteoporosis (see table 9.1). This was done for the 3 month follow-up, because at this stage the women have had time to assimilate the bone scan information and their perceptions may be more stable. The correlations between independent variables are shown in table 9.2 to aid interpretation of the results. (Beliefs about "rescue" factors such as treatment were not assessed at the three month follow-up so could not be included in this analysis).

Results: As predicted, beliefs about one’s risk for developing osteoporosis, one’s ability to cope if one had osteoporosis /low bone density and the “seriousness” of osteoporosis / low bone density beliefs were all associated with anxiety about osteoporosis. In all cases, the more negative the belief, the greater the anxiety. The result itself entered the regression after beliefs about risk and coping.

Table 9.1 Results of stepwise multiple regression analysis performed to examine whether anxiety/worry about osteoporosis 3 months after a bone scan was associated with beliefs about risk, “cost”, coping ability assessed at the same point in time.

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F value
Risk perceptions (composite)	0.551	0.572	0.572	0.571	F _(1,333) = 445.2****
Coping beliefs (composite)	0.175	0.629	0.057	0.627	F _(2,332) = 281.9****
Result of bone scan	0.118	0.637	0.008	0.634	F _(3,331) =193.8****
“Cost” beliefs (composite)	0.165	0.646	0.009	0.642	F _(4,330) =150.8****

****p<0.00005

Table 9.2 Correlations between anxiety/worry about osteoporosis and beliefs derived from the cognitive model of anxiety, 3 months after the bone scan.

	Anxiety about osteoporosis	Risk beliefs	Cost beliefs	Coping beliefs
Risk beliefs	0.77	-	-	-
“Cost” beliefs	0.57	0.46	-	-
Coping beliefs	0.57	0.47	0.80	-

In all cases, high ratings were more negative, i.e. indicated more anxiety, higher risk perceptions and more negative beliefs about one’s ability to cope or the “cost” of osteoporosis.
n=308 and p<0.0005 for all correlations.

9.4 Predicting pre-scan risk perceptions: comparing relative contributions of perceptions of certain risk factors for osteoporosis and general health anxiety tendencies (See table 9.3)

A stepwise multiple regression analysis was used to examine the extent to which pre-scan risk perceptions could be accounted for by the following pre-scan measures: beliefs that one has certain risk factors for osteoporosis, tendency to worry about one’s health (Health Anxiety Questionnaire score), having a current medical condition, depression and trait anxiety.

Results: Higher pre-scan risk perceptions were associated with reports of a family history of osteoporosis, having a medical condition (other than osteoporosis) which may affect bone density, HAQ score (main

section) and reporting pain as a possible symptom of osteoporosis.

The following variables failed to enter: having a current medical condition for which one is receiving treatment, reporting symptoms of osteoporosis other than pain, the Beck Depression Inventory (BDI) and the Spielberger trait anxiety inventory (STAI-trait).

Table 9.3 Results of a stepwise multiple regression analysis to examine the relative contributions of risk factors for osteoporosis and general health anxiety in the prediction of pre-scan risk perceptions.

Independent variables (measures taken before scan)	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Family history of osteoporosis	0.284	0.091	0.091	0.089	F _(1,373) =37.5****
Another medical condition which may affect bone density	0.202	0.152	0.060	0.147	F _(2,372) =33.3****
Symptoms of health anxiety in past 6 months (HAQ)	0.159	0.175	0.023	0.168	F _(3,371) =26.2****
Reporting pain as a possible symptom of osteoporosis	0.129	0.191	0.016	0.182	F _(4,370) =21.9****
Pre-scan measures which did not enter after the above variables: having a current medical condition for which one is receiving treatment, reporting fractures or symptoms of osteoporosis (other than pain), BDI, STAI-trait..					

****p<0.00005

9.5 Investigation of the relative contribution of pre-scan beliefs and the scan result in predicting anxiety about osteoporosis at 3 month follow-up (See table 9.4)

Stepwise multiple regression analysis was used to examine the extent to which pre-scan beliefs or behavioural tendencies, and the scan result, were associated with anxiety and worry about osteoporosis 3 months after the bone scan. Other factors which might be expected to influence persistent anxiety, such as a family history of osteoporosis or symptoms of low bone density, were also included.

Results: Greater anxiety was associated with more negative beliefs about the seriousness and consequences of low bone density/osteoporosis, a lower scan result, more negative beliefs about one’s risk for osteoporosis, more negative beliefs about how well one would cope if one had low bone density or osteoporosis, more negative treatment beliefs (stating that osteoporosis can’t be cured) and a higher score on the main scale and the Avoidance scale of the HAQ.

The following pre-scan variables did not enter: a family history of osteoporosis, prevention beliefs, the BDI, the STAI-trait, symptoms which may be due to low bone density, the number of possible

osteoporosis- treatment measures mentioned, the Cost and the Reassurance scale of the HAQ and having another medical condition which may affect bone density.

Table 9.4 Results of a stepwise multiple regression analysis predicting anxiety about osteoporosis at the 3 month follow-up from pre-scan beliefs and the scan result.

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F Sig. of F
Seriousness/cost beliefs (composite)	0.213	0.184	0.184	0.181	F _(1,295) =66.4****
Result of bone scan	0.288	0.282	0.099	0.278	F _(2,294) =58.0****
Risk beliefs (composite)	0.218	0.343	0.060	0.336	F _(3,293) =51.0****
Coping beliefs (composite)	0.136	0.364	0.021	0.356	F _(4,292) =41.8****
Stating that it's not possible to cure low bone density	0.145	0.385	0.020	0.373	F _(5,291) =36.4****
HAQ- main section	0.122	0.399	0.015	0.387	F _(6,290) =32.1****
Avoidance scale of the HAQ	0.100	0.409	0.009	0.394	F _(7,289) =28.5****
Pre-scan measures which did not enter after the above variables: family history of osteoporosis, prevention beliefs, BDI, STAI-trait, symptom(s) reported before the scan, number of possible osteoporosis- treatment measures reported prior to scan, Cost section of the HAQ, Reassurance scale of the HAQ, having another medical condition which may affect bone density.					

****p<0.00005

9.6 Predicting change in anxiety about osteoporosis between the initial assessment and the three-month follow-up (See table 9.5)

Stepwise multiple regression analysis was used to examine the extent to which change in anxiety about bone density and worry about osteoporosis (between the initial ratings and the 3 month follow-up) could be accounted for by initial beliefs about osteoporosis derived from the cognitive model, general health anxiety over the past 6 months, the BDI, STAI-trait and the result of the bone scan, having a family history of osteoporosis, believing that one has a medical condition which may affect one's bone density and reporting symptoms of osteoporosis.

Results: A larger decrease in anxiety about bone density was associated with higher perceived risk before the scan, a higher scan result, lower perceived likelihood of developing a serious illness other than osteoporosis in the near future. Believing that one has a medical condition that might affect one's bone

density was associated with a smaller decrease in anxiety.

The following pre-scan variables did not enter: coping, prevention and “cost” beliefs about osteoporosis, HAQ- main section, HAQ-cost section, Reassurance scale of HAQ, Avoidance scale of HAQ, BDI, STAI-trait, reporting symptoms of osteoporosis or a family history of osteoporosis.

Table 9.5 Results of a stepwise multiple regression analysis examining predictors of the change in anxiety between initial assessment and 3-month follow-up.

Independent variables ^a	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Risk beliefs (composite)	-0.630	0.263	0.263	0.261	F _(1,297) =106.1****
Result of bone scan	0.293	0.346	0.083	0.342	F _(2,296) =78.4****
Perceived likelihood of developing a serious illness other than osteoporosis in near future	0.132	0.359	0.013	0.353	F _(3,295) =55.2****
Belief that one has a medical condition which may affect bone density	0.121	0.372	0.013	0.364	F _(4,294) =43.6****
Pre-scan measures which did not enter after the above variables: coping, prevention and “cost” beliefs, HAQ, HAQ-cost section, Reassurance scale of HAQ, Avoidance scale of HAQ, BDI, STAI-trait, reporting symptoms of osteoporosis, family history of osteoporosis.					

^aPsychological predictors were assessed before the scan. ****p<0.00005

9.7 Predicting change in perceived likelihood of developing osteoporosis (in the near future) between the initial assessment and the three- month follow-up (See table 9.6)

Stepwise multiple regression analysis was used to examine the extent to which change in the perceived likelihood of developing osteoporosis in the near future (between the initial ratings and the 3 month follow-up) could be accounted for by initial beliefs about osteoporosis derived from the cognitive model, general health anxiety over the past 6 months, the result of the bone scan, the BDI, STAI-trait, having a family history of osteoporosis, believing that one has a medical condition which may affect one’s bone density and reporting symptoms of osteoporosis.

Results: A greater decrease in likelihood perceptions was associated with having higher risk perceptions before the scan, a higher scan result, the score on the main section or the Cost section of the HAQ and stating that osteoporosis can’t be cured.

The following pre-scan variables did not enter: coping, prevention and “cost” beliefs, beliefs about how

many different ways osteoporosis can be treated, Reassurance scale of HAQ, Avoidance scale of HAQ, BDI, STAI-trait, reporting symptoms of osteoporosis, family history of osteoporosis.

Table 9.6 Results of a stepwise multiple regression analysis examining factors associated with the change in ratings of the likelihood of developing osteoporosis (in the near future), between initial assessment and 3-month follow-up.

Independent variables ^a	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Risk beliefs (composite of three beliefs before the scan)	-0.595	0.254	0.254	0.252	F _(1,298) =101.5****
Result of bone scan	0.317	0.347	0.093	0.343	F _(2,297) =78.9****
Cost scale of the HAQ	0.126	0.374	0.027	0.368	F _(3,296) =55.2****
Stating that osteoporosis can't be cured	0.101	0.383	0.009	0.375	F _(4,295) =45.8****
HAQ- main section	0.100	0.392	0.008	0.381	F _(4,294) =37.9****
Pre-scan measures which did not enter after the above variables: coping, prevention and "cost" beliefs, beliefs about how many different ways osteoporosis can be treated, Reassurance scale of HAQ, Avoidance scale of HAQ, BDI, STAI-trait, reporting symptoms of osteoporosis, family history of osteoporosis.					

^aPsychological predictors were assessed before the scan. ****p<0.00005

9.8 Prediction of change in beliefs about the seriousness of below-average bone density (See table 9.7)

In previous chapters it was shown that the group of women receiving a low bone density result demonstrated a decrease in ratings of perceived seriousness of below-average bone density between the initial and 3 month follow-up. There were indications that women who tended to worry about their health were less likely to show this decrease in seriousness ratings. Here, stepwise multiple regression analysis is used to examine whether pre-scan variables about osteoporosis derived from the cognitive model and the scan result were associated with the extent of change in seriousness ratings in the women who received below-average results. Several other variables were included because they might be expected to affect seriousness ratings: symptoms of osteoporosis reported before the scan, a family history of osteoporosis and the belief that one has a medical condition which may affect bone density.

Results: Greater reduction in seriousness ratings was associated with more negative ratings of the consequences or seriousness of low bone density/osteoporosis before the scan, more positive ratings of how well one would cope if one found that had low bone density or osteoporosis, the result of the scan, a lower

score on the subscale of the HAQ which had questions about one's psychological reaction to unexplained bodily sensations or symptoms (e.g. tendency to worry such symptoms/sensations, think that they are a sign of illness, feel a need to know what they mean and difficulty in thinking of other things), stating that osteoporosis can't be cured and the Avoidance scale of the HAQ.

The following variables did not enter: symptoms of osteoporosis reported before the scan, family history of osteoporosis, risk beliefs, Reassurance scale of HAQ, Cost section of HAQ, beliefs that one has a medical condition which may affect bone density and the following subscales or items from the HAQ: preoccupation with thoughts of illness, behavioural responses to bodily sensations/symptoms or fear of serious illness, perceived vulnerability to serious illness, beliefs that one has serious illness, a tendency for worries to return after initial reassurance when one has seen a doctor.

Table 9.7 Results of a stepwise multiple regression analysis examining pre-scan predictors of changes in ratings of the seriousness of below-average bone density, in women receiving a below-average bone density result.

Independent variables ^a	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Cost/seriousness beliefs (composite)	-0.475	0.082	0.082	0.079	F _(1,275) =24.7****
Coping beliefs (composite)	0.248	0.140	0.057	0.133	F _(2,274) =22.2****
Result of bone scan	-0.233	0.197	0.057	0.188	F _(3,273) =22.3****
Subscale of HAQ: psychological reaction to unexplained bodily sensations/symptoms	0.171	0.223	0.026	0.212	F _(4,272) =19.5****
Stating that osteoporosis can't be cured	0.129	0.239	0.016	0.225	F _(5,271) =17.0****
Avoidance of illness-related situations before the scan	0.122	0.253	0.014	0.236	F _(6,270) =8.2***
Pre-scan measures which failed to enter after the above: prevention beliefs, symptoms of osteoporosis reported before the scan, family history of osteoporosis, risk beliefs, Reassurance scale of HAQ, Cost section of HAQ, belief that one has a medical condition which may affect bone density, the following subscales of the HAQ: preoccupation with thoughts of illness, behavioural responses to bodily sensations/symptoms, fear of serious illness, perceived vulnerability to serious illness, belief that one has a serious illness, tendency for worries to return after initial reassurance when one has seen a doctor.					

^aPsychological predictors were assessed before the scan. ****p<0.00005

9.9 Prediction of attempts to forget or distract oneself from the result (See table 9.8)

Stepwise multiple regression analysis was used to examine the extent to which attempts to forget about the result or distract oneself from thinking about it could be accounted for by the result of the bone scan and certain measures taken before the scan: symptoms of general health anxiety in the previous 6 months (the

HAQ score), the Avoidance scale of the HAQ, anxiety about osteoporosis before the scan, frequency of thoughts about osteoporosis before the scan, symptoms of osteoporosis, believing that one has a medical condition which may affect bone density, a family history of osteoporosis, a current medical condition for which one is receiving treatment, the BDI and the STAI-trait.

Results: Attempts to forget about the result or distract oneself from thinking about it were associated with a low bone scan result, believing that one has a medical condition which may affect bone density, symptoms of health anxiety in the 6 months prior to the scan and the frequency of thoughts about osteoporosis prior to the scan. The rest of the variables described above did not enter.

Table 9.8 Results of a stepwise multiple regression analysis concerning the prediction of attempts to forget about the result or distract oneself from thinking about it.

Independent variables ^a	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Result of bone scan	0.288	0.101	0.101	0.098	F _(1,294) =33.1****
Another medical condition which may affect bone density	0.146	0.133	0.032	0.127	F _(2,293) =22.5****
HAQ- score of main section	0.125	0.155	0.021	0.146	F _(3,292) =17.8****
Frequency of thoughts of osteoporosis in past week (assessed prior to scan)	0.120	0.168	0.014	0.157	F _(4,291) =14.7****
Pre-scan measures which did not enter after the above variables: BDI, STAI-trait, anxiety and worry about osteoporosis prior to the scan, current medical condition, family history of osteoporosis, symptoms of osteoporosis, Avoidance scale of HAQ, cost scale of HAQ.					

^apsychological measures were taken before the scan ****p<0.00005

9.10.1 Examination of the extent to which anxiety/worry at week follow-up was associated with forgetting and distraction attempts over the previous week (See table 9.9)

A stepwise multiple regression analysis was performed in order to test the prediction (derived from the cognitive-behavioural model of health anxiety) that attempts to forget or distract oneself from thinking about the result would be associated with anxiety and worry about osteoporosis, a week after the bone scan.

It was found that attempts to distract oneself did significantly predict anxiety but attempts to forget about the result did not enter.

Table 9.9 Results of a stepwise multiple regression analysis examining the extent to which forgetting and distraction attempts reported at the week follow-up were associated with anxiety and worry reported at the same point in time.

Independent variables	Beta	R ²	Adjusted R ²	F
Number of attempts to distract oneself from thinking about result	0.408	0.167	0.165	F _(1,465) =93.1. p<0.00005
Attempts to forget about the result did not enter after this.				

9.10.2 Predicting anxiety/worry at 3 month follow-up from forgetting and distraction attempts reported the week follow-up (See table 9.10)

A stepwise multiple regression analysis was performed in order to test the prediction (derived from the cognitive-behavioural model of health anxiety) that attempts to forget or distract oneself from thinking about the result a week after the scan would be associated with anxiety and worry about osteoporosis at the 3 month follow-up. It was found that attempts to distract oneself were significantly associated with anxiety but attempts to forget about the result did not enter.

Table 9.10 Results of a stepwise multiple regression analysis examining the extent to which forgetting and distraction attempts reported at the week follow-up predict anxiety and worry reported at the three month follow-up.

Independent variables	Beta	R ²	Adjusted R ²	F
Attempts to distract oneself from thinking about result	0.263	0.069	0.066	F _(1,294) =21.8****
Attempts to forget about the result did not enter after this.				

Clinically-relevant analyses

9.11 Predicting distress about osteoporosis at the 3 month follow-up from on-the-day ratings (See table 9.11)

In a health-screening situation it may not be possible to get patients to complete questionnaires before the day of the scan or to complete lengthy questionnaires. Thus it is important to investigate the extent to which brief on-the-day measures can predict longer-term distress. A stepwise multiple regression analysis was used to examine the relative contribution of on-the-day measures and the result of the bone scan in the prediction of distress 3 months after a bone scan. The longer-term distress measure was a composite of measures of anxiety about bone density, worry about osteoporosis and need for reassurance 3 months after a bone scan.

Results: Need for reassurance immediately after the scan, perceived likelihood of developing osteoporosis at any point in the future (after the scan), need for reassurance before the scan and anxiety about bone density immediately after the scan were associated with distress at the three month follow-up. The following variables did not enter: the result of the bone scan, perceived likelihood of developing osteoporosis in the near future (before or after the scan), perceived likelihood of developing osteoporosis at any point in the future (before scan), anxiety about osteoporosis before the scan, perceived seriousness of below-average bone density (before or after the scan), feeling sad/low (before or after the scan).

Table 9.11 Results of a stepwise multiple regression analysis examining the extent to which measures taken on the day of the scan are predictive of distress concerning osteoporosis 3 months later.

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Need for reassurance immediately after scan	0.236	0.386	0.386	0.384	F _(1,310) =194.8****
Perceived likelihood of developing osteoporosis at any point in the future (after scan)	0.224	0.453	0.067	0.449	F _(2,309) =127.9****
Need for reassurance before scan	0.229	0.481	0.028	0.476	F _(3,308) =95.2****
Anxiety about bone density immediately after scan	0.207	0.500	0.019	0.494	F _(4,307) =76.8****
Variables which did not enter after the above: result of bone scan, perceived likelihood of developing osteoporosis in the near future (either before or after scan), perceived likelihood of developing osteoporosis at any point in the future anxiety (before scan) anxiety about osteoporosis before the scan, perceived seriousness of below-average bone density (either before or after the scan), feeling sad/low (before or after scan).					

****p<0.00005

9.12 Predicting distress about osteoporosis 3 months after the bone scan using measures from the initial questionnaire and from the day of the scan (See table 9.12)

A stepwise multiple regression analysis was performed to examine whether measures taken at the initial assessment (about two weeks before the scan) could help account for distress about osteoporosis at the 3 month follow-up, in addition to the on-the-day variables identified as important in the previous analysis. In addition to measures of health anxiety (the scales of the HAQ) or beliefs derived from the cognitive-behavioural model (risk, cost, prevention, coping and treatment beliefs), the other measures were included because of their potential effect on distress after a bone scan, such as a family history of osteoporosis or symptoms which may related to low bone density.

Results: Only the following variables were associated with distress concerning osteoporosis 3 months after the scan: need for reassurance about one's bone density after the scan, perceived likelihood of developing osteoporosis (at any point in the future) after the scan results, anticipated ability to cope if one found that one had low bone density or osteoporosis (before the scan), anxiety about bone density after the scan, stating that one can't increase low bone density once it is established (before the scan) and need for reassurance immediately before the scan.

The following pre-scan variables did not enter: result of the bone scan, HAQ-main section or Cost section, Reassurance scale of HAQ, Avoidance scale of HAQ, "cost" beliefs about osteoporosis, risk beliefs about osteoporosis, prevention beliefs, total number of prevention or treatment measures mentioned, having a medical condition which may affect bone density, menopausal status, reporting symptoms of osteoporosis, family history of osteoporosis, the BDI and the STAI-trait.

Table 9.12 Results of a stepwise multiple regression analysis examining predictors of distress about osteoporosis 3 months after a bone scan using measures taken 2 weeks before scan and on the day of the scan

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Need for reassurance immediately after scan results	0.193	0.406	0.406	0.404	F _(1,266) =181.7****
Perceived likelihood of developing osteoporosis at any point in the future (after scan)	0.213	0.472	0.066	0.468	F _(2,265) =118.5****
Anticipated coping ability if one had low bone density or osteoporosis (before scan)	0.206	0.521	0.049	0.515	F _(3,264) =95.6****
Anxiety about bone density after scan	0.235	0.537	0.016	0.530	F _(4,263) =76.3****
Stating that you can't increase low bone density (before scan)	0.133	0.556	0.019	0.548	F _(5,262) =65.7****
Need for reassurance immediately before scan	0.163	0.572	0.016	0.562	F _(6,261) =58.1****
Variables which did not enter after the above: result of bone scan HAQ-main section, HAQ-cost section, Reassurance scale of HAQ, Avoidance scale of HAQ, menopausal status, "cost" beliefs about osteoporosis, risk beliefs about osteoporosis, prevention beliefs, total number of prevention or treatment measures known about before the scan, having a medical condition which may affect bone density, reporting symptoms of ost.before scan, family history of ost., BDI, STAI-trait.					

****p<0.00005

9.13 Predicting reassurance/ information-seeking in the three months following a bone scan from on-the-day ratings (See table 9.13)

A stepwise multiple regression analysis was performed in order to examine the extent to which measures taken on the day of the scan can account for reassurance- or information-seeking in the 3 months following the bone scan.

Results: The following were associated with reassurance- or information-seeking: anxiety about osteoporosis after the scan, need for reassurance immediately before the scan and perceived likelihood of developing osteoporosis at any point in the future (assessed after the scan). The following variables did not enter: the result of bone scan, general anxiety or low mood (before or after scan), perceived seriousness of below-average bone density (before or after scan), perceived likelihood of developing osteoporosis in the near future (before or after the scan), perceived likelihood of developing osteoporosis at any point in the future (before the scan) and need for reassurance after the scan.

Table 9.13 Results of a stepwise multiple regression analysis examining the extent to which reassurance/information-seeking in the 3 months following the scan can be predicted by ratings of feelings and beliefs on the day of the scan.

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Anxiety about osteoporosis immediately <u>after</u> scan	0.229	0.156	0.155	0.153	F _(1,304) =56.0****
Need for reassurance immediately <u>before</u> scan	0.178	0.191	0.036	0.186	F _(2,303) =35.8****
Perceived likelihood of developing osteoporosis at any point in the future, after scan	0.160	0.204	0.013	0.197	F _(3,302) =25.9****
Variables which did not enter the above: result of bone scan, general anxiety or low mood (before or after scan), perceived seriousness of below-average bone density (before or after scan), perceived likelihood of developing osteoporosis in the near future (before or after scan), perceived likelihood of developing osteoporosis at any point in the future (before the scan), need for reassurance after the scan.					

9.14 Predicting reassurance/ information seeking from measures taken at the initial assessment and on the day of the scan (See table 9.14)

A stepwise multiple regression analysis was performed to examine whether measures taken at the initial assessment (about two weeks before the scan) could help account for reassurance- and information-seeking

in the 3 months after the bone scan, in addition to the on-the-day variables identified as predictors in the previous analysis.

Results: The following variables were significant predictors of reassurance or information seeking: anxiety about bone density after the scan, reporting preventative behaviours before the scan, the Reassurance scale of the HAQ, need for reassurance immediately before the scan, perceived likelihood of developing osteoporosis at any point in the future (after the scan) and perceived likelihood of developing a serious illness other than osteoporosis (before the scan).

The following variables did not enter: result of the bone scan, HAQ-main section, HAQ-cost section, Avoidance scale of HAQ, coping beliefs, “cost” and risk beliefs, knowledge of treatment/preventative measures/causes of osteoporosis, BDI, STAI-trait, menopausal status, family history of osteoporosis and symptoms of osteoporosis.

Table 9.14 Results of a stepwise multiple regression analysis examining the extent to which reassurance/information-seeking can be predicted from measures used at the initial assessment and on the day of the scan

Independent variables	Beta	Cumulative R ²	Change in R ²	Cumulative adjusted R ²	F
Anxiety about bone density after scan	0.239	0.176	0.176	0.173	F _(1,261) =55.7****
Whether or not the woman reports osteoporosis-preventative behaviour before scan	0.191	0.223	0.047	0.217	F _(1,260) =37.2****
Reassurance scale of HAQ	0.173	0.258	0.035	0.249	F _(3,259) =30.0****
Need for reassurance immediately before the scan	0.147	0.274	0.017	0.263	F _(4,258) =24.4****
Perceived likelihood of developing osteoporosis at any point in the future (immediately after the scan results)	0.181	0.286	0.012	0.272	F _(5,257) =20.6****
Perceived likelihood of developing a serious illness (other than ost) in the near future	-0.116	0.297	0.011	0.280	F _(6,256) =18.0****
Variables which did not enter after the above: result of bone scan, HAQ-main section, HAQ-cost section, Avoidance scale of HAQ, anxiety, worry or need for reassurance reported in the initial questionnaire, cost or coping or risk beliefs, knowledge of treatment/preventative measures/causes of osteoporosis, BDI, STAI-trait, menopausal status, family history of osteoporosis, symptoms of osteoporosis.					

In order to explore possible reasons why the presence of osteoporosis-preventative behaviour(s) before the scan was significantly associated with reassurance/information-seeking afterwards, t-tests were performed on ratings of feelings about osteoporosis before the scan. These indicated that women who reported

preventative behaviours before the scan felt more anxious about their bone density ($t_{(412)}=-3.0$, $p<0.005$), more in need of reassurance about their bone density ($t_{(409)}=-3.0$, $p<0.005$), had higher ratings of the likelihood of developing osteoporosis ($t_{(412)}=-3.0$, $p<0.005$) and the seriousness of below-average bone density ($t_{(401)}=-2.1$, $p<0.05$) but were not significantly different in their ratings of the likelihood of preventing symptoms of osteoporosis if one has low bone density ($t_{(401)}=0.2$) than women who did not report preventative behaviours before the scan.

9.15 Discussion

Summary of results

As predicted, pre-existing beliefs were associated with psychological and behavioural reactions to bone density screening. The actual result of the bone scan entered first in only one of the analyses in which it was used as an independent variable alongside psychological ones, and in analyses which used on-the-day psychological measures, it failed to enter. Both specific pre-scan illness beliefs (i.e. about osteoporosis) and general pre-scan health beliefs and symptoms of health anxiety were associated with reactions at the 3 month follow-up. Pre-scan levels of depression and trait anxiety did not enter the regression equation in any of the multiple regression analyses.

Results regarding the basic cognitive model of perception of threat

As predicted by the cognitive model of anxiety used in this research, beliefs about one's likelihood of developing osteoporosis, ability to cope if one found that one had low bone density and the "cost" of osteoporosis / low bone density were associated with anxiety about bone density assessed at the same point in time (three months after the bone scan). "Cost" beliefs accounted for only a small amount of variance after the other variables but this is not surprising since they had a moderately high correlation with risk and coping beliefs which entered earlier in the analysis.

Treatment beliefs were not examined at the three month follow-up and thus could not be used in this regression analysis. It was expected that the women would have learned that it was impossible to "cure" osteoporosis, while undergoing the screening. However, since there is now increasing evidence that certain drugs are able to increase bone density, future studies could include questions about treatment beliefs.

Pre-scan risk perceptions

As expected, women who reported that they have a family history of osteoporosis or a medical condition which might be affecting their bone density, had higher pre-scan risk perceptions. This is consistent with previous research into risk perceptions for heart disease which has found that people do seem to use risk factor information, at least to some degree, when estimating overall risk (e.g. Marteau, Kinmouth, Pyke and Thompson, 1995; Avis, Smith and McKinley, 1989). Women who reported that they had pains which could be due to low bone density also had higher risk perceptions before the scan.

Higher scores on a questionnaire assessing symptoms of general health anxiety over the previous 6 months were associated with higher pre-scan risk perceptions, although scores on a measure of trait anxiety were not. This is consistent with the idea that risk perceptions regarding osteoporosis will be associated more strongly with levels of general health anxiety than with trait anxiety.

Prediction of anxiety about osteoporosis at the 3 month follow-up using pre-scan variables

Beliefs about the “cost” or seriousness of low bone density/osteoporosis before the scan entered the regression equation for anxiety about osteoporosis at the 3 month follow-up before the actual result of the bone scan. This is consistent with the prediction from the cognitive model of health anxiety that reactions to health screening will be moderated by pre-existing beliefs about illness. Furthermore, pre-scan risk perceptions were associated with anxiety after the result itself had entered, which indicates that beliefs about one’s risk after a bone scan are not simply a direct function of the actual result - pre-existing beliefs about one’s risk are still important.

Further data consistent with the cognitive model came from the finding that pre-scan perceptions of how one would cope if one found that one had low bone density / osteoporosis were associated with longer-term distress, as were treatment beliefs (i.e. stating before the scan that osteoporosis could not be cured). A tendency to avoid illness-related situations before the scan was also related to anxiety about osteoporosis at the 3 month follow-up. It is possible that women who tend to use avoidance as a coping strategy may have been less likely to find out about or begin preventative measures, or find out other more positive interpretations of their result: hence they will not have their fears disconfirmed. However, since these types of avoidance were not assessed after the scan this possibility cannot be examined here.

In summary, the findings are consistent with the cognitive model of anxiety: pre-existing beliefs about risk, cost, coping and “rescue” (treatment) factors were all associated with anxiety about osteoporosis at the 3 month follow-up, as was a pre-existing tendency to use the coping strategy of avoidance.

Prediction of the change in anxiety about osteoporosis

Pre-scan risk beliefs were associated with change in anxiety after screening- those with higher pre-scan beliefs showed greater reductions in anxiety. This indicates that for some of those who had felt particularly at risk beforehand, the scan result seems to provide reassurance. Prior risk beliefs entered the regression equation before the actual scan results, which is consistent with the hypothesis that prior beliefs about osteoporosis will play a key role in determining reactions to bone density screening. More general illness beliefs also seemed to be important- those with high ratings of perceived likelihood of developing a serious illness other than osteoporosis in the near future showed a smaller reduction / larger increase in anxiety. In addition, women who felt that they had a medical condition which may affect bone density showed a smaller decrease in anxiety; they may have felt that if their condition is currently affecting their bone density, then a good result now does not necessarily indicate a good level of bone density in the future .

Prediction of changes in perceptions of the likelihood of osteoporosis in the near future

People with higher risk perceptions before the scan showed a larger decrease in their ratings of the likelihood of developing osteoporosis in the near future. This may partly reflect the fact that most people received an average or above-average result, so many people with high pre-scan risk perceptions will believe that is appropriate to reduce their risk perceptions. The scan result itself was also associated with change in risk perceptions, as would be expected. People with higher levels of health anxiety over the past six months show a smaller decrease in their likelihood ratings. According to the cognitive-behavioural model, this may be because these people have certain dysfunctional assumptions about health and illness (e.g. "I'm generally vulnerable to illness" or "it's better to regard oneself as being at risk because otherwise one may become complacent") which will affect the way that new risk information is interpreted. People with more negative "cost" beliefs and people who stated that osteoporosis can't be cured also show a smaller decrease (or larger increase) in their risk perception. This may be because these types of negative beliefs are likely to cause higher levels of anxiety about their bone density both before and after the scan. Higher levels of anxiety can make aversive situations appear more likely to occur (Butler and Mathews, 1983) hence acting against a minimization of one's risk for osteoporosis. Furthermore, high levels of anxiety may trigger certain coping responses (such as attempts to forget the result) that may prevent the woman from cognitively restructuring the situation or focusing on reasons why she is not at high risk; this kind of process may be necessary if one is to reduce one's likelihood perceptions after a low result.

Prediction of the extent of minimization of the seriousness of below-average bone density

This may be the first study to find factors associated with individual differences in the degree of minimization of seriousness. Croyle, Sun and Louie (1993) found that the degree of minimization is not significantly related to pre-screening measures of self-esteem, repressive coping style or monitoring / blunting coping style.

In the present study, people who before the scan had higher cost/seriousness beliefs tended to show a decrease in ratings of the seriousness of below-average bone density after the scan. This could be due to information gained while having the scan- for example, the graph and explanation provided at the time of the scan may help clarify the point that one can have below-average bone density without being at extremely high risk of fracture, at younger ages at least.

People who received a low scan result also tended to show a decrease in ratings of seriousness of below-average bone density. This may be because many of these people discover that it is possible to have low bone density without having any symptoms. However, the presence or absence of symptoms which might be related to low bone density reported before the scan does not predict changes in ratings of seriousness. An alternative explanation of this decrease in ratings of seriousness in those with a low result is that it is a way of minimizing the health threat and may in fact be an adaptive coping strategy (as discussed in earlier chapters). Consistent with this hypothesis is the finding that people who before the scan thought that they would cope badly if they found that they had low bone density, do not tend to show the minimization effect. Furthermore, people who tended to avoid illness-related situations or stimuli in the 6 months prior to the scan were also less likely to show the minimization effect; one possible explanation for this is that avoidance behaviours may be associated with cognitive avoidance, which would prevent the person cognitively restructuring the situation. Similarly, people who tend to react in an adverse way to ambiguous bodily sensations (e.g. with worry, thoughts that the sensations are signs of illness, wondering what the sensations means and difficulty in thinking of anything else) showed less minimization of the seriousness of low bone density. Reactions to health threats such as worry and heightened attention to the threat may prevent the kind of cognitive restructuring that might be involved in minimization, and these responses are probably the result of maladaptive beliefs about illness which are also likely to be incompatible with a minimization of a health threat.

People who stated before the scan that osteoporosis cannot be cured were less likely to show minimization of the seriousness of below-average bone density. This is consistent with the idea that minimization may be a kind of “motivated reasoning”- that people are constrained in arriving at their

preferred conclusions by their ability to construct reasonable justifications for these conclusions: clearly if one believes that it is not possible to reverse a decrease in bone density then it will be less easy to minimize the seriousness of having below-average bone density.

In conclusion, the decrease in seriousness ratings may be partly due to excessively negative ratings before the scan. Since the scan result itself predicted minimization, the results are also consistent with the hypothesis that minimization is a way of coping with a low bone density result. As predicted, people who tend not to cope well with health threats and those who had predicted that they would cope poorly if they were found to have low bone density, show less or no minimization effect.

Prediction of attempts to forget about the result or distract oneself from thinking about it

A low scan result was more strongly associated with attempts to forget about or distract oneself from thinking about the result than any pre-scan measures, which is not surprising, since there would be no obvious reason why someone would try to forget a good result. People who had a medical condition which they think may be affecting their bone density were also more likely to use these strategies; this could be partly because they are more anxious about osteoporosis and/or because the other illness acts as a cue for thoughts of osteoporosis. People who tend to worry about their health show more attempts to use such strategies, which is consistent with cognitive-behavioural theory which suggests that such people are likely to experience greater anxiety and preoccupation with health worries after a health threat and are likely to use such strategies in an attempt to reduce the worrying thoughts (Salkovskis, 1996). Women who reported more thoughts of osteoporosis before the scan were also more likely to try to forget/distract, which may indicate that the scan did not remove preoccupation in all of those who tended to think about osteoporosis before the scan.

Prediction of anxiety about osteoporosis from attempts to forget about the result or distract oneself from it

The cognitive-behavioural model of health anxiety suggests that attempts to forget or distract oneself from the result may act to maintain anxiety. Consistent with this, reports of attempts to distract in the week following the scan were associated with anxiety at the week and 3 month follow-ups. Of course the results are also compatible with the idea that attempts to distract are simply the result of anxiety without actually acting to maintain it. It is not possible to test these possibilities further using the current data set. Attempts to forget did not enter the regression equation, presumably because of the high degree of co-occurrence between the strategies.

Prediction of distress about osteoporosis at the 3 month follow-up using on-the-day ratings

Using ratings taken on the day of the scan it was possible to predict 50% of the variance in distress about osteoporosis 3 months later. However, it should be noted that some of the predictor variables are the same variables used in the composite at 3 months. Although the ratings made after the scan results were clearly more strongly associated with distress at 3 months, need for reassurance about one's bone density immediately before the scan was also associated with longer-term distress, which is consistent with the view that pre-existing concerns and beliefs will mediate reactions to a bone scan.

The finding that only 50% of the variance in longer-term distress is accounted for by on-the-day measures is consistent with predictions from the cognitive-behavioural model of health anxiety. This model would say that immediate reactions to a health threat will not be entirely predictive of longer-term distress for the following reason: most people with a low scan result will feel some immediate distress, but the coping mechanisms they use will determine whether distress is reduced or maintained. Indeed, if one adds in pre-scan measures to the regression analysis one finds that people who before the scan said that they would cope badly if they found that they had low bone density were more distressed at the 3 month follow-up: this may partly reflect a knowledge that one tends to cope badly with health threats.

Stating that bone density can't be cured is another pre-scan variable which is associated with persistent distress if used in addition to the on-the-day ratings. The finding that beliefs about one's ability to cope and the possibility of treatment are associated with longer-term distress is consistent with the cognitive-behavioural model. It is possible that if measures of these beliefs had been used in the questionnaire given on the day of the scan, it would have been possible to account for more variance using only on-the-day measures.

Prediction of reassurance or information-seeking

The finding that only 30% of the variance in reassurance/information-seeking was accounted for by the measures used in this study is likely to be due to the nature of the dependent variable. Unfortunately, because of length limitations in the follow-up questionnaires, the women were not asked about the extent to which reassurance was the goal behind attempts to seek further advice or further information about osteoporosis in the 3 months after the scan; it is likely that some women will have sought further information without feeling in need of reassurance. Measures derived from the cognitive-behavioural model would be expected to be predictors of reassurance-seeking rather than information-seeking in general; this could be examined in future studies.

In terms of on-the-day ratings, anxiety about osteoporosis was the variable which was the most strongly associated with reassurance- or information-seeking in the 3 months after the scan, which indicates that reassurance is likely to have been a goal of some of these behaviours. However, anxiety was not the only predictor- perceived likelihood also entered the regression equation - so it seems that some people with a low result may be seeking further advice without being purely motivated by anxiety felt immediately after the scan. Need for reassurance about one's bone density before the scan was also associated with reassurance/information-seeking afterwards, which is consistent with the idea that pre-existing concerns will partly determine reactions to a bone scan.

As expected, a pre-scan tendency to seek the reassurance about health matters was associated with reassurance/information-seeking about the scan result in the three months after the scan. High pre-scan ratings of the likelihood of developing a serious illness other than osteoporosis in the near future were also associated with greater reassurance/information-seeking, consistent with the idea that a tendency to worry about one's health in general may be a predictor of responses to bone density screening.

Women who were already taking some preventative action were more likely than others to seek information or reassurance after their result. These women were more anxious about their bone density, felt more at risk of developing osteoporosis, felt more in need of reassurance and thought that below-average bone density was more serious than women not performing preventative behaviours; this set of beliefs may play a causal role in reassurance or information-seeking after the scan.

Clinical applications

Given that measures taken before or on the day of the scan were associated with distress 3 months later, it may be possible to use such measures to identify women who are particularly high risk of persistent distress; they could be given some kind of intervention to help prevent long-term distress. This will be discussed in more detail in the next chapter.

Future research

Before firm conclusions can be drawn from the findings presented in this chapter, cross-validation is needed, in which the regression analyses are repeated using a new sample of women undergoing bone density screening. In order to examine whether the CB model is useful as a general model in predicting reactions to health screening, similar regression analyses need to be performed using reactions to a different type of screening, such as predictive genetic testing for multifactorial disease.

Chapter 10: General Discussion

The main aim of the research presented in this thesis was to investigate whether measures derived from a general cognitive-behavioural model of health anxiety could be used to predict reactions to bone density screening. The research was also intended to examine the processes involved in reactions to health screening in more detail than most existing research, by investigating not only distress but also interpretations of the result and changes in different types of illness beliefs.

Summary of results

Women volunteering for bone densitometry felt more at risk for osteoporosis (compared to other women), and more in need of reassurance about their bone density than women attending a GP clinic. They also knew more about osteoporosis and rated the likelihood of being able to prevent symptoms of osteoporosis (if one has low bone density) more highly than women in the GP sample. It is possible that these beliefs and knowledge may have influenced the woman's decision to volunteer for bone density screening, or they may be a result of the impending appointment. Bone densitometry volunteers reported higher levels of health anxiety over the previous 6 months and more reassurance-seeking about their health than people in the general population, but less avoidance of illness-related situations. Levels of depression and trait anxiety were not significantly different in the bone density volunteers than in previously described general population samples.

For the sample of women having their first bone density scan, there was a post-scan decrease in anxiety about osteoporosis and risk perceptions. There was no change in perceptions of the likelihood for developing other serious illness, which indicates that bone density screening appears to have specific effects on people's beliefs about osteoporosis. There were no significant changes in the ratings of anxiety about osteoporosis and risk perceptions in the control group (women seeing their GP), so the changes after bone density screening do not appear to be simply due to contact with a health professional. Women having their second scan also showed a decrease in anxiety and risk perceptions, although their ratings were higher at each point in time than those of women having a first scan.

Between the ratings two weeks before the scan and immediately before the scan, there was generally a decrease in ratings of anxiety and risk perceptions. Women who received a high bone density result then show further decreases in ratings of anxiety and risk perceptions after the scan. The women who received a low result showed increases in these ratings, relative to their ratings immediately before the scan, although there was generally no significant change relative to their ratings two weeks before the scan. Women having

their second scan who believed that they had lost bone between their two scans showed an increase in anxiety, while women who believed that their bone density had increased showed reductions in anxiety. A substantial minority of women having second scans were wrong in their conclusion about whether their density had changed between the two scans. Women having first or second scans were often wrong or uncertain about whether they had osteoporosis.

When the groups of women having their first scan were subdivided further, in terms of pre-existing health anxiety, it was found that people with high and low levels of health anxiety react differently to bone density screening. Before they received a low result, women with high and low ratings of health anxiety were not significantly different in terms of their anxiety about osteoporosis and likelihood of developing osteoporosis in the near future. However, after the scan, women with low levels of health anxiety show reductions in their ratings of anxiety and the likelihood of developing osteoporosis, despite their “bad” result. In contrast, women with higher levels of pre-existing health anxiety showed an immediate increase in anxiety immediately after the scan and at the 3 month follow-up still had higher ratings of anxiety about osteoporosis and risk perceptions than women with lower levels of health anxiety.

Women with low levels of pre-existing health anxiety also showed a decrease in their ratings of how serious it is to have below-average bone density, if they themselves received a low scan result. There was some indication that women with high levels of health anxiety do not show this decrease to the same extent, although the difference was not a strong one. However, when women with extremely high or low levels of pre-existing health anxiety were followed-up for an average of 14 months after the scan, it was clear that the minimization of seriousness after a low result did not occur in the highly health anxious group, although it was sustained in those with low levels of health anxiety. In addition, at the 14 month follow-up the highly health anxious group still had higher ratings of anxiety about their bone density and likelihood of developing osteoporosis than the low health anxiety group, after adjusting for initial levels. It was also found that after a high bone density result the highly health anxious group showed an increase in worry about osteoporosis and need for reassurance between the 3 month and 14 month follow-ups. This indicates that a “good” result from bone density screening does not seem to be reassuring in the longer-term, for women with high levels of pre-existing health anxiety.

Predictions derived from the cognitive-behavioural model of health anxiety were generally supported. For example, pre-scan ratings of specific beliefs about osteoporosis (i.e. vulnerability, “cost”, treatment and coping beliefs) and a general measure of health anxiety were all associated with anxiety about osteoporosis three months after the bone scan. Pre-scan “cost” beliefs were a better predictor of anxiety

about osteoporosis three months after the scan than the actual scan result.

Strengths of the research

This research into the psychological effects of bone densitometry differs from most previous research into the effects of health screening. One of the main differences is that a psychological model was used to guide the research. This model was used to derive hypotheses about pre-scan measures which could be used to predict reactions to screening. It also provided a framework for the choice of outcome measures, which were intended to reflect the specific effects which may occur, rather than global measures of psychiatric diagnoses or “caseness”. (A possible reason why some previous studies failed to find any evidence of distress is that the measures used were too general). The present research had a prospective design which allows pre-existing characteristics of the participants to be taken into account when interpreting reactions to screening. The characteristics of people who didn’t complete all of the questionnaires were also described in order to give an indication of the extent to which the findings from those who did complete all the questionnaires would generalize to others. Furthermore, feelings were assessed at 6 points in time, for up to 14 months after the scan, which allowed a more detailed examination of the change in feelings over time than is reported in many studies. Although only a subgroup of the women were sent the 14 month follow-up questionnaire, this allowed resources to be focused on maximizing compliance to this questionnaire, resulting in a 95% return rate.

Limitations of the research

There are a number of limitations to the research described in this thesis. Firstly, the sample who underwent bone density screening may be biased, since it could be argued that Oxford samples are typically more middle-class and more highly educated than other samples. Furthermore, the way in which the volunteers were recruited (adverts in newspapers and on the radio, word of mouth) may have resulted in a sample which are not representative of women who would undergo screening if different recruitment methods were used. However, it is unlikely that bone density screening will ever be used as a type of total population screening- it is more likely that women will have to request or opt into screening - so the fact that volunteers were used may not unduly limit possible conclusions. The several thousand women screened in Oxford showed higher mean bone densities than the 600 volunteers used for the reference sample in the scanning machine, which meant that more received “above average” results than would have been expected if the two samples were

more similar. This finding means that the overall level of distress identified in the present study is likely to be lower than it would have been if there had not been this disproportionately large number of above-average scan results.

A second problem is that people who took part in the psychological research are probably not representative of all of the women screened. There is limited evidence to support this view - women who returned only the initial questionnaire had higher levels of trait anxiety than women who returned all the questionnaires. In future studies such women could be contacted again, to try to get a higher response rate, which would enable any possible differences to be examined in greater detail. It was also found that volunteers who only completed the brief on-the-day measures were more anxious about osteoporosis before the scan and although their anxiety levels were not significantly different immediately afterwards, it is possible that some of their anxiety will have returned later. If this is the case, the levels of anxiety reported in this study will be an underestimate of the anxiety experienced by the sample as a whole. In future studies it may be a good idea to target this subgroup specifically.

The exclusive use of standardised outcome measures (i.e. with population norms available), would have ensured comparability between this study and studies into the effects of other types of screening. The decision not to do so was partly due to a deliberate focus on changes in specific feelings and beliefs rather than on general psychological morbidity. Once these specific questions had been included, there was little space to include additional standardised outcome measures, for it had been decided that the follow-up measure should be as brief as possible in order to maximize compliance. The present study represents the first stage in the development of specific measures which could be more widely applied.

There is a problem in the interpretation of the pre-scan assessments. Ratings are significantly lower immediately before the scan than two weeks earlier and it possible that neither set of ratings are an entirely appropriate baseline, since they may both be affected by the fact that the subjects are aware that they are soon to have a bone scan. The fact that this was detected in the present study represents a strength of the research - in many other such studies, this discrepancy would not be detected and the validity of the chosen baseline just assumed. A future study could ask subjects to complete psychological questionnaires and then offer them the chance to be screened. This type of method could also be used to compare the reactions of women with high and low levels of health anxiety to the offer of screening and the screening itself: the initial questionnaire could be given to a general population sample, the women with high or low scores on the Health Anxiety Questionnaire could then be asked if they would like to be screened and their immediate and longer-term reactions could be assessed.

Ideally the study would have included a further control group, drawn from the general population, to act as a comparison group for beliefs about osteoporosis. The control group used (GP attenders) may have different beliefs about osteoporosis than women in the general population. Future studies may also consider control groups undergoing a different type of screening rather than a GP consultation.

The assessment of reassurance-seeking could have been improved. Women were asked whether they had sought further help or advice, but were not asked about the extent to which this behaviour was driven by anxiety or the need for reassurance. In future studies there should be a differentiation between different types of advice-seeking. Similarly, the way in which women attempted to forget about the result could have been investigated in more detail - for example, whether they tried to suppress the thought or attempted to convince themselves that the result was not worth worrying about. Beliefs about whether or not the woman believes that she has osteoporosis could be assessed before the scan as well as afterwards. Furthermore, beliefs about treatment were only assessed using open-ended questions and in future studies it may be preferable to use 0 - 100 visual analogue scales.

Ideally the information which the radiographers gave to patients when they handed over their results would have been recorded and compared. This would have been enormously difficult in practical terms and there were not sufficient resources to organise to recording or analysis of the results. It is also possible that the fact that they were being taped would alter how the radiographers communicated the results. There was no evidence that the interpretations differed depending on which radiographer had scanned the woman. However, it is possible that there was something about the more health anxious women which elicited a different type of comment from the radiographer about the result and that this difference was contributing to the greater anxiety shown by these women.

In the present study open-ended questions were used to elicit interpretations because there had been no previous work into the kind of interpretations made after this type of screening. This provided useful qualitative data but in future research, subjects could be presented with various interpretations and asked to indicate how much they agree with them. This would allow a quantitative investigation of the extent of particular misinterpretations.

Comparison between results from the bone density study and previous research

As expected, women who received a low result were more worried about osteoporosis than women who received a high result. This finding is consistent with evidence from a study by Rubin and Cummings (1992), although they did not assess the degree of concern. Their findings that preventative behaviours

increased in both groups after the scan but were more frequent in the low result group is also consistent with the findings of the present study.

Studies into the effects of other types of screening have also often found that high-risk test results are associated with greater distress than low-risk results (e.g. Wardle, Pernet and Stevens, 1995) although it should be noted that some studies have failed to find any evidence of elevated distress in the high-risk group (e.g. Mann, 1981; Moum, Naess, Sorenson, Tambs and Holmen, 1990). One factor contributing to the inconsistent findings in the literature may be the type of measures used - specific measures (e.g. assessing worries about health, as used in the present study and by Wardle et al., 1995) may be more likely to detect an effect than more global measures (e.g. of psychiatric "caseness", as used by Mann, 1981). Another reason may relate to the kind of follow-up care provided to the patients, since some of the studies which found no adverse effect of screening provided follow-up care in a way which was specifically aimed to minimize distress and was well beyond what could be expected in ordinary clinical practice (e.g. Mann, 1981). In the present study women were not given follow-up care from the unit providing the scans, except that they could see the project physician if they requested to do so. Anecdotal evidence from discussion with the women undergoing bone densitometry indicated that some women were distressed that their GP did not take their scan result seriously.

In some studies which failed to find any significant effects of screening, results were presented in a way which was intended to minimize any adverse reactions- for example, in one such study, participants received post-test counselling conducted in a "warm, positive, upbeat" manner, were told that the risk factor (blood cholesterol) is a condition largely under an individual's control and were provided with information about how the person should change their behaviour (Havas, Reisman, Hsu and Koumjian, 1991). In the present study the radiographers appeared to be trying to present results in a way in which would not cause unnecessary distress, but the main focus of the communication was on conveying the meaning of the graph on which the result was shown. It was not the radiographer's job to give advice about preventative behaviours. Future studies could examine whether changing the method of result presentation would affect levels of distress after bone density screening.

One of the most interesting findings of the research presented in this thesis is that women who received a low scan result show a decrease in their ratings of the seriousness of below-average bone density. This "minimization" of seriousness had been shown in previous laboratory studies concerning a fictitious risk factor (e.g. Ditto, Jemmott and Darley, 1988) but had never previously been investigated in a prospective study involving a real health test. Furthermore, previous research has failed to identify any

factors which relate to individual differences in minimization (e.g. Croyle, Sun and Louie), while in the present study it was found that scores on parts of the Health Anxiety Questionnaire and certain pre-existing beliefs about the condition in question were associated with the extent of minimization after a low scan result.

Marteau, van Diuyn and Ellis (1992) found that after carrier testing for Tay-Sachs disease, people with positive results felt less optimistic about their future general health than non-carriers, even though the recessive gene poses no risk to their own health. In the present study there was no evidence that receiving a low scan result affected one's beliefs about the likelihood of developing other serious illness, except in those with very high levels of pre-existing health anxiety, and even here the effect was not quite statistically significant. One explanation for the difference between these two studies is that people react differently to information about their genes than about risk factors such as bone density. However, it should be noted that in the study by Marteau et al. (1992), the groups of people with positive and negative results were sampled from different populations, so it may not be appropriate draw firm conclusions about the group difference which was found.

After a high scan result, it was found that some women drew inappropriate conclusions about their overall state of health or lifestyle (e.g. I'm 100% healthy"). This is consistent with findings from a previous study which investigated such an effect (Tymstra and Bieleman, 1987). In the present study it was also found that women with high levels of pre-existing health anxiety showed only temporary reassurance after a high scan result. This had not previously been shown in a screening study but it is consistent with two single case experiments with hypochondriacal patients by Salkovskis and Warwick (1986). They found that when a doctor provided reassurance about the patient's health, this produced immediate but only transient reductions in anxiety.

In the present study, the proportion of women who completed at least one questionnaire before the scan and one afterwards was 98% and the proportion completing each of the 5 questionnaires used in the main study (i.e. not including the 14 month follow-up) was 58.3%. Inspection of the screening studies summarised in Appendices A and B indicate that none include as many assessment points as in the present research, except for genetic testing studies, which are not directly comparable since these include psychological assessment as an integral part of the testing process. Of the other studies, the one which has the most assessment points is Wardle et al.'s (1993) study into ovarian cancer screening which had 4 assessment points. They found that 91% responded in some way to the study (compared to at least 98% in the present research) but they do not report what proportion of women complete all the questionnaires.

Reelick, de Haes and Schuurman (1984) have 3 assessment points but again do not report the proportion who completed all the questionnaires. They do report that 56.6% took part in the pre-test and the first post-test assessments, compared to the 58.3% who took part in all five of the assessments in the present research. The other prospective studies reviewed in Appendices A and B have at the most 2 assessment points which are not an integral part of the testing process. The return rates for these studies were generally slightly higher than the 58.3% found in the present study but these rates would probably have been lower if they had included as many different assessment points as were included in the present research.

In the present study it was found that women who failed to return any of the follow-up questionnaires had higher pre-scan STAI-trait scores than women who returned all the questionnaires. This is consistent with the finding of Marteau, Cook et al. (1992) that women who didn't complete all the follow-up questionnaires after prenatal testing had higher STAI-trait scores than those who completed all the questionnaires.

Implications of the research

Implications for the research for theories of hypochondriasis and reactions to health threats

Consistent with cognitive models of anxiety, it was found that anxiety about osteoporosis was associated with particular beliefs about osteoporosis: that one is likely to develop osteoporosis, that osteoporosis is particularly aversive or serious, that one would have much difficulty coping with it and that it is not possible to treat osteoporosis. Since these beliefs before the scan were associated with anxiety three months afterwards, the results are consistent with the CB hypothesis that pre-existing beliefs about illness will influence how a person reacts to a health threat. The finding that a person's appraisal of a health threat is important in determining reactions to the situation is consistent with some studies which have examined how people cope with illness, using Leventhal's self-regulation theory. For example, a cross-sectional study by Earll, Johnston and Mitchell (1993) found that patients with motor neurone disease who rated their condition as "very serious" had significantly higher ratings of anxiety and depression than patients who rated their condition as either "somewhat" or "not very serious". Leventhal's model does not make specific predictions about which aspects of representations will be associated with distress and does not specify which factors are involved in the maintenance of distress. The cognitive-behavioural model of health anxiety is an alternative way of predicting distress after the receipt of health risk information, but Leventhal's model is wider in scope than the CB model (i.e. it does not only concern distress) and is useful

as general framework into how people cope with illness.

Women who reported a pre-existing tendency to worry about their health reported more anxiety and higher risk perceptions after a low density result than women with no such tendency, although the two groups showed no significant differences in these ratings before the scan. There was also an indication that the health anxious women were less likely to show the minimization of the seriousness of a low density result which was apparent in the latter group. General tendencies to worry about one's health are not mentioned in Leventhal's model, which focuses on beliefs about the illness in question. Furthermore, since less than half of the women reported symptoms and there was no evidence of different levels of symptoms in the two groups, the findings are inconsistent with the theories of Barsky (1992) and Kellner (1986), which both focus on the experience of symptoms rather than the interpretation of medical information in their models of the processes involved in health anxiety or hypochondriasis. However, the findings are more consistent with the CB model, which suggests that people who tend to worry about their health have relatively enduring negative beliefs and assumptions about illness which may be quite general (rather than focused on a particular disease) and which will influence how they react to health threats. The fact that these results were found in women with differing levels of sub-clinical health anxiety is consistent with the notion of a continuum of health anxiety throughout the population. Other results consistent with the CB model include the findings that anxiety about osteoporosis three months after a bone scan was associated with a pre-scan tendency to avoid illness-related situations and attempts to distract oneself from thinking about the result in the week after the scan; the CB model suggests that these type of behaviours can maintain health anxiety.

Information provision for women undergoing bone densitometry

By investigating women's interpretation of their scan result it was possible to identify points of confusion that might be usefully addressed in the information provided to women undergoing bone densitometry. These include the relationship between a scan result and the diagnosis of osteoporosis, the relationship between one's current bone density and future risk for osteoporosis (which could be further clarified), the association between density in the spine and density in other parts of the body, and natural variation between different vertebrae. The interpretation of second scans seemed to cause the most confusion and it may be appropriate for the printout of the results of second scans to include an indication of change in bone density, accompanied by information about how to interpret any change. However, it should be noted that since the clinical implications of bone density screening are not well established, even if there was a provision of more

detailed information, there would still be considerable ambiguity about the meaning of a scan result. Indeed, it could be argued that providing more information will actually increase the perceived ambiguity of the meaning of the result. Experimental studies are needed to examine the effects of different types of information provision with regard to the accuracy of interpretation of the scan result, psychological distress and preventative behaviour.

Identification of people vulnerable to experiencing the most distress after health screening

Many new types of health screening are being developed, and as they become available there will be a need for methods of (i) preventing or minimizing the distress which may result, (ii) identifying individuals who are likely to experience persistent distress and providing some kind of preventative intervention tailored to their particular concerns (iii) identifying individuals who are already distressed as a result of the screening so that they can be given some kind of intervention to reduce their distress. The results presented in this thesis indicate that it was possible to identify which people had become distressed after the scan and who were likely to still be distressed at the 3 month follow-up, using questions which did not take long to complete and were easy to administer. It is also possible to make approximate predictions about which people are particularly likely to experience persistent distress after bone density screening on the basis of pre-scan ratings. Furthermore, pre-scan beliefs associated with post-scan distress were identified and these could be addressed in the information given to all women undergoing screening.

An important way of improving prediction of distress may be to focus more on factors which may be maintaining distress, which were only briefly considered in the research presented in this thesis. Future research could include experimental studies in which some subjects are asked to respond to thoughts of the illness or risk factor in certain ways, such as by trying to suppress the thought (which is expected to maintain distress; Trinder and Salkovskis, 1994). Another factor which could be assessed in an attempt to improve prediction is social support - another “external” coping resource in addition to the treatment and prevention beliefs which have already been assessed. The way in which treatment beliefs are assessed should also be altered in future studies so that self-referent beliefs are measured rather than just knowledge; this may also improve prediction of distress.

It is clearly important to establish whether the CB model used in this bone density study will also be useful in identifying some of those likely to experience distress after other types of health screening. The model is likely to be particularly applicable to situations where there is ambiguity about the meaning of the results, such as in risk factor testing, since misinterpretation is more likely in these tests. Genetic testing for

multifactorial diseases will provide very ambiguous information, since relatively little is known at this stage about the meaning of a positive result from this type of testing, so it would be very interesting to apply the CB model in this area. Given the number of genetic tests which are likely to soon be available, it would be extremely useful to be able to identify people who are likely to experience distress after testing, so that scarce resources could be targeted at these individuals.

There has been little previous research attempting to predict which people become the most anxious after risk factor screening. The Miller Behavioural Style Scale (MBSS; Miller, 1987), which was designed to assess the amount of information which the person would prefer in threatening situations, was found to be unrelated to the extent of minimization in laboratory studies of risk factor testing (Croyle, Sun and Louie, 1993). There is some evidence that people who score highly on the “monitoring” scale of the MBSS were more anxious after a positive test result in tests designed to detect disease at early stages (e.g. ovarian cancer screening; Wardle et al., 1993). However, studies reporting this effect do not report the amount of variance in distress which can be explained using the questionnaire. Miller had not originally predicted the greater distress in “monitors” and although she has recently suggested reasons for the finding (see Schwartz, Lerman, Miller, Daly and Masny, 1995), there are alternative explanations consistent with the cognitive-behavioural model of health anxiety (i.e. that the monitoring is not the original cause of the distress but a result of increased threat perceptions, although it may maintain anxiety; see Appendix A). One of the advantages of the CB model compared to Miller’s approach is that there is already a successful treatment for severe health anxiety based on the CB model, and it is likely that the kinds of techniques used in this therapy could be adapted for use in health screening situations.

Interventions to prevent or minimize distress after bone density screening

According to the CB model of health anxiety, the ways in which people respond to health threats are partly determined by their pre-existing specific beliefs. It is suggested that people who tend to worry about their health have particularly negative beliefs about health and illness which make them vulnerable to interpreting new health information in more negative ways than others. It is also proposed that the ways in which people tend to respond to health threats will determine whether anxiety is maintained. The research in this thesis provided evidence consistent with these ideas. For example, it was found that higher levels of anxiety about osteoporosis three months after the scan were associated with a pre-existing tendency to worry about one’s health and certain types of pre-scan beliefs about osteoporosis (the belief that it is not possible to treat osteoporosis, very negative beliefs about the “cost” or seriousness of osteoporosis / low bone density beliefs,

or about one's ability to cope if one had low bone density or osteoporosis, or high risk perceptions). A pre-scan tendency to avoid illness-related situations was also associated with greater anxiety about osteoporosis three months after the scan, after these other factors had been taken into account.

Some of these pre-scan factors which are associated with anxiety about osteoporosis after the scan could be addressed in information given to women undergoing screening, in an attempt to prevent or minimize distress. It may be preferable to try to modify dysfunctional assumptions before the scan, because otherwise they (or the resulting anxiety) may bias interpretation of the result. With regard to beliefs about "cost", which were found to be the strongest predictor of anxiety after screening, one could present information about people with low bone density who have suffered relatively little from the fractures or who have managed to reduce or control the burden of osteoporosis in some way. One could also point out that since the woman knows that she is at risk, preventative and early treatment methods are available which will mean that even if she does develop osteoporosis, the symptoms will probably not become as severe as the symptoms they have seen in their relatives or friends.

To reduce risk perceptions one could emphasize that factors such as family history, early hysterectomy and so on are only risk factors, not indications that osteoporosis is inevitable. Again one could emphasize that preventative behaviours may help to reduce their risk of future fractures. Coping beliefs could be addressed by providing case histories of people who have managed to cope successfully with being at risk for osteoporosis or with osteoporosis itself. One could provide information about the inadvisability of certain responses such as avoidance, thought suppression and repeated reassurance-seeking. It could be pointed out that these, and other responses may be an indication that the primary problem may be one of anxiety rather than low bone density.

It is possible that tailoring information towards the kinds of dysfunctional beliefs shown by the woman may improve the success of the intervention. Women could be screened before the scan and given a certain leaflet depending on their psychological vulnerabilities and their result. If further work was carried out into the types of maladaptive beliefs which are the most common, these could be assessed directly before the scan. For example, one could have certain statements such as "Since osteoporosis is in my family I will develop it myself" and the woman could be asked to rate the extent to which she agreed with the statement on a 7-point bipolar scale from "disagree strongly" to "agree strongly". It should be noted that women with high levels of health anxiety may need information about how to cope with a high result, since there was evidence that anxiety about osteoporosis and need for reassurance decreases immediately after the scan but then returns over time in this group.

Although leaflets are a convenient way to convey detailed information, it may also be possible for the radiographer who gives the result to alter what they say slightly depending on pre-existing vulnerabilities. Currently the radiographer does little for at least 7 minutes while the scan takes place, so if a pre-scan questionnaire was analysed during this time, it would be possible for the radiographer to have an idea of the kinds of beliefs which could be taken into account when communicating results. This should be very structured to ensure that radiographers modify their advice in appropriate ways. For example, if a woman believes that it is not possible to prevent symptoms occurring if one has low bone density, the radiographer could be trained to emphasize things that can be done to prevent further bone loss. The radiographer has a very limited amount of time in which to talk to the woman, but what he or she says could have greater impact than written information, which some people may not even read. The radiographer could also mark parts of the leaflet to which the woman should pay special attention, depending on their responses to earlier questionnaires. Evaluating the impact of such an approach would be relatively straightforward.

In order to reduce excessive distress after a bone density scan, one may also wish to consider the way in which people with low levels of health anxiety may be coping if they receive a low scan result. After the scan, these individuals tend to show a reduction in their ratings of how likely it is that they will develop osteoporosis, despite their low result. This group also shows reductions in their ratings of how serious it is to have below-average bone density. Reductions in likelihood ratings were associated with reductions in anxiety about bone density, as were reductions in seriousness ratings (although the latter to a non-significant degree). Tibben et al. (1994) have argued that this kind of process may be a form of denial which prevents adequate processing of the health information and could eventually lead to psychological maladjustment. However, there was no evidence of an increase in psychological distress at the 14 month follow-up in those who had minimized the seriousness of a below-average result at the three months after the scan. Furthermore, if complete denial were occurring, it would be expected that preventative behaviours would not increase, but they do, and in fact greater minimization in the low health anxious group tended to be associated with higher numbers of preventative behaviours at the 3 month follow-up (although the direction of causation cannot be established with the existing data). This finding is consistent with the view that minimization can be an adaptive way of controlling anxiety which may facilitate more problem-oriented coping (Cohen and Lazarus, 1979). In order to examine whether minimization is indeed an adaptive strategy with regard to the reduction of distress and facilitation of preventative behaviours, future studies could

attempt to induce minimization in one group and compare the effects of this manipulation with a control condition. However, little is known about the mechanisms of minimization, so more work may be needed in this area first. It has been suggested that people are overly optimistic about health threats because they selectively focus on reasons why they are not at risk and fail to take into account all of their risk-increasing attributes (Weinstein, 1984). It is possible that minimization after a health threat also involves such a process, and future studies could investigate whether optimism or minimization can be induced by asking subjects to dwell on the reasons why the health threat is not serious for them.

If minimization does involve a selective focus on the positive aspects of the situation, it may be possible to aid this process after bone density screening by providing written information which the person may be able to use in order to arrive at the conclusion that the threat is not severe. For example, one could emphasize the different ways in which it may be possible to prevent further bone loss. However, given that all of the women should have already been aware that preventative methods are available, it is important to consider why some individuals don't minimize the threat. It may be useful to consider minimization as the result of "motivated reasoning". Kunda (1990) argues that "there is considerable evidence that people are more likely to arrive at conclusions that they want to arrive at, but their ability to do so is constrained by their ability to construct seemingly reasonable justifications for these conclusions". There was some evidence consistent with this notion in the research presented here. For example, people who (before the scan) believed that they would find it difficult to cope with low bone density or osteoporosis, or stated that it is impossible to cure osteoporosis, were less likely to show a reduction in their ratings of seriousness of below average bone density after the scan. In other words, pre-existing negative beliefs about osteoporosis may have limited the extent to which the person could appraise a low bone density result as being "not serious". This brings us back to the idea that it may be important to change pre-existing dysfunctional beliefs.

This research presented in this thesis also indicated that high scores on the Health Anxiety Questionnaire and subscales of it were associated with less minimization. It is therefore possible that women with high levels of health anxiety should be particularly targeted for help minimizing the meaning of the result. However, it should be noted that if this is attempted, the effect on preventative behaviours should be closely monitored, since in the health anxious group there was a tendency for those who showed reductions in seriousness ratings to show smaller increases in preventative behaviours. (The relationship was in the opposite direction for group with low levels of health anxiety). It may be that different types of minimization may have been occurring in the high and low health anxious groups- an adaptive kind in those with low levels of health anxiety and a maladaptive kind in some of those with high levels of health anxiety.

However, this is highly speculative and the matter requires further investigation.

There are numerous ways in which beliefs and behaviours in people with high levels of health anxiety may be preventing them from minimizing the seriousness of the situation of their risk for illness in an adaptive way (as discussed in chapter 8). For example, people who tend to worry about their health are likely to have various dysfunctional assumptions about health and illness which may bias their interpretation of new health information in a negative direction. They may also lack positive beliefs about themselves in relation to illness which may be helpful in minimizing a health threat for those with lower levels of anxiety. Because people with a tendency to worry about their health are likely to interpret a bone scan result in a negative way, this will cause anxiety, which in turn will result in selective attention towards threat-relevant information. If minimization involves some kind of reasoning focusing on positive aspects to the situation, then this selective attention towards threat may prevent minimization occurring. Furthermore, responses to health threats which are often made by health anxious individuals, such as distracting oneself from thinking about it, will prevent the kind of “motivated reasoning” which may be necessary in order to minimize the threat. Health anxious individuals may also have “meta-cognitive” beliefs about the merits of minimizing a health threat, (e.g. “it is important not to disregard warning signs about one’s health because otherwise disease may quickly develop to the stage at which it can’t be cured” or “not worrying about your health is tempting fate”). Thus, there are numerous reasons why beliefs and behaviours identified as problematic in the CB model may prevent people from minimizing a health threat in an adaptive way. Modifying such beliefs and behaviours may allow these individuals to minimize the health threat in an appropriate way and experience lower levels of anxiety.

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(References to articles mentioned in Appendix A are given at the end of Appendix A).

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Appendix A

Psychological effects of receiving risk information from health screening

Introduction

Medical knowledge about risk factors for different diseases is rapidly increasing and this knowledge is being used to identify people which are particularly likely to develop certain conditions. Although a major implicit aim in testing for risk factors is total prevention or effective treatment through identification of the pathogenesis of particular diseases, this is unlikely to be obtainable in the near future, if ever. At the moment, the identification of risk factors may enable people to change their behaviour or undergo prophylactic surgery to try to prevent the disease, to undergo more intensive screening to ensure early detection, or to simply prepare themselves for the onset of the disease. The factors involved may be genetic, environmental (e.g. exposure to toxins at the workplace), behavioural (e.g. smoking) or physical changes such as cervical intraepithelial neoplasia. In the following section there is a summary of previous literature on the psychological effects of health screening which involves the identification of risk factors. (It should be noted that the following sections only summarize the findings and do not mention every relevant study). The main topics will be: predictive genetic testing, hypertension screening, cholesterol screening, mammography, cervical smears and the informing of workers who have suffered occupational exposure to toxins.¹ Results from studies using a laboratory paradigm designed for the examination of reaction to risk factors will also be described. The effects of genetic counselling in the absence of genetic testing are not described here since the evidence is only anecdotal. HIV testing will not be covered because it differs in certain important ways from the other types of testing (e.g. HIV is infectious). Also, although health education campaigns inform the public about risk factors, it is usually impossible to measure the reactions of people who learn for the first time that they are at risk through such campaigns, so the effects of health education are not discussed here.

Psychological effects of genetic testing

It is likely that almost all major disease susceptibility genes will be identified in the next 5-10 years (Department of Health, 1995). This will lead to opportunities for the genetic screening of high risk groups and perhaps whole populations. Here I am going to discuss the psychological effects of “predictive” or “presymptomatic” genetic testing in adults, focusing on the reactions of the individual who has the test, rather than others such as their spouse. The existing literature on the psychological effects of testing currently focuses mainly on testing for Huntington’s Disease although there are also a few studies which outline reactions to testing for breast/ovarian cancer and Alzheimer’s Disease.

Genetic testing for Huntington’s Disease

Reactions to a high-risk result from genetic testing for Huntington’s Disease

Huntington’s Disease (HD) is inherited by autosomal dominant transmission and thus occurs in roughly half of the offspring of the affected person. It is a currently incurable progressive disease of the brain that causes movement disorder, dementia and affective disturbances. The gene is completely penetrant so that all who inherit it develop the disease, assuming that they survive until the time of onset (which is usually around 40 years of age).

People who receive a high-risk result after genetic testing for HD often initially react with shock, dismay and anger (e.g Tyler et al. 1992). There is also an increase in pessimism about the future, as indicated by scores on the Beck Hopelessness Scale (Tibben et al. 1994). In the 3 months after testing, Meissen et al. (1988) found that all of their high-risk patients showed evidence of periods of moderate or severe depression.

Mammography is primarily designed to detect cancer but it can pick up benign disease which indicates that the woman is at increased risk of developing breast cancer in the future. Cervical smear tests are often construed as a means of detecting cancer but they are actually designed primarily to prevent cancer by detecting abnormalities which indicate that cancer may develop in the future.

Codori and Brandt (1994) found that some problems are still evident when people were questioned 1-6 years after the test. In their study, 88% of those at high risk reported that they had experienced negative effects of testing. These effects included: finding the result an emotional burden (47%), thinking about HD more often since the test (24%), searching for symptoms more often since the test (12%), continuing to feel "uncertainty" since the result (18%) and feeling guilty that they may have passed on the gene to their children (18%). Wiggins et al. (1992) report that after a high risk result there were frequent requests for physical examinations, a need for continued support and a need for reassurance that results of DNA testing are not synonymous with a diagnosis. Anxiety about HD has generally not been directly assessed, although it may be inferred from the feelings of uncertainty, symptom searching and requests for reassurance. Negative effects have been reported concerning intimate and family relationships: for example, Byrne and Bamforth (1994) describe a case where a woman with a high-risk result became depressed and reported suicidal preoccupation after her fiancé called off the marriage because she had the HD gene.

However, psychological reactions to a high-risk result for HD have generally been less severe than expected. For example, it had been predicted that suicides would occur as a result of genetic testing (e.g. Kessler, 1987), while none have yet been reported. Although people who have received a high-risk result for HD often show some initial distress, most of this tends to dissipate within a few months of testing (e.g. Meissen et al., 1988, Wiggins et al., 1992, Tibben et al. 1994). When Codori and Brandt (1994) asked people who had been tested at least a year ago about the positive effects of testing, all those with a high-risk result mentioned at least one benefit of having been tested. Benefits included a reduction in preoccupation with HD, relief of uncertainty, improvement in the relationship with one's spouse and an ability to plan one's life better.

It should not necessarily be assumed that the lower-than-expected distress in HD testing indicates that the psychological effects of genetic testing in general will be fairly benign. There are various reasons why the adverse effects of HD testing have not been as severe as anticipated. Firstly, Tyler et al., (1992), Wiggins et al. (1992) and others report that some people refused to take part in follow-ups because they were too distressed- in the case of Tyler et al. this was 17% of their sample of those at high risk. Therefore it is likely that assessments of the severity of psychological effects after HD testing are underestimates. However, it could be argued that even taking into account those who did not take part in the follow-ups, the number of people showing severe distress was lower than expected.

A second possible reason for the lower than expected distress is that all the patients who have been tested so far have received extensive pre- and post-test counselling. This is an important point, since as genetic testing becomes more widespread it will be impossible to provide such a high level of support. Thirdly, the people who have undergone testing are a selected sample: for example, those who have a psychiatric illness are refused testing and self-selection also seems to occur. There is evidence that those who have chosen to have HD testing are the people most likely to cope relatively well with a high-risk result: they have high levels of resourcefulness and low tolerance for uncertainty (Bloch, Fahy, Fox and Hayden, 1989; Tibben et al., 1994). People who are particularly distressed by the uncertainty of a 50% risk feel that knowing for certain - whatever the result - is better than not knowing (Hayes, 1992). In contrast, people who decide against testing tend to be less concerned about relieving uncertainty, feel more hopeless, more depressed and are more likely to believe that a high-risk result would have a very negative effect on their quality of life (e.g. Bloch et al., 1989; Tibben et al., 1992). Those that choose not to be tested may therefore represent a more vulnerable group and it should not be assumed that the lower-than-expected levels of distress seen in the subgroup who have been tested would also apply to the at-risk population as a whole.

A fourth point is that changes in levels of distress may not be as severe as expected because these people have known for some time that they have a 50% risk for HD and are likely to already feel distressed about the situation. Tibben et al. (1994) found that although scores on the General Health Questionnaire did not change significantly after testing, the pre-test scores were already only slightly below the cutoff point, indicating that some individuals may be at risk for psychological problems. It should be noted that all the research into the psychological effects of genetic testing has involved people who were already aware of that the disease was in their family- if someone without such awareness received a positive result, their psychological reaction may be much more severe. Given that some insurance companies want to ask people take genetic tests and since commercial companies will be keen to promote testing, it is certainly possible that some people will find that they have genes for an illness with no prior appreciation of their risk.

It has also been suggested that those at high-risk are denying or minimizing their distress (e.g. Tibben et al. 1994). This can take the form of complete denial of feelings, or placing hope on the possibility

of a cure or in things such as the protection of God or “thinking positive thoughts to ward off disease”. (Tibben et al. 1994; Codori and Brandt, 1994). Codori and Brandt point out that those at high risk also seem to try to focus on what they have gained and how they can cope rather than dwelling on the negative aspects. In their sample, 11 of the 17 people in the high risk group underestimated their chances of developing HD. These authors suggest that such processes may be appropriate in asymptomatic people at high risk for HD since they are not yet ill and there are no health-related actions required. In contrast, Tibben suggests that denial may lead to psychopathology in the future.

Finally, it is important that patients with a high-risk result are followed further to see how they react as they get nearer to the point where onset of HD is likely to occur- it is possible that distress and continual monitoring of symptoms may greatly increase at this time.

Reactions to a low-risk result from HD testing

As expected, people who receive a low-risk result experience relief and sometimes guilt about the family members who do have the gene (Tibben et al. 1992). However, more people with a low-risk test result show substantial difficulties coping with their new risk status than had been anticipated (approximately 10% of the low-risk group, according to Huggins et al. 1992). Those with the most negative reactions were often those with unrealistic expectations about the effect of a low-risk result or those who had already made irreversible life decisions based on the belief that they would be affected - such as being sterilised or running up huge debts (Huggins et al., 1992). Tibben et al. (1992) found that 88% reported numbed feelings lasting at least 6 months and the authors suggest that the reason for this is that “most non-carriers were neither emotionally nor cognitively equipped to assimilate the notion that their adaptation to the threat of HD had, after all, been totally unnecessary”. Furthermore, Tibben et al. (1992) found that 56% of non-carriers in their group remained preoccupied with the possible development of any involuntary movements and the threat of disease and 44% sometimes questioned the reliability of the test.

Genetic testing for breast/ovarian cancer

Genetic testing for one of the genes responsible for susceptibility to breast/ovarian cancer, BRCA1, has begun in research settings. Cancer susceptibility associated with BRCA1 mutations is inherited in an autosomal dominant fashion and is highly penetrant, producing a risk of breast or ovarian cancer which approaches 80-90% by age 70.

Watson et al. (1995) report in a letter to the Lancet that for 11 women and 2 men who have undergone linkage testing for BRCA1, “*Generally, state anxiety was low at initial consultation and remained low at all subsequent evaluations*” [my italics]. They do not discuss how many people failed to show this general pattern. They note a slight but non-significant increase in psychological morbidity around the time of the blood sampling. However, they do not report the results separately for those receiving good and bad results and do not report which types of psychological measures they used.

Lynch et al. (1993) found that of the 9 women given a low risk result, 7 expressed disbelief. Many of the women still wanted intensive surveillance and prophylactic surgery, although after counselling only 1 woman still felt this way. At the follow-up (3-6 weeks after disclosure), half of the low risk women still felt worried and half were optimistic. Of the 8 who received high-risk results, all were worried after disclosure and 3 expressed disbelief, although 5 were relieved. At follow-up, 5 of the 7 high-risk women interviewed said that they were depressed, 5 expressed mood lability, 2 were pessimistic and 3 reported that they had needed help coping with the information (in addition to the post-disclosure genetic counselling). The severity of these psychological effects are not known since they were assessed using questions with yes/no answers.

Thus the studies from the two groups reporting the effects of linkage testing for the BRCA1 breast and ovarian cancer predisposition gene show slightly contradictory results, although both are clearly limited by the small numbers of subjects. It should be noted that all the patients received extensive counselling before and after testing.

There is no evidence about the psychological characteristics of those who have actually undergone BRCA1 testing. However, in a study of attitudes towards testing in women with a family history of ovarian cancer, Lerman, Daly, Masny and Balshem (1994) found that women who reported more mood disturbance, more worries about cancer and higher risk perceptions were more likely to say that they would want to be tested for BRCA1. These factors were also associated with the expectation of more severe psychological effects after testing. This pattern is in the opposite direction to that seen in HD, where people who chose to

have testing are less depressed, less hopeless, have lower risk perceptions and anticipate a less severe reaction than people who did not want to be tested. One possible explanation for this discrepancy is that far fewer women will actually have a BRCA1 test than the expressed an interest beforehand (as happened with HD testing), and that those who do have a BRCA1 test may show a similar psychological pattern to those who chose to be tested for HD. However, there are certain important differences between breast cancer and HD- for example, the former can be treated and perhaps prevented. Thus a woman knows that even if she does have the gene, action may be taken (such as prophylactic surgery) which in itself may help to reduce her anxiety. In contrast, for people at risk for HD, a genetic test may take away whatever little hope they had and might therefore be avoided by some of those who are particularly distressed.

Genetic testing for susceptibility to Alzheimer's Disease

In some families Alzheimer's Disease (AD) is inherited as an autosomal dominant trait. Lannfelt, Axelman, Lilius and Basun (1995) have found a genetic mutation which is a rare cause of AD and have performed mutation analysis for the 3 people. Two were found to be non-carriers and no psychological side effects were observed for these people. The person with the mutation "immediately reacted with anxiety, sorrow, depressive feelings, and for a period of 1 month, suicidal thoughts". During the following 6 months the individual had recurrent feelings of hopelessness and depressive thoughts. One year later the individual was "at work and coping well with the situation".

Psychological effects of genetic testing: conclusion

Genetic testing clearly has the potential to produce extreme distress. However, the psychological impact of genetic testing is poorly understood. In the first testing programme, for HD, certain predictions were not realised (e.g. suicides), while other effects of testing were not anticipated (e.g. substantial adverse reactions in the low risk group). It is also likely that new issues will arise as testing becomes more widespread for other diseases. For example, it is possible that genetic testing will lead to a sense of fatalism in some people which may act as a barrier to potentially useful preventative health behaviours. On the other hand, it is likely that some individuals found to have a genetic susceptibility to a multifactorial disease will become obsessive about behaviours which may minimize their chance of developing the disease. There may also feelings of *invulnerability* after a negative test result which could lead to a failure to perform preventative health behaviours.

Given the rapid developments in genetic testing and the likelihood that there will be pressures to introduce new genetic tests before they have been properly evaluated (Clarke, 1995), there is an urgent need for models of the psychological effects of testing for susceptibility for disease, which could be used to help predict likely reactions to new tests as they become available. Since genetic counselling resources will become increasingly stretched, it would also be valuable to have a way of identifying people who are likely to experience distress after testing, so that scarce resources could be targeted at these individuals.

Psychological effects of screening for hypertension

Adverse effects of hypertension screening have been shown to include increased absenteeism (Haynes, Sackett, Taylor, Gibson and Johnson, 1978), greater worry about one's health (e.g. Milne, Logan and Flanagan, 1985), decreased marital satisfaction (Mossey, 1981) and increased general psychological distress (e.g. Soghikian, Fallick-Huneler, Ury and Fisher, 1981). The effects ascribed to the hypertension labelling do not seem to be a result of side effects of medication (e.g. Charlson, Alderman and Melcher, 1982) or the medical condition itself, since unaware hypertensives show no differences from normatensives on these measures.

However, the findings of absenteeism and psychological effects have been inconsistent, with a number of studies finding no adverse effects of hypertension screening (e.g. Moum, Naess, Sorenson, Tambs and Holmen, 1990). There are various possible reasons for the contradictory findings. One likely explanation concerns the type of follow-up care given to patients. In clinical trials where follow-ups have been intensive, adverse effects seem to have been minimized, and in one such study there was even a decrease in scores on the GHQ after testing (Mann, 1981), which the author attributed to the regular supportive follow-up interviews with a nurse (these visits occurred every two weeks for the first 3 months and then quarterly for the remainder of the first year). However, these studies have provided care beyond what is usually given in the community and there is little evidence regarding what constitutes "adequate" counselling and follow-up.

A second possible explanation for some of the contradictory findings is that studies which use psychiatric morbidity or global distress as outcome measures seem to be less likely to find effects than studies which use more specific measures relating to perceptions of one's health and health worries. A third possible reason concerns the way that patients are informed of their raised blood-pressure, which has not been standardized between studies. Rudd et al. (1986, 1987) found that people who were reassured and told that a single measurement can be unreliable showed lower anxiety and absenteeism than people who receive a more traditional message which emphasizes the seriousness of the problem. In the reassurance condition the educator "actively solicited and discussed the subject's perceptions and concerns about hypertension and its' management, attempting to reduce inappropriate fears". The patients were taught how to measure their own blood pressure and were shown how variability is to be expected, in order to "desensitize them to the determination process". In the "traditional" condition, educators gave educational materials and answers to specific questions but "no formal attempts to reassure". The finding that the "reassurance" condition was associated with fewer adverse outcomes is consistent with the prediction derived from the cognitive-behavioural model of health anxiety that addressing the person's idiosyncratic perceptions and concerns will be the most effective way of reducing misunderstanding and anxiety. Fourthly, Rudd et al. (1987) point out that in studies where almost a whole workforce has been screened, the negative effects have been more severe than in studies where the subjects are people who have volunteered for screening. They argue that when people are given the option to be screened, those most vulnerable to reacting badly to a positive result often chose not to attend. Consistent with this view is the finding of Stoate (1989) that people who had attended screening for cardiovascular disease factors (including blood pressure) had lower levels of psychological distress than a randomly chosen control group from the same practice who were not invited for screening. A fifth possible reason for inconsistent findings is that in at least one of the studies which failed to find adverse effects of screening (Mann, 1981), people were excluded from the trial if their GP considered that they had a psychiatric disorder which would imply erratic compliance with a drug regime and clinic attendance or if their "current mental state or social problems appeared to be sufficiently distressing for the trial to be an unnecessary burden". It is possible that patients with these characteristics may be more likely to show an adverse reaction to screening.

Thus it seems that hypertension screening can lead to psychological distress, but this may be minimized or prevented if people are not encouraged to take part against their wishes, are given reassuring feedback which addresses their concerns and receive intensive follow-up appointments with a health professional. Of course in most non-research situations, these requirements may not be met.

Psychological effects of cholesterol screening

There have been a few reports of adverse psychosocial effects of cholesterol screening although these have all been retrospective studies. Brett (1991) describes six people who became distressed after a high-cholesterol result, including one man who became so afraid of having a heart attack that he stopped doing his daily exercise and had to be hospitalized for chest pains for which medical tests could find no cause. Fischer, Guinan, Burke, Karp and Richards (1990) sent a questionnaire to people who had been screened a year earlier and found that with increasing levels of cholesterol there were increasing levels of "disturbance" as assessed on a 5-point scale. They also found lower self-reported general health in the high-cholesterol group but no evidence of increased absenteeism.

Two prospective studies have found little evidence of adverse psychological effects of cholesterol screening (Havas, Reisman, Hsu and Koumjian, 1991; Hyman, Flora, Reynolds, Johannson and Farquhar, 1991). In both of these studies, the way in which the news of high cholesterol was presented is likely to have minimized the seriousness of the test result. In the study by Havas et al., the procedure was devised using lessons from the studies of hypertension screening: the participants received counselling conducted in a "warm, positive, upbeat" manner and were told that blood cholesterol is a condition that is largely under an individual's control. Unfortunately this may have been misleading, since more recent evidence suggests that moderate dietary changes (as suggested in their study) may be ineffective in lowering cholesterol. It is likely that some participants in this study experienced distress later on, when they found that their dietary changes made no difference. In addition, the counselling given in the Havas et al. study only lasted 5 minutes, which may have reinforced the impression that the problem was not too serious. In the Hyman et al. study this conclusion is also likely to have occurred, since there was no individualised counselling at all - participants simply received a pamphlet about low-fat eating and those with high cholesterol were told to see their doctor. Of the 77% who took part in the 3 month follow-up, only 32% had discussed their

cholesterol level with their doctor and since the proportion was 34% in those with satisfactory cholesterol, the authors conclude that many of the physician visits occurred primarily for other reasons. This implies that the participants with raised cholesterol had not perceived their result as a serious problem.

Thus for both studies the lack of any adverse psychological consequences may have been partly the result of a minimization of the seriousness of the problem by those giving the results. Clearly there is a delicate balance to be reached between avoiding undue psychological and raising concern enough to ensure that further action will be taken. It should also be noted that about 20% in each study failed to take part in the follow-up and the drop-outs may have included some who were trying to deal with distress by avoiding the issue.

Psychological effects of screening for multiple cardiovascular risk factors

Two studies have examined the psychological effects of cardiovascular screening which involved the calculation of an overall risk score from both cholesterol and blood pressure measurement together with an assessment of other risk factors such as smoking and obesity. Tymstra and Bieleman (1987) found that 19% had been astonished to find that they were at risk for cardiovascular disease and 8% said that they had become anxious or uncertain. They also noted that half of those who received a low-risk result endorsed the view that their result meant that they did not need to change their behaviour (even though on behavioural factors they did not differ significantly from the group who received a high risk result). This “certificate of health” effect needs further investigation. Horowitz et al. (1980) followed up men for three years after cardiovascular screening and found that over a third of men reported some intrusive thoughts or attempts to avoid thinking about the news of their increased risk. Even three years later, between one twentieth and a tenth of the sample reported that “any reminder brings back emotions about it” or “I get waves of feeling about it”.

It is possible that receiving a high risk estimate based on a number of factors may be threatening than receiving a high result from a single test, because one is not able to minimize the result by thinking that positive aspects of one’s behaviour “cancel out” the risk from high blood pressure or high cholesterol. Furthermore, in some cases individuals would have learnt that they had both high cholesterol and high blood pressure. The findings of adverse psychological reactions in these two studies may also reflect the fact that they asked specific questions rather than using global measures of distress.

Stoate (1989) found that adults who received a low risk result when screened for risk factors for cardiovascular disease showed an increase in levels of psychological distress. He reports that some people felt that the letter they were sent about risk factors made them feel that they had been negligent. Stoate suggests that the screening may have also increased distress by making people more aware of their own mortality.

Cervical screening

Although positive cervical smear tests can reveal cancer, they can also indicate cervical intraepithelial neoplasia (CIN- which are “pre-cancerous” changes which are associated with a greater risk of cancer) or benign conditions such as inflammation. It has been shown that smear test results which do not indicate invasive cancer but are nonetheless not “normal” can cause severe distress. For example, Palmer, Tucker, Warren and Adams (1993) found that women who had been diagnosed as having CIN a week earlier showed levels of intrusions and avoidance that were similar to people having experienced trauma such as loss of a parent. A week after these women had had treatment, (3-6 weeks after diagnosis), their scores on the same measures had not changed significantly. Wardle, Pernet and Stephens (1995) found that a week after receiving the test result, women with “borderline” results or inflammation - an even less serious diagnosis than CIN) - were more worried and fearful of cancer than women who received negative results. Reelick, de Haes and Schuurman (1984) found that the distress associated with a positive smear result was no longer evident at the 6 month follow-up, although women felt more ill at follow-up than they did before the smear test result. Other effects of positive smear tests include feeling differently about one’s body and about sex (Wardle et al.,1995).

Wilkinson, Jones and McBride (1990) suggest that the distress associated with an abnormal smear result may be due to the fact that pre-cancerous means “early cancer” to most women. They found that women who were sent a leaflet explaining the meaning of a positive result showed less state anxiety and were less likely to think that they had cancer than women who did not receive a leaflet.

Breast cancer screening

There are certain non-malignant breast problems (e.g. atypical hyperplasia) which indicate that a woman has a greater risk of developing breast cancer in the future. There is evidence that women who have abnormal mammograms which turned out not to indicate cancer on further investigation report more cancer worries and disturbances in their daily functioning three months later than women with negative mammograms (Lerman et al., 1991). However, it is not possible to determine whether this distress is because they initially believed that they had cancer or because they are interpreting their abnormal mammography as evidence that they are at future risk. If the latter is the case then many are likely to be overestimating their future risk, since statistically it is probable that only a few of the women actually had atypical hyperplasia.

There have been no psychological evaluations of women who have been told that they have a benign breast disease which indicates that they are at increased risk of cancer in the future. Baum (1989) has observed that this information can cause great anxiety and recommends that these women should not be informed of their risk “unless they are to enter trial of prevention that will reduce their psychological load”. However, other doctors recommend that these women should be informed because they should have regular clinical examinations or self-examinations, so there is clearly a need for research into the psychological impact of providing this risk information.

Psychological reactions to notification of work-related risks

Lebovits, Chahinian, Gorzynski and Holland (1981) interviewed 10 people who had been diagnosed as having asbestos-related mesothelioma. When asked about how they had reacted when they had learnt about the risk associated with being exposed to asbestosis (which had occurred before diagnosis in 9 of the cases), denial and minimization of the risk were reported to be the predominant psychological reactions. None of 8 smokers stopped as a result of the risk information and none of the workers had gone to see their doctor about it. Studies by Houts and McDougall (1988) and others have found that the psychological consequences of notifying and screening workers exposed to carcinogens are not generally serious, although minimization is sometimes apparent.

Health risk appraisals

Health Risk Appraisal is “a procedure for using epidemiological and vital statistics data to provide individuals with projections of their personalized mortality risk ...” (Schoenbach, Wagner and Beery, 1987). Although HRA is probably the most widely used health education strategy for promoting individual behaviour change in the USA (DeFries & Fielding, 1990), research has found that it seems to have only a small (or no) effects on behaviour (e.g. Schoenbach et al., 1987) and risk perceptions. Both pessimistic and the more prevalent optimistic risk perceptions seem difficult to reduce. (Avis, Smith and McKinlay, 1989; Weinstein and Klein, 1995; Lerman et al., 1995). It is possible that HRA is largely ineffective because it often does not give people new information, unlike screening tests for physical abnormalities (unless it includes new information about cholesterol levels, for example). Alternatively, it may not provide the kind of information which people use when assessing their risk - the ways in which people construct risk estimates are poorly understood. HRA fails to address idiosyncratic beliefs which may be important such as “I look just like my mother who died from breast cancer so I’m more likely to develop cancer than my sister, who looks more like our father”. It also does not consider the types of variables which may be maintaining false beliefs, such as anxiety causing selective attention to the threatening information about the illness in question. Although the cognitive-behavioural model of health anxiety suggests some of the ways in which pessimistic health beliefs develop and are maintained, little is known about the mechanisms by which people produce and maintain optimism. Weinstein and Klein (1995) tested four theoretically-based methods for reducing optimism but each failed to reduce it and some increased it. These authors suggest that optimism reduces anxiety and maintains self-esteem, so there is a strong motivational drive to maintain it. They conclude that any attempt to change risk perceptions is hampered by the variety of strategies that people can use to arrive at optimistic conclusions. Clearly, more theoretical work is needed in the field of risk perceptions if health professionals wish to change them.

Laboratory research into psychological reactions to risk factors

Croyle, Ditto and their colleagues have studied the psychological effects of risk factor testing in a laboratory setting, using a paradigm which involves “testing” participants for a fictitious risk factor (see Croyle and Ditto, 1990, for review). A phenomenon which has been the focus of much of their work is denial - in

particular, minimizing the seriousness of the problem and questioning the validity of the test. They have found that subjects who were led to believe that they had tested positive for the risk factor rated the test as a significantly less accurate predictor of the risk factor than did negative-result subjects. In addition, positive-result subjects showed significantly lower ratings of the seriousness of having the risk factor than subjects who thought that they had tested negative. Croyle and Sande (1988) found that positive-result subjects endorse more of a list of "typical symptoms of TAA deficiency" (the risk factor) than negative-result subjects. This indicates that the lower seriousness ratings in the positive-result group cannot be simply be a result of these subjects concluding that the deficiency can't be serious because they don't have symptoms. Ditto, Jemmott and Darley (1988) found that if subjects were led to believe that the risk factor was easily treated, they showed no differences in their ratings of seriousness than test-negative subjects. The authors conclude that this is consistent with the hypothesis that denial is a motivated process designed to reduce the perception of threat. In other words, if the situation is perceived as being less threatening because treatment is available, denial does not occur to the same extent.

Croyle and colleagues have found that college students who have been randomly assigned high blood pressure or high cholesterol readings also show lower seriousness ratings than subjects who have been assigned low readings, so the phenomenon is not exclusive to their fictitious risk factor (Croyle, 1990; Croyle, Sun and Louie, 1993). However, there is a need for the process of minimization to be investigated in non-student populations and in prospective studies of people who are undergoing real health screening. In the existing screening literature, minimization of the seriousness of the risk factor in health screening has only been described qualitatively and with cross-sectional or retrospective methods.

Predicting reactions to health screening

a) Predicting psychological reactions using demographic variables, the type of information provided or treatment compliance

A few studies have examined the effects of post-test information or treatment on distress. Rudd et al. (1986) found that people who were reassured and told that a single measurement can be unreliable showed lower anxiety than people who receive a more traditional message which emphasizes the seriousness of the problem (as discussed earlier). Wilkinson, Jones and McBride (1990) found that women who were given a leaflet explaining the meaning of a positive smear result showed less state anxiety and were less likely to think that they had cancer than women who did not receive a leaflet. Mossey (1981) found that patients who had been told that they needed to take drugs to control the blood pressure were more likely to show adverse effects than patients who had simply been informed that they had high blood pressure or patients who had been assigned to an education program in which they were told "high blood pressure is serious; left untreated, it is a risk factor for other conditions; conscientious compliance with prescribed treatments is recommended". Patients who had been told that they should take drugs generally had more negative ratings on feelings of "goodness", "aliveness", "powerfulness", marital adjustment and self perceived health, after the relevant baseline psychological rating had been entered. The proportion of the variance in distress which was explained by the information condition was low: between 3-9% at the 6 month follow-up and less at the 12 month follow-up. Higher blood pressure at the follow-up assessments and compliance to medication were also associated with higher distress. This is consistent with findings by Harlan et al. (1986) that participants who were on treatment a year after screening had more negative perceptions of their health. It should be noted that in both of these studies, patients were not randomly allocated to the treatment / no treatment groups, so those receiving treatment may have had more severe problems with their blood pressure. In the Mossey (1981) study, for some of the analyses, symptoms at 6 months and recent life events were also associated with distress.

Mann (1981) investigated factors which may be associated with the decrease in scores on the GHQ after hypertension screening which was found in his study. He found that decrease in scores on the General Health Questionnaire at 3 months and one year after hypertension screening could not be explained by the drugs given to reduce blood pressure (propanol is a known anxiolytic), people dropping out of the trial or instability in blood pressure. He concludes that the regular follow-up interviews with clinic nurses may have been beneficial for trial patients.

Regarding cervical screening, Lerman et al. (1991) found that adverse reactions after a positive cervical smear test were more pronounced among those women who did not comply with colposcopy. From

their cross-sectional data it is not possible to establish whether or not the excessive psychological distress predated the non-compliance.

Havas, Reisman, Hsu and Koumjian (1991) found that after a high cholesterol result, there was a significant decrease in ratings of "feeling good". This change was not associated with the sex of the participant, ethnic group, income, length of time in education, family history of heart attack, and prior knowledge that cholesterol was high, but was associated with being older. Younger people and those who were more educated were more likely to show improvements in ratings of health outlook after screening, but none of the other variables were significantly associated with increases in this rating.

b) Predicting psychological reactions to health screening using pre-test psychological measures

There have been very few studies which have examined whether it is possible to predict psychological reactions to risk-factor testing using pre-test psychological variables. Regarding risk perceptions after the scan, Codori and Brandt (1994) found that there was a non-significant tendency for people who underestimated their risk for HD after a high risk result to have reported lower risk perceptions prior to the test than people who did not underestimate their risk. Lerman et al. (1995) found that risk counselling about breast cancer in women with a family history of breast cancer was significantly less effective among those with higher base-line levels of breast cancer preoccupation. This may partly be because anxiety was probably also high in this group, and anxiety has been shown to be associated with an attentional bias towards threatening information. The women may have selectively attended to the information about their increased risk due to family history - which is not negligible - and paid less attention to the fact that their personalized computer estimate did not match their previous perceived risk. According to a cognitive-behavioural viewpoint, in order to reduce over-estimates it would be necessary to elicit and modify the idiosyncratic beliefs that were resulting in the high risk estimate (e.g. I look very similar to my mother who died of cancer and therefore share most of her genes).

There have been two studies looking at pre-scan psychological predictors of distress after risk-factor testing. Reelick, de Haes and Schuurman (1984) found that distress a week after a positive cervical smear result was greater in women who were worried about the result before it was known. Tibben et al. (1993) found that the number of intrusive thoughts about HD experienced six months after genetic testing were predicted by pre-test denial/avoidance, the test result and pre-test intrusions. They also report that significant predictors of post-test scores on the Beck Hopelessness Scale (BHS) were pre-test scores on the BHS, pre-test absence of denial/avoidance behaviours and unsatisfactory social support; the result itself was not a significant predictor. This study highlights the fact that one cannot predict reactions to genetic testing simply on the basis of the test result and indicate the importance of pre-existing psychological factors in determining response to screening.

In areas other than risk factor testing, there have been a number of previous studies assessing whether it is possible to predict reactions to stressful situations using the Miller Behavioural Style Scale (MBSS), (Miller, 1987). This questionnaire is intended to assess two different types of coping strategies- monitoring, which is a preference for information, and blunting which is an avoidance of threat-relevant information. A number of studies have found that "high" monitors show greater distress under stressful circumstances than "low" monitors- for example, Wardle et al. (1993) found that women with a monitoring coping style were more adversely affected by a positive result from an ovarian cancer screening test. There is also evidence that people fare better if the information provided is matched to their coping preference (Miller and Mangan, 1983). However, it has been found that monitoring and coping styles do not seem to be associated with the extent to which people "minimize" health threats (Croyle, Sun and Louie, 1993).

As Miller's formulation of monitoring has developed it has begun to include concepts derived from cognitive theories of anxiety. However, her current position (outlined in Schwartz, Lerman, Miller, Daly and Masny, 1995) differs in certain crucial ways from cognitive-behavioural models of anxiety. Miller asserts that high monitors scan for threat-relevant cues and this process generates a high degree of intrusive ideation, although she does not specify a possible mechanism for this process. She writes that "monitors tend to encode neutral or ambiguous information as highly threatening and to perseverate on this information, leading to exaggerated perceptions of personal risk. The high level of perceived risk and the high degree of intrusive ideation may result in heightened anxiety". In contrast, the CB model would say that "intrusive ideation" and a tendency to "encode neutral or ambiguous information as highly threatening" will result in monitoring. The CB model asserts that certain beliefs can lead the person to monitor for threatening stimuli and that the monitoring will usually occur within a specific domain. For example, someone who feels

that they are about to have a heart attack may monitor chest sensations and someone who thinks that they are in danger of being attacked will be on the look-out for suspicious looking people- but the opposite pattern is unlikely to occur. In contrast, Miller's approach is to consider monitoring as a general trait. Miller's questionnaire would not be able to predict which individuals are particularly likely to show distress in different types of threatening situations (e.g. which people are particularly vulnerable to distress after a health threat and which people are more likely to react with distress to a social threat). Thus although some studies have found that monitors show greater distress in various different threatening situations, this is likely to be due to some kind of general factor (the exact nature of which is unclear) which can account for fairly small amounts of the variance. The CB model would argue that larger amounts of the variance in distress could be predicted by assessing pre-existing beliefs about the particular threatening situation. According to the CB models, selective attention to threat may maintain anxiety but it is beliefs which will cause the initial distress. Miller's formulation thus represents something similar to just one of the several maintenance components of CB models of anxiety.

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(The references for the main part of the thesis are immediately after the final discussion)

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Appendix B: Details of studies mentioned in Appendix A : study design, recruitment methods, proportion of screened participants who entered the psychological study, proportion of subjects who returned follow-up questionnaires, measures used and summary of problems.

It should be noted that these tables corresponds to the papers cited in appendix A and do not mention every study that has been carried out in these areas. “Prospective” is used to refer to studies in which the first point is before the screening results- other studies with multiple assessment points will be referred to as “longitudinal”.

Studies are arranged alphabetically within the particular type of health test.

Abbreviations: STAI- Spielberger’s State-Trait Anxiety Inventory

BDI- Beck Depression Inventory

BHS- Beck Hopelessness Inventory

IES- Impact of Event Scale

GHQ- General Health Questionnaire

General problems: One problem which affects the majority of studies is that the baseline psychological characteristics of the participants are not described in relation to the general population so the extent to which the findings will generalize to other samples is unclear.

Genetic testing for Huntington's Disease

General problems in the research into the effects of HD testing
In studies of Huntington's Disease testing it should be remembered that those undergoing testing are a highly selected sample. Not only is there evidence that those who chose to be screened are more psychologically healthy than the sample as a whole, but the testing programs ensure that no-one who is seen to be currently psychologically vulnerable is allowed to be tested.
In all cases of genetic testing reported so far, those tested will have a proven family history of the disease in question, and it is not known to what extent results from these people will generalize to people who did not previously perceive themselves as being at familial risk.
Although in all protocols extensive counselling was given before and after the results, the nature of this counselling is not described.

Authors	Nature of study and timing of assessments	Recruitment and sample	Proportion entering psychological study	Follow-ups	Measures	Summary of problems
Bloch, Fahy, Fox & Hayden, 1989	Cross-sectional (before testing, exact time not specified)	People who requested testing. They must be assessed to be free from major psychiatric disorders and serious suicidal risk at the time of testing.	Psychological assessment was integral part of the testing process. Results from the first 51 people to complete the initial assessment are used in this study.	N.A.	Global Severity Index of SCL-90R, Mental Health Index of the General Well-being scale, the Behaviour Survey, Reasons for Living scale. Attitudes towards testing (nature of this questionnaire not specified)	

Byrne & Bamforth, 1994	Single case report	Woman had been referred for psychiatric treatment	N.A.	N.A.	N.A.	Clinical observation	Only one subject and clinical observation
Codori and Brandt, 1994	Mainly cross-sectional (1-6 years after testing) although they had a little pre-scan information	Participants in their testing program were contacted between 1 and 6 years after testing. (People had been excluded from testing is they had symptoms of HD or current serious psychological disorder “or any condition that compromises subjects’ capacity to fully evaluate risks and benefits”).	100% (17) of the high-risk sample and 91% of (51) low-risk sample	N.A.	9 questions about effects of testing which allowed the person to choose responses from a checklist or give their own response. Visual analogue scales for perceived risk.	9% of the low risk sample didn’t participate. This is approximately the frequency at which it has been suggested that severely adverse effects occur in low-risk subjects and their findings may be an underestimate of distress.	
Hayes, 1992	Single case self-report	Woman wrote to journal to describe her experiences of being tested	N.A.	N.A.	Self-report	Only one subject	
Huggins et al., 1992	Prospective case reports (Several months before and then differing follow-up points for the 6 people)	6 people with low risk results were selected for this series of reports because they had shown adverse reactions	Psychological assessment was integral part of the testing process. N=6	Subjects were only selected if follow-up data was available	General Severity Index of SCL 90-R, BDI	The small number of subjects may limit the extent to which their conclusions about reasons for distress in low risk subjects will generalize.	

Meissen et al., 1988	Longitudinal (Immediate reactions to results, then 3 days later, 3 months, 9 months and 1 year)	People who requested linkage testing after seeing an announcement in the newsletter of the Massachusetts Chapter of the HD society of America. People were excluded if they had schizophrenia or unipolar or bipolar depression, a suicide attempt within the previous 10 years, intended to commit suicide if the result were positive, or drug or alcohol abuse. A psychiatrist evaluated others for their suitability for testing if they had moderate depression, recent stressful life events, family history of suicide, attempted suicide more than 10 years earlier or contemplation of suicide related to HD.	Psychological assessment was integral part of the testing process. 4 people had positive results, 7 had negative and 5 were uninformative. (One of these tests was a prenatal test, but they do not specify which of the results corresponds to this test.	Not specified.	Observer ratings of initial reactions. The type of assessments made at subsequent follow-ups are not specified.	No baseline data. Nature of assessments not specified.
Tibben et al., 1992	Retrospective and cross-sectional (1 year after test)	Adults who had requested testing. People were excluded from testing if they had a major mental illness or intended to commit suicide after an unfavourable result or had neurological manifestations of HD.	Psychological assessment was integral part of the testing process. 9 high and 9 low test results	88%	Attitude Questionnaire, Beck Hopelessness Scale, GHQ, Multidimensional Locus of Control, Defense Mechanisms Inventory. Interviews were also carried out.	No baseline data. Only one interviewer and interview did not seem to be standardized, so many of conclusions from the interview are highly subjective. Small numbers of subjects.

Tibben et al., 1994	Prospective (Before testing -exact time not specified, after disclosure and 6 months later	Adults who had requested testing. People were excluded from testing if they had a major mental illness or intended to commit suicide after an unfavourable result or had neurological manifestations of HD.	Psychological assessment was integral part of the testing procedure. N=73	100%	Impact of Event Scale; Beck Hopelessness Scale; GHQ.	
Tyler et al., 1992	Cross-sectional (after results)	Self-referrals for testing as well as referrals from GPs and hospital consultants. People were excluded from testing if they had “current significant mental symptoms” or had a recent history of serious mental illness or drug misuse. Also if they showed “equivocal signs of HD”.	Baseline psychological assessment was an integral part of the testing procedure but was not reported here. N=40	3 of the 40 tested refused to take part in follow-ups and each was very distressed.	Clinical observation of psychological effects	Clinical observations only. Baseline psychological characteristics were assessed but have not been reported.
Wiggins et al., 1992	Prospective (Several months before testing, then at a week, 6 months and 12 months later)	People who requested testing. They must be assessed to be free from major psychiatric disorders and serious suicidal risk at the time of testing.	Participation in psychological data collection was integral of testing process. N=135	24 of the 40 for whom the test was not informative dropped out before follow- up.	General Severity Index from Symptom Checklist 90-R. BDI General Well-being Scale	Conclusions about the no-change group are limited by the fact that over half of those for whom the test was uninformative dropped out.

Genetic testing for breast / ovarian cancer						
Authors	Nature of study and timing of assessments	Recruitment and sample	Proportion entering psychological study	Follow-ups	Measures	Summary of problems
Lerman, Daly, Masny & Balshem, 1994	Cross-sectional	Subjects were identified by their relatives, who were undergoing treatment for ovarian cancer 19% refused to give permission to contact their relatives and 20% did not have eligible relatives	Of 131 relatives contacted, 121 completed the interview but 15% of these did not return psychological questionnaires so the final sample was 103 (79% of those contacted)	N.A.	Profile of Mood States, Miller Behavioural Style Scale, risk perceptions and cancer worries (using Likert-style items)	Quite a large proportion (at least 34%) of the potential sample did not take part, either because their relatives did not want them to be contacted or because they refused or dropped out.
Lynch et al., 1993	Longitudinal-immediately after disclosure and 3-6 weeks later	176 members of a family known to carry the BRCA1 gene were sent information about the test. 50 of 176 who were invited underwent linkage analysis.	Baseline psychological assessment was an integral part of the pre-test process. In this study the reactions of 8 women with high risk results, 13 women with low risk results are reported together with 2 high risk and 2 low risk men.	84% (21) completed the 3-6 week follow-up.	Structured interview assessing emotional impact with yes/no questions about depression, anger, relief, worry, confusion, pessimism, sleep disturbance and emotional lability.	No baseline data regarding psychological distress. Small number of subjects.
Watson et al., 1995	Prospective (Exact time of assessments not specified)	People who were part of the breast/ovarian cancer consortium study were offered testing. Of 32 people who were offered testing, 13 participated	Psychological assessment seems to have been integral part of the testing process. 13 subjects	Not specified	Measures of "general mental health, anxiety state and intrusive thoughts about cancer" but the names of the measures were not given	Small number of subjects. Since their report is only a letter to a journal there are no details, so it is not possible to comment on the method.

Genetic testing for Alzheimer's Disease							
Authors	Nature of study and timing of assessments	Recruitment and sample	Proportion entering psychological study	Follow-ups	Measures	Summary of problems	
Lannfelt, Axelman, Lilius and Basun, 1995	Case study (although two others are briefly mentioned)	60 people were invited to have testing because it was known that their family were at risk for Alzheimer's Disease from a certain mutation. Only 3 agreed to be tested.	N.A.	N.A.	Clinical observation	Only one subject received a positive result. Clinical observation only.	

Hypertension screening						
	Nature of study and timing of assessments	Nature of recruitment for screening and/or psychological part of the study	Proportion of those screened who entered the psychological study	Return follow-up questionnaires	Measures	Summary of problems
Charlson, Alderman and Melcher, 1982	Prospective Absenteeism throughout the year before and the year after screening	99% of 2495 employees of an insurance company agreed to be screened for hypertension. 273 had high blood pressure. 239 normotensives were randomly chosen as the control group.	There was not a psychological study to which the participants had to "opt in"; absenteeism was assessed through company records. 94.9% (259) of those with high blood pressure were assessed (of those not used- 3 had retired, 2 were on extended sick leave, 8 left their job). Data not presented for the normatensives.	N.A.	Absenteeism from attendance records	Homogeneous sample. Some of those who were not considered because of retirement or leaving the job may have been influenced in their decision to leave because they attributed their high blood pressure to the job. The way in which risk information was conveyed is not described.
Haynes, Sackett, Taylor, Gibson & Johnson, 1978	Prospective Absenteeism throughout year before and year after screening	Random sample (n=5400) of employees in industrial setting were screened (They don't report any refusals to be screened)	94% (245) of those with high blood pressure (some previously aware and some not)	90% (208) of those who opted in	Absenteeism (from company records), treatment compliance and blood pressure control	No normotensive or unscreened control groups. Subjects all male and working for same company- homogeneous sample. The way in which risk information was conveyed is not described.
Mann, 1981.	Prospective. (Immediately before screening, 3 months later and a year later)	Participants were recruited from general practices, industrial health centres and a community health project. The proportion of those asked to attend who actually took part is not reported.	Proportion of those screened who entered the psychiatric study is not reported.	598 completed the first 3 months of the trial (proportion of total sample not specified). Of these, 516 (86.2%) completed the year follow-up.	GHQ, Hostility and Direction of Hostility questionnaire.	Patients were excluded if they had a history of psychiatric disorder or if their "current mental state or social problems appeared to be sufficiently distressing for the trial to be an unnecessary burden". These decisions were left to GPs and it is not specified how many were excluded in this way or the exact reasons for exclusions.

Milne, Logan & Flanagan, 1985	Cross-sectional (One group assessed within 6 months of diagnosis and the other between 1-3 years after diagnosis)	Employees who had taken part of industrial blood pressure screening and whose screening records were on file in a certain hospital. Selected for lack of significant health problem apart from hypertension.	99.3% (n=150) 50 diagnosed within last 6 months, 50 diagnosed 1-3 years previously and 50 controls with low BP	N.A.	Structured interview, including rating scales for worry about health, health status, absenteeism.	No baseline data. Interviewer was not blind to blood pressure result or time since diagnosis. Subjects had actively sought blood pressure reading and/or medical care so are a selected sample. No untreated hypertensive group.
Mossey, 1981	Prospective (First assessment was "during screening phase before results were given", then 6 months and 12 months later)	Same sample as Haynes et al. (see above)	94% (245) of those with high blood pressure	92% (210) for first 6 months (86% of all those with high BP)	Locke Wallace Marital Adjustment scale & semantic differential scales assessing attitudes about self	See comments under Haynes et al. (above)
Moum, Naess, Sorenson, Tambs and Holmen, 1990	Prospective (Immediately before the test, before the results and 1-3 years later)	74977 adults in a county in Norway were screened for hypertension (86% of those invited). They estimate that if those who had died or moved were excluded, take-up of the test was at least 90%.	All of those screened had to complete the first questionnaire immediately before the test. 84% (62784) of those screened completed returned the pre-result questionnaire.	Of the group who completed the first 2 questionnaires, all the hypertensives and a random sample of 4000 normotensives were sent follow-up questionnaires. 80-81% from both samples returned them.	6 questions designed to assess overall "psychological/subjective/ emotional wellbeing". (They include validity analyses for these questions)	Subjects were screened for diabetes and lung disease at same time and these results do not seem to be controlled for. The way in which risk information was conveyed is not described. Two of their questions will be given high scores by people who are physically ill but not necessarily distressed.

Rudd et al. 1986	Randomized controlled trial. Prospective. (Immediately before screening and 6 months later)	Workers at electronics plants 48% of eligible workers were screened. 5% (296) had high BP.	5005 (85%) of those screened completed the psychosocial questionnaires at time 1.	54% completed the 6 month follow-up psychosocial questionnaires.	STAI (state and trait) Spanier Adjustment Scale, GHQ. Also "personal sense of well-being, job satisfaction and concerns about participation in the study".	Only 48% of those offered hypertension screening took part, and of these only 54% completed the follow-up questionnaire.
Rudd et al, 1987	Randomized controlled trial. Prospective. (Immediately before screening, 6 months later and one year later)	(See Rudd et al. 1986, above)	5888 subjects completed baseline questionnaires (100% of those screened) Of these, 296 sustained hypertensives and 769 randomly selected normal controls were chosen as the two main comparison groups for follow-up	91-94% of high BP group did not drop out, but only 67-73% of normotensives stayed in the study. All of the random 18% of high BP group who were telephoned for additional details agreed to talk to experimenter.	Absenteeism for the year before and after testing.. Overall health perceptions, knowledge about hypertension and demographic variables were assessed at time 1.	Only 48% of those offered hypertension screening actually took part, a much lower figure than most of the other studies into absenteeism after worksite screening.
Soghikian, Fallick-Hunkeler, Ury & Fisher, 1981	Cross-sectional (Time since screened for blood pressure not assessed but would have varied widely)	Health plan members who had voluntarily chosen to have a multiphasic checkup were asked whether they had previously been told that they were hypertensive	82.3% (52, 948) of those who had the check-up	N.A.	5 questions (yes/no answers) about worrying and stress (content not specified). Adapted from Cornell Medical Index and Minnesota Multiphasic Personality Inventory	Scales not validated. Subjects had chosen to have check-up and may be more concerned about their health than average person. Cross-sectional only; those who already knew their blood pressure may have had higher pre-existing distress levels. For example, it is possible that pre-existing psychological distress in these people was associated with more visits to their doctor and hence more opportunities to discover their high blood pressure.

Stoate, (1989) - see under cardiovascular risk factors

Cholesterol testing							
	Nature of study and timing of assessments	Recruitment	Proportion entering psychological study	Follow-ups returned	Measures	Summary of problems	
Brett, 1991	Retrospective (Unspecified and various lengths of time since screening)	6 cases selected from clinical practice by the author because they showed adverse effects of screening	N.A.	N.A.	No measures used, just unstandardized observations of the author.	Small number of subjects. The author had not met the patients before testing so cannot provide details of pre-testing characteristics. Anecdotal data only.	
Fischer, Guinan, Burke, Karp & Richards, 1990	Retrospective and cross-sectional (1 year after screening)	Volunteer screening program held at shopping mall.	62% return rate (n=672).	N.A.	2 subscales of the General Wellbeing Schedule. Standardized questions about knowledge of cholesterol, and follow-up care undertaken.	No baseline data.	
Havas, Reisman, Hsu & Kournjian, 1991	Prospective. (Immediately before screening and 2-4 months later).	Volunteers recruited through posters, website newsletters and notices in mass media.	100% (n=1093)	79% (867) had both baseline and follow-up data.	Health perceptions questions selected from RAND Corporation general health perceptions questionnaire	Selection of questions not validated. No normotensive control group. Subjects were told that cholesterol is largely under the individual's control, but since then dietary changes have been shown to be often ineffective, so this may have minimized their distress in an inappropriate way.	
Hyman, Flora, Reynolds, Johansson & Farquhar, 1991	Prospective (Immediately before test and 3 months later)	184 people recruited through newspaper advertisements.	100% (n=184)	77% (143)	6 items from General Well-being Schedule. Two items from Stanford Five-City study about health perceptions. Self-reported absenteeism, restricted activity and physician visits.	Only selected items used from scales - the validity of these individual items is not known.	

Screening for multiple cardiovascular risk factors						
	Nature of study	Recruitment	Proportion entering psy. study	Follow-ups	Measures	Summary of problems
Horowitz et al. 1980	Retrospective and longitudinal (Yearly assessments, 1-3 years after screening).	Volunteer sample recruited from San Francisco area were screened.	Subjects were excluded from the psychological study if they had overt heart disease, other major illness, "geographic instability". The proportion of those eligible to take part who actually entered the study is not reported.	Of the 575 men who agreed to take part and for whom all other information was available, 486 (84.5%) completed all 3 follow-ups (1,2, and 3 years after screening)	Impact of study stress scale and Experiential stress scale	Sample all male. No baseline data. First assessment point was a year after screening and early impact may be forgotten by this time. No control group. The way in which risk information was conveyed is not described.
Stoate, 1989	Prospective (Immediately before screening and 3 months later)	People of a certain age registered at a general practice were offered a free health check. The number offered the test is not specified but 215 accepted. Only those with normal results are included in this study. Controls were people who had not been invited for a health check.	All screened participants (n=215) completed the first questionnaire but only 82.2% of the control group.	87.9% of the screened group completed the follow-up and 68.8% of the control group completed both questionnaires.	GHQ	The way in which risk information was conveyed is not described.
Tymstra & Bieleman, 1987	Retrospective (2 months after screening)	All the men in a small town in the Netherlands were invited by their GPs to take part in screening for cardiovascular risk factors. 267 (62%) took part.	79% (210) of the participants and 56% (90) of non-participants	N.A.	Open-ended questions about motives for taking part. Questions about findings of the screening, changes in behaviour (nature of questions unspecified) and a question about whether the result was proof that they did not need to change their way of life.	Unstandardized questions. Retrospective. Sample all male.

Cervical cancer screening						
	Nature of study and timing of assessments	Recruitment methods	Proportion entering psychological study	Follow-ups	Measures	Summary of problems
Palmer, Tucker, Warren & Adams, 1993	Cross-sectional (One week after diagnosis and one week after treatment)	Women who had been diagnosed as having CIN. It is not specified if they had smear in response to a letter from their GP or for some other reason.	Of those approached, 50% of those with negative and 96.2% of those with positive results agreed to take part. 20 were selected from each group. Women who had asked not to be contacted at home were not approached but numbers not specified.	All of those who completed first stage also completed the second (ie 20 in each group).	Impact of Events Scale; State Trait Anger Scale; Multi-dimensional health locus of control; semi-structured interview to explore understanding or condition and experience of treatment	No baseline data. The way in which risk information was conveyed is not described.
Reelick, de Haes & Schuurman, 1984	Prospective (3 measurement points: before results were known (exact time not specified), a few days after the results, then after treatment for the positive group).	All women with positive smear in Rotterdam between certain dates (n=175). Random sample of women from same place with inconclusive (n=175) or negative smears (n=350)	84% (n=418) participated in the pre-test.	Of the 418 who participated, 87% with a positive smear took part in post-test1 (compared to 95% of women who needed rescreening and 97% of those with a negative smear). For post-test 2, 142 women with positive results were invited- 114 (80%) took part.	Structured interviews with both closed and open-ended questions. 6-point Semantic Differential of 10 contrast pairs for how woman was feeling; 4-point Likert scales for various topics such as having children, menstruation.	Does not describe the way in which risk information was conveyed. Does not describe baseline psychological characteristics of those who didn't complete follow-ups.

Wardle, Pernet & Stephens, 1995	Cross-sectional (one week after test result)	Women who had smear tests were recruited from 2 health practices. 139 women with any kind of abnormality and 203 age-matched controls were sent a questionnaire.	51% (71) of women with positive results and 61% (123) of women with negative results	N.A.	State anxiety scale of the STAI GHQ Questions about health, body image, concern about fertility or illness and pessimism about future health	No baseline data.
Wilkinson, Jones & McBride, 1990	Randomised controlled trial of informational intervention after positive smear result	Women who had received a positive smear were randomly allocated into "leaflet" (n=29) and "no leaflet" condition (31)	The proportion of those offered the chance to take part who actually participated is not specified. There were 29 subjects in the "leaflet" condition and 31 in the "no leaflet" condition	Not specified	Structured interview during consultation: Psychiatric history; understanding of the result; health perceptions The STAI was given before and after the consultation.	

Breast cancer screening							
Authors	Nature of study and timing of assessments	Recruitment	Proportion entering psy. study	Follow-ups	Measures	Summary of problems	
Baum, 1989	Clinical observation	Women attending breast clinics (numbers unspecified)	N.A.	N.A.	None	Only subjective impressions of distress levels in women attending clinics.	
Lerman et al. 1991	Cross-sectional, 3 months after mammography (and at 15 months just to check whether had repeat mammogram)	Women who had had mammograms as part of free US Healthcare Check program	85% (n=308)	80% (n=247)	Telephone interview	No baseline data for psychological factors. Actual diagnosis not reported.	

Notification of work-related risks							
Authors	Nature of study and timing of assessments	Recruitment	Proportion entering psychological study	Follow-ups	Measures	Summary of problems	
Houts & McDougall, 1988	Cross-sectional (5 years after notification of health risk)	Workers were telephoned 5 years after notification of health risks at work. Control group were randomly selected from union membership, were from same industry but had not been exposed to asbestos	90% (133) of notified workers and 91% (137) of control group	N.A.	Telephone interview: socio-demographic characteristics, Demoralization Scale, attitudes towards health, whether had talked to counsellor in past year, whether took medicine in order to relax, whether smoked	No baseline data. The event occurred 5 years prior to assessment so even people who experienced very substantial long-term negative effects will go undetected if their problems resolved within this time period. Similarly their other measure of psychological distress do not assess specific effects such as effects on health perceptions. Although the various sources of risk information are described, the content of the risk messages is not.	
Lebovits, Chahinian, Gorzynski and Holland, 1981	Retrospective (Varying lengths of time since informed of risk)	10 patients with malignant mesothelioma	100%	N.A.	Semi-structured interview regarding reactions to risk information, smoking behaviour, feelings about the disease etc.	Small sample. No standardized questionnaires. Patients had already been diagnosed with disease which may have influenced their memories of their reactions to the risk information.	

Health Risk Appraisals							
Authors	Nature of study and timing of assessments	Recruitment	Proportion entering psychological study	Follow-ups	Measures	Summary of problems	
Avis, Smith & McKinlay, 1989	Prospective (Immediately before HRA and 2 months later). Random assignment to different types of Health Risk Appraisal	Recruited by random digit dialling of residential households in 15 neighbourhoods in Boston area.	Not specified in this article	Not specified in this article	Interviews, including questions about perceived health status and personal health risks compared to average person of same age and sex.	No control group who received no HRA. The proportion who already knew their blood pressure or cholesterol levels are not reported, although those who already knew that they had high blood pressure are excluded.	
Lerman et al., 1995	Randomized controlled trial (Risk assessment for breast cancer or general health information)	Subjects were identified by their relatives who were being treated for breast cancer	52% (227) of those invited to participate completed the intervention visit.	Of 227 who did first part, 88% (200) completed the 3 month follow-up	Intrusion subscale of Revised Impact of Event Scale, risk perceptions for developing breast cancer in their lifetime (0-100 scales)	Only half of those approached took part and they were more anxious and more educated than those who refused.	
Weinstein & Klein, 1995	4 experimental studies attempting to alter risk perceptions	Visited homes in the New Jersey communities for one study, otherwise students who were taking part for course credit	85.7% (222) for community study, Numbers were 164-374 for the studies involving students	N.A.	Personal risk for future health threats relative to average person of the same age	Three experiments involved only undergraduates.	

Laboratory research into psychological reactions to risk factors							
Authors	Nature of study and timing of assessments	Recruitment and sample	Proportion entering psychological study	Follow-ups	Measures	Summary of problems	
Croyle and Sande, 1988	Experimental (False good or bad test result) Measures taken immediately after the test.	Undergraduates who participated for extra course credit	6 subjects were excluded because they reported suspicions about the study, leaving 79 students	N.A.	Mood ratings on four 9-point scales, perceived seriousness and test accuracy on 22-point scales, symptoms, risk behaviours,	Student volunteers. Fictitious test for non-serious risk factor- may not be generalizable to real-life screening.	
Ditto, Jemmott & Darley, 1988	Experimental (False good or bad test result) Measures taken immediately after the test.	Students volunteers	4 were excluded because they were suspicious of the manipulation, leaving 72 subjects	N.A.	Perceptions of threat, false-positive rate of test, prevalence of risk factor, seriousness of risk factor, likelihood that risk factor leads to disease	As above	
Croyle, 1990	Experimental (False good or bad result) Measures taken after the false feedback.	Undergraduates who volunteered for a "health survey in which blood pressure would be measured"	40 in first study, 80 in second	N.A.	Perceived seriousness (after testing)	As above	
Croyle, Sun & Louie, 1993	Cross-sectional (Immediately after test result)	Recruited for cholesterol testing in the mass media.	227 adults	N.A.	Perceived seriousness (after testing)	No baseline data on seriousness ratings so it's possible that there were pre-existing differences	

Predicting individual differences in reactions to health screening							
a) Using predictors other than pre-scan psychological measures Rudd et al. (1986), Mossey (1981) and Mann (1981) - see under hypertension screening. Wilkinson et al. (1990) - see under cervical screening. Havas et al. (1991) - see under cholesterol testing.							
Lerman et al. 1991	Cross-sectional and retrospective (3 months after screening)	Women recruited from two clinics. Telephoned 3 months after a cervical smear test.	70% (224) of those who for whom contact had been attempted.	N.A.	Demographics, screening and sexual history. Multiple choice questions for cancer worries, tension, mood, sexual interest, sleep patterns.	No baseline data and it would have been useful to see initial responses to the screening as well, to see if these predicted whether the woman would comply with colposcopy.	
Harlan et al. 1986	Prospective (immediately before screening and a year later)	Multicentre study but recruitment methods not specified in this paper.	Not specified.	92%	Multiple choice questions regarding perceived health, health worries, physical activity.	The questions they use are not validated and some may not be very sensitive.	
B) Using pre-scan psychological measures as predictors Codori and Brandt (1994) - see under testing for Huntington's Disease. Lerman et al. (1995) - see under Health Risk Appraisals. Reelick, de Haes and Schuurman - see under cervical cancer screening. Croyle, Sun and Louie (1993) - see under laboratory research.							
Tibben et al. 1993	Prospective (Exact time of baseline assessment not specified, then at disclosure and 6 months later)	Participants had requested testing for HD	Psychological baseline assessment was integral part of testing. 29 high risk 44 low risk	100%	IES BHS GHQ Social Support Questionnaire		

Wardle et al. 1993	Prospective (6-15 weeks before testing, after each scan and at 3 month follow-up)	Women recruited for ovarian screening through national media. Control group were recruited from nominated neighbours of the screening participants and staff at Kings College. 500 were invited for screening- 66% (332) attended.	Of the 332 attending screening, 80% (266) completed baseline data. Of 350 questionnaires sent to control group, 53% (186) were returned.	The first follow-up was returned by 81% (189) of those with negative scans and 81% (56) of those with positive scans. The second follow-ups were completed by 75% of those with negative results, 69% of those with positive results and 65% of those who had had surgery. The 3 month follow-ups were completed by 79% of those with negative results, 63% of those with scan 1 positive results and 65% of those who had had surgery. 63% of those screened completed both baseline and 3 month follow-up. It should be noted that the numbers returned follow-ups include some (number unspecified) who did not complete the baseline assessment. The proportion completing all follow-ups is also not reported.	Perceived risk of cancer and worry about cancer compared to before the scan. Shortened version of the Miller Behavioural Style Scale, the two subscales of the Hospital Anxiety and Depression Scale; GHQ.	
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Appendix C- The Health Anxiety Questionnaire

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, over the past six months. Identify the statement by ringing the letter next to it i.e. if you think that statement (a) is correct, ring statement (a) ; it may be that more than one statement applies, in which case, please ring any that are applicable.

1. a. I do not worry about my health.
 b. I occasionally worry about my health.
 c. I spend much of my time worrying about my health.
 d. I spend most of my time worrying about my health.
2. a. I notice aches/pains less than most other people (of my age).
 b. I notice aches/pains as much as most other people (of my age).
 c. I notice aches/pains more than most other people (of my age).
 d. I am aware of aches/pains in my body all the time.
3. a. As a rule I am not aware of bodily sensations or changes.
 b. Sometimes I am aware of bodily sensations or changes.
 c. I am often aware of bodily sensations or changes.
 d. I am constantly aware of bodily sensations or changes.
4. a. When I have an unexplained bodily sensation or change I rarely worry about it.
 b. When I have an unexplained bodily sensation or change I sometimes worry about it.
 c. When I have an unexplained bodily sensation or change I often worry about it.
 d. When I have an unexplained bodily sensation or change I always worry about it.
5. a. Resisting thoughts of illness is never a problem.
 b. Most of the time I can resist thoughts of illness.
 c. I try to resist thoughts of illness but am often unable to do so.
 d. Thoughts of illness are so strong that I no longer even try to resist them.
6. a. I never worry about dying.
 b. I occasionally worry about dying.
 c. I often worry about dying.
 d. I worry about dying most of the time.
7. a. When I have an unexplained bodily sensation or change, I rarely think that it is a sign of illness.
 b. When I have an unexplained bodily sensation or change, I sometimes think that it is a sign of illness.
 c. When I have an unexplained bodily sensation or change, I often think that it is a sign of illness.
 d. When I have an unexplained bodily sensation or change, I always think that it is a sign of illness.
8. a. As a rule I am not afraid that I have a serious illness.
 b. I am sometimes afraid that I have a serious illness.
 c. I am often afraid that I have a serious illness.
 d. I am always afraid that I have a serious illness.
9. a. I do not have images (mental pictures) of myself being ill.
 b. I occasionally have images of myself being ill.
 c. I frequently have images of myself being ill.
 d. I constantly have images of myself being ill.
10. a. It usually feels extremely unlikely that I will develop a serious illness in the near future.
 b. It usually feels unlikely that I will develop a serious illness in the near future
 c. It usually feels as though there is some likelihood that I will develop a serious illness in the near future.
 d. It usually feels likely that I will develop a serious illness in the near future.

11.
 - a. If I notice an unexplained bodily sensation or change I don't check to see how it develops.
 - b. If I notice an unexplained bodily sensation or change I check it occasionally to see how it is developing.
 - c. If I notice an unexplained bodily sensation or change I check it frequently to see how it is developing.
 - d. If I notice an unexplained bodily sensation or change I constantly check on it.
12.
 - a. The idea that I have a serious illness is senseless.
 - b. The idea that I have a serious illness might be sensible.
 - c. The idea that I have a serious illness is probably sensible.
 - d. The idea that I have a serious illness is realistic.
13.
 - a. I do not avoid situations which trigger thoughts of death or dying.
 - b. I sometimes avoid situations which trigger thoughts of death or dying.
 - c. I often avoid situations which trigger thoughts of death or dying.
 - d. I always avoid situations which trigger thoughts of death or dying.
14.
 - a. If I notice an unexplained bodily sensation I ignore it.
 - b. If I notice an unexplained bodily sensation I focus on it from time to time.
 - c. If I notice an unexplained bodily sensation I focus on it often.
 - d. If I notice an unexplained bodily sensation I constantly focus on it.
15.
 - a. I don't usually examine my body.
 - b. I often examine my body.
 - c. I examine my body daily.
 - d. I examine my body constantly.
16.
 - a. I do not have any difficulty taking my mind off thoughts about my health.
 - b. I sometimes have difficulty taking my mind off thoughts about my health.
 - c. I often have difficulty in taking my mind off thoughts about my health.
 - d. Nothing can take my mind off thoughts about my health.
17.
 - a. I am lastingly relieved if my doctor tells me there is nothing wrong.
 - b. I am initially relieved but the worries sometimes return later.
 - c. I am initially relieved but the worries always return later.
 - d. I am not relieved if my doctor tells me there is nothing wrong.
18.
 - a. If I hear about an illness I never think I have it myself.
 - b. If I hear about an illness I sometimes think I have it myself.
 - c. If I hear about an illness I often think I have it myself.
 - d. If I hear about an illness I always think I have it myself.
19.
 - a. If I notice an unexplained bodily sensation or change I rarely try to find out the cause.
 - b. If I notice an unexplained bodily sensation or change I sometimes try to find out the cause.
 - c. If I notice an unexplained bodily sensation or change I often try to find out the cause.
 - d. If I notice an unexplained bodily sensation or change I always try to find out the cause.
20.
 - a. My health worries do not interfere with my life.
 - b. Occasionally my health worries interfere with my life.
 - c. Often health worries interfere with my life.
 - d. I am unable to do anything because of my health worries.
21.
 - a. I never believe that I am going to die soon.
 - b. I sometimes believe that I am going to die soon.
 - c. I often believe that I am going to die soon.
 - d. I constantly believe that I am going to die soon.
22.
 - a. I am never afraid of visiting my doctor because of my health worries.
 - b. I am sometimes afraid of visiting my doctor because of my health worries.
 - c. I am often afraid of visiting my doctor because of my health worries.
 - d. I am too afraid to visit my doctor because of my health worries.

23. a. Worries about my health do not stop me thinking about other things.
b. Worries about my health sometimes stop me thinking about other things.
c. Worries about my health often stop me thinking of other things.
d. I am so worried about my health that I can think of nothing else.
24. a. If I notice an unexplained bodily sensation I never feel a need to distract myself from it.
b. If I notice an unexplained bodily sensation I sometimes try to distract myself from it.
c. If I notice an unexplained bodily sensation I often try to distract myself from it.
d. If I notice an unexplained bodily sensation I always try to distract myself from it.
25. a. The idea that I have a serious illness never seems sensible.
b. The idea that I have a serious illness sometimes seems sensible.
c. The idea that I have a serious illness often seems sensible.
d. The idea that I have a serious illness always seems sensible.
26. a. My previous illnesses were properly treated.
b. My previous illnesses could have been slightly better treated.
c. My previous illnesses could have been much better treated.
d. My previous illnesses were seriously mismanaged.
27. a. If I have a bodily sensation or change I rarely wonder what it means.
b. If I have a bodily sensation or change I often wonder what it means.
c. If I have a bodily sensation or change I always wonder what it means.
d. If I have a bodily sensation or change I must know what it means.
28. a. I do not avoid situations where illness is prominent.
b. I sometimes avoid situations where illness is prominent.
c. I often avoid situations where illness is prominent.
d. I always avoid situations where illness is prominent.
29. a. I usually feel at very low risk for developing a serious illness.
b. I usually feel at fairly low risk for developing a serious illness.
c. I usually feel at moderate risk for developing a serious illness.
d. I usually feel at high risk for developing a serious illness.
30. a. I rarely have images of myself dying or dead.
b. I occasionally have images of myself dying or dead.
c. I frequently have images of myself dying or dead.
d. I constantly have images of myself dying or dead.
31. a. If I notice an unexplained bodily sensation I never mention it to others.
b. If I notice an unexplained bodily sensation I sometimes mention it to others.
c. If I notice an unexplained bodily sensation I often mention it to others.
d. If I notice an unexplained bodily sensation I always mention it to others.
32. a. As a rule, I do not think about what it would be like if I were seriously ill.
b. I sometimes think about what it would be like if I were seriously ill.
c. I frequently think about what it would be like if I were seriously ill.
d. I constantly think about what it would be like if I were seriously ill.
33. a. I do not usually feel at all vulnerable to serious illness.
b. I usually feel slightly vulnerable to serious illness.
c. I usually feel moderately vulnerable to serious illness.
d. I usually feel extremely vulnerable to serious illness.
34. a. If I notice an unexplained bodily sensation or change I never try to reassure myself about it.
b. If I notice an unexplained bodily sensation or change I sometimes try to reassure myself about it.
c. If I notice an unexplained bodily sensation or change I often try to reassure myself about it.
d. If I notice an unexplained bodily sensation or change I always try to reassure myself about it.
35. a. I never think I have a serious illness.
b. I sometimes think I have a serious illness.
c. I often think I have a serious illness.
d. I usually think that I am seriously ill.

36.
 - a. It usually feels extremely unlikely that I will become ill (in any way) in the next few weeks.
 - b. It usually feels unlikely that I will become ill (in any way) in the next few weeks.
 - c. It usually feels as though there is some possibility that I will become ill (in any way) in the next few weeks.
 - d. It usually feels likely that I will become ill (in any way) in the next few weeks.
37.
 - a. As a rule I am not afraid of developing a serious illness.
 - b. I am sometimes afraid of developing a serious illness.
 - c. I am afraid of developing a serious illness most of the time.
 - d. I am afraid of developing a serious illness all the time.
38.
 - a. It is extremely unlikely that I have an undiagnosed serious illness.
 - b. It is fairly unlikely that I have an undiagnosed serious illness.
 - c. It is fairly likely I have an undiagnosed serious illness.
 - d. It is very likely I have an undiagnosed serious illness.
39.
 - a. If I think about developing a serious illness I feel a little scared.
 - b. If I think about developing a serious illness I feel moderately scared.
 - c. If I think about developing a serious illness I feel very scared.
 - d. If I think about developing a serious illness I feel terrified.
40.
 - a. When I have a pain, I rarely think that it is a sign of illness.
 - b. When I have a pain, I sometimes think that it is a sign of illness.
 - c. When I have a pain, I often think that it is a sign of illness.
 - d. When I have a pain, I always think that it is a sign of illness.
41.
 - a. It usually feels extremely unlikely that I will die soon.
 - b. It usually feels as if there is a fair chance that I will die soon.
 - c. It usually feels as though I will probably die soon.
 - d. It usually feels as though I am going to die soon.
42.
 - a. If I notice an unexplained bodily sensation I never do anything to try to get rid of it.
 - b. If I notice an unexplained bodily sensation I sometimes try to get rid of it.
 - c. If I notice an unexplained bodily sensation I often try to get rid of it.
 - d. If I notice an unexplained bodily sensation I always try to get rid of it.
43.
 - a. If I notice an unexplained bodily sensation I don't find it difficult to think about other things.
 - b. If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things.
 - c. If I notice an unexplained bodily sensation I often find it difficult to think about other things.
 - d. If I notice an unexplained bodily sensation I always find it difficult to think about other things.
44.
 - a. If I hear about a certain illness it never causes me to worry about other illnesses.
 - b. If I hear about a certain illness it sometimes causes me to worry about other illnesses.
 - c. If I hear about a certain illness it often causes me worry about other illnesses.
 - d. If I hear about a certain illness it always causes me to worry about other illnesses.
45.
 - a. My family/friends would say I do not worry enough about my health.
 - b. My family/friends would say I have a normal attitude to my health.
 - c. My family/friends would say I worry too much about my health.
 - d. My family/friends would say I am a hypochondriac.
46.
 - a. My GP would say I do not worry enough about my health.
 - b. My GP would say I have a normal attitude to my health.
 - c. My GP would say I worry too much about my health.
 - d. My GP would say I am a hypochondriac.
47.
 - a. I think I worry too little about my health.
 - b. I think I have a normal attitude to my health.
 - c. I think I worry too much about my health.
 - d. I think I am a hypochondriac.

For the following questions, please think about what it might be like if you had a serious illness of a type which particularly concerns you (such as heart disease, cancer, multiple sclerosis and so on). Obviously you cannot know for definite what it would be like; please give your best estimate of what you think might happen, basing your estimate on what you know about yourself and serious illness in general.

48. a. If I had a serious illness there is a good chance that I would still be able to have a reasonable quality of life.
b. If I had a serious illness there is a small chance that I would still be able to have a reasonable quality of life.
c. If I had a serious illness there is only a very small chance that I still would be able to have a reasonable quality of life.
d. If I had a serious illness there is no chance that I would still be able to have a reasonable quality of life.
49. a. If I developed a serious illness there is a small chance that it would be very painful.
b. If I developed a serious illness there is a moderate chance that it would be very painful.
c. If I developed a serious illness there is an extremely high chance that it would be very painful.
d. If I developed a serious illness it would definitely be very painful.
50. a. If I developed a serious illness there is a small chance that it would be fatal.
b. If I developed a serious illness there is a moderate chance that it would be fatal.
c. If I developed a serious illness there is an extremely high chance that it would be fatal.
d. If I developed a serious illness it would definitely be fatal.
51. a. If I developed a serious illness there is a small chance that it would involve prolonged suffering.
b. If I developed a serious illness there is a moderate chance that it would involve prolonged suffering.
c. If I developed a serious illness there is an extremely high chance that it would involve prolonged suffering.
d. If I developed a serious illness it would definitely involve prolonged suffering.
52. a. If I had a serious illness I would still be able to enjoy things in my life quite a lot.
b. If I had a serious illness I would still be able to enjoy things in my life a little.
c. If I had a serious illness I would be almost completely unable to enjoy things in my life.
d. If I had a serious illness I would be completely unable to enjoy life at all.
53. a. If I developed a serious illness there is a good chance that modern medicine would be able to cure me.
b. If I developed a serious illness there is a moderate chance that modern medicine would be able to cure me.
c. If I developed a serious illness there is a very small chance that modern medicine would be able to cure me.
d. If I developed a serious illness there is no chance that modern medicine would be able to cure me.
54. a. If I developed a serious illness my family and friends would not act in a pitying way towards me (or it would not bother me if they did).
b. If I developed a serious illness my family and friends would act in a fairly pitying way towards me.
c. If I developed a serious illness my family and friends would act in a very pitying way towards me.
d. If I developed a serious illness my family and friends would act in an exceedingly pitying way towards me.
55. a. If I had a serious illness my belief in my own worth would not change.
b. If I had a serious illness my belief in my own worth would be slightly affected.
c. If I had a serious illness my belief in my own worth would be strongly affected.
d. If I had a serious illness my belief in my own worth would be destroyed.
56. a. A serious illness would ruin some aspects of my life.
b. A serious illness would ruin many aspects of my life.
c. A serious illness would ruin almost every aspect of my life.
d. A serious illness would ruin every aspect of my life.

57. a. If I developed a serious illness my family and friends would not reject me.
b. If I developed a serious illness my family and friends might reject me.
c. If I developed a serious illness my family and friends would probably reject me.
d. If I developed a serious illness my family and friends would definitely reject me.
58. a. If I had a serious illness I would not feel that I had lost my dignity.
b. If I had a serious illness I would feel that I had lost a little of my dignity.
c. If I had a serious illness I would feel that I had lost quite a lot of my dignity.
d. If I had a serious illness I would feel that I had totally lost my dignity.
59. a. I would not feel ashamed if I developed a serious illness.
b. I would feel slightly ashamed if I developed a serious illness.
c. I would feel moderately ashamed if I developed a serious illness.
d. I would feel deeply ashamed if I developed a serious illness.
60. a. If I developed a serious illness I would be able to tolerate loss of independence.
b. If I developed a serious illness I would have some difficulty tolerating loss of independence.
c. If I developed a serious illness I would have considerable difficulty tolerating loss of independence.
d. If I developed a serious illness I would find loss of independence completely intolerable.
61. a. If I developed a serious illness, my family would be able to cope without me.
b. If I developed a serious illness, my family would have some problems coping without me.
c. If I developed a serious illness, my family would have great difficulty coping without me.
d. If I developed a serious illness, my family would be completely unable to cope without me.
62. a. If I developed a serious illness my family and friends would care.
b. If I developed a serious illness my family and friends would care to some extent.
c. If I developed a serious illness my family and friends would not care very much.
d. If I developed a serious illness my family and friends would not care at all.
63. a. If I developed a serious illness there are many people who would be able to support me.
b. If I developed a serious illness there are several people who would be able to support me.
c. If I developed a serious illness there are one or two people who would be able to support me.
d. If I developed a serious illness there is no-one who would be able to support me.
64. a. I would cope very well if I developed a serious illness.
b. I would cope fairly well if I developed a serious illness.
c. I would cope badly if I developed a serious illness.
d. I would be unable to cope if I developed a serious illness.

Choose a number from the scale below to show how much you would avoid each of the situations listed below because of fear or other unpleasant feelings. Then write the number you chose in the space provided.

0.....1.....2.....3.....4.....5.....6.....7.....8
Would not Slightly Definitely Markedly Always
avoid it avoid it avoid it avoid it avoid it

- i. Consulting your family doctor.....
- 2. Visiting a friend in hospital.....
- 3. Visiting a relative in hospital.....
- 4. Going to a hospital for treatment.....
- 5. Talking about illness.....
- 6. Reading about illness.....
- 7. Visiting a hospital for other reasons
(e.g. delivering a message).....
- 8. Watching TV programmes about illness.....
- 9. Listening to radio programmes about illness.....
- 10. Thinking about illness.....

Choose a number from the scale below which best describes how often you seek reassurance about your health, from each of the sources described below. Then write the number you have chosen in the space provided.

0.....1.....2.....3.....4.....5.....6.....7.....8
Never Rarely Sometimes Often Daily

- 1. Friends.....
- 2. Family.....
- 3. Reading books.....
- 4. Checking body for changes.....
- 5. Family doctor.....
- 6. Nurses.....
- 7. Hospital outpatient clinic.....
- 8. Hospital casualty.....
- 9. Other (specify).....

Appendix D - The Whiteley Index (Pilowsky, 1967)

Below is a list of questions about your health. For each one, please circle the number indicating how much this is true for you.

	1 = Not at all	2 = A little bit	3 = Moderately	4 = Quite a bit	5 = A great deal
	Not at all	A little bit	Moderately	Quite a bit	A great deal
1. Do you worry a lot about your health?	1	2	3	4	5
2. Do you think there is something seriously wrong with you body?	1	2	3	4	5
3. Is it hard for you to forget about yourself and think about all sorts of other things?	1	2	3	4	5
4. If you feel ill and someone tells you that you are looking better. do you become annoyed?	1	2	3	4	5
5. Do you find that you are often aware of various things happening in your body?	1	2	3	4	5
6. Are you bothered by many aches and pains?	1	2	3	4	5
7. Are you afraid of illness?	1	2	3	4	5
8. Do you worry about your health more than most people?	1	2	3	4	5
9. Do you get the feeling that people are not taking your illnesses seriously enough?	1	2	3	4	5
10. Is it hard for you to believe the doctor when he or she tells you there is nothing for you to worry about?	1	2	3	4	5
11. Do you often worry about the possibility that you have a serious illness?	1	2	3	4	5
12. If a disease is brought to your attention (through the radio, television, newspapers or someone you know), do you worry about getting it yourself?	1	2	3	4	5
13. Do you find that you are bothered by many different symptoms?	1	2	3	4	5
14. Do you often have the symptoms of a very serious disease?	1	2	3	4	5

Appendix E- The Beck Depression Inventory (Beck et al. 1961)

Name: _____

Date: _____

On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling the past week, including today! Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

- | | |
|---|--|
| <p>1. 0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and I can't snap out of it.
3 I am so sad or unhappy that I can't stand it.</p> <p>2. 0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel that the future is hopeless, and that things cannot improve.</p> <p>3. 0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I can see is a lot of failures.
3 I feel I am a complete failure as a person.</p> <p>4. 0 I get as much satisfaction out of things as I used to.
1 I don't enjoy things the way I use to.
2 I don't get real satisfaction out of things anymore.
3 I am dissatisfied or bored with everything.</p> <p>5. 0 I don't feel particularly guilty.
1 I feel guilty a good part of the time.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.</p> <p>6. 0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.</p> <p>7. 0 I don't feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.</p> <p>8. 0 I don't feel I am any worse than anyone else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults. I am purposely
3 I blame myself for everything bad that happens.</p> <p>9. 0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.</p> <p>10. 0 I don't cry any more than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.</p> <p>11. 0 I am no more irritated now than I ever am
1 I get annoyed or irritated more easily than I used to.
2 I feel irritated all the time now.
3 I don't get irritated at all by the things that used to irritate me.</p> | <p>12. 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.</p> <p>13. 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions than before.
3 I can't make decisions at all anymore.</p> <p>14. 0 I don't feel I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe that I look ugly</p> <p>15. 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.</p> <p>16. 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1 - 2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.</p> <p>17. 0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.</p> <p>18. 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.</p> <p>19. 0 I haven't lost much weight, if any, lately.
1 I have lost more than 5 pounds.
2 I have lost more than 10 pounds.
3 I have lost more than 15 pounds.</p> <p style="text-align: right; margin-right: 50px;">I am purposely trying to lose weight by eating less
☐ Yes ☐ No</p> <p>20. 0 I am no more worried about my health than usual.
1 I am worried about physical problems such as aches
2 I am very worried about physical problems and it's hard to think about much else.
3 I am so worried about my physical problems that I cannot think about anything else.</p> <p>21. 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.</p> |
|---|--|

Appendix F- the Beck Anxiety Inventory (Beck et al. 1988)

Name: _____

Date: _____

Instructions: Below is a list of common symptoms of anxiety. Please read each item in the list carefully. Indicate how often you experienced each symptom during the past week, including today, by circling the corresponding number in the column next to each symptom.

	Never	Occasionally	Frequently	Almost all the time
1. Numbness or tingling.	0	1	2	3
2. Feeling hot.	0	1	2	3
3. Wobbliness in legs.	0	1	2	3
4. Unable to relax.	0	1	2	3
5. Fear of the worst happening.	0	1	2	3
6. Dizzy or light-headed.	0	1	2	3
7. Heart Pounding or racing.	0	1	2	3
8. Unsteady.	0	1	2	3
9. Terrified.	0	1	2	3
10. Nervous.	0	1	2	3
11. Feelings of choking.	0	1	2	3
12. Hands trembling.	0	1	2	3
13. Shaky.	0	1	2	3
14. Fear of losing control.	0	1	2	3
15. Difficulty breathing.	0	1	2	3
16. Fear of dying.	0	1	2	3
17. Scared.	0	1	2	3
18. Indigestion or discomfort in abdomen.	0	1	2	3
19. Faint.	0	1	2	3
20. Face flushed.	0	1	2	3
21. Sweating (not due to heat).	0	1	2	3

Appendix G, part 1- the Spielberger State Anxiety Inventory (Spielberger, 1983)

STAI Form Y-1

Name _____ Date _____ S _____
Age _____ Sex: M _____ F _____ T _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right now*, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

NOT AT ALL
SOMEWHAT
MODERATELY SO
VERY MUCH SO

- | | | | | |
|--|---|---|---|---|
| 1. I feel calm | ① | ② | ③ | ④ |
| 2. I feel secure | ① | ② | ③ | ④ |
| 3. I am tense | ① | ② | ③ | ④ |
| 4. I feel strained | ① | ② | ③ | ④ |
| 5. I feel at ease | ① | ② | ③ | ④ |
| 6. I feel upset | ① | ② | ③ | ④ |
| 7. I am presently worrying over possible misfortunes | ① | ② | ③ | ④ |
| 8. I feel satisfied | ① | ② | ③ | ④ |
| 9. I feel frightened | ① | ② | ③ | ④ |
| 10. I feel comfortable | ① | ② | ③ | ④ |
| 11. I feel self-confident | ① | ② | ③ | ④ |
| 12. I feel nervous | ① | ② | ③ | ④ |
| 13. I am jittery | ① | ② | ③ | ④ |
| 14. I feel indecisive | ① | ② | ③ | ④ |
| 15. I am relaxed | ① | ② | ③ | ④ |
| 16. I feel content | ① | ② | ③ | ④ |
| 17. I am worried | ① | ② | ③ | ④ |
| 18. I feel confused | ① | ② | ③ | ④ |
| 19. I feel steady | ① | ② | ③ | ④ |
| 20. I feel pleasant | ① | ② | ③ | ④ |



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Appendix G, part 2- the Spielberger Trait Anxiety Inventory (Spielberger, 1983)

STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

ALMOST NEVER
SOMETIMES
OFTEN
ALMOST ALWAYS

- | | | | | |
|--|---|---|---|---|
| 21. I feel pleasant | ① | ② | ③ | ④ |
| 22. I feel nervous and restless | ① | ② | ③ | ④ |
| 23. I feel satisfied with myself | ① | ② | ③ | ④ |
| 24. I wish I could be as happy as others seem to be | ① | ② | ③ | ④ |
| 25. I feel like a failure | ① | ② | ③ | ④ |
| 26. I feel rested | ① | ② | ③ | ④ |
| 27. I am "calm, cool, and collected" | ① | ② | ③ | ④ |
| 28. I feel that difficulties are piling up so that I cannot overcome them | ① | ② | ③ | ④ |
| 29. I worry too much over something that really doesn't matter | ① | ② | ③ | ④ |
| 30. I am happy | ① | ② | ③ | ④ |
| 31. I have disturbing thoughts | ① | ② | ③ | ④ |
| 32. I lack self-confidence | ① | ② | ③ | ④ |
| 33. I feel secure | ① | ② | ③ | ④ |
| 34. I make decisions easily | ① | ② | ③ | ④ |
| 35. I feel inadequate | ① | ② | ③ | ④ |
| 36. I am content | ① | ② | ③ | ④ |
| 37. Some unimportant thought runs through my mind and bothers me | ① | ② | ③ | ④ |
| 38. I take disappointments so keenly that I can't put them out of my
mind | ① | ② | ③ | ④ |
| 39. I am a steady person | ① | ② | ③ | ④ |
| 40. I get in a state of tension or turmoil as I think over my recent concerns
and interests | ① | ② | ③ | ④ |

Appendix H - the Padua Inventory (Sanavio, 1988)

The following statements refer to thoughts and behaviours which may occur to everyone in everyday life. For each statement, choose the answer which best seems to fit you and the degree of disturbance which such thoughts or behaviours create. Rate your replies as follows:

0 = not at all, 1 = a little, 2 = quite a lot, 3 = a lot, 4 = very much

Rating (0,1,2,3,4)

- | | |
|---|-----------|
| 1. I feel my hands are dirty when I touch money. | [] |
| 2. I think even slight contact with bodily secretions (perspiration, saliva, urine etc.) may contaminate my clothes or somehow harm me. | [] |
| 3. I find it difficult to touch an object when I know it has been touched by strangers or by certain people. | [] |
| 4. I find it difficult to touch rubbish or dirty things. | [] |
| 5. I avoid using public toilets because I am afraid of disease and contamination. | [] |
| 6. I avoid using public telephones because I am afraid of contagion and disease. | [] |
| 7. I wash my hands more often and longer than necessary. | [] |
| 8. I sometimes have to wash or clean myself simply because I think I may be dirty or 'contaminated'. | [] |
| 9. If I touch something which I think is 'contaminated' I immediately have to wash or clean myself. | [] |
| 10. If an animal touches me, I feel dirty and immediately have to wash myself or change my clothing. | [] |
| 11. When doubts and worries come to my mind, I cannot rest until I have talked them over with a reassuring person. | [] |
| 12. When I talk I tend to repeat the same things and the same sentences several times. | [] |
| 13. I tend to ask people to repeat the same things to me several times consecutively, even though I did understand what they said the first time. | [] |
| 14. I feel obliged to follow a particular order in dressing, undressing and washing myself. | [] |
| 15. Before going to sleep I have to do certain things in a certain order. | [] |
| 16. Before going to bed I have to hang up or fold my clothes in a special way. | [] |
| 17. I feel I have to repeat certain numbers for no reason. | [] |
| 18. I have to do things several times before I think they are properly done. | [] |
| 19. I tend to keep checking things more often than necessary. | [] |
| 20. I check and recheck gas and water taps and light switches after turning them off. | [] |
| 21. I return home to check doors, windows, drawers etc., to make sure they are properly shut. | [] |
| 22. I keep on checking forms, documents, cheques, etc. in detail to make sure I have filled them in correctly. | [] |
| 23. I keep on going back to check that matches, cigarettes etc. are properly extinguished. | [] |
| 24. When I handle money I count and recount it several times. | [] |
| 25. I check letters carefully many times before posting them. | [] |
| 26. I find it difficult to make decisions, even about unimportant matters. | [] |
| 27. Sometimes I am not sure I have done things which in fact I know I have done. | [] |

Rating (0,1,2,3,4)

- | | |
|---|-----------|
| 28. I have the impression that I will never be able to explain things clearly, especially when talking about important matters that involve me. | [] |
| 29. After doing something carefully, I still have the impression I have either done it badly or not finished it. | [] |
| 30. I am sometimes late because I keep on doing certain things more often than necessary. | [] |
| 31. I invent doubts and problems for most of the things I do. | [] |
| 32. When I start thinking of certain things, I become obsessed with them. | [] |
| 33. Unpleasant thoughts come into my mind against my will and I cannot get rid of them. | [] |
| 34. Obscene or dirty words come into my mind and I cannot get rid of them. | [] |
| 35. My brain constantly goes its own way and I find it difficult to attend to what is happening around me. | [] |
| 36. I imagine catastrophic consequences as a result of absent-mindedness or minor errors which I make. | [] |
| 37. I think or worry at length about having hurt someone without knowing it. | [] |
| 38. When I hear about a disaster, I think it is somehow my fault. | [] |
| 39. I sometimes worry at length for no reason that I have hurt myself or have some disease. | [] |
| 40. I sometimes start counting objects for no reason. | [] |
| 41. I feel I have to remember completely unimportant numbers. | [] |
| 42. When I read I have the impression I have missed something important and must go back and reread the passage at least two or three times. | [] |
| 43. I worry about remembering completely unimportant things and make an effort not to forget them. | [] |
| 44. When a thought or doubt comes into my mind, I have to examine it from all points of view and cannot stop until I have done so. | [] |
| 45. In certain situations I am afraid of losing my self control and doing embarrassing things. | [] |
| 46. When I look down from a bridge or a very high window, I feel an impulse to throw myself into space. | [] |
| 47. When I see a train approaching I sometimes think I could throw myself under its wheels. | [] |
| 48. At certain moments I am tempted to tear off my clothes in public. | [] |
| 49. While driving I sometimes feel an impulse to drive the car into someone or something. | [] |
| 50. Seeing weapons excites me and makes me think violent thoughts. | [] |
| 51. I get upset and worried at the sight of knives, daggers and other pointed objects. | [] |
| 52. I sometimes feel something inside me which makes me do things which are really senseless and which I do not want to do. | [] |
| 53. I sometimes feel the need to break or damage things for no reason. | [] |
| 54. I sometimes have the impulse to steal other people's belongings, even if they are of no use to me. | [] |
| 55. I am sometimes almost irresistibly tempted to steal something from the supermarket. | [] |
| 56. I sometimes have the impulse to hurt defenceless children or animals. | [] |
| 57. I feel I have to make special gestures or walk in a certain way. | [] |
| 58. In certain situations I feel an impulse to eat too much even if I am then ill. | [] |
| 59. When I hear about a suicide or crime, I am upset for a long time and find it difficult to stop thinking about it. | [] |
| 60. I invent useless worries about germs and diseases. | [] |

Appendix I- the Anxiety Sensitivity Index (Reiss et al., 1986)

Name _____ Today's Date _____

Circle the *one* phrase that best represents the extent to which you agree with the item. If any of the items concern something that is not part of your experience (e.g., "It scares me when I feel shaky" for someone who has never trembled or had the "shakes"), answer on the basis of how you think you might feel *if you had* such an experience. Otherwise, answer all items on the basis of your own experience.

1. It is important to me not to appear nervous.

Very Little A Little Some Much Very Much

2. When I cannot keep my mind on a task, I worry that I might be going crazy.

Very Little A Little Some Much Very Much

3. It scares me when I feel "shaky" (trembling).

Very Little A Little Some Much Very Much

4. It scares me when I feel faint.

Very Little A Little Some Much Very Much

5. It is important to me to stay in control of my emotions.

Very Little A Little Some Much Very Much

6. It scares me when my heart beats rapidly.

Very Little A Little Some Much Very Much

7. It embarrasses me when my stomach growls.

Very Little A Little Some Much Very Much

(Over)

8. It scares me when I am nauseous.

Very Little A Little Some Much Very Much

9. When I notice that my heart is beating rapidly,
I worry that I might have a heart attack.

Very Little A Little Some Much Very Much

10. It scares me when I become short of breath.

Very Little A Little Some Much Very Much

11. When my stomach is upset, I worry that I might be seriously ill.

Very Little A Little Some Much Very Much

12. It scares me when I am unable to keep my mind on a task.

Very Little A Little Some Much Very Much

13. Other people notice when I feel shaky.

Very Little A Little Some Much Very Much

14. Unusual body sensations scare me.

Very Little A Little Some Much Very Much

15. When I am nervous, I worry that I might be mentally ill.

Very Little A Little Some Much Very Much

16. It scares me when I am nervous.

Very Little A Little Some Much Very Much

Appendix J - Questionnaires used in the bone densitometry study

The initial questionnaire: this contained the questions shown below and also the Health Anxiety Questionnaire (see Appendix C), the Beck Depression Inventory (see Appendix E) and the Spielberger Trait Anxiety Inventory (see Appendix G, part 2).

Section A of the questionnaire contains questions which were generally asked at only this first assessment.

Section B ("Feelings about osteoporosis") was used at the initial assessment, the week follow-up and the 3 month follow-up.

Bone Density Screening Survey

1. Age.....
2. Relationship status (single,with partner,divorced etc.)
3. Occupation (or previous occupation).....
4. Education level (e.g. "O" levels, "A" levels, diplomas, university or polytechnic degree, doctorate)
.....
5. Number of children.....
6. Women attend bone density screening for various different reasons, for example: they have a family history of osteoporosis; they have symptoms that might be related to bone density; they feel at risk for some other reason such as a medical condition, their weight/height, their diet; they are concerned about whether to take Hormone Replacement Therapy (HRT) or do something else to prevent bone loss; curiosity; simply because the rest of their friends were coming for screening.

Please describe all your reasons for attending (you may have several, including some not listed here).

7. Have you ever had a bone density scan before? Yes / No
If so, please specify:

a) where you had the scan

b) when you had the scan

c) why you had the scan
8. Are you pre-menopausal / currently menopausal / post-menopausal? (please underline as appropriate)
If you are post-menopausal, how long is it since you last menstruated?
.....
9. Do you currently take HRT? Yes / No
If so, how long have you been taking it?
10. Have you taken HRT in the past but stopped? Yes / No
11. Are you concerned about whether or not to take HRT? Yes / No

12. Have you been for other health checks or screening in the past five years? Yes / No
If so, please write the number of checks in the space provided:

Cervical smear test.....
Breast examination.....
Mammography (breast x-ray).....
Blood pressure reading.....
Cholesterol test.....
Other (please specify).....

13. Do you currently have a medical condition for which you are receiving treatment? Yes / No
If so, please specify:

14. Do you have, or have you had in the past, a medical condition that you think may affect your bone density (either directly or indirectly) Yes / No
If so, please specify:

15. Do you have, or have you had in the past, any symptoms/fractures which you think may be related to having weak bones? Yes / No
If so, please specify (including things that you are not sure about):

16. Do you have a family history of osteoporosis? Yes / No
If so please specify:

17. Do you do or take anything to try to prevent or slow down bone loss? Yes / No
Please describe everything that you do/take:

18. Do you limit your activities in any way in order to reduce your chances of falling and fracturing yourself? Yes / No

19. How often have you thought about osteoporosis or bone weakness in the past week? (please tick one of the following)

Not at all _____
Once or twice _____
Several times _____
Every day _____
More than once a day _____

20. Please describe what the term "osteoporosis" means to you, mentioning both your knowledge and feelings about the areas listed below.

We are interested in what you know and feel as you are filling in this questionnaire, without reference to written material from elsewhere.

If you don't know anything, please put "don't know".

a) what the condition is

b) the causes

c) ways you can prevent osteoporosis

d) ways you can treat osteoporosis

e) the effects osteoporosis can have on your life in general

f) anything else you know or feel about osteoporosis.

Health Interest

Please select the statement which best describes your feelings or behaviour over the past six months.

Identify the statement by ringing the letter next to it.

1.

- a. I make little effort to keep healthy.
- b. I put a moderate amount of effort into keeping healthy.
- c. I put a large amount of effort into keeping healthy.
- d. I put an enormous amount of effort into keeping healthy.

2.

- a. I am not interested in health issues.
- b. I am fairly interested in health issues.
- c. I am very interested in health issues.
- d. I am extremely interested in health issues.

3.

- a. My lifestyle is not affected by efforts to keep healthy.
- b. My lifestyle is slightly affected by efforts to keep healthy.
- c. My lifestyle is moderately affected by efforts to keep healthy.
- d. My lifestyle is dominated by efforts to keep healthy.

4.

- a. I never read magazines/books about keeping fit and healthy.*
- b. I occasionally read magazines/books about keeping fit and healthy.
- c. I often read magazines/books about keeping fit and healthy.
- d. I regularly read magazines/books about keeping fit and healthy.

(* this does not include slimming magazines/books)

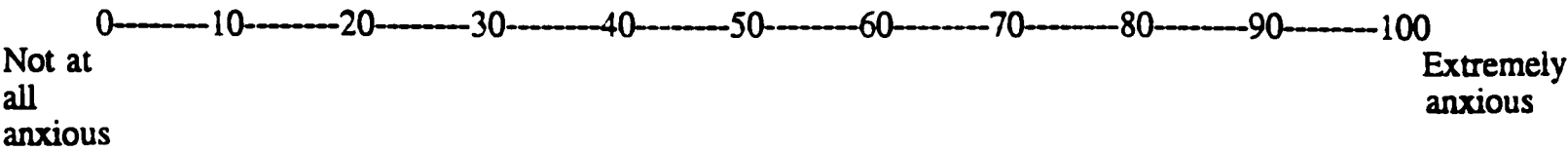
Appendix J (part b)

This section of the initial questionnaire was also included in the week and 3 month follow-up questionnaires.

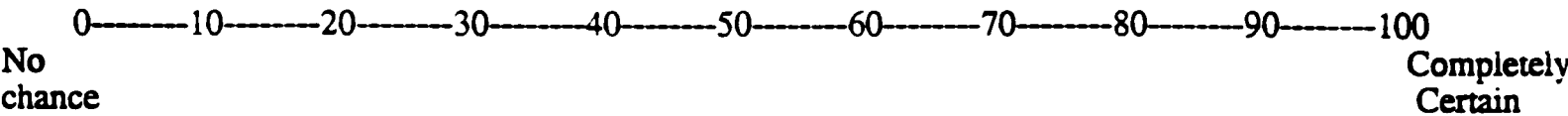
Feelings about osteoporosis

Please place a cross on the point of the scale that best describes your feelings about osteoporosis. Some of the questions may ask you to imagine certain situations: these questions may seem difficult but even if you are not sure, please give your best guess and answer all the questions.

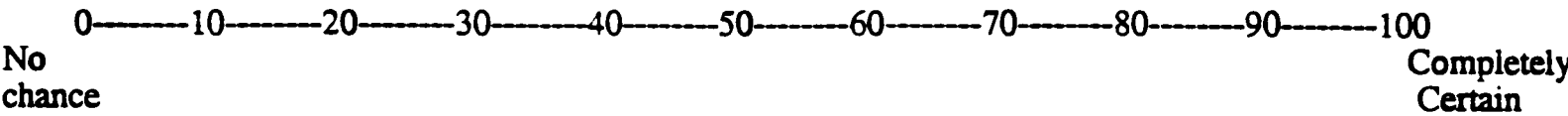
1. How anxious do you feel about your bone density?



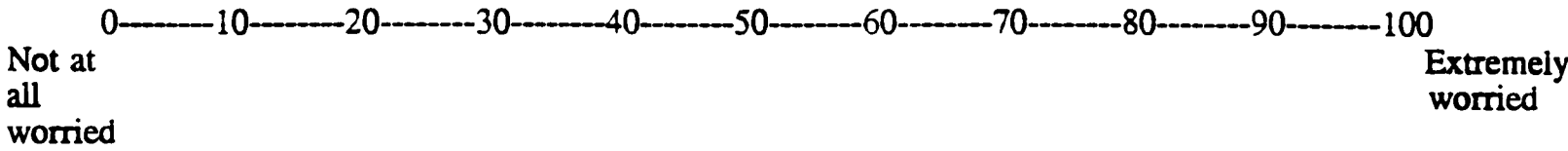
2. How likely do you feel it is that you will develop osteoporosis or symptoms related to bone weakness in the near future? (Please rate you feelings rather than what you think a "rational" or "correct" answer would be).



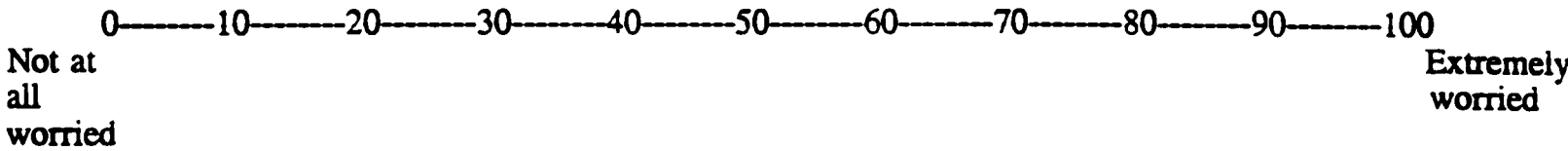
3. How likely do you feel it is that you will develop osteoporosis or symptoms related to bone weakness at any point in the future? (Please rate your feelings rather than what you think a "rational" or "correct" answer would be).



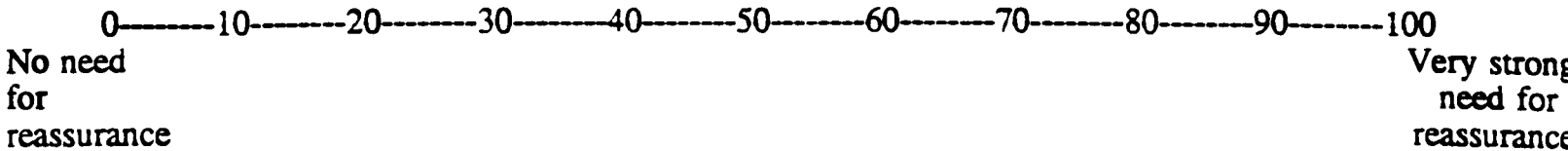
4. How worried do you feel about developing osteoporosis and symptoms related to bone weakness?



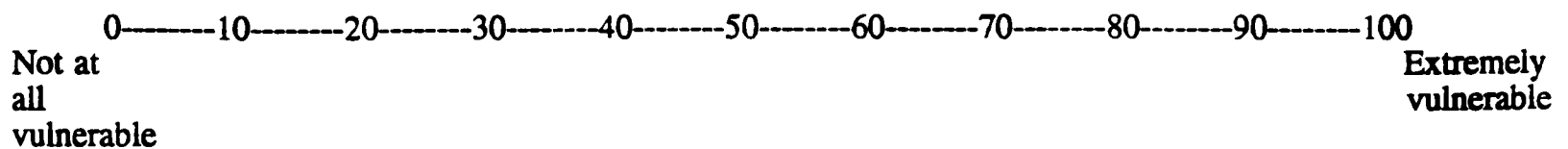
5. How worried are you about falling and fracturing your bones?



6. How much do you feel in need of reassurance about your bone density?



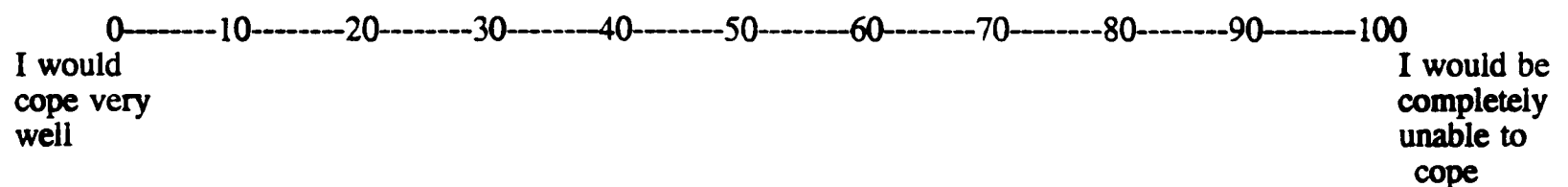
7. How vulnerable do you feel to developing osteoporosis or symptoms related to bone weakness in the future?



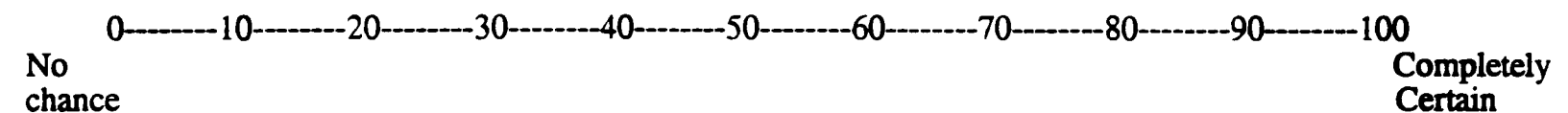
8. Compared to other women (of your age), how "at risk" do you feel for developing osteoporosis or symptoms relating to bone weakness in the future? (tick one of the following)

- Much less at risk than the "average" woman.....
Less at risk than the "average" woman.....
Slightly less at risk than the "average" woman.....
At the same risk as the "average woman".....
Slightly more at risk than the "average" woman.....
More at risk than the "average" woman.....
Much more at risk than the "average" woman.....

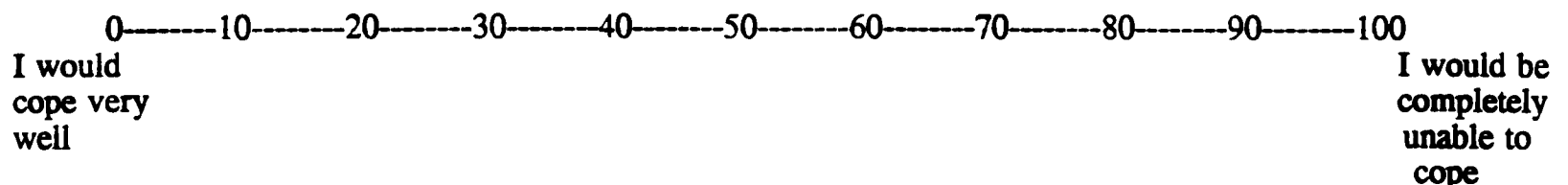
9. If you found that you had low bone density, how well do you think you would cope?



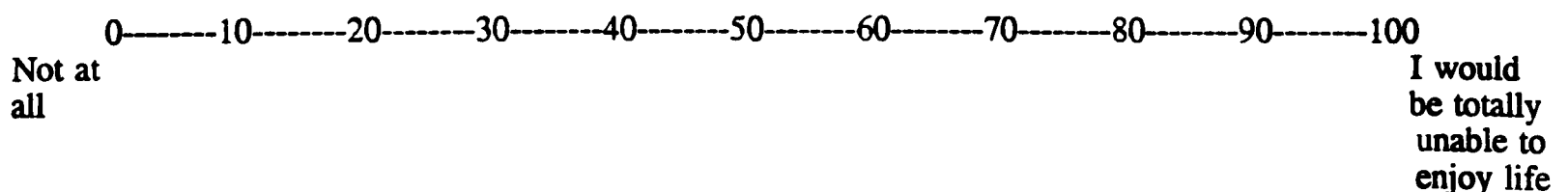
10. If you have low bone density, how likely is it that you will be able to do something about it to prevent the symptoms of osteoporosis?



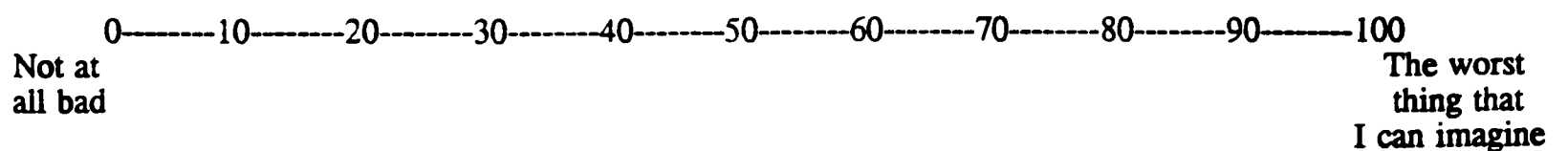
11. If you developed osteoporosis or symptoms related to bone weakness, how well do you think that you would cope?



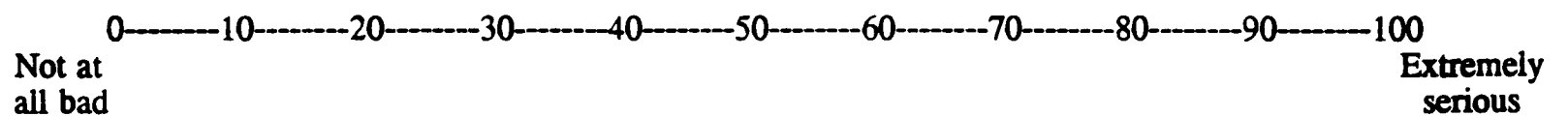
12. Would having osteoporosis or symptoms related to bone weakness affect your ability to enjoy life?



13. In general, how bad do you think the consequences of osteoporosis or symptoms relating to bone weakness would be for you?

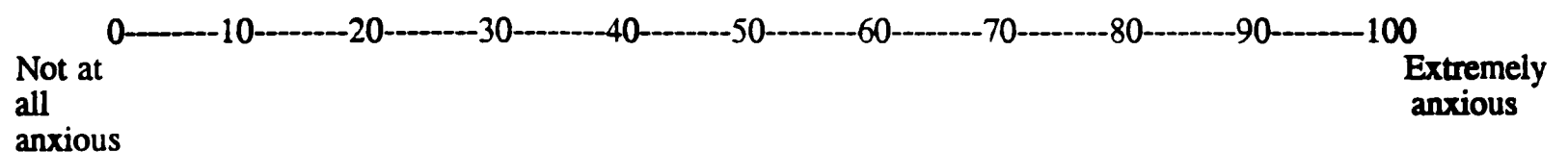


14. How serious a threat to health is below-average bone density?

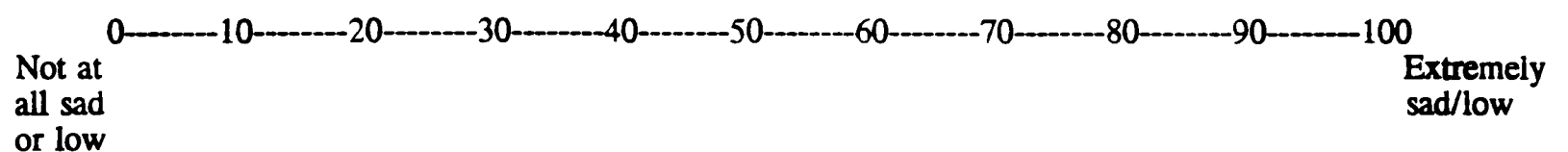


Please place a cross on the point of the scale that best describes your feelings in general at the moment.

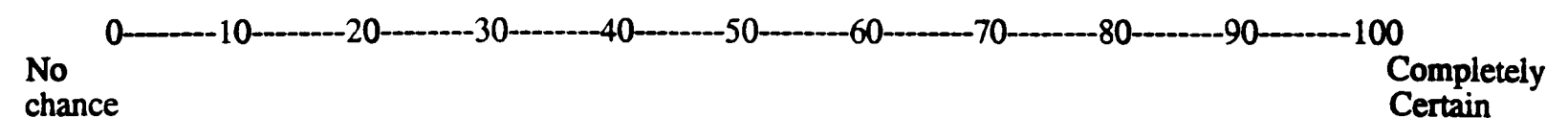
15. How anxious do you feel?



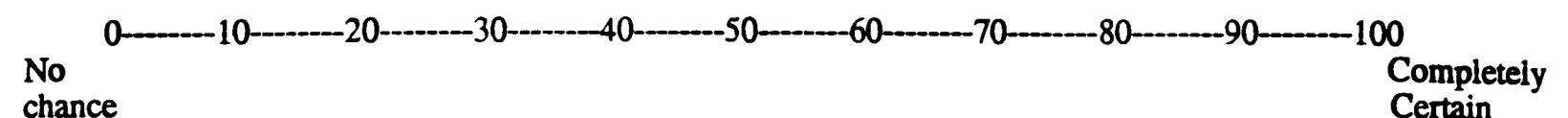
16. How sad or "low" do you feel?



17. How likely is it that you will develop a serious illness (other than osteoporosis) in the near future?
(Please rate your feelings rather than what you think a "rational" or "correct" answer would be.)



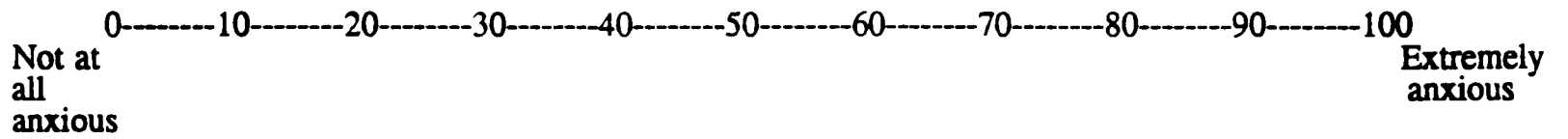
18. How likely is it that you will develop a serious illness (other than osteoporosis) at any point in the future?
(Please rate your feelings rather than what you think a "rational" or "correct" answer would be.)



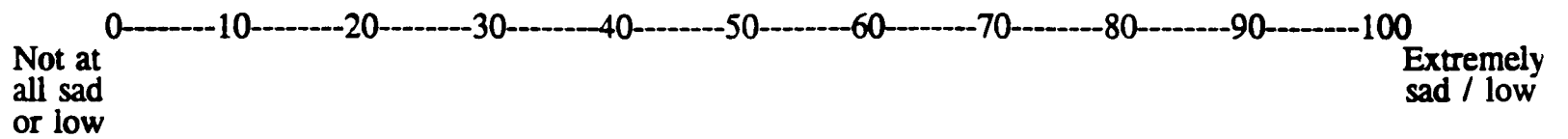
Appendix K - questions given on the day of the bone density scan
(The same questions were given before and after the scan)

Please place a cross on the point of the scale that best describes your feelings at this moment.

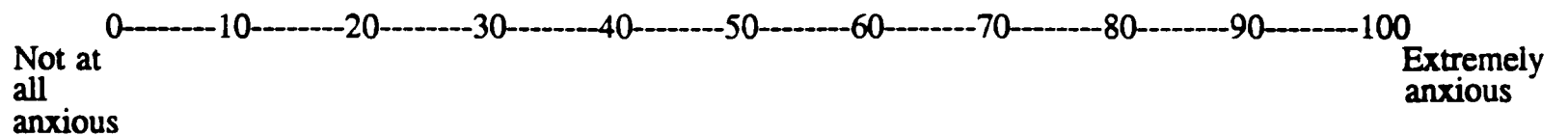
1. How anxious do you feel?



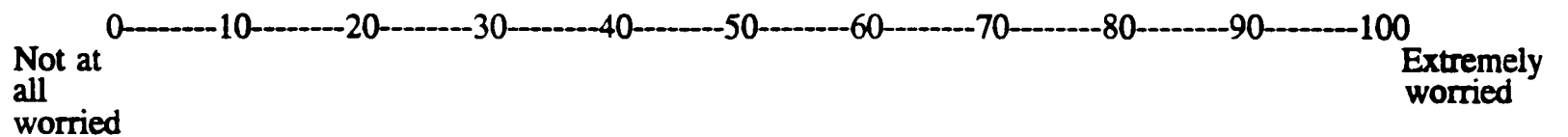
2. How sad or "low" do you feel?



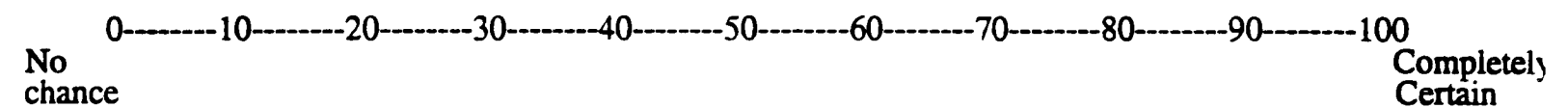
3. How anxious do you feel about your bone density?



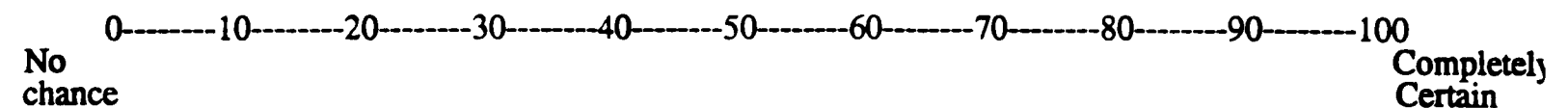
4. How worried do you feel about developing osteoporosis and symptoms related to bone weakness?



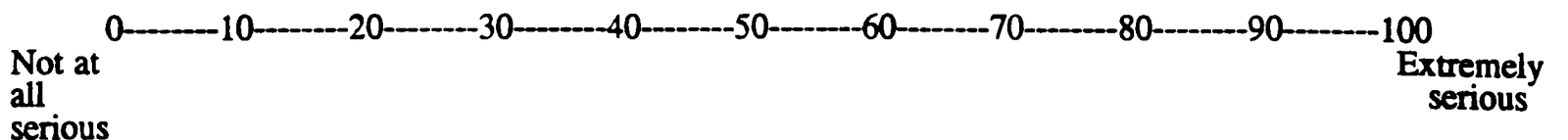
5. How likely do you feel it is that you will develop osteoporosis or symptoms related to bone weakness in the near future? (Please rate your feelings rather than what you think a "rational" or "correct" answer would be).



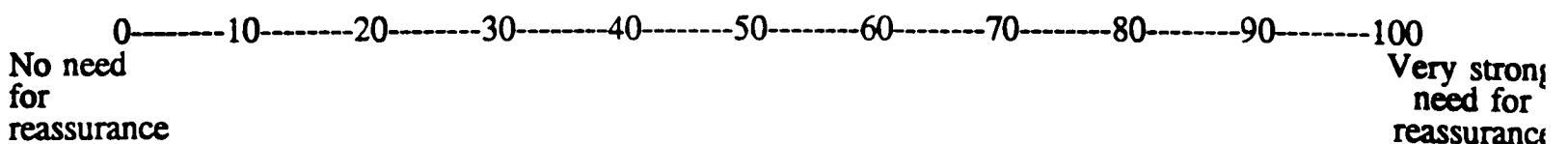
6. How likely do you feel it is that you will develop osteoporosis or symptoms related to bone weakness at any point in the future? (Please rate your feelings rather than what you think a "rational" or "correct" answer would be).



7. How serious a threat to health is below-average bone density?



8. How strongly do you feel in need of reassurance about your bone density?



Appendix L- the week follow-up questionnaire

Section B of the initial questionnaire (“Feelings about osteoporosis”) was also included- see Appendix J part B.

Please complete these questions about a week after the bone scan.
(It is important that you do not fill in these questions straight after the scan)

1. Which of the following best describes your result?

Much higher bone density than average for my age.....
Moderately higher bone density than average for my age.....
Slightly higher bone density than average for my age.....
Average bone density for my age.....
Slightly lower bone density than average for my age.....
Moderately lower bone density than average for my age.....
Much lower bone density than average for my age.....

- | | |
|---|----------|
| 2. Have you contacted your GP about your result? | Yes / No |
| 3. Did you speak to Dr Shipman (the project physician) about your result on the day of the scan? | Yes / No |
| 4. Have you spoken to Dr Shipman about your result since the day of the scan? | Yes / No |
| 5. Have you discussed your result with any other medically trained person? | Yes / No |
| 6. Do you intend to ask for more medical advice about your result? | Yes / No |
| 7. Have you tried to find out more about osteoporosis since the scan? | Yes / No |
| 8. Do you intend to find out more information about osteoporosis? | Yes / No |
| 9. Do you intend to go for another scan in the next few months? | Yes / No |
| 10. Do you think that you will go for another bone density scan at any point in the future? | Yes / No |
| 11. Have you talked to friends/family to get their opinion about your result? | Yes / No |
| 12. Have you talked to friends/family about your feelings regarding your result? | Yes / No |
| 13. Do you intend to change your behaviour in any way because of your result? (e.g. stopping/starting preventative or treatment measures, limiting your activities to reduce your chances of falling and fracturing yourself)
If so, how? Please describe in detail: | Yes / No |

If so, are you worried or concerned about having to make these changes?

Yes / No

14. How often did you think about your scan result in the rest of the day after the scan? (please tick one of the following)

Not at all _____
Once or twice _____
Several times _____
Many times _____
I couldn't stop thinking about it _____

15. How often did you think about your scan result in the week after the scan?

Not at all _____
Once or twice _____
Several times _____
Every day _____
More than once a day _____

16. How anxious have you felt about your result over the past week?

Not at all anxious _____
Very slightly anxious _____
Slightly anxious _____
Moderately anxious _____
Very anxious _____
Extremely anxious _____

17. How concerned have you felt about your result over the past week?

Not at all concerned _____
Very slightly concerned _____
Slightly concerned _____
Moderately concerned _____
Very concerned _____
Extremely concerned _____

18. When you had got your result how long did it take you to forget about it?

A few minutes _____
An hour or so _____
A day _____
Several days _____
I still think about it _____

19. Did you deliberately try to forget about it?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

20. Did you do anything to distract yourself from thinking about it?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

21. Did you try to reassure yourself about it?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

22. Do you have, or have you had in the past, any symptoms / fractures that might be related to your bone density? Yes / No
If so, please specify (including things that you are not sure about):

23. Since the scan, how often have you wondered whether symptoms that you have now or have had in the past may be related to your bone density?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

24. Since the scan, how often have you thought about what it would be like if you developed the symptoms of osteoporosis (or more symptoms if you have some already) ?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

25. Are you more, or less worried about osteoporosis since the scan? (please tick one of the following):

Much less worried.....
Less worried.....
A little less worried.....
Neither more or less worried.....
A little more worried.....
More worried.....
Much more worried.....

26. What do you think that your result means? (please summarise briefly)

27. Is there anything important about your result that you feel unclear about? Yes / No
If so, please specify:

Appendix M - 3 month follow-up questionnaire

Section B of the initial questionnaire (“Feelings about osteoporosis”) was also included- see Appendix J part B.

Bone Density Screening Survey

Please complete these questions about three months after your bone density scan.

1. Do you have osteoporosis? (Please tick one of the following)

Definitely.....
Probably.....
Don't know.....
Probably not.....
Definitely not.....

2. Which of the following best describes your result?

Much higher bone density than average for my age.....
Moderately higher bone density than average for my age.....
Slightly higher bone density than average for my age.....
Average bone density for my age.....
Slightly lower bone density than average for my age.....
Moderately lower bone density than average for my age.....
Much lower bone density than average for my age.....

3. Have you discussed your result with your GP ? Yes / No
4. Do you intend to discuss your result with your GP in the future? Yes / No
5. Have you contacted Dr Shipman (the project physician) about your result? Yes / No
6. Have you seen (or do you intend to see) Dr Smith or another specialist about your result? Yes / No
7. Have you discussed your result with any other medically trained person? Yes / No
8. Have you tried to find out more about bone density or osteoporosis since the scan? Yes / No
9. Do you intend to find out more information about bone density or osteoporosis? Yes / No
10. Will you go for another bone density scan in the next few months? Yes / No
11. Do you think that you will go for another bone density scan at any point in the future? Yes / No
12. Have you talked to friends/family to get their opinion about your result? Yes / No
13. Have you talked to friends/family about your feelings about your result? Yes / No
14. Do you do anything to help prevent or slow down bone loss? Yes / No
If so, please describe everything that you do:
15. Do you intend to change your behaviour in any (other) way because of your result? (e.g. stopping/starting preventative or treatment measures, limiting your activities to reduce your chances of falling and fracturing yourself) Yes / No
If so, how?

16. If you have changed or intend to change your behaviour since the scan, are you worried or concerned about making these changes? Yes / No

17. How anxious have you felt about your result over the past few days?

Not at all anxious _____
Very slightly anxious _____
Slightly anxious _____
Moderately anxious _____
Very anxious _____
Extremely anxious _____

18. How often have you thought about osteoporosis or bone weakness in the past week?

Not at all _____
Once or twice _____
Several times _____
Every day _____
More than once a day _____

19. When you had received your result how long did it take you to forget about it ?

A few minutes _____
An hour or so _____
A day _____
Several days _____
Several weeks _____
I still think about it _____

20. Did you deliberately try to forget about it?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

21. Did you do anything to distract yourself from thinking about it?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

22. Did you try to reassure yourself about it?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

23. Do you have, or have you had in the past, any symptoms / fractures that might be related to your bone density? Yes / No
If so, please specify:

24. Since the scan, how often have you wondered whether symptoms that you have now or have had in the past may be related to your bone density?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

25. How sure are you that you have/don't have symptoms relating to bone weakness?

I am sure that I have symptoms relating to bone weakness.....

I think that I probably have symptoms related to bone weakness.....

I have no idea whether I have symptoms related to bone weakness.....

I think that I probably don't have symptoms related to bone weakness.....

I am sure that I don't have symptoms related to bone weakness.....

26. Since the scan, how often have you thought about what it would be like if you developed the symptoms of osteoporosis (or developed more symptoms if you already have some)?

Never _____ Once or twice _____ Several times _____ Many times _____ Every day _____

27. Are you more, or less worried about osteoporosis since the scan? (please tick one of the following):

Much less worried.....

Less worried.....

A little less worried.....

Neither more or less worried.....

A little more worried.....

More worried.....

Much more worried.....

28. What did your result mean? (Please summarise briefly)

29. Was there anything important about your result that you are unclear about? Yes / No
If so, please specify:

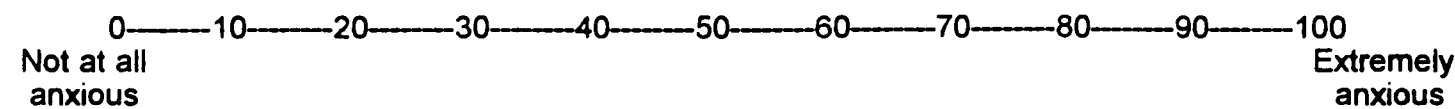
30. Are you now taking part in the HRT research trial at the Bone Densitometry Unit? Yes / No
If so are you taking HRT or in the control group? HRT / Control

Appendix N - longer-term follow-up questionnaire

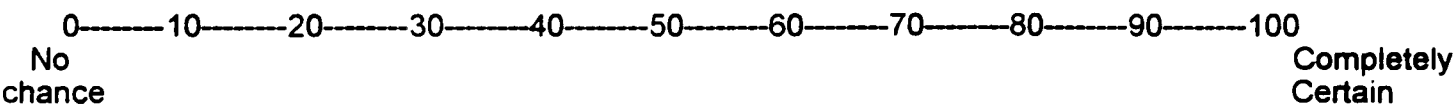
- a. How many bone density scans have you had?.....
- b. Do you do anything to help prevent / slow down bone loss, or avoid fractures? Yes / No
If so, please describe everything that you do:

Please place a cross on the point of the scale that best describes your feelings about osteoporosis.
Some of the questions may ask you to imagine certain situations: these questions may seem difficult but even if you are not sure, please give your best guess and answer all the questions.

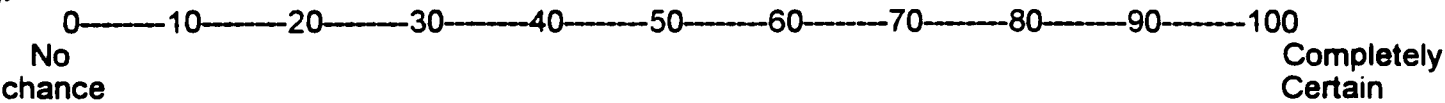
1. How anxious do you feel about your bone density?



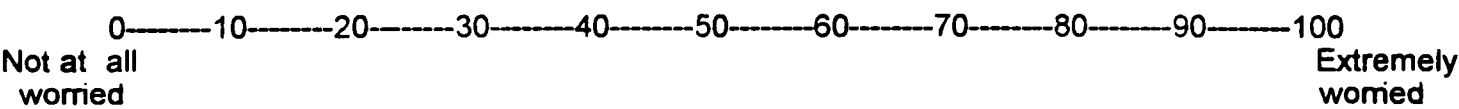
2. How likely do you feel it is that you will develop osteoporosis or symptoms related to bone weakness in the near future? (Please rate your feelings rather than what you think a "rational" or "correct" answer would be)



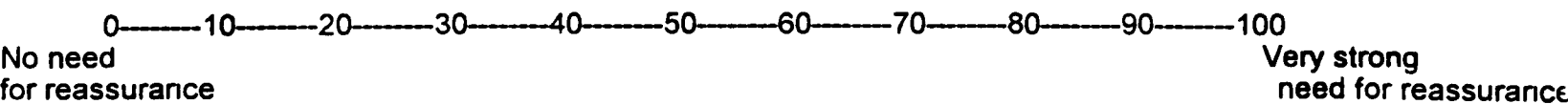
3. How likely do you feel it is that you will develop osteoporosis or symptoms related to bone weakness at a point in the future? (Please rate your feelings rather than what you think a "rational" or "correct" answer would be).



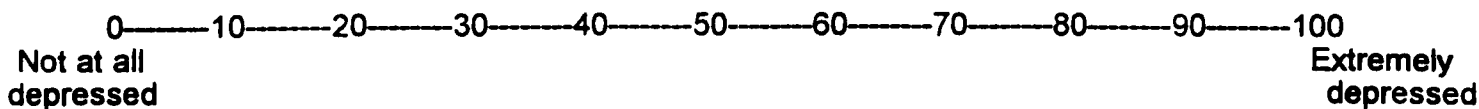
4. How worried do you feel about developing osteoporosis and symptoms related to bone weakness?



5. How much do you feel in need of reassurance about your bone density?



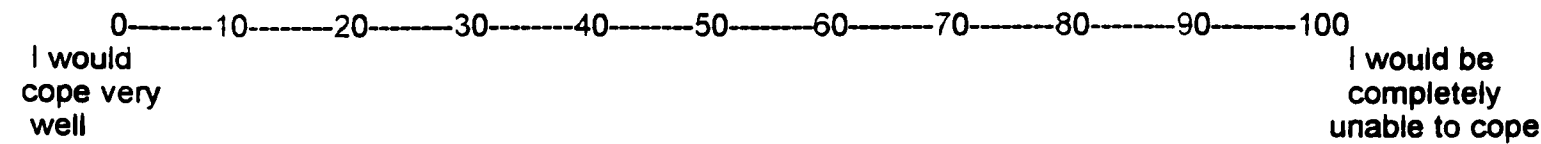
6. How depressed do you feel about osteoporosis.?



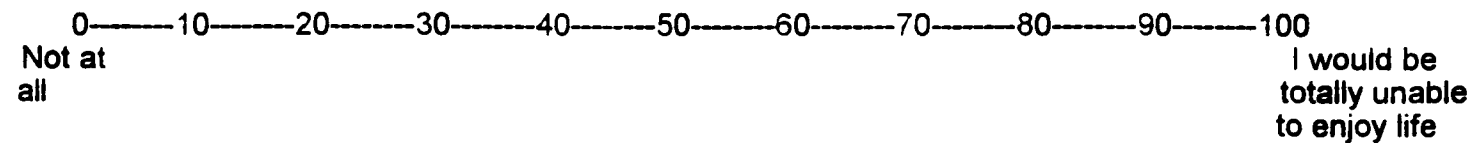
7. Compared to other women (of your age), how "at risk" do you feel for developing osteoporosis or symptom relating to bone weakness in the future? (tick one of the following)

- Much less at risk than the "average" woman.....
- Less at risk than the "average" woman.....
- Slightly less at risk than the "average" woman.....
- At the same risk as the "average" woman.....
- Slightly more at risk than the "average" woman.....
- More at risk than the "average" woman.....
- Much more at risk than the "average" woman.....

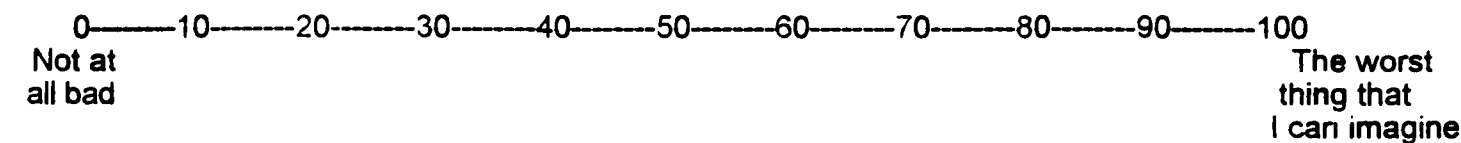
8. If you developed osteoporosis or symptoms related to bone weakness, how well do you think that you would cope?



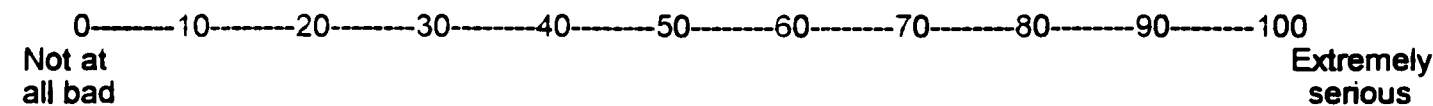
9. Would having osteoporosis or symptoms related to bone weakness affect your ability to enjoy life?



10. In general, how bad do you think the consequences of osteoporosis or symptoms relating to bone weakness would be for you?

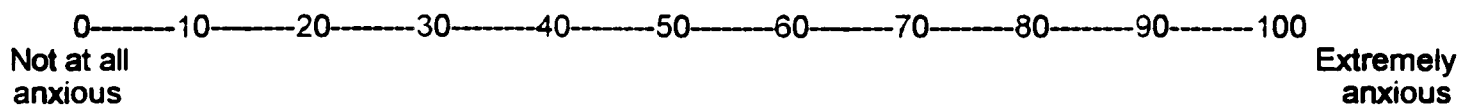


11. How serious a threat to health is below-average bone density?

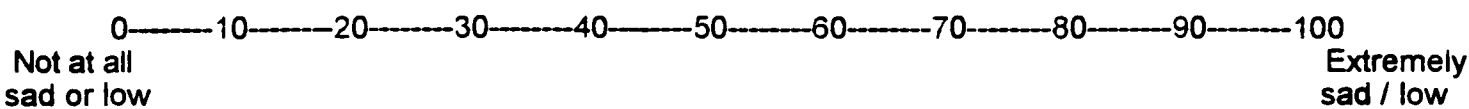


Please place a cross on the point of the scale that best describes your feelings in general at the moment.

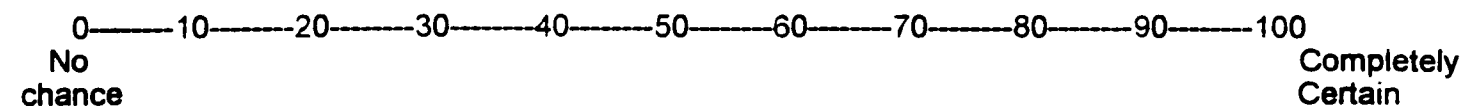
12. How anxious do you feel?



13. How sad or "low" do you feel?



14. How likely is it that you will develop a serious illness (other than osteoporosis) in the near future? (Please rate your feelings rather than what you think a "rational" or "correct" answer would be.)



18. Do you have osteoporosis? (Please tick one of the following)

- Definitely.....
- Probably.....
- Don't know.....
- Probably not.....
- Definitely not.....

19. How sure are you that you have/don't have symptoms relating to bone weakness?

- I am sure that I have symptoms relating to bone weakness.....
- I think that I probably have symptoms related to bone weakness.....
- I have no idea whether I have symptoms related to bone weakness.....
- I think that I probably don't have symptoms related to bone weakness.....
- I am sure that I don't have symptoms related to bone weakness.....

Thank you very much for your help.
Further comments:

**Appendix O - the letter sent to volunteers before their scan,
from the bone density research group.**

BONE DENSITOMETRY RESEARCH GROUP

NUFFIELD ORTHOPAEDIC CENTRE Windmill Road, Headington Oxford OX3 7LD

Tel. 0865 227445

Ref: 1APPINPO.DOC 2007/93

Dear Volunteer,

Osteoporosis, which is essentially the thinning of the bone, is a major health problem for women in our society. The new technique of bone densitometry is being used to show those people who are at risk of developing fractures later in their life. The problem mainly concerns women, in the ten to fifteen years following the menopause, where the rate of bone loss is at it's highest. We are undertaking a study to look at the general population to try and identify those women at risk. To do this we are taking a bone density measurement on one occasion followed by further measurements at intervals of approximately 12 months to show those women most at risk of losing bone at a higher rate. This study will be followed by studies which will try to stop this loss of bone with therapeutic intervention such as hormone replacement therapy and drugs which effect bone metabolism.

The measurement is based on an x ray technique and the dose is extremely low. It is approximately 0.6 microsieverts and the normal daily exposure in the environment is about 7 microsieverts per day. You will be asked to lie still on a table for 8 to 9 minutes. It is only necessary to remove your shoes. There is no discomfort or pain. We will give you a copy of your results and also send a copy to your GP. If we find that your readings are low this will be communicated to your general practitioner. Dr Roger Smith who specialises in bone metabolism at the NOC can take referrals from general practitioners of patients with low bone densities through the usual NHS channels. Your GP will be informed of the result.

If you agree to participate in the study, we will ask you to fill in a confidential questionnaire about your health and lifestyle.

You need not take part in this study and you can leave it at any time without affecting your normal health care in any way.

We suggest you keep this letter and show it to anyone concerned with your medical care. If you have any questions or problems, please contact me. My telephone number is 0865 227442.

Yours sincerely

Dr A. John Shipman
Project physician
COREC NO. 2719

Appendix P - information given to volunteers to help them interpret their result

BONE DENSITOMETRY RESEARCH GROUP

NUFFIELD ORTHOPAEDIC CENTRE Windmill Road, Headington Oxford OX3 7LD

Tel. 0865 227445

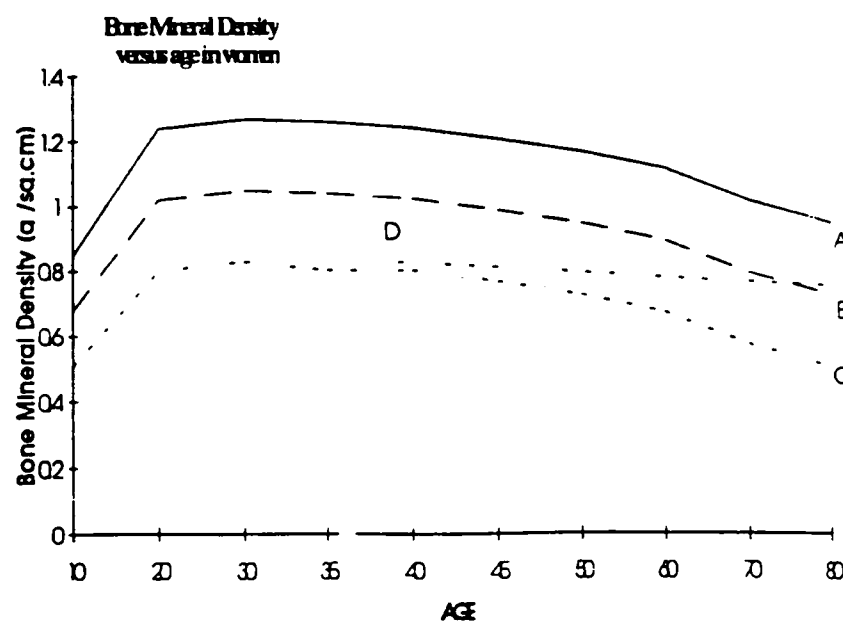
Ref: HEADED.P.DOC 02/11/92

27 January, 1993

INTERPRETING YOUR RESULTS

After your bone mineral density has been measured you will be asked to wait for the results to be analysed.

Your bone density reading will be handed to you and will be shown as a cross on a graph which is illustrated below. The graph shows bone mineral density (BMD) on the vertical scale age on the horizontal scale. The data are derived from BMD measurements from many thousands of women. You can also see that a fall in BMD is a problem for all women following the menopause. It is therefore important that all women have an adequate dietary calcium intake. Note that BMD rises to a maximum at age 30 - 35.



B = Arithmetic mean (female), A & C = 2 Standard deviations above and below the mean

There are three curved lines on the graph labelled A, B and C. The middle line B is the mean or average of all the bone mineral density readings. Lines A and C show the spread of readings in the normal population studied : 95% of all normal women fall between lines A and C.

The straight horizontal line D shows the level below which women will probably have lost some bone and hence may suffer bone fractures in accidents more easily than women who have higher bone densities.

If your reading is above line B we shall inform your GP that it is not exceptional.

Some older women may have a reading above line B but below the horizontal line D. Although this would imply an increased risk of fracture it may be that treatment is not desirable except for maintenance of a calcium rich diet and care in avoiding accidents.

If your reading is between lines B and C we shall inform your GP that the reading is below the mean. We would not expect any treatment to be advised if you have not reached the menopause. You should be aware that a calcium rich diet and full activity should be maintained and at the menopause you may discuss preventative treatment for osteoporosis with your doctor. If you are experiencing the menopause or have passed it we suggest that you consider having a further reading to see whether the density is constant or falling. We will soon be starting a study which involves a series of regular measurements over two years and you may wish to consider joining it. If so please give your name to the receptionist now and we will contact you shortly with further details. You may then want to consult your doctor about osteoporosis preventative treatment. In the meantime, make sure that your diet contains calcium rich foods as suggested in our diet leaflet.

You may have a reading below the horizontal dotted line D and be over the age of 40. In this case it is most likely that you have already lost some bone. You should be having adequate dietary calcium and be considering hormone replacement therapy.

If your reading is below line C our project physician will review your result and correspond accordingly with your doctor. If you would like to discuss such a result with the project physician please ask at reception about arrangements for telephoning him or returning for a discussion.

A few volunteers have readings above line A. This is usually good.

The project physician reviews all these results and will correspond with your doctor if he observes an abnormality. You may make arrangements to consult the project physician if you have any cause for concern.

If you have an exceptional result which the project physician believes should be assessed fully, he will advise your doctor that Dr Roger Smith, metabolism expert at the Nuffield Orthopaedic Centre will consider referrals from GP's through the usual NHS arrangements.

We will try to give you as much information that we can but ask you to note that we cannot give you treatment directly. This is the responsibility of your own doctor. We are, however carrying out studies into the prevention of osteoporosis and the alleviation of menopausal symptoms. We may be able to offer you treatment as part of these other studies.

Thank you for joining our study. Please read our leaflet describing the next stages in our research and your possible involvement.

Yours sincerely

A . John Shipman project physician
22/03/93INTRPHD.DOC

Appendix Q

Part 1) Coding system for responses to the question: "What does your result mean to you?"

Five variables are used to code the responses. Most people will score on either A or B (although in a very few cases they might score on neither or both). Usually where they do not specifically state the physical meaning of their result, this can be interpreted from their other comments. For example, if they feel that they should start preventative behaviours, their result is probably perceived as low.

Note that numbers can be combined where necessary, with the lowest number first. For example, if a woman says that her scan shows a decrease from last time and she sees this as bad her score on B would be 28.

A: Bone density / osteoporosis : positive or neutral

- 1 very good result (e.g. "I'm in the top 2%", "I've got very high bone density")
- 2 good result, positive interpretation - bones are healthy/satisfactory,/ there's nothing to worry about- positive evaluation (or implied positive evaluation: if someone says that if means that their lifestyle is fine this indicates a positive interpretation)
- 3 above average result but without positive evaluation (if 'better' than average, score 2)
- 4 decreased likelihood of osteoporosis/fracture - "e.g. I'm unlikely to get osteoporosis."
- 5 good now but -anything that implies the current state is temporary, that reassurance will be short-term only, that the woman has reservations in deducing anything about the future ie "my bones are ok at the moment", "I shouldn't be complacent"
- 6 decrease likelihood of osteoporosis in the future but.... e.g. I'll be ok in the future as long as I continue to take calcium
- 7 average / normal bone density is average: without positive interpretation
- 8 no change (from previous scan) no sig. diff from last time
- 9 increase from last scan

4 trumps 1 and 2

2 trumps 1 and 3

5 trumps 2, 3 and 4

B: Bone density or osteoporosis: negative

- 1 below average bone density (but without implying that this is necessarily bad or that bones are weak or that have necessarily lost bone already)
- 2 low bone density (rather than below average- more negative, not simply variation of the norm) but without stating that she has lost bone or is at increased risk now, or her answer has negative implication without being specific.
- 3 lost bone (first scan only) e.g. I must prevent further loss
- 4 increased risk of osteoporosis in future or problems in the future
- 5 increased risk of fracture now /bones brittle/weak now
- 6 will get osteoporosis (more definite than increased risk)
- 7 have got osteoporosis now
- 8 decrease from last time or deterioration from last time
- 9 decrease from last time but could be machine error, or not sig., or no greater than normal loss
- 10 below average but in the acceptable/ average/normal range

4 trumps 2

5 trumps 2

7 trumps 2,3,5

Occasionally people who have had two scans will score on both A and B e.g. they may show no change between scans and their bone density is low.

C. Emotional meaning

Again, numbers can be combined if more than one applies.

- 1 positive-pleased, happy,
- 2 relieved, reassured
- 3 negative-disappointed, regret, anxious, concerned
- 4 no need to worry/concern at the moment
- 5 surprised-better than expected
- 6 surprised-worse than expected
- 7 feel lucky, fortunate
- 8 not surprised / confirmation of expectations
- 9 optimistic that if takes action things will improve

2 trumps 4 eg if she says that she's very relieved, there's no need to worry, just score 2

D. Implications for further action

- 1 **Lifestyle fine already**, no need for change in action eg no HRT
endorsement of what already doing, "I'm doing the right things", "HRT is working"
- 2 **need for preventative/treatment/limiting** fall type of action/ be more aware of bone density
e.g consider HRT, calcium
This can be continuing or initiating action
- 3 **need or intention to have a further scan**
- 4 **mentions family history as reason for continued caution** eg wants to have further checks because of her mother, or will keep an eye on it / take supplements even though her result was good, because of family history.

E. Miscellaneous

- 1 **other-not classified**
- 2 **ok in spine but might not be elsewhere** eg "its ok at least in the area scanned"
- 3 **pleased to know sooner rather than later**
- 4 **causal attribution about why her bone density has turned out like this, or search for reasons**
eg I'm not getting enough calcium in my diet
It's due to coeliac condition
It's a mystery
- 5 **wished hadn't had test. or wonder whether should have had**
- 6 **symptoms /pains/back problems etc are not due to low bone density.**
- 7 **I'll get/have got arthritis**
- 8 **didn't understand, not sure what results means**

Appendix Q, part 2.

Combination of categories A and B into a single scale representing interpretation of scan result in terms of the level bone density or risk for osteoporosis

- 1 Very good result
- 2 Decreased likelihood of osteoporosis
- 3 Good result or Reduced likelihood of osteoporosis, as long as continue preventative measures
- 4 Above average
- 5 Good now but could decrease
- 6 Normal
- 7 Average
- 8 Below average but in the satisfactory/normal range
- 9 Below average
- 10 Low or Increased risk in future
- 11 Lost bone and / or Increased risk of fracture now
- 12 Will get osteoporosis
- 13 Have already got osteoporosis

Appendix R: Interpretations of change in bone density between two scans

Interpretations of “no change” since the previous scan

Of the nineteen women who described their result as indicating no change, thirteen had indeed showed a change of less than 1.5%, the machine error. Another three were correct in as far as they showed a change (or projected change) of less than 2.5%.

One woman who said that she had not changed, had actually shown a noticeable increase (4.8%) in just 6 months. She said that her GP had told her that her increase “fell within the parameters of medical/statistical error” although the policy in the research trial is that a difference of 2.5% or more is seen as a noticeable change. However, she and her GP were happy that their had been no fall, so their interpretation does not seem to be problematic.

Two women were probably being too optimistic when they described their result as showing no change. One had shown a 3.2% decrease in twelve months and the other had shown a 2.1% decrease in seven months (which translates to -3.6% if it is assumed that she shows the same rate of decrease for a year).

Thus of the sixteen women who wrote that their bone density had not changed, three were incorrect.

Interpretation of an increase since the previous scan

Eight of the sixteen women who said that their bone density had increased had shown an increase of at least 2.5%, so were correct in their conclusion. Another subject showed a change of under 2.5% in eight months, but the increase would be larger than 2.5% if this change is multiplied to indicate her projected change at twelve months.

One woman who incorrectly described her decreased result as a increase at the three month follow-up had been correct at the week follow up and seems to have realised the correct implications of her result even though she hadn't remembered the correct direction. However, another woman said that her result was better than last time and was very pleased about it, while in fact she had lost 1.9% of her bone density.

Five women who described their result as an increase had gone up by less than 2.5% even if their rate was adjusted to a year's equivalent change. One of these five women showed a change of less than 1.5%.

Thus, if one uses the 2.5% per year cut-off point, it could be argued that of the sixteen women who said that their result showed an increase, 9 were correct and 7 were incorrect.

Interpretations of a decrease since the previous scan

Of the eight woman who described their result as a decrease, four had indeed shown a decrease of more than 2.5%. Two more women showed a decrease of more than 2.5% if their result is adjusted as being equivalent to a year between scans. Two women were inaccurate in that their results showed a decrease of less than 2.5% even if this adjustment if made. No women interpreted their result as a decrease if they had actually shown an increase.

Interpretations of a decrease which could be due to machine error

Of the four women who said that their decrease could be due to machine error or within the acceptable rate of loss, one was correct in that her decrease was less than 1.5%. However, two had shown a decrease which was larger than 2.5% and one women had actually shown an increase in bone density..

Conclusion

Of the 47 women who described their result in terms of change in bone density, 15 (31.9%) were incorrect, if 2.5% is used as the cut-off value for significant change.