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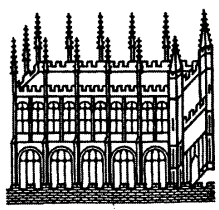

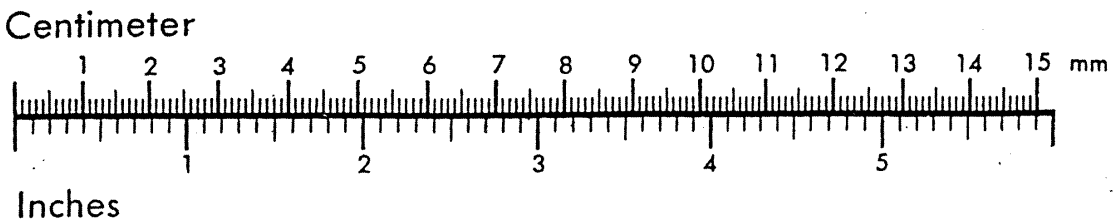

Exploring experiences of adolescent inpatient treatment for anorexia nervosa: A retrospective, qualitative study with young adults, reflecting on their experiences of inpatient treatment and discharge.

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Exploring experiences of adolescent inpatient treatment for anorexia nervosa: A retrospective, qualitative study with young adults, reflecting on their experiences of inpatient treatment and discharge.

Abstract

Aims:

Given the paucity of research into young people's views about treatment for anorexia nervosa (AN), the high rates of relapse following inpatient care, and debates about its effectiveness for this client group; this study intended to explore young peoples' experiences of inpatient psychiatric treatment for a diagnosis of (AN). It aimed to explore young people's views about what was helpful and unhelpful about their treatment in general adolescent unit settings, and about experiences of discharge and re-adjustment to the outside world. It also aimed to explore whether there may be any aspects of inpatient care which may compound intrinsic features of AN – such as issues of control and low self-esteem.

Design and Method:

This is a retrospective, qualitative study using data collected through semi-structured interviews. Seven young adults (between 16 and 23 years) were interviewed about their past experiences of adolescent inpatient treatment for AN. Interview transcripts were then analysed using interpretative phenomenological analysis (IPA).

Results & Conclusions:

Four super-ordinate themes emerged from participants' accounts of their treatment and discharge experiences: 'Removal from normality versus connecting with the outside world'; 'Treated as another anorexic versus a unique individual in distress'; 'Control and collaboration'; and 'The importance of peer relationships'. Participants provided views that were balanced and useful, many of which were in-line with the extant literature. Findings more unique to this study concerned the salience of a sense of being removed from 'normality'; a view that ones' developmental needs were not always addressed; and the value placed on positive relationships with fellow inpatients. Findings also suggested that more authoritative approaches to inpatient care may indeed serve to compound features of AN – particularly a sense of ineffectiveness and isolation. Suggestions for clinical practice and further research are outlined.

(Abaigeal Offord, Harris Manchester College, Trinity Term, 2004).

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INTRODUCTION

1.0: Introduction

Anorexia Nervosa (AN) can be a very serious condition with mortality rates estimated to exceed all other adolescent psychiatric disorders, including depression (Herzog *et al.*, 1992). As a consequence of severe weight loss, poor physical health, parental and professional concern and a perceived resistance to more 'voluntary' treatment, the decision is made to hospitalise a number of teenagers (Gowers *et al.*, 2000). The short term benefits of hospitalisation are acknowledged as inpatient treatment can prevent a fatal outcome for many (Wood & Flower, 2000, Meads *et al.*, 2001), and is generally effective in achieving substantial weight gain. However inpatient treatment is highly expensive, associated with high rates of relapse and re-admission, and raises many complex ethical issues regarding the coercive nature of care. Furthermore, very little stringent research has been carried out to investigate its more long-term effectiveness; therefore its relative cost and benefits are not clearly established. Until very recently no studies had investigated young people's views on their inpatient treatment for AN. Our knowledge about what is helpful or unhelpful from a client's perspective is therefore extremely limited. This study aims to explore the views of seven young adults in detail as they look back over their experiences of adolescent inpatient treatment, discharge, and the follow-up support they received from services.

1.1: THE IMPORTANCE OF CLIENT VIEWS:

Over the past 10 years government initiatives have stressed the importance of 'consumer involvement' in the evaluation of healthcare services (Newton, 2001, Department of Health, 1998,1999). Research suggests that the perceptions of clients often differ considerably from the views of clinicians (von Essen & Sjoden, 1991, Babiker & Thorne, 1993). Therefore obtaining clients' views regarding the treatment they receive is vital for the effective planning of services and treatment options. Despite these findings acceptability of treatment from a client's perspective is generally a neglected area of research, particularly in the field of mental health (MH). This may be partly due to a widely held belief that psychiatric patients are 'automatically incapable of providing a rational or valid opinion about the services they are using' (Rogers *et al.*, 1993, p.3).

Even less research has been carried out exploring clients' experiences of eating disorder (ED) treatment. This is perhaps particularly important given the quite substantial drop-out rates for this treatment - approximately 1 third for psychological treatments (Mahon, 2000), and 50% for inpatient treatment (Button *et al.*, 1997). Although it has been suggested that such drop-out rates may reflect patients' dissatisfaction with the treatment they receive (Mahon, 2000), it has also been suggested that, within anorexia nervosa, patients often fail to recognise the need for treatment (Mahon, 2000, Fennig *et al.*, 2002).

This issue may result in their views being regarded as inconsequential:

'There may be general scepticism about the patient's ability to know what is best for her and an illusion that negative treatment experiences may be ignored as superficial due to the symptom denial and failure to recognize the need for treatment' (Rosenvinge & Kuhlefelt-Klusmeier, 2000, p.294).

However studies have demonstrated that patients with eating disorders are clearly able to provide views which are balanced, reflective and useful (see section 1.4), and that they can recognize the necessity of less palatable aspects of treatment (Bell, 2003). Indeed, The National Institute for Clinical Excellence (NICE, 2004) have explicitly recommended that patient satisfaction should be considered a routine outcome in research into the effectiveness of eating disorder treatment.

Adolescent mental health has also been a neglected area of research and 'very little is known about how those in this age group in Great Britain view and experience health care' (Buston, 2002, p.231). A significant lack of concordance has been found between the views of carers/professionals and adolescent service-users, further accentuating the need to explore adolescent views on treatment (Buston, 2002). The importance of giving young people a voice in order to develop more effective 'young person friendly' inpatient CAMHS was also stressed in a recent study by Young Minds (Street & Svanberg, 2003).

It seems clear therefore that in order to help identify factors critical to treatment effectiveness for young people with eating disorders, the views of young people who have experienced such treatment must be explored in more detail.

1.2: AN IN ADOLESCENTS:

1.2.1: Diagnostic Criteria & Co-morbidity

AN is an eating disorder characterised by a refusal to maintain a minimally normal body weight, an intense fear of gaining weight and a significant disturbance in the perception of body shape and size (American Psychiatric Association, 2000). Weight-loss may be achieved through dieting, fasting, and/or excessive exercise ('restricting' sub-type). A 'binge-eating/purging' sub-type includes regular engagement in binge eating and/or purging – including self-induced vomiting and laxative misuse. AN is often accompanied with other psychiatric diagnoses such as anxiety disorders, depression, personality disorders and obsessive-compulsive disorder (Agras *et al.*, 2004).

1.2.2: Aetiology

In common with other psychiatric disorders, the aetiology of AN is considered to be multi-factorial (Gowers & Bryant-Waugh, 2004). Biological, social and psychological factors have all been found to be relevant, with different factors interacting at different stages of illness (Lask, 2000). Common risk factors for the development of AN include

dieting behaviour, stressful life events, specific patterns of family interaction, low self-esteem and perfectionism (Tozzi *et al.*, 2003).

1.2.3: Prevalence

Over 90% of cases of AN occur in females (American Psychiatric Association, 2000). Epidemiological studies suggest that the prevalence of eating disorders in adolescence has increased during the past 60 years (Lucas *et al.*, 1991). A recent review of such studies suggests that the average prevalence rate found for young females with AN is about 0.3%, with females aged between 15-19 years representing approximately 40% of all identified cases (van Hoeken *et al.*, 2003). Eating disorders are generally ranked as the third most common chronic illness in adolescent females (Kreipe *et al.*, 1995).

1.2.4: Course and Prognosis

Age of onset with AN is usually in early to late adolescence. The disorder then follows a highly variable course with some fully recovering after their index episode and others developing a fluctuating course of weight gains and losses, or a chronically deteriorating course. Mortality rates generally range between 3-10% (Steiner & Lock, 1998).

1.3: THERAPEUTIC INTERVENTIONS FOR ADOLESCENTS WITH AN

1.3.1: Current situation – clinical context

Currently interventions for young people with AN include a number of individual, group and family therapy approaches (see section 1.3.6), and a range of medication and nutritional supplements. Treatment settings include specialist inpatient units, general adolescent units, outpatient services and day hospitals (both private and public sector). Admission may in some circumstances also be in a pediatric ward or a specialist adult ED service.

The relative merits of these settings and treatments are so far unclear, and relatively little is known about the efficacy of interventions for AN at any age. Therefore provision for adolescents with ED tends to be guided by recommendations found in recent national and professional guidelines (e.g. Kreipe *et al.*, 1995, NICE, 2004). Gowers & Bryant-Waugh's (2004) useful summary of these guidelines includes the following:

- services should closely involve parents, family members and other agencies (school, GP etc) in the child's care;
- Services should be delivered in an age-appropriate manner, taking account of developmental, social and educational needs; and
- services (whether ED or general) should have experience and expertise in managing young people with ED.

1.3.2: Treatment outcome studies – problems with the research

Compared to other serious psychiatric problems, there has been a comparative dearth of treatment research for the treatment of AN (Agras *et al.*, 2004). Of the few published studies on the treatment of adolescents with AN, the majority did not employ control groups and most lacked random selection of participants or assessment of specific interventions. The majority of those that tout the efficacy of a specific treatment modality are not methodologically sound (see Patel *et al.*, 2003). Furthermore methodological differences - such as heterogeneity within therapies given the same name, varying outcome measures, and varying definitions for recovery, make combining results in any meaningful way extremely difficult (see Jarman & Walsh, 1999, or Gowers & Bryant-Waugh, 2004).

1.3.3: Service settings

Inpatient treatment is clearly effective in the short-term for achieving substantial weight-gain (see Treasure *et al.*, 1995). However relapse and re-admission following adolescent inpatient treatment are very common (see section 1.6.1.2). Research comparing the longer term effectiveness of different types of service setting is extremely limited.

Meads *et al.* (2001) carried out a systematic review of outpatient versus inpatient care in AN, concluding that there is no evidence to indicate that inpatient treatment is any more

or less effective in the long term. Gowers *et al.* (2000) found that those adolescents who received inpatient treatment had a significantly poorer outcome than those who had not. However this study was not randomised, and these researchers acknowledged that a number of factors which influence the decision to admit are also factors likely to predict poor outcome, such as only the most severe and perhaps least motivated to change being hospitalised (Gowers *et al* 2000, Gowers, 2000).

Although it is assumed that specialist ED services are likely to be more effective than general adolescent units, there are a lack of studies that might provide evidence to support this assumption (Gowers & Bryant-Waugh, 2004). Day-patient treatment might provide a promising alternative to inpatient care (Treasure & Schmidt, 1999). However the relative effectiveness of these two settings have yet to be adequately assessed.

1.3.4: Inpatient Admission and Discharge

Recommendations about when to admit young people with AN include: the presence of malnutrition, serious medical complications, other forms of self-destructive or suicidal behaviour, the need for a more comprehensive assessment and failure of outpatient treatment (Kreipe *et al.,* 1995, Honig & Sharman, 2000). However, in reality it has been argued that the decision to admit is based more on circumstantial factors (such as clinical judgement and availability of care) rather than scientifically based ones. In all cases, the need for inpatient treatment and urgent weight restoration should be balanced alongside the educational and social needs of the young person (NICE, 2004).

Upon discharge, facilitating a smooth transition to outpatient care and providing continuity of care post-discharge is advised (Kreipe *et al.*, 1995). Post-hospitalisation, psychological treatment should be provided for approximately 12 months along with regular monitoring of physical and psychological risk (NICE, 2004).

1.3.5: Aims of inpatient treatment

NICE (2004) guidelines state that the key priorities of inpatient treatment are to provide skilled implementation of re-feeding , with careful physical monitoring, in combination with wider psychosocial interventions. Due to the multiple needs of this client group the importance of a multidisciplinary approach is universally accepted.

The goal of inpatient treatment is to help achieve both physical and psychological health (Kreipe *et al.,* 1995). However although there is general agreement about the need to adopt a holistic approach, inpatient services tend to differ in their 'balance' between addressing physical and psychological needs (Gowers *et al.*, 2002). This European survey also found great variations in the 'use' of inpatient treatment; average length of stay and treatment style (ranging from strict behavioural regimes to individually designed client therapy) differed considerably between services. The following evidence relating to the cognitive effects of starvation, combined with the serious risks to physical health with

this age group, often mean that weight–gain becomes the primary goal of adolescent inpatient treatment.

1.3.5.1: *Risks to physical health*

In adolescents with AN, there is an immediate risk of significant growth retardation, pubertal delay and peak bone mass reduction, which have potentially irreversible effects on physical development (Steiner & Lock, 1998, Kreipe *et al.*, 1995). This sense of urgency puts pressure on clinicians to intervene earlier and perhaps more aggressively with young people in order to normalise nutritional and metabolic state through strict re-feeding programmes (Manley *et al.*, 2001).

1.3.5.2: *Starvation effects*

There is clear evidence that starvation results in cognitive changes such as the reduced capacity for complex thought and reduced concentration (Keys, 1950, Fairburn *et al.*, 1999). This can lead to more polarised thinking, a lessened ability to make decisions or engage in complex activities and a more rigid preoccupation with food, weight and shape (Duker & Slade, 1988). Arguably therefore, one's ability to engage meaningfully in traditional psychodynamic psychotherapy is limited until ones nutrition is improved (Bruch, 1978, Maloney *et al.*, 1983). It has even been suggested that psychotherapy may be detrimental during this acute phase (Danziger *et al.*, 1999). The view is that adolescents are not able to engage in treatment interventions that require insight, problem

solving, abstract thinking and logic until their weight has stabilised (Patel *et al.*, 2003, p252).

Given these issues, psychological or emotional input is often not adequately prioritised, or even withheld, until one's target weight is achieved (see Danziger *et al.*, 1999). However research also suggests that even when in a state of starvation, patients should be offered continual psychological and emotional input, appropriate to their level of capacity, in order to discuss fears, and support an acceptance of weight gain (Maloney *et al.*, 1983, Duker & Slade, 1988). Indeed recent recommendations stress ongoing psychological/emotional support. Individual appointments, separate from parent/carers should be offered to every young person receiving inpatient treatment (NICE, 2004). Psychological aspects of care should focus both on eating behaviour, attitudes to weight and shape and on wider psychosocial issues.

1.3.6: Psychological Therapies

The differing ways in which the aetiology and maintenance of AN have been conceptualised has led to a number of different approaches to psychotherapeutic treatment. Lask (2000) in his overview of the management of adolescent AN, points out that, in practice, the 'choice of specific therapies is in practice determined more by availability than by need' (p.168). The main approaches used are as follows:

1.3.6.1: *Family Therapy:*

Family Systems theories conceptualise AN as occurring very much within a familial context, rather than at an intra-psychic level alone. Traditional theories, such as Minuchin (1978) emphasised the dysfunctional organisation of the family of a child with an eating disorder. More recent approaches view the family as a 'resource for recovery' rather than the cause of the problem – attempting to involve parents as partners, and reducing the sense of parental guilt and blame. The precise goals and strategies employed by a family therapist depends upon the particular theory to which they adhere (see Honig, 2000).

1.3.6.2: *Psychodynamic Approaches:*

Psychodynamic theories, unlike family approaches, focus on the 'inner world reality' of the young person (Magagna, 2000, p.262). They emphasise the place of infancy and subsequent experiences in shaping these realities. Anorectic symptoms are viewed as having unconscious meaning, often of a sexual, aggressive or hostile nature (see Cooper, 2003). Again there are different slants in theory. However, the goals of both psychoanalytic and object relations approaches are to achieve insight by making repressed conflicts conscious. Psychodynamic strategies in therapy may include free association, interpretation, a focus on past relationships and the use of the unconscious.

1.3.6.3: *Cognitive Behavioural Therapy (CBT):*

Cognitive- behavioural models of AN, in contrast, focus on the here and now and the role of conscious thought processes and behaviours in both precipitating and maintaining the disorder. The belief that 'thinness is a value of inestimable worth' is viewed as pivotal to the disorder, accounting for all subsidiary beliefs and behaviours (Cooper, 2003). Cognitive therapy techniques include psycho-educational work, a collaborative, problem-solving approach between therapist and client, identifying unhelpful thoughts and beliefs about eating, weight and shape, and cognitive re-structuring techniques (see Cooper, 2003).

1.3.6.4: *Behavioural Approaches:*

Behavioural approaches rest on the assumption that food refusal is a learned response that needs to be changed (Bruch, 1978). Interventions such as behaviour modification, contingency management and activity management are amongst those used as part of overall inpatient treatment programmes. Re-feeding is often achieved using a 'level' or 'graded' system based on behaviour modification principles. 'Privileges' (such as access to desirable activities) are allowed based on progressive weight gain and level status (see Ramjan, 2003, Vandereycken, 2003). This approach has been found to effectively facilitate the process of weight-gain, at least in the short-term (Patel *et al.*, 2003). However strict behavioural regimes popular in the 1980's have been heavily criticised for their inevitable use of deprivation and restriction of privileges. Although more lenient

approaches have been promoted recently, arguably most impatient programmes continue to use some type of behavioural or contingency management, albeit more implicitly (Vandereycken, 2003).

1.3.6.5: ***Motivational Enhancement Therapy (MET):***

Based on the trans-theoretical model of change (Prochaska *et al.*, 1998), MET aims to enhance motivation and engagement by using motivational interviewing techniques and processes which flexibly 'match' the client's 'stage of change' (see Blake *et al.*, 1997). Ambivalence about change and denial or lack of insight is a fundamental consideration in the treatment of young people with AN (Blake *et al.*, 1997, Geller & Drab, 1999). The importance of improving motivation and adherence in this client group has therefore been stressed, along with the need for further RCTs using this promising approach (Gowers & Bryant-Waugh, 2004).

Other therapies used with this client group include Interpersonal Psychotherapy (IPT), Cognitive Analytic Therapy (CAT), Dialectical Behaviour Therapy (DBT) and Multiple Family Group Therapy (see Gowers & Bryant-Waugh, 2004).

In their recent review of the evidence base, Gowers & Bryant–Waugh (2004) state that there is insufficient evidence to conclude that any one specific form of psychotherapy is most effective for adolescents with AN, or is most acceptable to clients. Most research is

with adult clients; caution must be used when applying these findings to the adolescent age-group.

Others conclude that research so far suggests family work to be the most effective treatment for adolescents with AN (e.g. Honig, 2000, Steiner & Lock, 1998). Indeed the NICE (2004) guidelines state that family work should be offered to all adolescents, including work to support siblings.

1.4: RESEARCH INTO PATIENT VIEWS OF INPATIENT TREATMENT

1.4.1: Adult Studies

Recently a small number of investigators and authors have begun to consider the views of adult clients with eating disorders on the treatment they have received (both inpatient and in other settings) (e.g. Petterson & Rosenvinge, 2002, Rosenvinge & Kuhlefelt-Klusmeier, 2000, Button & Warren, 2001, Newton, *et al.*, 1993, Newton, 2001, Tozzi *et al.*, 2003, Shelley, 1997, Eivors *et al.*, 2003). Studies have included qualitative studies, the use of postal questionnaires, patient satisfaction surveys, and the presentation of narrative accounts.

There are a number of important similarities in the findings of these studies. These include the following:

- clients often viewed the effectiveness of psychological therapies (e.g. family therapy) quite differently to clinicians;
- a positive experience of individual psychotherapy was often seen as crucial to recovery, helping to achieve insight and understanding of underlying issues;
- helpful qualities for a therapist included empathy and understanding but also being perceived as having expertise in treating eating disorders;
- support gained through self-help groups was often viewed as being equally important to recovery as professional care;
- motivation to change was very important in terms of how effective treatment was perceived to be. Most participants did not feel ready to voluntarily seek treatment until on average 21 years old (approximately 5 years after onset of eating disorder);
- recovery was perceived as a much broader phenomenon than purely an absence of symptoms - a narrower definition which has often been stressed by clinicians;
- unhelpful aspects of treatment included experiencing a loss of self-worth and demoralisation, and not being treated as an individual;
- a focus/over-emphasis on weight, shape and eating was consistently viewed negatively;
- enforced rapid weight-gain during inpatient treatment was viewed as having been detrimental to ones mental health; and

- people were able to acknowledge the necessity of inpatient treatment and view it as beneficial, even if admitted against their will.

Nearly all authors and investigators concluded that existing services were inadequate in meeting the needs of patients. Many of the findings, particularly the high value placed on talking treatments, were in line with psychiatric service user research generally (see Rogers *et al.*, 1993 & Faulkner, 1997). Bell (2003) concluded from her review of qualitative studies, that effective engagement and treatment of patients with eating disorders should include the following:

- supportive, empathetic and understanding relationships;
- help with wider psychological change;
- patients being given some degree of control over the process and pace of treatment; and
- staff learning to develop and maintain more collaborative working relationships with patients.

1.4.2: Studies involving adolescents

1.4.2.1: *Young people on ED treatment:*

Extensive searches of the research literature revealed only 3 previous studies of adolescent experiences of eating disorder treatment.

Colton (2002– unpublished doctoral thesis) explored how young people experienced their current specialist inpatient treatment for AN, and attempted to relate this to their stage of change. She found that almost half of all participants rated themselves as being at the 'action' stage and a further 32% at the contemplative stage[1] – perhaps at a more motivated level than many would expect of this client group. The key themes which emerged from semi-structured interview data and qualitative analysis were the following: 'What is the illness that I have?', 'Do I want to get well?', 'Being with others: support versus distress', 'Being an individual versus just another anorectic' and 'Collaborating in treatment versus being treated'. Patients also stressed their need to feel understood and helped, rather than blamed for their illness, and their desire to be asked about their views on treatment more often. Colton calls for further studies, also looking at ED inpatient treatment in *general* adolescent units.

[1] Action stage = making attempts to stop the behaviour. Contemplative stage = starting to think seriously about changing behaviour (Blake *et al.*, 1997)

Gowers & Bryant-Waugh (2004) report on a Norwegian study which found low acceptably of adolescent inpatient treatment for AN. Young people often reported feeling pressured and 'watched', with authoritarian and restricting aspects of treatment causing anger & ambivalence (p.75). Cockett (1992) found adolescent inpatients valued individual psychotherapy and exercise most highly and family therapy least highly.

1.4.2.2: *Young people on MH services:*

In a recent qualitative study of inpatient CAMHS, young peoples' voices regarding inpatient care stressed the importance of collaboration in their own care and the creation of an informal environment (Street & Svanberg, 2003). Buston (2002), in her qualitative study exploring adolescents' views of mental health services found that adolescents placed much value on a 'supportive', understanding relationship with a clinician, meaning one which is empathic, accessible and continuous. Although it has been suggested that adolescents may be more vocal and critical than adults due to their developmental stage (Piersma, 1987), Buston found that her participants made both positive and negative comments, expressing views that were clear and useful.

1.4.2.3: *Views of Nurses and Parents:*

Two recent qualitative studies exploring nurses'/clinicians' experiences found the theme of 'control' to be central to understanding the treatment of young people with AN. Nurses frequently described power struggles between themselves and patients, with mutual

distrust developing as a consequence of this struggle. Generally, experiences were characterised by frustration, conflict and disillusionment (Ramjan, 2003, Jarman *et al.*, 1997).

Parents have often reported feeling 'blamed and shamed' by health professionals for their child's ED and also 'shut-out' and uninvolved during periods of inpatient treatment. They identify a lack of, and need for support (e.g. see McMaster *et al.*, 2004, and Gowers & Bryant-Waugh, 2004).

1.5: POSSIBLE CONFOUNDING EFFECTS OF HOSPITALISATION

Qualities perceived to be 'shared' by young people with AN have often been blamed for poor outcome (e.g see Agras *et al.*, 2004). These include denial, lack of motivation, being manipulative and competitive, and being 'untreatable'. In fact Goldberg *et al.* (1980) actually conclude that treatment outcome in AN is likely to be a product of individual patient variables rather than the specific types of intervention used.

However, in contrast to this view, several authors and researchers have suggested that inpatient treatment may actually compound some of the negative, intrinsic features of AN - including low self-esteem, a sense of ineffectiveness and worthlessness and a sense of isolation.

1.5.1: Issues of control and self-esteem

Both patient views and theoretical conceptualisations of the development and maintenance of AN have stressed the centrality of the need for control over eating as a response to a loss of control over ones lives; or to a sense of ineffectiveness and low self-worth (e.g. see Bruch, 1962, Fairburn *et al.*, 1999, Button & Warren, 2001, Shelley, 1997, Tozzi *et al.*, 2003). Bruch (1978) and Duker & Slade (1988) in particular have warned how inpatient ED treatment often uses authoritative interventions that disempower the patient in order to achieve weight-gain. These are likely to increase the person's sense of ineffectiveness and failure and 'risk annihilating her sense of self which is already fragile' (Duker & Slade, 1988, p.49). They argue that some inpatient procedures attempt to 'legitimise' this coercion using misguided behavioural theory. Indeed Eivors *et al.* (2003) found that a perceived loss of control was the central theme leading to drop-out from ED treatment. Inpatient conditions may create a sense of passivity and vulnerability which may serve to increase a sense of lost control (p.105).

1.5.2: Social isolation and relating to peers

Bruch (1978) and Button & Warren (2001) also stressed the social isolation caused by suffering from AN, and the impact this can have on social relationships. Duker & Slade (1988) propose that starvation impairs the anorexic patient's ability to relate to others. This is perhaps particularly significant for adolescent sufferers at a time when 'families

and peers ought to provide a milieu to support social development' (Kriepe *et al.*, 1995, p.479). Being in hospital will obviously further increase the potential for isolation. Furthermore living alongside other young people with AN may serve to reinforce an 'anorectic identity' (Vandereycken, 2003, p.413).

Garfinkel *et al.*(1985) propose that adolescents in 'mixed' psychiatric units are often likely to experience criticism from other patients, angry about the disproportionate staff time required for eating disordered patients. Alternatively however, being treated in a specialised inpatient service may lead to competition between patients to be the 'most ill' and in need of most attention. Again, anger and criticism between patients at different stages of the recovery process may have a negative affect on the young person's self-esteem .

1.5.3: A need for further research

Gowers *et al.* (2000, and Gowers 2000) suggest that these intrinsic features of anorexia may actually make teenagers with AN particularly vulnerable to some of the negative side effects of hospitalisation. However these potentially negative consequences remain extremely under-researched.

1.6: THE CURRENT STUDY

1.6.1: Rationale

1.6.1.1: *Why focus on adolescents?*

Adolescent patients with AN have distinct needs from adult patients and are likely to find different things helpful in terms of inpatient treatment. Several authors have recently stressed the specific psychosocial issues relevant to this age group and that treatment should be carefully tailored to the individual's developmental stage (Steiner & Lock, 1998, Kreipe *et al.*, 1995). Inpatient treatment for young people should consider their differing social and educational needs, the close involvement of parents/carers and the need to address the completion of puberty in psychological as well as physical terms (see Gowers and Bryant-Waugh, 2004 & NICE, 2004). However specific recommendations about how to do this in practice are scarce.

Literature regarding the treatment of young people also tends to suggest a greater degree of denial, ambivalence about change and resistance to treatment in these patients (e.g. Ramjan, 2003, Manley *et al.*, 2001, Lask, 2000) and that taking account of the sufferer's high need for control is more difficult due to potentially irreversible consequence to growth and fertility if interventions are not prompt (see section 1.3.5.1). Establishing therapeutic relationships and a collaborative approach may therefore require particular skills with this client group.

Given that early intervention for psychiatric disorders is usually associated with a better outcome, it seems vital that we develop a better understanding of what treatment interventions are likely to be effective in helping younger people suffering from AN. This echoes the view of Gowers & Bryant-Waugh (2004) who recently called for research into patient perspectives in order to contribute towards improved service delivery for adolescent patients.

1.6.1.2: *Why explore discharge experiences?*

Research suggests high relapse and re-admission rates for these clients, as weight-gain achieved during admission is frequently lost following discharge (Vandereycken, 2003, Treasure *et al.*, 1995).

Bruch (1978) commented on how relapse is likely when the focus is purely on weight-gain and underlying psychological issues are not addressed. Many of her patients therefore appeared to be discharged as 'improved' but were actually more depressed or suicidal due to hospitalisation perhaps compounding their difficulties (see section 1.5). Gowers *et al.* (2000) also point out that any gains made are often not generalisable as support and safety found inside the unit may be lost upon return to the outside world.

Fennig *et al.* (2002) propose an explanation for such high relapse rates following adolescent inpatient treatment for AN. They suggest that the 'purpose' of AN initially is to establish some control over overwhelming emotions and events in the young person's

life. Inpatient care provides a short term 'external psychic organizer' so the patient can effectively 'give up' this solution. At discharge however, the abrupt message the young person receives, is that they must once again maintain the struggle on their own. These authors also hypothesize that young people make a fairly rapid 'physical recovery' (achieving their target weight whilst an inpatient), but that a full psychological recovery is not achieved. This can lead to the young person being discharged during a particularly vulnerable interim period - which they name the 'physical recovery stage'.

Psychiatric service users generally have stressed inadequate provision for discharge preparation and a lack of follow-up support (see Rogers *et al.*, 1993). Clients talk of hospitalisation creating disability and dependence, de-skilling and dis-empowering them, thereby making adjustment back to life in the outside world extremely difficult. Young Minds have also pin-pointed a particular area of concern being the lack of support and resources for young people on discharge from inpatient care, leading to a 'revolving door' of re-admissions (Street & Svanberg, 2003).

Despite these findings, research into preparation for discharge, aftercare or relapse prevention in young people with AN remains extremely minimal.

1.6.1.3: The researchers own perspective – why this study was chosen:

My experiences before starting clinical psychology training included work as a healthcare assistant in a general adolescent inpatient unit. Many of the young people I worked closely with had the diagnosis of AN. My nursing colleagues appeared to have a joint perception of these patients as being extremely difficult to treat and difficult to trust. Many of the interventions used were quite restrictive and sometimes quite punishing. I remember in my role as a naïve new graduate, asking colleagues about the rationale behind some of these standard practices, and failing to get an adequate explanation. I noticed the battle that occurred between staff and patients with AN, as well as the battle within the individual patient as she was torn between striving to get better and feeling a strong attachment to her illness, almost as a coping strategy to manage difficult emotions.

During my undergraduate and doctoral training in psychology I developed an interest in qualitative research. I find the richness of data for exploring personal meanings particularly relevant to effective psychological research.

My current therapeutic training has predominantly been in CBT, however systemic and narrative approaches also interest me. During my recent specialist work with young people with EDs (outpatients), I also found the use of motivational interviewing techniques very effective in establishing collaborative working relationships with clients.

1.6.2: Aims and Research Questions

As outlined above, there is a lack of conclusive evidence regarding the effectiveness of inpatient treatment for young people with AN; and about whether there may be any potentially negative consequences of inpatient care which may compound features of the illness. Our knowledge about what clients find helpful and unhelpful is also extremely minimal. There are no known studies that focus on the experiences of young people with AN treated in *general* adolescent units. Furthermore, given the high rates of relapse and re-admission, there is a significant lack of research into discharge experiences and relapse prevention. The current researcher therefore intended to ask young adults to look back on their experiences of general adolescent inpatient treatment for AN, and their experiences of discharge and follow-up support, and to describe what they found helpful and unhelpful about these experiences.

The study aimed to answer the following research questions:

- What aspects of inpatient care are viewed as helpful and unhelpful and why?

- Do participants think that any aspects of hospitalisation have an impact on issues such as control, isolation and self-esteem?

- How was discharge and subsequent adjustment to the outside world experienced? What factors aided this or made it more difficult?

It was predicted that these young people would have useful, balanced and important things to say which could help inform healthcare professionals in developing more effective services.

METHOD

2.0. Method

2.1: PARTICIPANTS

Seven participants were recruited either via the past inpatient records of general adolescent units (General AUs), or via face-to-face contact with clinicians in adult ED outpatient services. A small sample size, of approximately 5-6 participants, is advised in order to carry out the detailed, nuanced analysis associated with Interpretative Phenomenological Analysis (IPA) (Smith, 2004, Smith & Osborn, 2003).

Inclusion criteria applied at the time of recruitment were as follows:

- female and aged between 16 and 23 years;
- had received past inpatient treatment in a general AU and were discharged from inpatient care between 2 to 5 years ago; and
- had received a primary diagnosis of AN at time of admission. Binge/purge subtype were to be included and those with co-morbid diagnosis of depression. Those who had a diagnosis co-morbid with psychosis would be excluded.

2.2: DESIGN

A retrospective, qualitative study using data collected through semi-structured interviews.

2.2.1: Rationale for method used

Exploring experiences *in retrospect* was chosen because sufficient time after discharge must have passed in order for participants to reflect usefully on their experiences of discharge and re-adjustment to the outside world. Also it seemed likely that views on the usefulness of treatment may be more helpfully elicited at a time when the client is not in a state of acute illness and distress. For example Griffiths (1998) found that bed-rest was viewed very differently during and after being an inpatient.

Due to the limited existing knowledge, lack of theory, or appropriate measures in this area, this study needed to be exploratory in nature. The use of *semi-structured interviews* and a *qualitative* method of analysis were viewed to be the most appropriate methodologies because they are 'especially suitable when one is particularly interested in complexity or process or where an issue is controversial or personal' (Smith, 1995, p.10). The current study is interested in the complex and highly personal process of experiencing psychiatric inpatient treatment, and then adjusting following discharge. Ethical issues around inpatient treatment, and the lack of evidence for its long-term benefits for these clients, also make it a controversial area to explore.

Semi-structured interviews are viewed as the most appropriate data collection method when trying to gain a detailed, rich picture of a respondents perceptions or accounts of a topic (e.g. Smith & Osborn, 2003). They allow participants maximum opportunity to speak about issues paramount to them, perhaps introducing novel topics that the researcher can then pursue. Participants are therefore perceived as experts on their own experiences. At the same time the use of an interview schedule to guide (but not to dictate) the interview, allows the interviewer to gather in-depth information relating to the aims of the study.

As Elliot *et al.* (1999) point out, the central purpose of a *qualitative approach* is to revise and enrich understanding rather than verify earlier conclusions or theory. The aim of qualitative research is to understand and then represent the experiences of people as they have lived through situations (Elliot *et al.*, 1999). Smith (1996) argues that qualitative methodology is able to obtain 'a richer account of how the person is thinking about, and dealing with, complex health-related questions' than if quantitative measures were used (p.265).

2.2.2: Rationale for the use of IPA

Interpretative Phenomenonologcial Analysis (IPA) was the method of qualitative analysis chosen because it is arguably particularly suited to exploring in detail how different individual patients may subjectively experience the same 'objective' illness/condition

(Smith *et al.*,1999, Smith, 1996). It recognises that individuals can experience the same situation in radically different and unique ways due to the fact that experience is mediated by thoughts, beliefs, judgements and expectations that the individual may bring (Willig, 2001, p.64). Individual experiences can then be integrated to obtain a composite picture which can tell us more about the phenomena under investigation than an individual case alone (Willig, 2001).

IPA is *Phenomenological* in that it is concerned with individuals' personal perception or account of an event (Smith *et al.*, 1999). It aims to capture the 'quality and texture of individual experience' to gain a better understanding of 'what it is like to live a particular moment or situation' from an 'insider' perspective (Willig, 2001, pp 53 & 63). A particularly important quality of IPA is that it also recognises the importance of the researcher's perspective, acknowledging that *interpretation* will be dependent upon the researchers own conceptions and standpoint (Willig, 2001, p.67). IPA does not claim to produce a definitive reading of participants' accounts, but recognises that the results of analysis are inevitably a 'co-construction between the participant and analyst, in that it emerges from the analyst's engagement with the data in the form of the participants account' (Osborn & Smith, 1998, p.67).

In terms of epistemology, IPA is clearly linked to phenomenology. However it also takes something from symbolic interactionism – with its concern for how meanings are constructed by individuals within both a social and personal world (Smith & Osborn,

2003, p.52). Although IPA is arguably somewhat similar to Grounded Theory (GT) in its processes of thematic analysis, IPA was thought to be a more suitable approach for the current investigation because it was specifically designed as a psychological research method, providing insight into the psychological worlds of participants. GT on the other hand was initially developed to study basic social processes (Willig, 2001).

Further rationale for the use of IPA was that it has a relatively transparent methodological procedure, with several systematic accounts of the analysis process now available in the literature.

2.3: PROCEDURE

2.3.1 Recruitment:

For participants recruited via past records of inpatient units, a member of the service identified all ex-inpatients who fitted the inclusion criteria. These people were then sent by the service, on the behalf of the researcher, an information sheet, a business reply envelope, and letter with a cut-off slip to return to the researcher with their telephone contact details should they be interested in taking part. This was sent to their address at the time of admission. For those under 18 an information sheet for parents was also enclosed along with a parental consent form. Potential participants were asked to include this signed parental consent form with their reply to the researcher.

For those participants recruited via adult outpatient services, primary therapists were asked to identify any clients in active treatment aged between 16 and 23 years who they believed to have received adolescent inpatient treatment for AN in the past. The therapist then gave out information sheets to such clients, at the same time discussing with them whether they met the study's inclusion criteria. These potential participants were then given seven days to read and digest the information sheet before being approached again by their therapist to ask them if they would be interested in taking part. Clients who expressed an interest were asked permission for their contact details to be passed to the researcher.

On receiving potential participants contact details, the researcher waited a minimum of four days before making telephone contact. During the telephone conversation participants were asked whether they had read and understood the information sheet and whether they had any further questions about the study. They were then asked whether they had made a decision about whether they would like to take part, or whether they would like to think about it further. For those agreeing to take part an interview was then arranged at a time and place convenient for the participant.

2.3.2: The interview

All interviews were carried out by the researcher and lasted between 1 hour and 1 hour 30 minutes. Four interviews took place in the participants' own homes, two in an interview room at their local outpatient service, and one in a clinic room at a local inpatient service.

All settings were free from interruptions from others and enabled privacy and confidentiality.

Before beginning the interview signed consent was taken for a) involvement in the study and b) the use of recording equipment.

2.3.2.1: ***Descriptive information:***

Prior to the interview the researcher administered a questionnaire to elicit descriptive information about participants- including factors such as age, social class and treatment history.

2.3.2.1: ***Interview content:***

Interviews were semi-structured. The researcher used an interview schedule to help guide questioning (see Appendix 1). This included open questions and prompts – relating to topics suggested by the research questions and existing research findings. Topics covered including the following:

- view on treatments received;
- perceived balance of addressing physical and psychological/emotional needs;
- how it was to be in a hospital environment;

- degree of control felt when in hospital;
- views on being around other patients (with/without an ED);
- views on one's sense of self whilst in hospital;
- relationships with family and friends outside the hospital (whilst an inpatient and following discharge);
- view on discharge experience (perceived readiness, preparation, follow-up support etc);
- adjusting to the outside world and managing one's ED following discharge; and
- most and least helpful aspects of services received.

Guidance on producing an interview schedule and semi-structured interviewing techniques were used (e.g. Smith 1995, Smith & Osborn, 2003, Willig, 2001).

Participants were told at the start of the interview that they were free to choose not to answer any questions and to take a break or finish the interview at any time. Time was allowed at the end of the interview for discussion about how the participant had found the interview, and to de-brief. None of the participants expressed any feelings of distress at this time. At the end of the interview participants were asked whether they would be prepared for the researcher to contact them a few months later in order to check the themes which emerged through analysing their interview (see section 2.3.5.2).

Interviews were tape-recorded and later transcribed verbatim.

2.3.3: Analysis

Transcribed interview data was coded and analysed thematically in accordance with the principles of Interpretative Phenomenological Analysis (IPA) (see Willig, 200, Smith *et al.*,1999, Smith & Osborn, 2003).

2.3.3.1: ***Coding of transcripts:***

Interview transcripts were analysed one by one. Each transcript was read carefully, making initial observations and descriptive comments/summaries (Phenomenological stage – notes along left hand margin). The transcript was then re-read and inferences were made about the nature and meaning of these experiences for the participant (Interpretative stage - notes along the right hand margin). Key words or emerging theme titles are noted at this stage. These may be phrases/words relating to psychological theory or existing research findings - should they be relevant to help interpret the text. Notably this is unlike traditional versions of Grounded Theory where the analyst is clearly not permitted to use existing knowledge or theoretical constructs within the analysis process (see Willig, 2001).

2.3.3.2: *Level of interpretation:*

Interpretation remained predominately at the first or second levels (described by Smith, 2004, pp 44-46). This was because the study aimed to represent participants views as closely as possible to the meaning each individual intended. Given the fact that young people with AN have rarely been given a voice, the researcher did not wish to analyse too far away from their comments. IPA is of course concerned with trying to understand experiences from the perspective of participants; 'to take their side' (Smith & Osborn, 2003).

2.3.3.3: *Clustering themes and producing tables:*

Emerging themes from the right hand column were then listed in order of occurrence. Their relationships to each other were then examined, incorporating themes into 'clusters'. Some themes acted as super-ordinate or 'master' themes, i.e. as an over-arching title to explain others. Other clusters needed to be given new labels to capture their essence.

A coherent table of super-ordinate and subordinate themes was then constructed, along with sample quotes. This was to ensure that the themes were truly present (or 'grounded') in the original text. Themes found to be not truly grounded in the text were discarded at this stage. Other identifiers of each theme were also noted on the table[2].

[2] i.e. the page and line number where further instances of each theme could be found.

Processes **2.3.3.1** to **2.3.3.3** were repeated for each transcript individually. To ensure transparency and auditability for the reader (see Elliot *et al.*, 1999) a worked example of this process for one participant is presented in Annex 1.

2.3.3.4: ***Integrating themes from all the interviews:***

Finally clusters of themes from all seven transcripts were integrated to generate a list of 'master themes'/super-ordinate themes which attempted to capture the quality of the participants' shared experiences. This was achieved by cutting up copies of all tables so that all subordinate themes, along with example quotes and identifiers were separated out. These were then shuffled, rearranged and re-grouped until they fell into a small number of clear overarching categories, or master themes for the group. This stage required the analyst to be selective and to discard subordinate themes or quotes. In IPA, themes are not selected purely on the basis of their prevalence within the text. Those themes which appeared marginal to other aspects of accounts or were not rich in meaning were often those which were discarded (see Smith & Osborn, 2003).

This whole process was carried out in an iterative manner. The researcher remained in close interaction with the text, referring frequently back to the original transcripts to ensure that themes were grounded in the data.

A further part of the analysis process was the writing-up - translating themes into a narrative account (section 3.0). This led to further interpretations and sensitivity to the nuances in the data.

2.3.4: Research diary

It is advised when conducting qualitative research to keep a reflective diary throughout the project to help ensure a 'reflexive stance' (Silverman, 2000). Reflexivity urges us to 'explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research' (Nightingale and Cromby, 1999, p 228). The researcher therefore kept a diary to record factors such as what they themselves were bringing to the interview process, and ideas, connections and themes emerging during the transcription and analysis process. Extracts from this can be found in Annex 2.

2.3.5: Credibility Checks

IPA clearly acknowledges the role of interpretation by the researcher/analyst (see section 2.2.2), therefore inter-rater agreement about coding of texts is not strictly appropriate when using this approach. However as the researcher wished to promote optimum rigor, or 'trustworthiness' in this study, they carried out the following measures:

2.3.5.1: ***Sharing the data with other analysts:***

The researcher formed part of a peer-supervision group made up of other researchers currently undergoing projects using IPA (as advised by Stiles, 1993).[3] Following the researchers own individual analysis process, pages of transcript, chosen at random, were shared with 4 other researchers. They then engaged in the process of analysing these pages, making notes in the rights and left-hand margins of the text [4]. A discussion then took place where fellow researchers fed-back to the researcher what salient themes emerged for them. This process served to clarify that the researcher's own thinking processes regarding prominent themes, were largely shared by others. It also helped the researcher to become more aware of her own biases and provided one means of auditing her chain of thinking from original transcripts to emerging themes. Individual supervision during the analysis process served as a complimentary way of auditing the researcher's work.

Once the 'master' list of themes for all had been constructed - combining the experiences of all participants, one fellow-researcher from the peer-supervision group acted to provide an audit trail for the entire analysis process. The researcher demonstrated their line of thinking from original transcripts, right through to final clustering. The auditor was satisfied that the researcher's thinking followed a coherent and logical path and that the final super-ordinate themes were truly grounded in the original texts.

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[3] This group met fortnightly for the period of 3 months.

4 This was carried out on 3 different interviews (first, middle and last), on 2-3 pages of transcript from each.

2.3.5.2: ***Member checking (Elliot et al., 1999) or Respondent validity (Mays & Pope, 2000):***

Once stages 2.3.4.1 to 2.3.4.3 had been carried out for each interview, the researcher contacted three of the participants again - to share with them the table of themes which had been constructed from their specific interview.

Feedback from participants served to clarify for the researcher that the salient themes that emerged were also viewed by participants as being highly important in their retrospective accounts of their experiences of treatment and discharge. It also served to clarify that quotes used to illustrate certain themes were not misunderstood/misinterpreted and were used in context in terms of the meaning they had for participants. This contributed a further degree of validity to the findings.

2.4: ETHICAL CONSIDERATIONS

Full information about the study was given to all participants and written consent was acquired. Parental consent was also acquired for participants under 18. Participants were informed that they could leave the study at any point should they wish and the voluntary nature of their participation was stressed at both recruitment and interview stages.

Data regarding participants was kept safely and anonymised to ensure confidentiality, and tapes were destroyed following transcription. Names used in the write-up have been changed and any descriptive information which may reveal the identity of participants has been omitted.

Participants were assured that their participation in the study, and any information they gave, would not affect their current treatment or treatment they might receive in the future. In order to address the potential for distress that discussing experience of past treatment might evoke, the researcher allowed time at the end of each interview for de-briefing, and to discuss ways to access further support should this be required.

In order to ensure that participants were protected from being 'over researched', clinicians involved in recruitment were asked to consider past research projects that clients may have been involved in and not to approach participants involved in similar research.

Ethical approval for the study was given by the Southeast Multi-Centre Ethics Committee (see Appendix 2).

RESULTS/ ANALYSIS

3.0: Results/Analysis

3.1: DEMOGRAPHIC DETAILS

All seven participants were female, white and of British nationality[5]. Socio-economic status (as assessed through parental employment) for all participants was either band I or II. One participant was recruited via adult ED services and the remaining six were recruited via past records at two general adolescent inpatient units. All were admitted voluntarily with the exception of Chloe who was sectioned on several occasions[6]. All had received a diagnosis of anorexia nervosa at the time of admission[7]. Sophie, Anna and Katie also received a co-morbid diagnosis of depression. Relevant information about each participant is outlined below:

Chloe was aged 21 at the time of the interview and was studying at university. She viewed herself as in recovery from her ED. She was first admitted to a specialist ED service at age 11 and spent 7 years in different inpatient services, with approximately 7 admissions to specialist ED units and a final 2 admissions to a general AU. She had also received a number of day-patient and outpatient services in the short time period between re-admissions (maximum of 1 month).

[5] All names have been changed to protect anonymity.
[6] Chloe could not recall which specific section of the MH Act that she had been detained under.
[7] Diagnostic criteria used was either ICD10 (World Health Organisation, 1993) or DSM IV (American Psychiatric Association, 1994).

Sarah was also studying and was aged 20 at the time of the interview. She considered herself in recovery from her ED. Sarah's first admission was to a general AU at age 17 and was for a period of 6 months. At 18 she was transferred to adult services where she has received both inpatient and outpatient care.

Sophie, aged 23, worked as a healthcare professional and considered herself recovered from her ED. At age 17 Sophie was admitted to a general AU for a period of 9 months, after which she received both day-patient and outpatient treatment.

Anna was aged 22 and was receiving day-patient treatment with an adult ED service at the time of her interview. She was first admitted for inpatient treatment at age 16 and received 2 separate admissions to a general AU, totalling 18 months as an inpatient. Both of these admissions were followed by day-patient and outpatient treatment.

Philippa, aged 16, was a student at school at the time of her interview, and considered herself in recovery from her ED. Her first admission was when she was aged 12 and was followed by a second admission to the same general AU, totalling 18 months as an inpatient. Outpatient treatment was provided on both occasions.

Katie was also a school student and was aged 17. She considered herself to be in recovery at the time of her interview. Katie's first admission was at age 11 and was to a specialist inpatient unit, lasting 1 year. She then received 2 separate admissions to the same general AU which totalled 15 months.

Beth, aged 19, was in training for an artistic profession at the time of her interview. She considered herself to still have an ED. She had received 1 admission to a general AU at age 15, which had lasted 5 months, and was followed by 4 months in day-patient care.

A summary of the treatment participants received whilst in inpatient care is shown in table 1.

Table 1: A summary of the forms of treatment participants reported receiving during their inpatient care

Treatment received:	**Chloe**	**Sarah**	**Sophie**	**Anna**	**Philippa**	**Katie**	**Beth**
Set Re-feed / ED programme	✓	✓	✓	✓	✓	✓	✓
Strict Behaviour modification weight-gain programme	✓	X	X	X	X	✓	X
Group work/ activities	Minimal	Towards end	✓	Towards end	Towards end	✓	✓
Individual sessions with a psychologist/ psychotherapist	✓	X	✓	Very minimal	X	X	Very minimal
Individual sessions with key-worker/ other healthcare professional	✓	✓	✓	✓	✓	✓	minimal
Family therapy/sessions	✓	✓	✓	✓	✓	✓	✓
Medication	?	✓	?	?	?	✓	✓

3.2: FINDINGS FROM THE INTERVIEWS

The following four super-ordinate themes emerged from participants' accounts of their adolescent inpatient treatment and discharge experiences:

A. Removal from normality versus connecting with the outside world

B. Treated as another anorexic versus a unique individual in distress

C. Control and Collaboration

D. The importance of peer relationships.

These will be presented in turn, along with their subordinate themes. Due to word restrictions only minimal quotations from transcripts could be used in the main body of the text. In order to illustrate the importance and richness of these themes within participant's accounts, a table of further quotations reflecting each theme is included in Annex 3.

Points to note:

During the interviews participants talked predominantly about their experiences of inpatient treatment in *general* AU settings. However many also mentioned their experiences of inpatient treatment in specialist ED settings. These experiences seemed useful in aiding reflections on what factors were helpful and unhelpful, and will be specified within the text.

When reflecting on their experiences several participants frequently commented that their behaviour had been difficult and had posed challenges for inpatient staff. They also talked about their 'stage' of illness (akin to stage of change – see section 1.3.6.5) and how this had affected their ability to engage with treatment. Although these factors are clearly important, a full discussion of them is beyond the limits of this project, and have already been discussed in full elsewhere (see Colton, 2002). The focus of this section will instead be on what participants found helpful and unhelpful during their inpatient stays, in spite of these factors.

3.3: SUPER-ORDINATE THEME A:

Removal from normality vs connecting with the outside world

For the majority of participants their experience of being an inpatient carried a pervasive sense of being removed from the normality of adolescent life in the world outside, and of 'real' life and development being temporarily suspended.

This appeared not only to affect participants' emotional well being and senses of self, but also posed challenges to subsequent re-adjustment to the 'real world' outside following discharge. Practices that encouraged connections with normality, and prepared adequately for discharge to the outside world, were generally viewed as helpful.

Subordinate themes **3.3.1 to 3.3.5** concerned feeling **removed from normality.**

3.3.1: Suspension of real-life

This sense of life being suspended is described clearly by Sophie:

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For Sophie this included a cessation of her friendships and in engaging in any 'useful', meaningful activities. Many areas of life seemed to have halted. Several participants were also acutely aware of life moving on for peers, whilst theirs remained stagnant. For Sarah this appeared to be a block to her progress:

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3.3.2: Suspension in development

For many, being in hospital meant their own social and emotional development was restricted or even arrested. Anna, for example, talked about her fear on discharge, that her development had been negatively affected by her inpatient stay:

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She expressed anger for how her inpatient experience had failed to encourage her to develop age-appropriate skills but instead had fostered dependence. This had had long-term implications for her:

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3.3.3: Compounding a sense of isolation

Chloe described how unit practices which encouraged isolation, such as bed-rest, actually mirrored certain aspects of anorexia:

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Other unit practices, such as inflexible visiting hours and lack of visiting space failed to foster connections with friends and relatives in the outside world, and were viewed as extremely unhelpful. Some units even used the withdrawal of contacts as part of behavioural reinforcement schedules. Many participants described experiencing a sense of overwhelming loneliness and isolation at times, which appeared to have been compounded by these practices.

For Anna this isolation from her family also affected her sense of self and belonging:

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3.3.4: Contrasts in structure and support

There were frequent comments about the difference between the high level of structure and support in the unit and that found in the world outside. This made adjusting to the outside world at weekends very difficult:

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The supportive and accepting atmosphere found in some units meant that many also struggled with this contrast:

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This also made for strong attachments to unit life and painful emotions on discharge. During the months following discharge these contrasts in structure and support were starkly apparent:

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For Anna adjusting to the absence of a regimented routine, and the need to make independent decisions was also very difficult:

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3.3.5: Gradual Preparation for discharge and continued support

Due to the stark contrast between life in hospital and life post-discharge, participants found careful discharge planning very important; as well as the continuation of a relatively high level of support. Abrupt transitions could be experienced as scary and rejecting:

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In contrast Katie describes her more successful transition process as gradual and collaborative:

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What was also helpful during this period was family and individual work which acknowledged and prepared for likely difficulties concerning discharge and re-adjustment, and helped develop coping strategies in advance.

Following discharge several participants felt that it would have been very helpful to receive ongoing psychological or emotional support from the practitioner they saw whilst an inpatient:

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Whereas others preferred support provided by local services in that it offered a 'fresh start' (e.g. Sarah).

It seemed important that support was provided at an appropriate level, adjusted to the person's stage of recovery. For Katie, for example, the support she described initially was too superficial and infrequent, and she felt this had perhaps contributed to her relapse. With the move towards complete recovery, having someone at a distance was viewed as sometimes irritating, but necessary and helpful:

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An ethos, which encouraged **connections with the outside world,** and normal adolescent life, was generally experienced as helpful. This is described in sections **3.3.6 to 3.3.7**.

3.3.6: Promoting normality

Many participants described their experiences of being observed after mealtimes. They commented that staff who were most helpful were those who were able to create a sense of normality – making this 'weird' experience not feel so 'weird' (Beth). Staff being able to balance a relaxed approach with more professional support when needed was clearly very important:

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Many found that creating a normal atmosphere over mealtimes, with staff and patients eating together, was also very helpful:

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For Philippa being in a general (rather than a specialist ED) unit minimised the focus on food thereby promoted normality and provided some incentive to get well:

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In contrast, practices that created a sense of abnormality were generally viewed as unhelpful:

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Rigidity over portion sizes and diet plans was often seen as helpful during the admission, but unhelpful when trying to eat more normally following discharge:

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3.3.7: Encouraging real world activities

Many participants felt that they were discouraged from engaging in real-world activities that they enjoyed. This was experienced as extremely unhelpful:

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Several people felt that encouraging some form of activity outside the unit would not have only helped their transition following discharge but also served as an incentive to get well:

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Similarly, after discharge what appeared to be the key to successful re-adjustment and recovery for many was having real-life incentives such as a college course, new friends or a job, which provided a focus away from one's eating difficulties, and a motivation to stay well.

For Anna a new job also helped her to develop important life-skills which had been stilted by her inpatient stay:

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3.4: SUPER-ORDINATE THEME B

Treated as another anorexic v's a unique individual in distress

There were several aspects of care that led participants to feel they were viewed simply as **another anorexic**, rather than being viewed or valued as an individual in their own right. These encompass subordinate themes **3.4.1 to 3.4.4**.

3.4.1: Staff assumptions about eating Disorders

Many participants described finding it unhelpful when staff conveyed certain assumptions about how young people with AN behave or think, and then applied these to all patients suffering from AN. This gave a strong message that one was perceived as an anorexic entity rather than a unique individual.

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These assumptions were often experienced as being over-simplistic, undermining, patronising and accusational. For example Chloe talks about the assumption of anorexics as being always irrational, and Sophie about dishonest food-avoidant behaviours:

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These assumptions often led to rules designed to address specific eating disordered behaviours, which were then applied indiscriminately within ED treatment programmes.

3.4.2: Blanket programmes

All units appeared to use set treatment programmes for anorexic patients, often called 'eating disorder programmes' or 're-feed' programmes. These were often perceived as very inflexible and quite punishing, especially when they were based on strict behavioural approaches. Often staff failed to offer adequate rationale for certain practices, leaving patients upset, confused and frustrated.

Chloe described her experience on a specialist adolescent inpatient ward, where the withholding of normal age-appropriate experiences was used as an incentive:

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Most felt that these programmes did not allow for individual difference, therefore patients were often left feeling punished for the behaviour of certain other people within their diagnostic group:

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Several participants felt that the very least helpful aspect of their inpatient treatment was the absence of truly individualised care. Beth was one of these people:

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3.4.3: Physical recovery prioritised over psychological recovery

Many participants described the use of a staged approach, with the primary focus being on weight gain and the prevention of weight loss behaviours; psychological input or emotional support being withheld until one's target weight was achieved. For many this led to a perception that staff were there simply to 'fatten them up'; their unique emotional and psychological needs not being viewed as important:

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The withholding of involvement in the group programme and of individual psychological input was viewed by many as illogical and punishing:

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Several participants acknowledged that the particular nature of psychological input needed to match their cognitive abilities at their stage of illness - in terms of one's ability

to concentrate and reflect on deeper issues. However they also maintained that some form of emotional support is necessary for any sustainable weight gain:

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A failure to address psychological issues could lead to a perception that hospitalisation merely compounded one's illness. For Chloe, enforced, quick weight-gain without corresponding psychological gain simply compounded her sense of a lack of control:

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3.4.4: Trauma and de-humanisation

Both Katie and Chloe's descriptions of their specialist ED inpatient treatment contained elements akin to post-trauma accounts, including nightmares and avoidance of reminders of the unit. These appeared to be linked to experiences during which they felt staff had distanced themselves so far from their humanity and distress that they felt almost de-humanised. When staff saw the eating disorder rather than the individual this dehumanisation seemed more likely:

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Chloe described how staff in a specialist ED unit seemed completely cut-off from her human distress :

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Aspects of inpatient treatment which were seen as most helpful were those which conveyed that patients were being viewed as a **unique individuals in distress**. The following 3 subordinate themes (**3.4.5 to 3.4.7**) describe how this can be achieved:

3.4.5: Recognising the ED as a symptom

Many participants stressed how their ED was just a symptom of more fundamental problems. Services were viewed as valuable when they recognised this and then helped to uncover and address the true underlying issues.

Chloe described an incident when she was in acute distress and was being restrained. However this was experienced in a supportive manner, which valued her as an individual who was battling against the anorexia – here, perceived as an external symptom:

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3.4.6: A holistic approach to the individual

Several participants talked about positive experiences of inpatient treatment being when the focus was not merely on weight, shape and eating, but also addressed other unique aspects of themselves and their lives; such as self-esteem, depressive thinking and help to

see the 'bigger picture' (Philippa). A co-ordinated multi-disciplinary team was viewed as vital to achieve this.

Sophie talked about the 'structure' that being an inpatient offered her:

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Services that addressed psychological and physical issues in parallel, truly recognising the emotional impact of weight gain, were viewed as most helpful. Although it was recognised that this may take longer and have a less dramatic impact on weight gain, this was clearly perceived as a more valuable approach (e.g. Chloe).

Several participants viewed their individual sessions with their key-worker or psychologist as the most helpful aspect of care – providing them with invaluable emotional and psychological support which validated their feelings:

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3.4.7: A holistic approach for families

It also seemed important that services recognised the impact the illness was having on families; successfully treating the whole individual included addressing these wider systemic issues. Chloe talked about times when her worries about this were ignored by her therapist:

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Several participants spoke about how services failed to provide adequate support for parents and about the impact this had on their own well-being:

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Many participants commented on their perception that services failed to provide adequate support for their siblings. Several talked about siblings being 'dragged' along to family therapy sessions that they subsequently found upsetting and confusing. Their illness and time in hospital sometimes had a long-term impact on their sibling relationships, even several years later.

3.5: SUPERORDINATE THEME C

Control and Collaboration

An issue which resonated throughout participants' accounts was that of being controlled and feeling powerless, versus a sense of collaboration and control over their own treatment and recovery.

There were 6 subordinate themes within this category.

3.5.1: A structured containment

Many participants reported that the relatively high degree of structure in the unit could be helpful and containing. Although many had complained about this controlled environment at the time, they now recognised that this had been necessary for their recovery. For example Chloe stated:

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One important aspect of this containing environment related to units being staffed by people experienced in working with people with eating disorders. Several participants talked about feeling unsafe with agency nurses who they were able to manipulate, thereby allowing them to avoid recovery:

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3.5.2: Initial taking away of control

Several participants reported that, on admission, an initial taking away of their control over eating was helpful and relieving:

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Sarah explained that when services tried to recruit a sense of collaboration with her at the early stage of admission this was not actually helpful:

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3.5.3: Powerlessness, punishment and inadequacy

Although initially having control over food taken away was generally viewed as helpful, over time this often became viewed as unnecessarily over-controlling. Participants talked about control being taken away in many other areas of their life, seemingly unrelated to their eating disorder treatment – such as not being allowed to use the telephone, participate in unit activities or see their families. This appeared to conpound one's sense of powerlessness.

Katie perceived staff in a specialist ED unit as not even attempting to recruit her collaboration at any stage:

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Anna expressed her anger about how taking away all control and her power to make choices and decisions had compounded her sense of inadequacy.

Furthermore, the use of rigid treatment regimes appeared to compound Sarah's sense of being a bad person:

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In part, it seemed to be staff assumptions about anorexic traits that fuelled this negative ethos:

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3.5.4: Doing Battle

The perception that services were being un-collaborative, rigid and controlling led some participants to start fighting back, perhaps hindering their recovery:

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Several participants also talked about developing a lack of trust in staff and becoming dishonest in order to take control of some non-food related areas of their life, such as wanting privacy to draw or read (e.g.Beth).

3.5.5: Collaborating in one's own care

In clear contrast to the above descriptions, successful inpatient treatment was often described with a strong sense of being involved in one's own care. This meant collaborating in decisions and being listened to rather than presided over:

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Ways of achieving this sense of empowerment and collaboration included practices such as plotting one's own weight chart, deciding on one's own goals or incentives and having staff available to listen to problems in a client-led manner.

Philippa described how being given clear factual information and a degree of control over weight-gain facilitated her acceptance of her revised target weight, and a relatively successful recovery following discharge:

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3.5.6: Collaborating within therapy

For those participants who had received psychological therapies whilst in inpatient care, approaches that were perceived as client-led and collaborative were viewed as extremely helpful and empowering. Sophie described her experience of cognitive-behavioural individual therapy:

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This was in contrast to a psycho-dynamic approach where she felt her own opinions were often ignored; the therapist having their own agenda. She found the use of interpretations particularly unhelpful as she felt that the therapist was in position of power relative to her particularly vulnerable position. Therefore telling her how she felt could be dangerously suggestive.

Similarly those who perceived family therapy as un-collaborative found it unhelpful in compounding their sense of helplessness. Beth talked about her therapist's misunderstanding her:

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Several people talked about staff trying to control rather than collaborate with parents, with a sense of blame rather than support being communicated:

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3.5.7: Preparing for discharge – handing back control

Chloe described how her experience in a highly structured specialist unit had failed to be collaborative and empowering, which meant she was simply not equipped to function successfully in the outside world. She had not learnt how to control her ED independently:

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Even when more collaborative approaches were attempted, participants often felt less control over their lives whilst in inpatient care. It was therefore very important that services provided appropriate preparation for the contrast in control necessary for life post-discharge.

Several participants talked about helpful unit practices that enabled them to *gradually* build up their level of control, such as being given more freedom, more say in decisions, and preparing one's own meals. In the absence of such careful preparation, participants

often described finding the sudden availability of freedom following discharge unmanageable:

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3.6: SUPER-ORDINATE THEME D

The Importance of Peer Relationships

A salient issue in participants' accounts of their inpatient and discharge experiences concerned how they felt they were able to relate to their peers, both inside and outside the hospital. There were 4 subordinate themes within this category.

3.6.1: Peers in the outside world

Most participants described a distancing from their peers prior to their admission. This appeared related to being entrenched in their illness, as well as due to a general lack of understanding by peers of how to relate to people with mental health difficulties:

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Following discharge, this lack of understanding appeared to continue, alongside the passage of time and peer-groupings inevitably moving on:

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3.6.2: Being alongside peers in distress

Although some people found being in general units (with people with a mixture of psychiatric problems) was scary on occasion, most found that being around people with other kinds of mental health difficulties helpful as it encompassed an acceptance by peers. This was a marked contrast to the stigmatisation many had experienced outside of hospital. Although some reported learning negative coping strategies such as self-harm from fellow inpatients, most reported having learnt about positive coping:

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However being able to identify strongly with fellow anorexic patients seemed particularly important for some participants. For example, Sarah found being in a specialised ED unit more helpful than her experience in a general AU:

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Several participants described a strong sense of community within their general AU and stressed the importance of friendships with other patients, partly because they offered a sense of genuine acceptance. Sometimes however, they felt that staff tended to discourage these friendships.

In contrast, when relationships with peers on the unit were more negative, this appeared to have a considerable impact on one's sense of well-being:

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3.6.3: Being alongside peers with AN

Being treated alongside other patients with AN was seen as both helpful – in terms of support and identification, and unhelpful – in terms of comparison and competition.

Several participants felt that they were very vulnerable to peer influence at the time. A desire to fit-in meant that further eating disordered behaviours were learnt from other patients and they became 'more anorexic' as a result of the experience. Anna described the impact another patient with AN had on her own thoughts and behaviour:

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The presence of others at different stages of illness frequently led to comparisons, guilt and competition. These thoughts and feelings were viewed as unhelpful in overcoming one's own eating difficulties:

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However, Philippa described how this negative peer influence very much depended on the stage of her illness and recovery. At later stages comparisons could be helpful:

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Participants also found that being with other young people with anorexia was helpful as it provided a strong sense of peer-identification. It also helped some feel less alone. This identification meant that helpful peer-support could be provided at times. Sophie, for expample described how shared issues salient for people with anorexia seemed quite distinct from those of other people, therefore a group specifically for patients with anorexia was a very helpful experience.

3.6.4: Being set-apart from peers

Some participants reported that in general AU's, having AN meant staff treated them very differently to other patients. This sometimes resulted in individuals not feeling like part of the inpatient community. Particularly due to special practices around mealtimes, some participants felt that their problems were exposed, unlike those of other patients. They also felt extremely stigmatised at times.

Sophie described how not being allowed to go to groups made her feel:

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Anna highlighted this sense of segregation and exposure of her problems as being one of the most unhelpful aspects of her experience in a general AU:

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DISCUSSION

4.0: Discussion

This section will begin by addressing the three original research questions in the light of the findings of this study. Findings relate primarily to patients' retrospective views concerning inpatient treatment in *general* AU settings. These findings will also be discussed in relation to existing research and relevant clinical literature. This will be followed by a critique of the study in terms of its methodological strengths and limitations. The clinical implications of this study, alongside previous research and clinical recommendations will be discussed, followed by suggestions for further research. A conclusion section will then follow.

4.1: ADDRESSING THE RESEARCH QUESTIONS

4.1.1: What aspects of inpatient care are viewed as helpful and unhelpful and why?

As found in previous studies of patients' views, these participants expressed views that were self-reflective and balanced (see section 1.4). They were able to distinguish between what they 'wanted' at a time when they may have been quite resistant to treatment, and what they actually 'needed' to aid their recovery.

4.1.1.1: *Removal from normality vs connecting with the outside world:*

Being in hospital was often accompanied by a strong sense of being removed from the normality of adolescent life in the real world. Practices that encouraged connections with the outside world and encouraged normal adolescent life were generally viewed as helpful. It is possible that normality was seen to offer an incentive to get well, along with the developmental desire at this age to feel normal rather than different. Creating a sense of normality around mealtimes was often viewed as helpful, along with the promotion of real-life activities and connections with the world outside. To some extent, being in a general AU amongst other young people who ate 'normally' was also helpful in this respect. Highly valued staff were those who were able to achieve a balance between chatting about the 'normal' world outside, and responding sensitively to emotional needs when required.

Unhelpful experiences were characterised by a perception that unit practices actively discouraged 'normal' activities (such as hobbies and education), and failed to facilitate connections with family and friends in the outside world. 'Abnormal' practices around mealtimes such as discouraging chit-chat, and "licking ones plates clean" were also viewed as unhelpful. This was possibly because they reinforced a focus on anorexic symptoms; stigmatised patients with ED (by treating them differently to other patients); and failed to promote 'normal' eating habits. A failure to encourage normal age-appropriate skills (such as doing laundry and decision making) was unhelpful as it

fostered dependence in the longer term, and led to a sense of one's development being suspended.

The creation of an 'informal environment' has been generally viewed as important by young people in inpatient CAMHS (Street and Svanberg, 2003) (see section 1.4.2). Although a promotion of normality was not high-lighted in Colton's (2002) study (see section 1.4.2.1), she does make reference to participants' desire for a more 'normal' teenage life. Authoritative programmes that allowed little freedom were linked to patients wanting some normality in their lives. Furthermore her participants spoke of sustained 'losses' in their lives whilst in hospital, including a loss of normality, a teenage lifestyle, home, family and friends. Perhaps because participants in the present study were reflecting on experiences in retrospect, rather than at the time of treatment, a sense of abnormality was more salient in their memories, and the longer- term impact of this was more apparent. Whereas for participants in Colton's inpatient study, it is possible that unit life seemed more 'normal', simply because it was their current reality.

4.1.1.2: *Being treated as an anorexic vs a unique individual in distress:*

In line with Colton's (2002) findings, a consistent view identified across participants' accounts was concerned with the un-helpfulness of practices and attitudes, which conveyed that one was perceived as 'just another anorexic'. These included assumptions about anorexic traits and behaviours that were applied within blanket, uniform programmes for all patients with ED. Within these programmes, the treatment of the

symptoms (e.g. anorectic 'behaviours' and weight-loss) was clearly prioritised over the individual's emotional or psychological needs. This was viewed as extremely unhelpful. Psychological input was even withheld in some cases, justification often being linked to a vague rationale regarding the psychological effects of starvation – e.g. impairing one's ability to think and concentrate. At its most extreme level, perceiving patients as simply anorexics appeared to lead some staff to distance themselves so far from the patient's human distress, that experiences akin to accounts of trauma were recalled.

Helpful alternative practices which conveyed a sense that the patient was valued as a unique individual in distress included: the recognition of the ED as merely a symptom of underlying psychological difficulties; a collaborative supportive approach to tackling this symptom; regular individual, client-led psychological input (at an appropriate level in parallel to weight-gain), and a holistic approach addressing the wider impact on parents and siblings.

This super-ordinate theme was unintentionally almost identical to Colton's (2002) theme of 'Being an individual versus just another anorexic'. This similarity in findings perhaps hi-lights the importance of this issue in the experiences of young people being treated for AN. Indeed Vandereycken (2003) emphasises that current inpatient treatment for ED patients is not genuinely individualised. MH service-users consistently stress the importance of a holistic approach where one is treated as an individual with unique needs (e.g. Faulkner, 1997). However findings regarding the perceived un-helpfulness of focusing on weight and shape issues are consistent with the adult literature (see section

1.4.1). In light of this Bell (2003) suggests that weight-restoration should be paced to match psychological change rather than vice versa. As identified in the adult literature, and by Colton's (2002) study, significant value was placed on individual psychological support; participants perceiving it as almost more important to recovery than weight-restoration. Although it is important to consider the effects of starvation on cognitive abilities, inpatient treatment recommendations now state that psychological issues should be addressed (presumably at a level adjusted to these effects) in parallel to facilitating weight-gain (see section 1.3.5.2).

In light of their findings, Eivors *et al.* (2003) proposed that professional labelling of patients as 'anorexic' may not be useful. Instead, seeing AN as a symptom of distress, and a means of controlling or coping with other underlying problems is more helpful. Similarly Manley *et al.* (2001) warned that when the 'problem' or ED is 'collapsed' onto the identity of the patient, an unhelpful pathologising view of the individual is likely to result.

4.1.1.3: *Issues of control and collaboration:*

Unhelpful experiences were characterised by over-controlling, rigid rules and a lack of genuine attempts to use collaborative approaches with the patient. In line with Colton's (2002) findings, the removal of control in other areas of life (not related to food or exercise) was perceived as particularly unhelpful.

Within participants' accounts of family therapy, several people reported experiencing a strong sense of parental blame and a failure to involve parents in their care. This, unfortunately, is in line with studies of parent experiences (see section 1.4.2.3). However, in recent years there has been a commitment in the systemic field to move away from the notion of an 'anorexic family', to remove a sense of blame and to achieve more collaborative partnerships with parents (see section 1.3.6.1). It is hoped therefore that patients treated more recently than these participants (i.e. less than 2 years ago) may have more positive experiences of family approaches.

Boundaries and structures that served to maximise the patient's control and involvement in their treatment and recovery, were viewed as supportive and helpful. In line with Manley *et al.* (2001) there was a sense of relief when control over food was initially taken away. In line with findings from adult studies, staff having expertise in eating disorders was also viewed as important (see section 1.4.1). Practices that empowered the patient and promoted collaborative care included: providing clear information, a degree of control over the pace of weight gain, collaborative approaches to therapy, and freedom and choice in other areas of life.

The central theme of 'control battles' versus a more collaborative approach has been found in a number of related studies (see Surgenor, 2003, Sallas, 1985 and sections 1.4.2 & 1.5.2). Authoritative approaches inevitably lead to tensions between staff and patients as the young person struggles to regain some control (Jarman *et al.*, 1997, Ramjan, 2003).

A failure to attempt to develop collaborative relationships with patients may be in part be due to professional anxiety about the physical health of the patient and the need to intervene quickly (see section 1.3.5.1). However, staff assumptions about negative traits in patients with AN may also contribute to these control battles, evoking fear and hostility (see Surgenor, 2003). There may often be a sense of blame towards patients, for somehow creating their own problems (Ramjan, 2003). However 'manipulative' behaviour can be more helpfully viewed as an understandable coping strategy for gaining some control within a strict regime (Surgenor, 2003, Sallas, 1985, Ramjan, 2003). Several of these authors have stressed the importance of allowing time to develop collaborative therapeutic relationships, mutual trust being viewed as an essential ingredient to successful treatment (Ramjan, 2003). Furthermore findings from Jarman *et al.* (1997) highlight that clinicians were often uncomfortable with implementing programmes that dis-empowered the child, as this was at odds with their usual choice of a client-centred style. Therefore developing ways to avoid such controlling treatment is also likely to be of benefit to nursing staff.

4.1.1.4: *The importance of peer relationships:*

Participants' accounts highlighted the importance of peer relationships whilst in hospital. Being in a general AU offered the potential for friendships and acceptance by peers in contrast to the stigmatisation often found in the outside world. Positive peer relationships and a sense of community were highly valued, along with being able to identify with others and learn positive ways of coping.

Being alongside others with mental health difficulties was rarely perceived as unhelpful, and didn't appear to encourage the use of negative styles of coping for these participants. However being alongside other patients with AN could be both helpful – in terms of strong identification and support, and unhelpful in terms of comparison and competition. Colton (2002) found very similar views in her study of inpatients at a specialist ED AU unit.

The current participants (treated in general AU's) often felt set-apart from the inpatient community by treatment regimes such as sitting on separate tables at mealtimes or not being allowed to participate in groups. This segregation was often perceived as stigmatising and unhelpful.

In contrast to findings from earlier studies (see Bruch, 1978, Duker & Slade, 1988, section 1.5.3) these young people did not tend to report any particular difficulties in establishing or maintaining friendships whilst in hospital. Difficulties in friendships prior to being in hospital were attributed more to a stigmatisation of MH problems and an entrenchment in one's illness, rather than to social difficulties.

When staff were perceived to be discouraging friendships with fellow patients, or if nastiness between patients was not dealt with, this was experienced as unhelpful. This reflects findings by Colton (2002), who reported that many inpatients commented on the

powerful nature of the patient group dynamics and the general change in atmosphere around times of admission and discharge.

Such findings concerning the importance of relating to fellow patients whilst in hospital, and comparison issues with other ED patients, may be an aspect of inpatient care particularly important to the developmental needs of adolescent patients. This may be due to the importance of peer relationships and the desire to 'fit-in' in this age-group.

4.1.2: Do participants think that any aspects of hospitalisation have an impact on issues such as control, isolation and self-esteem?

This question concerned whether participants felt that any aspects of hospitalisation had compounded any intrinsic features of their illness (see section 1.5).

4.1.2.1: ***Control and Self-esteem:***

Over-controlling rigid programmes, and staff assumptions about patients with AN certainly led participants to feel out of control (even powerless), and under-valued as individuals. Practices such as the withholding of normal age-appropriate activities and group or individual psychological input were experienced as compounding one's sense of being a bad person, deserving of punishment. Staff members who conveyed a sense of mistrust and accusation also relayed this message.

In line with adult findings, quickly enforced weight-gain was seen as detrimental to one's MH (see section 1.4.1), making individuals feel even more out of control. Duker & Slade (1988) explain how slower approaches to weight-gain that address psychological and physical change in parallel can help to maintain some sense of personal autonomy.

A failure to encourage the development of age-appropriate skills whilst an inpatient was also seen to negatively impact on one's sense of inadequacy and perceived self-efficacy following discharge. Treasure *et al.* (1995) highlight the importance of helping young people with AN receiving inpatient care to progress developmentally, in order to help them feel more 'in control'.

Given the underlying feelings of worthlessness, ineffectiveness, and sense of being regulated by the demands of others often found in people suffering from AN; Duker & Slade (1985) and Bruch (1962, 1978) stress the importance of collaborative approaches that enable people with AN to feel like active participants in their own lives. Linked to this issue, the type of therapy used on an individual basis may convey mixed messages about one's sense of worth. In the current study several participants reported finding psychoanalytic approaches unhelpful, in that they felt that the therapist tended to over-interpret their lives and told them how they felt. A perception that professionals in power had misunderstood them by analysing information in the wrong way could compound a sense of helplessness. Cognitive-behavioural approaches were viewed by some participants as more collaborative and problem-focused and therefore more helpful. This is in keeping with Bruch's (1962) clinical impression, that psychoanalytic interpretations

could reinforce a sense of defectiveness by suggesting that that the anorexic client did not know what they themselves felt, and that 'fact-finding' approaches worked more successfully with these clients. However a preference for CBT over psychoanalytic approaches has not been highlighted in other studies on patients' views on psychological treatment.

4.1.2.2: *Social isolation and relating to peers:*

Several participants felt that being in hospital compounded their sense of isolation from the 'real world' and evoked profound feelings of loneliness and a lack of 'belonging'. This was compounded further by unit practices that made connections with people in the outside world more difficult – such as inflexible visiting hours and lack of private space to spend time with family or friends.

In general AUs being treated very differently from peers could also evoke a sense of not belonging in the inpatient community and even stigmatisation. Unlike the suggestions of Garfinkel *et al.* (1985) (see section 1.5.3) participants in the current study did not report any particular criticism or jealousy towards them from patients with different diagnoses. In fact the friendships and acceptance offered by fellow patients appeared to be positive in promoting self-worth, and possibly decreasing this sense of isolation

4.1.3: How was discharge and subsequent adjustment to the outside world experienced? What factors aided this or made it more difficult?

Discharge was experienced in a number of different ways, depending on how 'ready' participants had felt, their attachment to or dependence on the unit, and whether discharge was abrupt or more gradual and supportive. Discharge could be an emotional, scary and difficult time, even for those who had reported finding their inpatient experience unhelpful. Similarly, adjustment to the outside world depended on a number of factors.

Factors that aided this transition or made it more difficult concerned the overall treatment approaches used by the unit throughout their stay. Also important were practices used to prepare for discharge, and follow-up support put in place during the months and years following discharge.

4.1.3.1: ***The overall treatment approach/ethos of the unit:***

One main aspect of treatment that appeared to affect successful transition following discharge was the unit's degree of contrast with the outside world. Highly structured units with regimented routines appeared to make re-adjusting more difficult. For example, the outside world often required people to be flexible with the timing and content of meals. Several participants reported struggling with this. If there were stark contrasts in the level of support being provided, abrupt discharge could be experienced as very frightening.

Treatment approaches that had taken away all control over decisions and failed to encourage the development of age-appropriate skills also made it more difficult to cope with the demands of life following discharge.

4.1.3.2: *Preparation for discharge:*

What aided transition for many participants was a gradual preparation that was experienced as supportive, collaborative and at one's own pace. Pre-empting likely difficulties by problem-solving potential coping strategies could be helpful during individual and family sessions.

Preparing for contrasts in control was also viewed as important. Participants needed to feel that they had developed their own 'tools' for managing their ED rather than feeling dependent on unit staff. Preparing one's own meals and gradually handing back freedom and control over decisions made discharge more manageable. During this time, encouraging activities outside the unit was suggested as a way of 'meeting normal people' and acting as an incentive to get well. Fennig *et al.* (2002) also suggest 'gradual and increasing exposure to daily activities in the community' as a strategy to minimise the likelihood of relapse after discharge.

A study by Lay *et al.* (2002) supports the need for adequate preparation prior to discharge, as opposed to an abrupt discharge following the achievement of one's target weight. These investigators found that maintaining one's target weight for longer periods before discharge reduced the likelihood of re-admission. However no other known studies have looked at this preparation phase in detail.

4.1.3.3: *Support following discharge:*

Many participants stressed the importance of a relatively high level of ongoing support from services following discharge, even though they may not have wanted this at the time. Unfortunately, few felt they had received this. Whether the AU or local community services should provide this depended on preferences of the individual and geographical location in relation to home. Ongoing support should then be carefully adjusted to fit one's stage of recovery. A clinician or therapist who knows the client well should be equipped to gauge this.

These findings support the views of both adult MH service-users, and young people, that more adequate support is required from psychiatric services following discharge from inpatient care (see Rogers *et al.*, 1993 & Street & Svanberg, 2003). Buston (2002) and Gowers & Bryant-Waugh (2004) also stress the importance of a supportive and *continuous* therapeutic relationship for young people.

Fennig *et al.*(2002) describe a new relapse prevention programme for young people with AN, specifically designed to aid transition to the outside world. This is achieved by maintaining the young person's sense of security, and conserving a strong therapeutic alliance. Results from their study indicated that relapse rates decreased from 40% to 15% in their psychiatric unit, providing some support for their hypotheses – regarding a particularly vulnerable phase for young people at discharge (see section 1.6.1.2).

Following discharge several participants also commented on the importance of having a new focus, which could act as an incentive to remain well - such as a new job or college course that one particularly enjoys.

Many also mentioned the difficulties they had experienced trying to reintegrate back into a group of friends after so much had changed. Often an acceptance by a new group of peers was very important to recovery. As with findings from adult studies, recovery seemed to be viewed as a much wider phenomenon than a change in weight and ED behaviours (e.g. Petterson & Rosenvinge, 2002).

4.2: CRITIQUE OF THE STUDY

Firstly the present study will be critiqued in terms of the Elliot *et al.* (1999) guidelines for publishing good quality qualitative research. A section discussing further strengths and limitations of the study will then follow.

4.2.1: Critique of the qualitative methodology (Elliot *et al.*, 1999)

Validity (or 'credibility') in qualitative research can be defined as the extent to which an account accurately represents the social phenomena to which it refers. Reliability (or 'confirmability') can be defined as the degree of consistency with which instances would be assigned to the same category by a different analyst, or the same analyst on different occasions (Silverman, 2000, p.174). Many qualitative researchers prefer to use the term 'trustworthiness' or 'rigour' to refer to both of these concepts. Ways of achieving rigour are included in the following sections.

4.2.1.1: *Owning one's perspective:*

In section 1.6.1.3 the researcher has outlined their reasons for choosing to carry out this study. This was provided in order to allow readers to interpret the researcher's data in light of potential biases, and to consider possible alternatives.

IPA deliberately acknowledges the interpretative element in the analysis process (see section 2.2.2). It is therefore recognised that this study will be 'biased' to some degree by the researcher's own personal context. For example it may be that findings about participants' preference for CBT over psycho-dynamic approaches were influenced by the researcher's own theoretical orientation.

Should the reader wish to track some of the researcher's emerging ideas about the data, or factors that may have influenced the interviews themselves, extracts from the researcher's reflective diary are provided (see Annex 2). This was hoped to aid further 'transparency' for the reader (Silverman, 2000).

4.2.1.2: *Situating the sample:*

In section 3.1 the author has provided basic demographic information about participants in order to aid readers in 'judging the range of persons and situations to which the findings might be relevant' (Elliot *et al.*, 1999, p.221) - i.e. judging its degree of 'transferability' (akin to generalisability).

These findings are most relevant to treating young female inpatients with a diagnosis of anorexia. However there may have been a selection bias. Those people who wished to take part may have possessed certain characteristics, not necessarily shared by many other young people treated for AN. For example, wanting their views to be heard in

order to complain about particularly negative experiences, or feeling recovered enough from their ED to feel able to face talking about their past experiences. Notably, only one participant was successfully recruited via adult ED services (still undergoing treatment for an ED). However participants recruited via past AU records included those still receiving intensive treatment for an ED, as well as those who perceived themselves to be recovered at the time of the study. Furthermore, several participants stated that their desire to take part was related to wanting to share positive experiences in order to help inform services for the benefit of other patients. It may be that some *other* factor, not accounted for in the collection of demographic data, may have influenced a wish to participate.

Further criticism pertains to the lack of homogeneity of the participants' experiences of treatment, in terms of duration and types of settings (see Smith & Osborn, 2003). Although all participants had experienced general AU treatment (the focus of interviews), several participants also talked about experiences of specialist ED AU treatment. This may have lessened the clarity of findings, as certain helpful or unhelpful factors may have been specific to one setting and not the other. Furthermore participants varied in the degree to which they perceived themselves as 'recovered' from their eating disorder at the time of interview. Including both recovered and non-recovered individuals in the study also limited homogeneity, and therefore perhaps the meaning and generalisability of findings. Unfortunately if the researcher had also included one specific recovery status within the eligibility criteria it is unlikely that enough participants would have been

recruited in the time available to conduct the study – recruitment already having been problematic.

4.2.1.3: *Grounding in examples:*

In order to allow readers to appraise the fit between the data and the researcher's understanding of it, quotes from participants' accounts have been used where possible to illustrate points and interpretations. Given that one of the study's aims was to provide these young adults with a 'voice', the researcher found the word-limit challenging as it meant she was unable to use as many quotes as she would have liked. In order to demonstrate further evidence of the representativeness of themes within participants accounts, and to minimise the likelihood of appearing 'anecdotal' (Silverman, 2000), the researcher also included a detailed table of themes and further quotes in Annex 3. It is also hoped that this would allow readers to 'conceptualise possible alternative meanings and understanding' if they should wish (Elliot *et al.*, 1999, p.222).

4.2.1.4: *Providing credibility checks:*

Methods used to check the credibility of interpretations and themes are outlined in section 2.3.5.

There is some debate about the uses of 'member checking' (see Silverman, 2000, Mays & Pope, 2000), and due to the interpretative element of IPA many believe that it is not

always appropriate. However, the current study was aiming to be more phenomenological than interpretative – i.e. get as close as possible to the participants' perceptions of their experiences in order to represent their previously unheard views. Therefore carrying out member checking is arguably an important strength of the study. If time had allowed, more than three of the participants would have been approached for their views on the data.

Regular sharing of data, and discussions about methodology with fellow members of the IPA peer-supervision group, and with supervisors, was also extremely helpful in reflecting on one's own biases and providing audits of the analysis process.

4.2.1.5: *Coherence:*

The researcher attempted to achieve integration, but also to present nuances in the data. Data was presented under super-ordinate and then subordinate themes with clear headings and sub-headings. As the researcher re-wrote and then fine-tuned this section, several drafts were read by supervisors and peers and their comments concerning coherence were addressed.

Smith (2004) points out that readers of a study using IPA; 'should be able to learn something about both the important generic themes in the analysis, but also about the life world of particular participants who have told their stories' (p42). The researcher

attempted to achieve this by presenting a demographic description of each participant separately, and by using names along with quotes in the analysis section.

Nuances in the data were more difficult to represent due to the strict word limit. It is possible that the researcher attempted to cover too many topic areas within the interviews. Focusing in more detail on specific aspects of inpatient or discharge experiences may have allowed for more nuances and in-depth interpretations to be presented.

4.2.1.6: *Accomplishing general vs specific research tasks:*

This study used only seven female participants from a relatively homogeneous sample (as advised by Smith & Osborn, 2003, when conducting IPA). In light of this, findings specific to this study should not be generalised to wider populations of young people, or to adults with EDs. Furthermore, definite clinical recommendations should not be made on the basis of these findings alone. However, some of these findings are more clearly in-line with existing literature. Here the case is stronger for making suggestions for clinical practice. As Smith & Osborn (2003) state; 'the power of the IPA study is judged by the light it sheds within this broader context' (p54).

Smith (2004) stresses the 'interrogative' and 'inductive' nature of IPA. Studies should aim to interrogate or illuminate existing research. Results of a detailed analysis of case studies do not stand on their own but should later be discussed in relation to the extant psychological literature. This has been addressed in section 4.1. IPA is also more

'inductive' than deductive. It aims to construct broad research questions leading to the collection of expansive data. This means that it may produce findings that are not necessarily predicted by existing research. In this case the salience of a sense of being 'removed from normality', and the importance of relationships with peers, were relatively novel findings.

4.2.1.7: *Resonating with readers:*

Both supervisors of this study had extensive experience in working clinically with patients with AN. Their comments, upon reading drafts, served to clarify that the narrative presented resonated clearly with their own clinical experiences, as well as adding new insights. Because findings presented are also in line with much of the extant literature on the views of patients, readers familiar with this should also find resonance. The researcher attempted to provide a balanced account and avoided the use of abstract jargon.

4.2.2: Other strengths and limitations of the study

4.2.2.1: *Giving people a voice:*

A clear strength of the study was that it gave young adults who had experienced adolescent inpatient treatment for AN a 'voice' to air their views and potentially add to the development of more effective services. Several participants repeatedly expressed

great enthusiasm for the study. Most talked at length about their experiences, appearing to have not previously had such an opportunity to be listened to.

4.2.2.2: *The interviews:*

The interviewer (researcher) felt able to engage participants well and develop a good rapport for interviewing, enabling participants to talk openly and honestly. However, on occasion it was felt that knowledge about the researcher's current clinical role (working with young people with EDs) may have influenced interviewees' perceived ability to speak critically of health-care professionals.

A criticism of the interview schedule may be that some questions appear less 'open' and more specific than would normally be recommended in a study using IPA (e.g. Smith & Osborn, 2003). The researcher had found through her own experience of working clinically and conducting research with younger people, that asking extremely open questions does not always generate a very detailed or reflective response. She therefore felt that preparing more specific questions and possible prompts would be helpful. These were only used on occasions where open questioning was not productive. Indeed this tended to be during interviews with younger participants.

4.2.2.3: *Scope and nature of the study:*

A limitation of the study is that the researcher may have tried to explore too wide an area of experience – looking at all aspects of inpatient treatment *and* factors affecting transition and discharge. Some of the very rich issues, such as those of control, or experiences of adjustment following discharge, would perhaps be given more justice within a qualitative study that attempted a more focused exploration of one of these topics in its own right. Arguably IPA is a method of analysis particularly suited to more in-depth analysis of a relatively narrow, specific area of phenomena. However the researcher initially chose to explore both treatment and discharge experiences in a broad sense as young patient's views on both of these areas have been greatly neglected in previous research. A strength of the study therefore is perhaps the breadth of clinically relevant information obtained, however a corresponding weakness is that the depth of information obtained has inevitably been more limited.

A final consideration is that the retrospective nature of the study meant that participants were being asked to recall experiences that occurred 2 to 5 years previously. Memories of past experiences may be less accurate than accounts of current experiences. Arguably, this could make for more balanced and reflective accounts, and was necessary in order to explore experiences of adjustment following discharge (see section 2.2.1). Furthermore, this study was more interested in perceptions of experiences and the meaning these had for participants, rather than accuracy about the nature of interventions themselves. In IPA 'the important reality is what people perceive it to be' (Willig, 2001, p.64).

4.4: CLINICAL AND RESEARCH IMPLICATIONS

4.4.1: Suggestions for clinical practice

The findings of this study, alongside the extant literature suggest the following implications for clinical practice. These suggestions apply to the inpatient treatment of young people with AN. The current findings suggest that many of these are vital in order to reduce the compounding effects of hospitalisation on the individual's underlying psychological difficulties, and to promote a more sustained recovery following discharge.

- Health-care professionals should develop ways of achieving collaborative working relationships with patients, involving them in their inpatient treatment and recovery. When taking away control over certain aspects of life is necessary, this should be explained in a clear, supportive manner and negotiated with the client and their families where possible. Control over areas of life, not related to ED symptomatology, should be strongly encouraged. As highlighted in NICE (2004), 'rigid inpatient behaviour modification programmes should not be used'. Where incentives are necessary these should be chosen by/negotiated with the young person. Useful strategies for managing control battles have been described elsewhere (see Sallas,1985, Honig & Sharman, 2000, Duker & Slade,1988).

- More collaborative relationships with parents need to be achieved, moving well beyond implications of blame. Parents should be genuinely valued as 'integral to the recovery process' (McMaster *et al.*, 2004). A greater level of support should be provided for parents outside of family sessions (Honig & Sharman, 2000), and after the patient has been discharged from inpatient care (McMaster *et al.*, 2004). Ways to engage and support siblings, and their relationships with patients are also extremely important. How best to achieve this requires further consideration.

- Connections with friends and family in the outside world should be strongly encouraged, through flexible visiting hours and appropriate visiting areas which offer privacy. Links to the outside world should not be used as a reward or 'privilege' (see also Honig & Sharman, 2000).

- Inpatient units should provide a range of activities appropriate to the developmental needs of young people (also see NICE, 2004) and which promote a connection with 'normal' adolescent life. Young Minds suggest the involvement of youth workers for this purpose (Street & Svanberg, 2003). Unless there is an immediate danger to physical health, patients with AN should be encouraged to participate in these activities. Patients should also be encouraged to develop age-appropriate life skills, and dependence on unit staff should be discouraged.

- Young people should be supported and encouraged to form positive relationships with fellow patients. Issues of comparison and competitiveness should be addressed in a direct, but supportive manner (see Honig & Sharman, 2000).

- An equal balance should be given to addressing the physical, emotional and psychological needs of the patient. A message that the sole focus of treatment is on achieving weight gain should not be conveyed. Regular individual sessions should be offered to every young person (NICE, 2004) and the orientation of therapy should be one which empowers and involves the young person. The level at which underlying psychological issues are explored, or more simple emotional support is offered, should be carefully gauged in a client-led manner and adjusted to suit the client (in terms of effects of starvation on cognitive processes and motivational issues).

- Due to the challenging nature of this work, inpatient staff should receive regular support, team building efforts, and training (see Ramjan, 2003 & Sansone *et al.*, 1988). The development of unhelpful negative assumptions about patients with AN should be monitored and challenged. Every effort should be made to view each patient as a unique individual, and their diagnostic traits as merely symptoms of other underlying difficulties (see also Manley *et al.*, 2001, p.154). Ways to develop more truly individualised treatment packages should be considered, which are feasible given constraints on resources and the importance of providing evidence based treatments.

- Preparation for discharge should be gradual and empowering. It should involve the gradual development of skills to manage one's own eating and the development of coping strategies for likely difficulties encountered in life post-discharge. Healthcare professions should not underscore the importance of the transition process. All decisions should be collaborative, with the whole process being perceived by the client as a supportive component of the recovery process (Vandereycken, 2003) rather than a rejection. In line with NICE (2004) guidelines (see section 1.3.4), intensive psychological support should be provided during the months following discharge – also monitoring physical risk. This should either be provided by unit staff or by local community services following a comprehensive hand-over. Continuous therapeutic relationships should be offered where possible.

- Given the insightful nature of these participants' accounts, it may be useful for current inpatients to have contact with slightly older people who have already been through the experience. Contact with 'recovered' anorexics has been also been recommended elsewhere (Eivors *et al.*, 2003).

- Finally, if inpatient treatment is to be made more acceptable to young people with AN, patients and ex-patients should be more directly involved in the planning, provision and evaluation of services (Treasure & Schmidt, 1999, Faulkner, 1997, Street and Svanberg, 2003). Perhaps all inpatient units should routinely seek feedback from patients following discharge, regarding the helpfulness/ un-helpfulness of a range of aspects involved in their treatment experience.

4.4.2: Suggestions for further research

Further research is required in the following areas:

- Qualitative studies with other young people diagnosed with AN to explore whether the more novel findings of this study are shared by others. For example, findings concerning the importance of promoting normality and peer relationships.

- Further studies need to investigate the importance of developmental factors and to consider how to provide more appropriate inpatient services for young people which may more effectively meet their developmental needs

- 'Control' has been found to be a very important concept when working with this client group (i.e. see Surgenor, 2003 & Jarman *et al.*, 1997). Further qualitative research is needed to explore the meanings and intricacies behind this concept and its role within staff-patient interactions.

- A great deal of research is required to develop more effective strategies for discharge preparation, the management of transition to the outside world, and relapse prevention.

- Studies are needed which systematically assess the relative advantages and disadvantages of different treatment settings for this client group (i.e. inpatient, day-patient, general AUs, specialist AUs). Vandereycken (2003) suggests the types of studies necessary to make these comparisons (pp.417-418). These should consider effects on all aspects of functioning including physical and psychological development (Gowers & Bryant-Waugh, 2004), and which young people might respond best to which type of setting. Gowers and colleagues are currently carrying out a trial comparing inpatient and outpatient management, which aims to further explore the potentially negative consequences of hospitalisation (see Gowers & Bryant-Waugh, 2004).

- Further research is required to explore the relationships between the effects of starvation on cognitive processes and how this affects a patient's ability to engage in therapy. So far the literature appears to indicate that more traditional psychodynamic approaches are not conducive in acute phases. Studies are needed to explore the possible uses of CBT and other therapeutic approaches.

- These findings suggest that there may be particular skills needed in establishing effective therapeutic relationships with this client group. MET (see section 1.3.6.5), with its focus on engaging clients and working empathetically with ambivalent clients appears to be a promising approach. Using tools to identify the patient's stage of change may allow better tailoring of treatments to individual needs (see Geller & Drab, 1999). More RCT's are needed comparing MET with other types of therapy.

CONCLUSION

5.0: Conclusions

This exploratory study has attempted to answer three broad questions about how young people experienced inpatient treatment for a diagnosis of AN.

- Participants provided insightful and balanced views about what they found helpful and unhelpful about their past inpatient treatment: Promoting a sense of normality and encouraging connections with the outside world were generally viewed as helpful. Positive relationships with fellow inpatients and ongoing psychological/emotional support were also viewed as being very helpful in meeting one's needs during admission. Practices that conveyed that individuals were viewed as 'anorexics', rather than individuals with unique emotional needs, were viewed very negatively. Over-controlling, rigid ED programmes were also viewed as unhelpful; involving clients and their families in collaborative, individualised interventions being highly valued by participants.

- Findings relating to the second research questions did tentatively suggest that particular aspects of inpatient care do appear to compound some intrinsic features of AN; such as a deep sense of isolation, ineffectiveness and worthlessness. However, creating more individualised, empowering and collaborative approaches to care, which encourage connections with the outside world, and positive relationships with peers in the hospital, may serve to minimise these potentially negative effects.

- Finally, there were several aspects of service provision, which helped make transition to the outside world more manageable. These included the ethos of the unit during one's admission (e.g. minimising contrasts with the outside world in terms of structure and control); preparing adequately for discharge in a gradual, collaborative manner; and ensuring the provision of a continuous, high level of support following discharge.

Many of these findings were in-line with the extant literature. Perhaps more unique to this study was the salience of a sense of being 'removed from normality' whilst an inpatient ; a view that ones' developmental needs were often not addressed; and the importance of relating to peers on the unit. These findings may be particularly relevant for this adolescent client-group. However due to the limitations of making generalisations based on this small sample alone, further research is required in these areas.

Recent guidelines (e.g. NICE, 2004), appear to be positive steps towards promoting more effective services for young patients with AN. However, what is extremely clear from the findings of this study, along with other recent research, is that some existing inpatient services do not use approaches that are perceived by their patients as being truly individualised, collaborative or holistic. To avoid compounding a sense of ineffectiveness and worthlessness in young people with AN, inpatient services should strive to empower patients, enhance self-esteem and encourage the accomplishment of developmental skills.

As Duker & Slade (1988) stated, regarding inpatient care:

'all interventions must be calculated to foster a sense of self: to increase, not decrease the sufferers self-respect. This applies even when some weight-gain is urgently required for the sake of physical safety' (p.142).

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APPENDICES AND ANNEXES
CONTENTS PAGE

For reasons of sensitivity most of the appendices and annexes have been removed from the electronic version of this thesis

Interview Schedule

Set the scene

Later on I'm going to be asking you about your experiences of being an inpatient and what things you found helpful and unhelpful about the treatment you received.

First of all I'd like you to try to remember as much as possible about the hospital you were admitted to. Imagine that I'm a young person who is about to be admitted there and I want to know a bit about the place. ***Can you tell me about it?***

Prompts:

- Where was it?
- Did you have your own room?
- What was the daily routine? (degree of structure)
- How many other people were there? What were they like?
- What sort of staff worked there? What were they like?

1) Could you tell me about the treatment plan you received when you were there?

Further questions/prompts:
- psychological vs physical
  eating plan/weighing etc

2) How did you find these things (above)? Looking back, do you think they were helpful/unhelpful and why?

3) Were any other issues addressed, besides you weight and eating? (e.g underlying issues/ emotional/psychological). Can you describe to me in your own words what this type of treatment was like?

Further questions/prompts:
- groups / individual/ family work?
- What were these experiences like? helpful/unhelpful and why?
- relationship with the therapist? What were they like, what was helpful/unhelpful etc

3) Thinking back to that time, did you think you wanted any help? Did you think that you had a problem with eating?

4) What was it like being in the hospital environment?
- how was it compared to being at home (structure/safety etc)
- was this helpful /unhelpful and why

5) How much control did you feel over what happened to you whilst you were there?
- was this helpful/ a good thing or a bad thing for you at that time?
- Is there anything that could have been done differently ?

6) What was it like being around other patients/ people with problems? (helpful/unhelpful and why)
- what was it like to be around people with the same kinds of problems as you (e.g. other people have mentioned competition/comparison issues?)

7) Looking back to that time and how you were feeling...how do you think you saw yourself as a person whilst at the hospital? What was your sense of yourself like? (e.g. self-esteem/identity/how worthwhile you felt)
- how was this compared to before going into hospital
- how was this compared o how you've seen yourself since?
- Treated respectfully/ as individual (other people said treated certain way because anorexic)

8) What was your relationship like with your family when you were in hospital?
- was it affected in any way? How?

9) What was your relationship with your friends outside like whilst you were in hospital?
- was it affected? How?

So far we've been talking about being an inpatient at the hospital and you've told me about .....and how you felt ..... (summarise and clarify main points). *Is there anything else you remember about being an inpatient that you'd like to tell me more about?*

Now I'm going to ask you to think back to the time when you were discharged from the hospital.
- Tell me what you remember about the day you were discharged (where to? Who was there? What happened?)
- How did you feel about returning home/to X?
- What were you hoping was going to happen next?
- Were there arrangements made about follow-up support?

10) How did you feel about being discharged?
- (Did you feel ready? Looking forward to it?)

11) Can you tell me a bit about the few months after discharge?
- how did you find managing your eating and weight again?
- How well did you feel that you were coping emotionally?
- How did you find any follow-up input from the hospital

(Helpful/unhelpful and why? How improve?)

C

- any other input received e.g. outpatient/GP/support groups/counselling etc.

12) What things made the time following discharge easier or more difficult for you?
if relapse/found things difficult:
- was there anything about the change between being in hospital and being in the outside world again that made coping with your eating disorder particularly difficult?
(e.g prompts: some people say loss of structure and safety / having to control eating again myself / still feeling I wanted to be thin / still lots of underlying psychological issues not dealt with).
- Can you think of any ways that his could be made easier

13) How did you find your relationships with your family and friends in the few months following discharge?
- were they changed by you being in hospital?
- How supportive were people around you?

14) Can you describe to me how you have coped with your eating disorder since discharge?
- any relapse? (how was this managed)
- what have been the most helpful and least helpful forms of support? (and why)

I've nearly finished asking the questions I wanted to ask you now. Are there any other things you would like to tell me, either about your experience of being an inpatient, or about your experience of discharge and the time afterwards?

15) What were the least helpful things about the way services were for you at that time?
- (If you could have *changed* anything what would it be?)

16) What were the most helpful things about the services you received at that time?
- (things keep the same?)

Time for Debrief:

- ask interviewee how found the interview.
- Find out if felt particularly difficult or distressing
- Check whether feeling ok to end session – what doing next (e.g back home/going to work).
- Discuss ways of accessing further support if necessary.

Worked example of the analysis process

The following pages provide a worked example of the process of coding the 4th interview transcript (Anna's interview), as well as the clustering of emerging themes, and the production of a table of themes. Anna's entire interview and table of themes could not be presented for reasons of confidentiality.

Coding of the interview transcript:

Annexe 1a contains four pages taken from Anna's original interview transcript. The original pages 2-5 were omitted to help protect her anonymity. 'I:' denotes that the interviewer (researcher) is speaking, and 'P:' that the participant (Anna) is speaking.

Notes along the *left hand-margin* are the researcher's initial observations and descriptive comments (the 'phenomenological' stage of analysis). As illustrated here, Anna's comments were sometimes simply para-phrased, or particular phrases she used were noted as summaries of what she was saying. Particularly interesting or significant parts of the text were also underlined at this stage. This was helpful later during the iterative process to ensure that themes were truly grounded in the original data.

Following this initial reading and coding of the text, the interview transcript was read a second time, making notes along the *right-hand margin*. Part of this process was inevitably influenced by having already read and coded interview transcripts 1-3. Here the researcher has made inferences about the nature and meaning of Anna's experiences, noting key words or emergent themes (the interpretative stage). For example, on page 1, descriptive comments in the left-hand margin - which paraphrased what Anna actually said; 'not real world', became; 'sense of unreality = salient' in the right hand margin. This later became a sense of being 'Removed from normality' (Super-ordinate theme A) once themes from all 7 interviews were integrated (see section 3.3 of results/analysis section).

Clustering Themes:

Firstly, all emerging themes/ key words from the right hand column were listed in order of occurrence, along with the page number on which they could be found. A process of clustering then occurred, where the relationships between these different themes was examined, and themes began to be moved around and grouped into clusters (using the cut and paste functions on the computer). Labels were given to clusters in an attempt to capture their essence. Part of this clustering process is shown in Annexe 1b.

Producing tables:

Finally these clusters of themes were used to construct a more coherent table of themes (see Annexe 1c). Super-ordinate themes are shown in bold type, with sub-ordinate themes underneath in normal type. In order to ensure that themes were truly grounded in the data, page numbers where occurrences of each subordinate theme could be found were provided in the 2nd column, along with example quotes from the text in the 3rd column. Subordinate themes were carefully checked against the original text and themes where no clear example could be found were discarded at this stage.

Unreality of unit

Unreality (1) includes other MH probs (1) - scary, unsafe (7)
Normality – chatting young nurses (2) (3)
Importance of continuing normality – feeling useful (3) (9)
Continuing real life priorities (4) (5) (19)* -should be more encouraged
Desire for normal parenting (4)
Contrast safety (and exposure/fear real world) (6) (12)
Contrast of control = unmanageable (11)
Artificial structured environment-leads anxiety if small changes (7)
Loss of sense of belonging (10)
Lack attempts integrate real world (10) – e.g. inflexible rules hampers relationships (11) (12) (19)*
Contrast with fun of normal adolescent life (12)
Real life progressing outside (void) (12)
Whole life in unit – attachment (13)
Acting normally positive , but interpreted as ED behav (15)

Segregation of ED (1) – no sense belonging unit (15) (19)* would change
Like punishment (1)
Treated differently, exposure of problems, inhumanity, stigmatised (2)

Focus eating (blanket approach, non-individualised) vs Holistic (person-centred, individualised)

Sole focus eating (1) (7)
Sole focus food unit target weight (3) (4) (6) (13)
Solely weight-gain therefore not ready leave (13)
Vs holistic – psy and food in parallel (18)
Unfairness blanket approach (once classified) (2)
All behaviours interpreted as ED – simplistic and wrong (15)
Inflexibility of rules (not person-centred) (4)
ED treated as one block (despite variability, individuality) – like punishment (2) (2)
Blanket approach leads suspicions, false assumptions, over-reactions (2) (9)
Inhumane treatment – over-vigilant, staring (3)
Not human/individual but an ED (3) (9) (14)
Being with other ED – leads more non person-centred treatment (9)
ED as symptom only (3) (8) (14)
Withholding groups – illogical, based false, rigid assumptions re ED (4)
E.g holistic approach (4)
Staff ignoring/opposing patients priorities (4) (5) (7)
Own priorities allowed (ED group) (6)
Simplistic, blanket approach = inhumane (5)
Punitive (6) (6)
Approach not person-centred (6) (8)
Due staff assumptions Ed becomes identity – live up expectations (7)
Assumptions/generalisations led fear make further ones e.g LD (9)
& afefcted beavhiour (15)
Vs being understood as an individual/human – not simplistic ED (14)

R

Groups as token gesture/incentive (not therapy) (3)

Nurses able to be flexible re creating normality and professional support (3)
Psycho-dynamic – over-interpretative, powerful vs CBT – moving forward (5)

Peer identification
Relating to others (age) (4)
Vulnerable to influence of other ED – seeking belonging, conformity (7) (10)
Ed becomes identity (7)
Feeling not alone – peer identification other probs (8)
Support of other ED (9)
Comparison issues other ED (10)
Lack of belonging/identity in unit (10)
Peer support as adults with ED (13)

Family
Family therapy:
Blame (5)
No rationale for screen (5)
Rec – more collaboration/involvement parents (11) (12)
Unit not condcuive to maintainign family relationships (12)

Control/Freedom (Contained vs powerless)
Gradually giving back (pos) (6)
Needs individualised approach to control (6)
Safe but totally powerless (6)
Unable to make own decisions, reduced confidence, incapable (11) (14)
Containment good but Collaboration imp – not doing it for me (8) – led resentment (8)
Need for some degree of choice (11) (14)*
Contrast of control = unmanageable (11)
Anger re taking all control away – failed treatment (14)
Collaborative treatment e.g (19)

Development
Arrested (6) (13) (18)
Encouraged dependence, no life-skill development (6) (18)
Has long-term impact re loss confident own abilities (6) (mirroring AN?)
Lack of belonging with peers – left behind, moved on (10)

Rules, restrcitions lackign logic (e.g cant go out in car) (14)

Increased awareness of mental illness (pos) (8)