WHAT FACTORS ASSIST CLINICANS TO DETERMINE DYING IN AN ACUTE HOSPITAL?

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AUTHOR'S DECLARATION AND WORD COUNT

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This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the relevant Ethics Committee.

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ABSTRACT

Background: The End of Life Care Strategy stated that there should be a reduction of expected deaths in the acute setting. In order to achieve this goal, when it has been identified that where the patient's preferred place of care is home, clinicians need to be able to recognise when a patient is dying in order to achieve their preferred place of death. The aims of this study were to identify any factors that help or hinder a clinician when they are determining when irreversible dying begins and to seek consensus on which of these topics would be useful to include in an education programme.

Method: A 3 stage mixed methods study was developed. Phase 1was a Systematic Review of current primary research in order to provide an evidence base for the study. Phase 2 involved unstructured interviews with clinicians in the acute setting utilising the Grounded Theory approach to the analysis identify potential factors. Phase 3 was a Delphi study used to identify which of these factors would be useful in an education programme.

Conclusions: The Systematic Review identified four themes "Patient Observation", "Knowledge of the Patient", "Communication" and "Attitudes of the Clinician". These were confirmed by the interviews and a further theme "Experience" identified. The over-arching theme emerging from the findings of the interviews was that clinicians have a fear of getting the timing of the recognition of irreversible dying wrong because the decision making process is so complex and this is exacerbated by fear of missing the treatable. Many factors identified in the interviews were acknowledged as factors that could be included in an education package. It was also identified that there is the need for a culture shift in society regarding death and dying and a change in the philosophy of care for health care professionals.

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Glossary of terms

Actively dying-patients with a survival expectation of hours or days

Co-morbidities- is the presence of one or more additional disorders (or diseases) co-occurring with a primary disease or disorder

Disease trajectory- Three distinct illness trajectories have been described for people with progressive chronic illnesses: a trajectory with steady progression and a clear terminal phase, mostly cancer; a trajectory with gradual decline, punctuated by episodes of acute deterioration, with more sudden, seemingly unexpected death; and a trajectory with prolonged gradual decline.

Dysphagic- being dysphagic is the medical term for having swallowing difficulties. Some people with dysphagia have problems swallowing certain foods or liquids, while others cannot swallow at all.

Dyspnoea- shortness of breath or breathlessness is the feeling or feelings associated with impaired breathing

End-of-life Care- the last twelve months of life, during which the patient, their family and their health care professionals become aware of the life limiting nature of their illness (DoH, 2008).

Glasgow Coma Scale (GCS)- is a neurological scale that aims to give a reliable, objective way of recording the conscious state of a person for initial as well as

subsequent assessment. A patient is assessed .against the criteria of the scale, and the resulting points give a patient score between 3 (indicating deep unconsciousness) and either 14 (original scale) or 15 (the more widely used modified or revised scale).

Intensive care Unit (ICU)- a specialist ward providing intensive care (treatment and monitoring) for people in a critically ill or unstable condition.

Integrated Care Pathway for the Dying- was a pathway covering palliative care options for patients in the final days or hours of life.

Irreversible dying- the patient who will die despite any medical treatment provided

Multi Professional Team- A team or group consisting of representatives from several different professional backgrounds who all have different areas of expertise.

Performance status- is an attempt to quantify general well-being and activities of daily life

Terminal- People who have a life limiting illness with an expected survival of 6 months or less

Terminal delirium- is characterised by anguish (spiritual, emotional, or physical), restlessness, anxiety, agitation, and cognitive failure.

CHAPTER 1

INTRODUCTION

1.1 Background and rationale

In order to initiate appropriate end of life care, recognising when irreversible dying begins is critical. If this is not achieved the care of the dying patient is likely to be compromised as important decisions about their medical care, including the withdrawing or withholding of treatment and the avoidance of burdensome and non-beneficial treatments will not be made (Alonso et al 2008; Basta L & Tauth J. 1996; Hall et al 2011; Sullivan et al, 2007).

On reviewing some of the available literature it became clear that the recognition of when a patient is irreversibly dying is an issue that has troubled clinicians (Chow et al 2001; Christakis et al 2000; Vigano et al 2000a). Hillman (2010) suggested that the determining of dying is very complex and includes issues relating to the unrealistic expectations of society, lack of support at the community level for those who are terminally ill, medical practitioners fear of litigation and increasing specialisation in single organ illnesses when the majority of patients who are actively dying will have multi organ failure and will suffer from multiple co-morbidities.

The End of Life Care Strategy (Department of Health (DoH), 2008) stated as one of its goals that there should be a 10% reduction of the number of expected deaths occurring in the acute setting year on year over the following three years. At the time this was published 58% of expected deaths were occurring in hospital when between 56% and 74% of people surveyed stated that they would like to

die at home (National Audit Office, 2008). More recently the 2010 Annual Report on the End of Life Care Strategy (DoH) confirmed these concerns with 55% of expected deaths still occuring in hospital and in 2011 the Third Annual Report (DoH) stated that this figure had only dropped to 53.3%, that is, had only dropped 4.7% over three years. By the End of Life Care Strategy Fourth Annual Report this figure has only dropped to 51% instead of nearer to the 42% target indicating that this goal is not being achieved as quickly as might be hoped. Realistically this proportion of deaths in hospital is unlikely to change very much given that logistically, families are spread further apart, the population is ageing and the present financial climate is restricting resources in the health care setting. A pragmatic way to address these concerns may be to ensure that the care provided for the dying is the best possible in the place where a high proportion of deaths occur, i.e. in the acute hospitals.

Although it is generally accepted that hospices are centres of excellence in the care of the dying, particularly for patients suffering from cancer, it would appear that even they, at times have difficulty with the determining of the dying phase (Chuang et al 2004; Dee et al 2011; Ellershaw et al 2003a; Ellershaw et al 2003b). Therefore, it feels appropriate to explore in more depth the problem of recognising when irreversible dying begins and to compare this process in differing acute environments in order to identify commonalities and differences. Once these have been identified it may be possible to identify the critical factors that help clinicians to recognise when irreversible dying has begun.

It is imperative that these patients are recognised in a timely fashion if we are to achieve optimal end of life care for dying people (McKeown et al, 2010). This concern was mirrored by Smith et al (2002) with the development of the ALERT™ (Acute Life-threatening Events Recognition and Treatment) course. They recognised that patients were dying unnecessarily as acute reversible deterioration was not being recognised early enough. Following the examining of available primary research, a training package was developed and implemented. They developed a series of case studies with the clinicians undertaking these in role play. One played the patient and another, the clinician. The remaining group observed and commented on the scenario with the support of a tutor. This has impacted hugely on the recognition of acute deterioration in the acutely ill patient. The ALERT™ course is now commonly used in UK NHS Trusts in order to train teams of clinicians to recognise acute deterioration. This has resulted in the problem of late detection of acute deterioration being largely resolved resulting in improved outcomes for the patient (Smith et al 2002). Potentially a similar complex intervention enabling the recognition of irreversible dying leading to appropriate action (i.e. neither over treating not under treating) could be developed in order to educate teams of health professionals using the guidance developed by the Medical Research Council (2008). This guidance emphasises the need to build the evidence base prior to development and testing of an intervention. In the area of recognition of dying, this includes identifying and examining any barriers and facilitators to this recognition in order to inform whether or not such a programme would be of use. Previous research into care at the end of life has identified that education has a positive impact (Bailey et al, 2010: Ostergaard et al, 2007) in this process. However, the underpinning

evidence for an education intervention in this area of practice has yet to be established.

This study aims to address these challenges by exploring the research question:

What factors assist clinicians to determine dying in an acute hospital?

1.3 Aims and Objectives

The aims of this study are:-

1. To explore factors that either helps or hinders a clinician when attempting to determine whether or not a patient is entering the irreversible dying phase. The definition of clinician in this context is a doctor or nurse who has direct contact with patients rather than being involved with theoretical or laboratory studies.

2. To seek consensus on which of these factors could be useful to include in an education programme to help with this process of determining the dying phase.

There are 3 objectives for this study. These are:

1. To identify and explore the factors that facilitate or prevent clinicians in the acute medical hospital setting to determine whether or not the patient has entered the irreversible dying phase.

2. To identify techniques that may be used to assist in the determining of the irreversible dying phase thus improving predictive accuracy.

To identify which of the factors identified by the in the acute medical hospital setting could be useful for inclusion in an education programme designed to help clinicians to determine the need to review the focus of care being provided to the dying patient.

1.4 Structure of Thesis

The thesis consists of nine chapters. Chapter 1 is an introduction to the study. Chapter 2 contains an initial literature review. The aim of this was to identify whether there was any knowledge currently available regarding the recognition of the patient who is thought to be irreversibly dying. Chapter 3 reports on the systematic review undertaken in order to describe the current evidence base in this area (Phase 1). The systematic review focussed specifically on factors that may be useful or a barrier for clinicians when recognising that a patient is irreversibly dying. This chapter indicated that there was a paucity of knowledge relating to this subject therefore Chapter 4 presents a critique of methodological decisions made in designing this study in order to provide an evidence base. Chapter 5 details the methods used in Phases 2 and 3 of the study, the interviews undertaken with clinicians in three acute clinical areas and the Delphi study. Chapter 6 presents the findings from the interviews undertaken in Phase 2 when analysed using Grounded Theory methodological principles. Having identified the potential factors and topics that clinicians may use in this context, a formal consensus process was conducted with a panel of experts as Phase 3.

Chapter 7 presents the findings of this Delphi study. Chapter 8 integrates the findings from the combined phases of this study. This includes a review of the original aims and objectives relating the findings of the study to these and also to the available literature and, finally, a critical appraisal of the study. Chapter 9 provides conclusions arising from the study. This includes possible recommendations for practice, policy, education and future research.

1.5 Summary

This chapter has provided an over-view of the issues addressed in this thesis. It provides a rationale for the study to be undertaken along with the aims and objectives. A brief structure for the thesis was also provided with a rationale for this structure. This chapter will now be followed by a literature review in order to identify whether there is any knowledge currently available regarding the recognition of the fact that the patient is irreversibly dying and therefore the appropriate timing of a change in the focus of a pattern of care currently being provided. The following chapter will explore some of the available literature.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The aim of the chapter was to identify existing evidence relating to any factors that may assist clinicians to determine when the focus of care being provided to a patient requires review as they are now considered to be irreversibly dying and to present the literature that was reviewed.

2.2 Definitions

There are many concepts and definitions that are used variably by clinicians in the care of the dying such as “end of life”, “actively dying” “terminally ill” and “terminal care”. Hence, initially a brief over-view of some of the terminology used in the health care setting relating to the patient who is irreversibly dying is provided below.

End of life care has been defined as the last twelve months of life during which the patient, their family and their health care professionals become aware of the life limiting nature of their illness (DoH, 2008). Palliative Care Australia (2008) defined it even more broadly as that part of a patient’s life where they are impaired by a fatal condition. This definition is not related to a time scale of any sort.

However Hui et al (2014) in their systematic review of definitions used by clinicians found that, when reporting on these concepts published authors defined the terms “end of life”, “terminally ill”, and “terminal care” as people who have a

life limiting illness with an expected survival of six months or less. Vigano et al (2000b) defined terminal care as when a patient was expected to live for approximately twelve weeks but acknowledged that currently there are no standard criteria with which to define the terminal phase of a patients' life. "Actively dying" however, was defined as having an expectation of hours or days for survival, whereas Tanneberger et al (2002) defined "terminal care" as being the management of patients during the last few days, weeks or even months. The authors also acknowledge in their paper that this lack of clarity and the uncertainty in the definitions used by clinicians can create further uncertainties in the day to day management of these patients.

For the purposes of this study the terms terminal care and end of life care will be used to refer to an expectation of the last few hours or days of life of a patient.

2.3 Search Strategies

A search was initially performed in October 2008 and repeated in September 2013 regarding the determining of the dying phase. Alerts were also set up on the various databases used in order to ensure that potentially useful papers were not missed. The MEDLINE, CINAHL and EMBASE databases and BMJ, PubMed and Ovid search engines using the search terms "clinicians" or "nurses or "doctors" and "care pathways" or "protocols" or "guidelines" or techniques" and "factors" or "determining" or "recognise" and "dying" or "terminal" or "futility" or "palliative" or "prognosis" were used. The search was limited to the period between the year 2000 and present day in an attempt to identify the most up to date and therefore the most relevant literature available (see Appendix A). The

Cancer Plan was released by the government in the year 2000: this was the first document released by them which identified the needs of the dying patient and the importance of delivering quality care to them. This therefore seemed a realistic start point. This search identified 32 papers relating to the difficulties clinicians have with the determining of when a patient may be entering the dying phase. Following this a hand search was also conducted. This was undertaken in five journals; the “European Journal of Palliative Care”, “Journal of Pain and Symptom Management “, “International Journal of Palliative Nursing”, “Palliative Medicine” and the “End of Life Journal”. This search identified one paper which was duplicated in the database search.

2.4 Literature Relating to the Determining of the Dying Phase

The following areas were consistently identified by various authors as potentially assisting or hindering clinicians when they are attempting to recognise irreversible dying.

2.4.1 Effectiveness of the clinicians.

Several authors highlighted how ineffective medical teams tended to be when attempting to determine the irreversibly terminal phase of life. This appeared to be the case even when the clinician took into consideration clinical survival predictors in order to ensure improved prognostication in the patient who had a longer life expectancy.

In order to improve care for the dying in the last few days of their lives it is imperative that these patients are identified early but the questionnaire

undertaken by Tanneberger et al (2002) informs us that the majority of clinicians tend to over-estimate life expectancy. This study considered whether errors in determining prognosis for terminally ill patients decreased as the qualification of the doctors increased. Findings would seem to suggest that it is possible that doctors who were more highly qualified were better at making decisions about prognosis. The over-estimation of life expectancy between those with lower qualifications compared with those with higher qualifications dropped from 63% to 39%. However it is not clear whether this is due to the higher qualification per se or whether other factors such as experience or place of work were also relevant and potentially skewed the numbers. The authors also suggested that doctors tend to use the more tangible measures in order to determine prognosis, such as site and spread of tumour. This would suggest that doctors regard these as more accurate gauges. Interestingly Tanneburger et al, 2002) state that patient symptoms should have a greater influence on this judgement although it is not clear how they came to this conclusion. They also asserted that the determining of prognosis for patients should be based on proven indices rather than intuition but did acknowledge that there are limits to this as a possibility. Given the same diagnosis and severity of disease it is probable that two different patients would respond to treatment in completely different ways. However, despite these concerns, it must be acknowledged the experience levels of the clinician may be relevant to this study.

The 269 patients that the 8 doctors were assessing in this study all had a cancer diagnosis and therefore there is also the potential that these results could differ when considering those patients with other life limiting diagnoses. This study also

examined the accuracy of doctor predictions when patient's had a possible prognosis of up to four months and therefore it is possible that these findings would differ when a shorter prognosis is being considered.

Vigano et al (2000a) in their prospective cohort study of 227 patients explored what measurements could be used once a patient had been diagnosed as terminal in order to predict length of life left to them. Once again they were examining those patients with a predicted survival of six months and therefore it might not be possible to extrapolate these findings to those whose life expectancy is much shorter. The authors did find a potential link with diagnosis, suggesting that a cancer diagnosis follows a clearer trajectory. The study indicated that clinical measurements such as serum levels and lymphocyte count could also have some bearing on this recognition process.

Christakis et al (2000) in their study of 343 doctors who provided survival estimates for 468 terminally ill patients reviewed the accuracy of the determining of the dying phase in their prospective cohort study. This paper once again confirmed previous findings that doctors tend to be inaccurate when predicting length of survival of patients. The majority of the doctors were overly optimistic, over-estimating survival by a factor of 5.3. However, they do acknowledge that none of the doctors participating in this study were specifically trained in end of life care. The authors also noted that the doctors in the upper quartile of practice experience were the most accurate.

Three further papers (Ellershaw et al 2003b; Murray et al 2005; Roberts 2005) explored the determining of the timing of treatment pattern changes in order to reflect that the patient was dying, also stating that when physicians attempt to prognosticate about expected survival of their patients they are nearly always wrong. In support of this they cite previous studies that identified that disease trajectories, particularly those associated with non-cancer diagnoses, are difficult to predict as they tend to follow the pattern of an acute deterioration followed by a period of stability. This makes it difficult to decide which episode of acute deterioration is likely to result in irreversible dying. They reinforced the findings already referred to, that physicians will tend to be overly optimistic about any prognosis. Murray et al (2005) reviewed data from previous studies that they had undertaken in order to identify differing trajectories for differing diseases which may assist in the recognition process.

This argument was further supported by Chow et al (2001) who undertook a systematic review of thirty-one publications which reviewed clinical prediction or prognostic factors. This once again confirmed that clinicians tended to be overly optimistic when trying to provide a prognosis for survival but also argued that clinicians tend to improve in this ability once they knew the patient and were able to observe the speed of their deterioration. The authors also stated that looking at the performance status of the patient tended to improve accuracy. There are limitations to the usefulness of this paper as it is not clear whether or not the experience levels of the clinician may have varied between the various papers being reviewed.

In their systematic review of eight studies Glare et al (2003) again identified that clinicians were overly optimistic when giving patients a prognosis with only 25% of doctors being accurate to within 1 week and 43% within 2 weeks. They identified that doctors tend to be more accurate in the determining of irreversible dying when the patient had a poor performance status. These studies were more globally spread, 50% of them being in the United Kingdom and the other half spread through Europe and America. The authors acknowledged that the review could be seen as flawed, as there were wide variations of experience amongst the clinicians in the various studies.

2.4.2 Possible Clinical Indicators

A further factor identified in the literature review was that of the physical symptoms exhibited by the patient when they were approaching the dying phase.

Jack et al (2003) explored the perceptions of nurses regarding the impact of implementation of the Integrated Care Pathway for the Dying in a hospital setting during their process of interviews. The issues surrounding the difficulties nurses face when determining the dying phase were not mentioned specifically in this paper but it was stated that the use of a care pathway for the dying could facilitate the care provided to the patient dying in their own home. The authors acknowledge the criteria that Ellershaw (2001) developed for the determining of the dying phase which is the presence of two out of four of the following criteria, these being that the patient is

- bed bound
- semi-comatose

- only able to take sips of fluid or no longer able to take fluids
- unable to take oral medication

and only then should the Liverpool Care Pathway for the Dying be implemented. However there is no examination of these criteria in this paper as to their validity or whether there are possibly any other indicators that could prove to be more accurate or useful in this decision making process. This qualitative study used focus groups in an attempt to identify the perceptions of the nurses who were using this pathway when caring for a dying patient. This method has benefits in that the group members can trigger ideas from each other. However there may also be the risk that the quieter members of staff may not have been heard. It is not clear whether or not this potential issue was addressed by the authors.

The physical assessment of a patient when determining the point at which the irreversible dying phase has potentially been reached was also explored and confirmed as useful by Chuang et al (2004). Their prospective cohort study considered the possibility that the severity of the symptoms a patient experienced may increase as death approaches. The symptoms that they found to be of significance in this context were dyspnoea ($P= 0.002$), tiredness ($P<0.001$), anorexia ($P<0.001$) and vomiting ($P=0.001$).

Yun et al (2001) in their prospective cohort study concentrated on a survival period of weeks rather than days in their study examining patients with a cancer diagnosis. In this study they reviewed 91 cancer patients and found that severe anorexia, severe diarrhoea and mild confusion can all three be predictors of poor survival.

The prospective cohort study performed by Pocock et al (2006) and the validation of a risk score by Rassi et al (2006) also dealt with the clinical symptoms the patient exhibited but, again, focussed on the accuracy of clinical prediction in specific diseases only. Both of these studies dealt with a comparatively long prognosis for the patient (between two and nine years). Pocock et al (2006) reviewed 7,599 patients with heart failure finding that the risks for the likelihood of death being the outcome increased in those aged over 60 years and that if these patients had been previously admitted within the last six months then their likelihood of dying soon increased from 52.7% to 73%. They also found that a low diastolic blood pressure indicated an increased risk, rising 11% for every 10mm Hg drop.

There were a further four papers which focused on the symptoms exhibited by patients as they approached the last few days of life confirming that physical assessment may have a role in the recognition of the irreversibly dying patient and the need to review the focus of a treatment pattern. Plonk and Arnold (2005), in their systematic review, identified that there may be six areas worth considering when attempting to recognise that a patient is dying, these being:-

- decreased communication near death
- anorexia and cachexia
- breathlessness
- accumulation of respiratory tract secretions
- physical pain
- terminal delirium.

Although the authors describe this paper as a systematic review there is little evidence of an extensive search strategy. They appear to have used only one database, MEDLINE, and do not inform us of the final number of relevant studies identified for inclusion in their review. They appear also to have considered the views of medical staff only. It would appear that no other health professionals were considered when conducting this study. These issues may reduce its reliability.

Moneymaker (2005) also identified many of the factors already mentioned but added that in the last few days of life other indicators could include:-

- a sudden but short lived improvement in the patient's condition
- a colour change to the extremities
- mandibular breathing
- eyes unfocussed combined with a sense of vacancy.

This paper was not primary research, but guidelines presented as a list of symptoms likely to be present from two weeks prior to death up to imminent dying. Although thought provoking and a possible indicator of potential factors to be considered there was no evidence base supporting any of the statements made.

Barham (2002) in her discussion paper confirmed many of the earlier suggested symptoms such as breathing patterns as potential indicators but also added that anorexia, conscious levels, confusion and increasing sleepiness may be signs

that the end of life might be approaching. This paper, again, did not involve any primary research.

The clinical factors which have been identified in the above papers as useful in recognising that patients are approaching the end of their lives were also supported by Gbenga (2009) and Morrow (2009) who, in their discussion papers both listed symptoms exhibited by a dying patient. These were:

- the body temperature lowering
- low blood pressure
- weak pulse
- increased perspiration
- colour changes, breathing changes
- increasing weakness
- anorexia
- restlessness
- and reduced consciousness levels.

Gbenga (2009) also supported Moneymaker's (2005) finding that there can be a sudden but short lived unexpected surge of energy from the dying patient. All of these factors confirm the findings reported earlier in this literature review.

Vigano et al (2000b) in their systematic review of 22 studies confirmed that there is a value in the assessment of the performance status of the patient being amongst the prognostic factors for length of survival for the terminally ill. The authors also identified that clinical prediction, the presence of cognitive failure,

weight loss, dysphagia, anorexia and dyspnoea all were factors when trying to prognosticate dying. They also stated that a diagnosis of lung cancer still indicates a low probability of survival. An abnormal pulse was also identified as a potential factor to be taken into consideration.

2.4.3 Determining the need to change the focus of care

The importance of the development of a tool in order to aid clinicians in the determining of the irreversible dying phase has been explored in many studies when attempting to determine that the time is appropriate to review the treatment pattern of the dying patient

The use of a tool for clinicians to help in this process was considered by Morita et al (2001) in their prospective cohort study. In this study conducted in two hospices they found that the recognition of the dying phase by doctors was more accurate if they had a tool to follow. They compared a group of doctors (n= 150) using their clinical skills only in order to determine the irreversible dying phase, to a second group of doctors (n= 108) on a different site who utilised the Palliative Prognostic Index as a tool to assist with the determining of dying. The study findings suggest that the use of this tool did improve the accuracy of prediction of length of survival by doctors (from 58% to 77%). In order to reduce the risk of contamination of one group of doctors by the other, they performed each study on different sites.

It is possible that their findings may have been skewed as a result of a lack of clarity regarding the selection process of the participating doctors. It is possible

that they may have had very different levels of experience or qualification which could account for these results, neither of which was reported by the authors. A further area of concern is that it was not made clear at what stage of their illness the patients were. It is possible that some patients were further advanced in their disease progression. It is also not clear whether this study was exploring factors providing a prognosis that may be weeks to months, or limited to identifying the last few days of life.

Vigano et al (2000a) in their prospective cohort study of 227 patients with advanced cancer as discussed earlier in section 2.4.1 explored what measurements could be used once a patient had been diagnosed as terminal in order to predict length of life left to them. The study identified no link with the performance status of the patient in this process, measured by using the Karnofsky Performance Status and Edmunton Functional Assessment tools.

Glare et al (2003) in their systematic review of eight studies described in section 2.4.1 stated that doctors tend to be more accurate in the determining of irreversible dying when the patient had a poor performance status which they measured using the Karnofsky Performance Status.

The observational study by Bennett et al (2000) explored how the patient's physical function may be used as a predictor in determining that there has been an irreversible change in the patient's condition. The researchers used a modified Barthel Index which scores 10 activities of daily living. The higher the score the more independent the patient is. This then can potentially be related to a good or

poor prognosis. The authors also identified that the rate of change of the patient's condition was a more successful measure as an indicator of survival rather than the more absolute measures. However, there are no details regarding sample size which could reduce the validity of this study.

A concern with the use of tools is that several of these rely on the self-reporting of symptoms. Several studies suggest that patients are likely to under report the severity of any symptoms that they are suffering (Dein, 2005; Turk et al 1999) and therefore the accuracy of some of the data collected may be suspect. It would be very difficult for a patient in the last days of life to complete these tools as they are so weak and debilitated and therefore, once again there is reduced likelihood of it being a suitable tool for the determining of when a patient is entering the last few days of life.

All of these tools have been validated for the measurement of the severity of illness of the patient rather than as a means of helping to recognise when a patient is irreversibly dying.

However, as Murphy (2011) suggests it is possible that, because the decision-making process for determining that someone is irreversibly dying is very complex there may be no one single diagnostic tool capable of determining impending death.

2.4.4 Attitudes of clinicians toward dying

A further factor that needs to be considered is whether or not the attitudes of the attending clinician towards caring for the dying patient could in itself impact on the process of determining the need to change a treatment pattern when it has been recognised that a patient is irreversibly dying.

The attitudes and opinions of doctors and nurses can impact hugely on both patients and their families (White et al, 2000). Leadbetter et al (2010), in their report on how the public would like to see their end of life care designed state that, at times, it is conceivable that there is either collusion with or avoidance of difficult conversations with families by clinicians. That is, the clinical team consider that a patient may be irreversibly dying but they avoid having that conversation with the patient and their family. The authors also state that there could be issues with the medical philosophy of “cure at all costs”; even when a patient decides that they wish to die the system strives to keep them alive against their will. In order to identify this information they undertook an on-line survey with 2,127 adults and focus groups with hospice staff, hospital staff, members of the public and the dying. They also undertook observational studies using the ethnographic approach in hospices and care homes and finally they interviewed bereaved carers and academics.

The factor of avoidance is also supported by Garrett (2000) who stated that accepting our own vulnerability around the issues of death and dying as clinicians, can be essential in order for us to be able to relate with patients and their families who face this situation. The author suggests that due to this fear,

which she felt was widespread amongst clinicians, there was the potential risk that clinicians would try to avoid these patients as it could be painful for the clinician themselves to become involved.

The fact that attitudes could also potentially relate to the expertise of the clinician was explored by Mallory et al (2006) in their review. They reported that many junior nurses struggle with issues concerning caring for the patient who is dying and may be uncomfortable when asked to talk to the family of these patients. These authors also highlighted the fact that this reluctance can result in the isolation of the patient and the avoidance of talking to these families by clinicians generally. They state that this would appear to be less of an issue as the experience levels of the clinician increases resulting in an expediential increase in their confidence levels.

Rousseau (2001) also informs us in his review that there could be occasions when caring for the dying when physicians themselves avoid facing the fact that the patient is dying. The author states that clinicians may continue to offer inappropriate treatment that may prolong life but in effect will only prolong suffering, rather than address their feelings of incompetence when faced with this scenario. He also discusses the concern that doctors feel that they have failed if a patient dies. The author states that in this situation it would appear to be easier for clinicians to continue with inappropriate treatment rather than confronting the situation honestly. This could then lead to aggressive treatments continuing inappropriately or indeed, the patient being completely abandoned. This concern was also supported by Bardy (2003).

The importance of the attitude of the clinician when determining when it was time for the clinician to change the treatment plan was further complicated by Wanrooij (2007) in her commentary when she identified that there was the possibility that there could be an issue with perceptions varying between clinicians and their patients. She found that it is possible that what the health care practitioner sees as a good death does not necessarily have the same meaning for the patient. This would suggest that the clinician must be aware of how their own beliefs and values can colour their decision-making processes and ensure their decisions reflect the needs of the patient and not their own.

Vejlgaard et al (2005) undertook a cross-sectional survey exploring the attitudes of doctors and nurses (n=347) in Denmark when caring for the dying. They identified that there was more of a tendency for nurses to reflect on existential issues and to consider the feelings this raised for them (80% v 63%). They also found that clinicians who worked in the community setting (as opposed to the hospital) tended to feel more positive about working with the dying. However, we are not provided with the statistics to support this finding.

This emphasises that there is the potential that the care setting could have an impact on the attitude of the clinicians. This was supported by Walker et al (2010) who conducted their study on the Intensive Care Unit and found that nurses working in this environment found that they needed to prompt doctors to withdraw treatment. They also suggested that there was a frustration for the nursing staff when the decision that a patient was dying remained with the senior doctor. It is possible that this could result in conflict between the two professions with the one

having the authority to make the decision whilst the other has the responsibility to then implement that decision.

2.4.5 The Role of Clinical Experience

An area identified earlier is the possibility that the experience levels of the clinician may have a bearing on the clinician's ability to determine the irreversible dying phase of a patients' life.

Tanneburger et al (2002) in their study of 269 patients being assessed by 8 doctors stated that the clinical estimation of an end of life prognosis required a greater level of experience combined with specific end of life care training. Mallory et al (2006) also argues attitudes of nurses caring for the dying can be improved with clinical experience of caring for the dying.

2.5 Summary and Conclusions

In summary, most of these papers, although of some relevance when clinicians are attempting to recognise the irreversibly dying phase do not address the question of what factors influence them when they are attempting to determine when the patient is irreversibly dying. The majority of studies related to a prognosis of weeks as opposed to hours or days; the crucial factors used by clinicians may or may not differ over these two time periods and the tools being used to assist are currently only validated for the identification of serious of illness, not in the recognition of irreversible dying. It has been made clear by this review however, that unless clinicians can improve the recognition of the patient entering the last few days of life there is a risk that the care of the patient could

be compromised as inappropriate interventional treatment might be continued and families could be left unprepared for the inevitable.

It is possible that some of the factors which have been identified may prove to be of relevance within the proposed study, such as the physical symptoms presented by the patient (Yun et al 2001); increasing severity of symptoms (Christakis et al 2000); decreased communication from the patient, anorexia and cachexia, breathlessness, respiratory secretions, pain and delirium (Moneymaker 2005; Plonk et al, 2005); restlessness and agitation (Moneymaker 2005); sudden, short lived improvement, a colour change to the extremities, mandibular breathing, eyes unfocussed and a sense of vacancy (Moneymaker, 2005) and the rate at which the patient is deteriorating (Bennett et al 2000). It is important to recognise that this may not be an exhaustive list and clinicians may identify other factors that are more useful to them.

This literature review has highlighted the paucity of evidence surrounding this topic suggesting the need to perform a more systematic review of primary research available in this field in order to identify more of an evidence base (MRC, 2008). This decision is supported by Clarke et al (2003) who state that systematic reviews have been found to facilitate decision-making in areas where either randomised controlled trials have not yet been performed or would be inappropriate.

Therefore the first phase of the study will be a systematic review in order to identify an evidence base. The aim of the proposed systematic review will be to:-

- Identify any factors that research indicates clinicians feel either helps or hinders them when they are trying to determine whether or not it is the right time to change the focus of a pattern of care in response to the fact that the patient is irreversibly dying.

CHAPTER 3

PHASE 1: SYSTEMATIC REVIEW

3.1 Introduction

In order to identify the current evidence base for factors that clinicians found either facilitated or were a barrier to recognising that a patient was irreversibly dying a systematic review of the literature was conducted. This chapter contains a comprehensive account of the process and findings of this systematic review. Specifically, the objectives of the systematic review are presented, followed by a detailed description of the design of the systematic review. Following this the results of the systematic review are presented, and finally a discussion of the implications of the review is provided.

3.2 Objectives of the Systematic Review

The objectives of this systematic review are to:-

- identify any relevant primary research which takes into consideration how clinicians determine that the appropriate time has been reached at which to review the focus of a treatment pattern in order to reflect the fact that the patient is now entering the last few days of life

- Identify whether this primary research also helps to determine how useful and accurate the factors identified are during the process of making this decision.

The systematic review question was designed by determining the population to be considered (doctors and nurses), the intervention (factors clinicians use in this recognition process), the context that the study is taking place in (hospital setting) and the outcome (determining a patient is entering the last few days of life and there is the need to review the focus of the pattern of care being provided). Therefore the question identified that requires exploration in this systematic review is "What factors assist clinical staff to determine dying in an acute hospital?"

3.3 Design

A protocol outlining the processes used for selection of the papers and the proposed method of analysis was developed. The design of this protocol covered:-

- inclusion and exclusion criteria for study selection
- search strategy
- the methods undertaken for study screening
- the appraisal of the quality of the studies
- the methods used for data collection
- the analysis of the data identified in each paper.

3.3.1 Inclusion/ Exclusion Criteria

All research papers were expected to report on a group of human participants, these could be either patients recruited to a study or clinicians involved in the decision making process or review of treatment provision.

The following criteria for inclusion/exclusion were then developed.

Inclusion criteria:

1. adult, human participants
2. primary research but of any validated methodology (qualitative, quantitative or mixed methodology)
3. related in some way to the determining that a patient may be entering the dying phase

Exclusion criteria:

a. studies related to animals
b. studies including children as participants
c. studies relating to Mental Health
d. studies relating to obstetrics
e. reviews or opinion articles
f. development of policy.

3.3.2 Search Strategy

In order to identify primary research papers which identified factors that clinicians felt either helped or hindered them when determining whether a patient may be irreversibly dying, the original study question was reformatted into the PICOT structure (Population, Intervention, Context, Outcomes, Time (Petticrew & Roberts, 2005)). The components of the review question using the PICOT format were identified as follows:-

- Population- Clinicians who have some responsibility in the recognition of the fact that a review of the focus of a treatment pattern may be required as it is thought that the patient may now be irreversibly dying. Any life-limiting illness was included although it was accepted that this may in itself be a factor in the process of this determination.

- Intervention- A change of the focus of a pattern of treatment is either considered and/or implemented because it is determined the condition of a patient is deteriorating and is irreversible.

- Context- Any hospital setting where this decision making process was seen to be taking place.

- Outcomes- The identification of any factors that clinicians felt either helped or hindered them when they were trying to determine whether or not to change the focus of a pattern of treatment being provided to a patient from a more aggressive style of management to palliative care.

- Time- The time period the literature search covered was limited to a period between the year 2000 and present day in an attempt to identify the most up to date and therefore the most relevant primary research. The Cancer Plan was released by the government in 2000: this is the first document that focussed on the needs of the dying patient and the importance of delivering quality care and therefore was felt to be a realistic start point.

Various search terms were identified. This was achieved by identifying any possible alternative words and also utilising the “explode” capability of the search engines. Test strategies were assessed by doing pilot searches and checking the relevance of the articles that the strategy then identified. Based on this testing various search terms and key words were used, rejected and added to. Eventually, amongst the terms identified for the final strategy were; “Health Care Professional”, “clinician”, “recognise”, “determine”, ”palliative”, “end of life”, “dying” and “futility” (See Table 3.1).

Table 3.1 Search terms or equivalent MeSH headings used for the Systematic Review

1. Health Care Professional;
2. Clinician;
3. Nurses;
4. Doctors;
5. 1-4/ or;
6. Behaviour;
7. Approach;
8. Decision making;
9. 6-8/ or;
10. Recognise;
11. Determine
12. Factors;
13. Techniques;
14. 10-13/ or;
15. Palliative;
16. End of life;
17. Dying;
18. Futility;
19. Terminally ill;
20. Prognosis;;
21. 15-20/ or;
22. 5 and 9 and 14 and 21

5, 9, 14 and 21 denote search terms listed were combined utilising the Boolean term OR between them e.g. meaning the database searched “Health Care Professional” OR “Clinician” OR “Nurses” OR etc. which provided results of any databases containing any of these terms. 22 indicates that the results of the searches conducted in5, 9, 14 and 21 were combined utilising the Boolean AND resulting in databases providing results containing items from each search group e.g. a database item including reference to “clinician”, “decision making”, “determine” and “dying”

MeSH, medical subject headings

The search was initially performed in September 2012 using the COCHRANE, MEDLINE, CINAHL, PROQUEST and EMBASE databases and Ovid search engines. This search was then repeated in September 2013 in order to identify whether or not any further relevant primary research papers had been published. An alert was set up on these databases to inform the researcher of any relevant new publications between these dates in order to ensure that all the most recent literature was identified. These searches used a combination of free text and MeSH terms as identified in Table 3.1. The various terms identified in each PICOT section were initially combined using the Boolean operators “OR” and then each PICOT section was combined using the Boolean operator “AND”.

A hand search was conducted of five journals; the European Journal of Palliative Care, Journal of Pain and Symptom Management, the International Journal of Palliative Nursing, Palliative Medicine and the End of Life Journal. These were checked by the principal researcher for any primary research papers of relevance to the question identified. These journals were chosen as they focus in particular on the provision of care at the end of life.

Reference lists from the final research papers identified were also reviewed for possible relevant research that could be included in this systematic review. This process conforms fully with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al, 2009).

3.3.3 Study Screening

Prior to undertaking the screening of potential research papers identified by the search, it was necessary to develop specific questions which would assist with the review. This would help to ensure that only those papers appropriate to this review were selected. Two questions were decided on following discussion with the researcher's supervisors; firstly, "What factors influence clinicians to change treatment patterns?" and secondly, where applicable, "How useful and accurate are these factors?" These questions were used for reference purposes whilst the screening of the papers was taking place in order to try and ensure that the researcher remained focussed on the requirements of the systematic review and was not distracted by papers that were "interesting" but not directly relevant.

Once the full text papers had been accessed one of the supervisors reviewed them independently in order to reduce the likelihood of bias on the part of the primary researcher. Papers meeting the following criteria were included:

- Match the PICOT criteria
- Address the study screening questions
- Report as primary research
- Conducted in any country but published in a peer reviewed journal in English
- Recruit adult participants (over 18 years).

Once these papers had been identified the following exclusion criteria were applied:

- Any duplicates
- Any interventions deemed inappropriate in the context of this study
- An inappropriate sample of participants
- An inappropriate type of study (i.e. not primary research).

Reviews (i.e. not primary research) were excluded in an attempt to reduce the likelihood of the duplication of evidence and also to ensure that the systematic review findings were evidence-based.

Following this the inclusion criteria were applied to the remaining papers as described in section 3.3.1.

3.3.4 Method of Appraisal of Selected Studies

If the researcher felt there was any uncertainty regarding whether or not to include a research paper this was resolved by the supervisors also reviewing the paper and discussing these concerns with the researcher and then coming to an agreement regarding its quality and applicability.

Quantitative methodologies are seen as providing an accurate description of reality (Marks et al 2004). Qualitative methodologies however, are designed in order to understand the meaning that individuals give to phenomena (Cresswell et al, 2007). The question posed in this study, “What factors assist clinicians to determine dying in an acute hospital?” is likely to identify research papers which use both of these methodologies and therefore the assessment of quality needed to take this into account. Assessing the quality of research papers specifically

dealing with qualitative research has triggered much debate resulting in limited consensus about the best methods of assessment (Oakley, 2000; Spencer et al, 2003). The decision was therefore made to evaluate all papers using the criteria developed for this purpose by Kmet et al (2004) who developed two critical appraisal scoring systems: one for quantitative studies and a second for qualitative methodologies. This development was driven in part by their own experience when they sought to conduct a systematic review in order to identify multiple social, ethical and legal issue; they found there was no tool available that could be used across a range of research topics and research designs. They also acknowledged that it would not be feasible to develop a single scoring system that would robustly appraise all methodologies thus the development of these two sets of criteria assessment. This enables the relative methodological quality of any identified research papers using robust methodologies to be assessed. Kmet et al (2004) suggested that a cut off summary score of between 0.55 and 0.75 would result in the identification of robust research; a cut-off point for this study was therefore set at 0.70 in order to ensure that only the most robust of studies were included in the review.

3.4 Results from the Systematic Review

3.4.1 Research Papers Identified

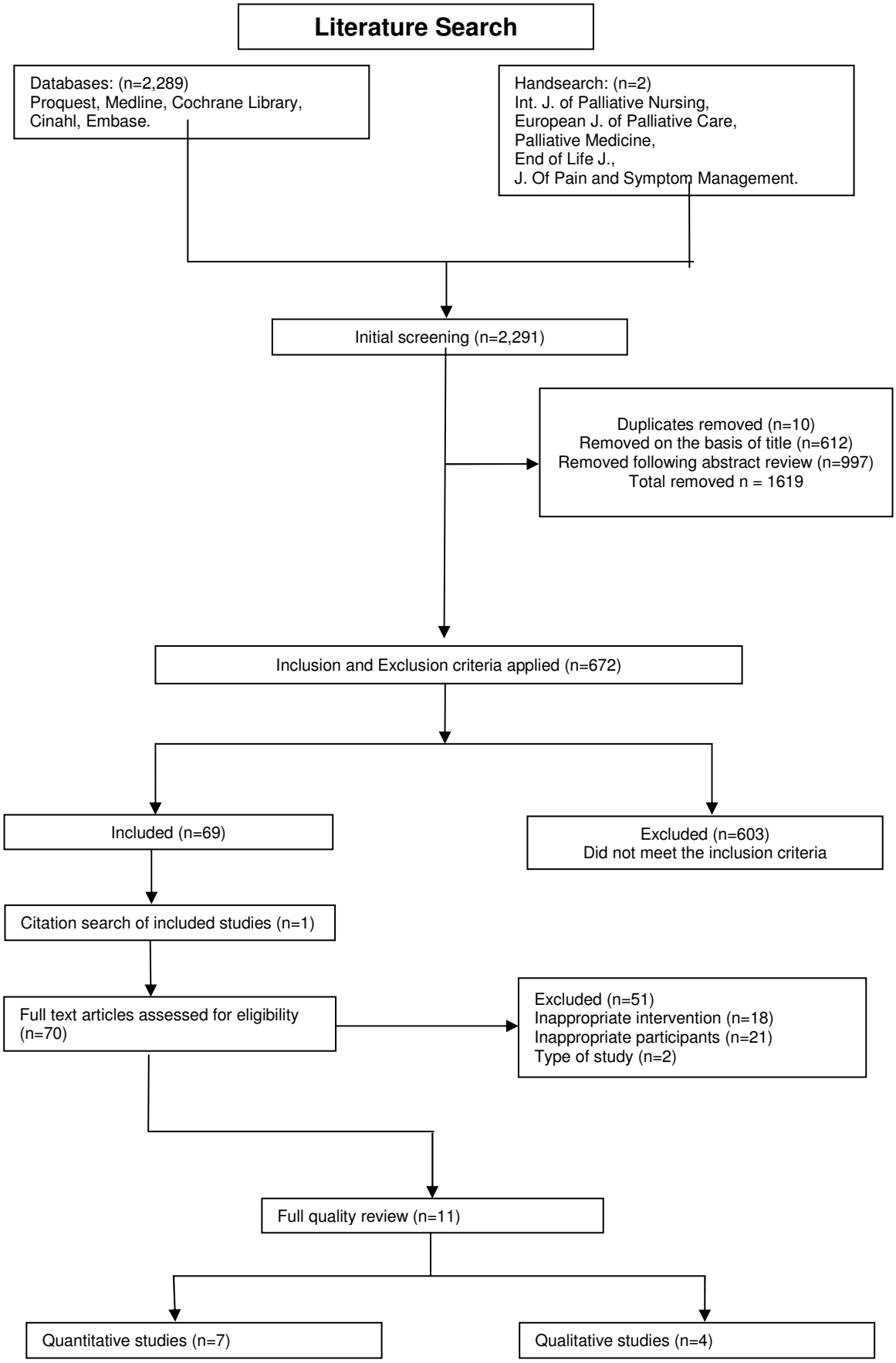
The initial database search identified 2,289 articles in total relating to the difficulties clinicians have with determining when to change from aggressive treatment to palliative care, when treating patients in the acute setting (CINAHL n=31, Cochrane library n=794, EMBASE n=773, Medline n= 581 and

PROQUEST n=110). The hand search also conducted at this time resulted in the identification of a further two potentially relevant research papers.

Once these papers had been identified and duplicates removed (n=10) the titles and abstract were reviewed and assessed for their relevance to this systematic review by the primary researcher. In order to assist in this process the two questions “What factors influence clinicians to change treatment patterns?” and secondly, “How useful and accurate are these factors?” were kept in front of the researcher in order to ensure that the focus on the question in hand was maintained resulting in 672 studies for review. The inclusion and exclusion criteria were then applied which excluded a further 603. One study was identified from the citations of the identified studies and was included. This resulted in 70 potentially relevant papers requiring full text study appraisal (see Table 3.2).Once this had been undertaken 11 papers were identified as potentially being appropriate for the full systematic review (see Table 3.2).

These 11 papers were then appraised using the assessment criteria developed by Kmet et al (2004).

Table 3.2 Search Strategy for the Systematic Review



3.4.2 Appraisal of Papers

The Kmet appraisal tool consists of a set of 14 questions for quantitative papers and 10 questions for qualitative and mixed methods papers.

Appraisal of the quantitative papers

Once the primary researcher had scored these papers using the Kmet appraisal tool they were re-scored separately by a second reviewer in order to reduce the likelihood of bias (see Table 3.3), resulting in scores ranging from 0.7 to1 with a mean score of 0.85. Hence all papers were retained in the systematic review

Table 3.3 Appraisal of quantitative studies using Kmet criteria

Checklist	Esteban et al (2001)	Frick et al (2003)	Harihara n et al (2003)	Le Conte et al (2010)	Mosenthal et al (2008)	Terra (2006)	Vigano et al (2000a)
Question/ objective clearly described?	2	2	2	2	2	2	2
Study Design evident and appropriate?	2	2	1	2	2	1	2
Method of subject/ comparison group selection or source of information/ input variables described and appropriate?	2	2	2	2	2	1	2
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	2	2	2	2
If interventional and random allocation was possible, was it described?	NA	NA	NA	NA	2	2	NA
If interventional and blinding of investigators was possible, was it reported?	NA	NA	NA	NA	NA	NA	NA
If interventional and blinding of subjects was possible, was it reported?	NA	NA	NA	NA	NA	NA	NA
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/ misclassification bias? Means of assessment reported?	2	2	2	2	2	1	2
Sample size appropriate?	2	2	2	2	2	1	2
Analytic methods described/ justified and appropriate?	2	2	2	2	2	1	2
Some estimate of variance is reported for the main results?	1	1	1	NA	NA	NA	2
Controlled for confounding?	NA	NA	NA	NA	NA	NA	2
Results reported in sufficient detail?	2	2	2	2	2	1	2
Conclusions supported by results?	2	2	1	2	2	2	2
Summary score	0.95	0.95	0.85	1	1	0.70	1

The summary score for quantitative studies is calculated by determining the total sum of scores, then subtracting it from the total possible sum (28- number of NA x 2), and then dividing the total sum by the total possible sum. Items are scored for the degree that they meet the criteria for each question detailed by the authors of the quality appraisal guidance: 2=yes, 1-partial, 0-no, NA=not applicable.

The inter-rater agreement of the initial scores by item between these papers ranged from 54.30% - 100% (see Table 3.4). The lower percentage was as a result of one outlier (see question 5). This had been caused by misunderstanding of the criteria by the primary researcher who assessed the fact that there was a tool used in the study as being an accurate measure, the quality of this intervention had not been taken into consideration when appraising the study. Therefore this section was re-scored following discussion with the second reviewer. This resulted in close to full agreement of the scores allocated to each criterion.

Table 3.4 Inter-rater agreement by item for quantitative studies

Checklist Item	Agreement for each item (%)
1	100.00
2	100.00
3	100.00
4	100.00
5	54.30
6	100.00
7	88.89
8	100.00
9	100.00
10	100.00
11	100.00
12	100.00
13	100.00
14	100.00

The same procedure was followed in the appraisal of the 4 qualitative papers identified. The scoring was undertaken by reviewing the 10 items as developed by Kmet et al (2004) (see Table 3.5).

The summary scores ranged from 0.70- 0.95 with a mean score of 0.875 hence the studies were all retained in the systematic review.

Table 3.5 Appraisal of qualitative studies using Kmet criteria

Checklist	Barnato et al (2012)	McBride et al (2006)	McCallum et al (2013)	Norton et al (2003)
Question/ objective clearly described?	1	2	2	2
Design evident and appropriate to answer study question?	2	1	2	1
Context for the study is clear?	2	2	2	2
Connection to a theoretical framework/ wider body of knowledge?	1	2	1	2
Sampling strategy described, relevant and justified?	1	2	1	1
Data collection methods clearly described and systematic?	2	2	2	1
Data analysis clearly described, complete and systematic?	1	2	2	1
Use of verification procedure(s) to establish credibility of the study?	2	2	2	0
Conclusion supported by the results?	2	2	2	2
Reflexivity of the account?	2	2	2	2
Summary score	0.80	0.95	0.90	0.70

The summary score for qualitative studies is calculated by dividing the sum of scores by the total possible sum (20). Items are scored for the degree that they meet the criteria for each question detailed by the authors of the quality appraisal guidance: 2=yes, 1= partial, 0= no. For these studies an assessment of this measure as being 'not applicable' is not permitted.

The inter-rater agreement by item between these papers achieved 100% across all items checked (see Table 3.6).

Table 3.6 Inter-rater agreement by item for qualitative studies

Checklist Item	Agreement for each item (%)
1	100.00
2	100.00
3	100.00
4	100.00
5	100.00
6	100.00
7	100.00
8	100.00
9	100.00
10	100.00

3.5 Data Collection and Analysis

In this next section, the process that was followed during the extraction of the data is described alongside the specific characteristics of the studies, identifying differences and commonalities. Finally, an analysis of the findings is provided.

3.5.1 Data Extraction

Data was extracted from each of the papers into a summary table (see Table 3.7) to enable comparison across all the studies. Irrespective of the methodology used in the original study all findings were subject to a thematic review in an attempt to identify commonalities and differences between the papers. They were also assessed across study characteristics which included risks of bias, comparison of interventions identified, methodologies used, geographical origin, limitations identified, participant characteristics, any outcomes identified and finally any themes identified. Each paper was read and re-read with notes being taken focussing on each of the above.

Table 3.7. SUMMARY OF STUDIES DETERMINING WHEN TO CHANGE A PATIENT'S TREATMENT TO END OF LIFE CARE

Reference and country	Aim	Study design	Patient group and sample	Findings
Barnato et al. (2012) United States	Authors explored the norms of decision making regarding the use of life sustaining treatments that contribute to their opposite extremes of end-of-life intensivity of treatment in an intensive care unit.	SSIV, OBS	80 patient observations, 23 staff and 3 family/patient interviews on a LI unit at an AMC. 73 patient observations, 26 staff and 4 patient/ family interviews on a HI unit at an AMC.	Initiation of LST in patients over 65 was similar except for feeding tubes. LI-AMC more likely to use a time limited trial of LST followed by withdrawal. Identified concerns about harm of commission versus omission.
Esteban et al. ((2001) Spain	Authors determined how frequently life support is withheld or withdrawn from critically ill patients, and how physicians and families agree on this decision.	CS	3,498 consecutive patients admitted to 6 Spanish medical- surgical ICUs.	6.6% (should be 6.46%) had therapy withheld or withdrawn 6.31% died in the ICU Age, SAPS11 and length of stay were higher in dying patients who had therapy withheld or withdrawn compared to patients dying despite receiving active treatment. 92.9% of cases the proposal to withdraw/ withhold treatment initiated by the doctor 7.1% proposal initiated by the family 28.3% family not involved in decision making process 9% of patients had expressed a wish to decline life prolonging treatment

Table 3.7. cont SUMMARY OF STUDIES DETERMINING WHEN TO CHANGE A PATIENT'S TREATMENT TO END OF LIFE CARE

Reference and country	Aim	Study design	Patient group and sample	Findings
Frick et al. (2003) Switzerland	Authors assessed the pattern of the prediction of ICU patients' outcome with regard to survival by nurses and doctors	PS (daily prognostic judgement)	547 patients over 18 years admitted to a 6 bedded medical ICU for more than 24 hours over a 1-yr period	79% judgements doctors and nurses agreed. Divergence of judgement occurred more frequently on those who eventually died and those who died in hospital. Those judged differently had higher SAPS 11 scores and a longer length of stay. Very little divergence when diagnosed with unstable angina or MI Divergence when diagnosed with cardiopulmonary arrest, shock, sepsis or septic shock
Hariharan et al. (2003) West Indies	Authors analysed the characteristics of moribund patients in an ICU highlighting dilemmas inherent in treating these patients	CNA	662 patients admitted to ICU over a 3 year period	4.5% were treated aggressively despite a prognosis indicating futility 86.7% of these no effort made to withhold any form of treatment. Age and APACHE 11score was higher in those who died Factors identified as influencing decisions:- Age of patient Legal considerations Family influences Surgeons refusal to accept futility

Table 3.7. cont SUMMARY OF STUDIES DETERMINING WHEN TO CHANGE A PATIENT'S TREATMENT TO END OF LIFE CARE

Reference and country	Aim	Study design	Patient group and sample	Findings
Le Conte et al. (2010) France/ Belgium	Authors described the characteristics of patients who die in ED and the decision to withhold or withdraw life support.	CNA	2,512 patients who died in French/ Belgian ED over a 4 month period.	73.6% patients LST initiated 56.7% patients received palliative care only 78.8% cases decision to withhold/ withdraw treatment made 58.4% cases decision discussed with family 19.9% cases decision made by single doctor
McBride et al. (2006) United States	Authors explored the practice of expert critical care nurses in end-of-life conflicts describing actions taken when nurses thought continued aggressive treatment was not warranted.	NA	21 critical care nurses from 7 facilities in the south-western United States	3 categories identified : Protecting or speaking for the patient Presenting a realistic picture Experiences of frustration and resignation.
McCallum et al. (2013) Australia	Authors described the provision of EoL care in an open high-dependency unit	SSIV	Purposive sample of 5 RNs from a pool of 25 working on the unit for more than 12 months who had cared for a dying patient.	3 themes identified:- Nurse as protector Conflict of care Peace and quiet
Mosenthal et al. (2008) United States	Authors explored whether early, structured communication in ICU would improve EoL care.	CNA	Baseline year- 286 trauma admissions to ICU. Intervention period- 367 trauma admissions to ICU	DNR orders similar in both groups 37% in baseline and 24% in intervention group had withdrawal of LST. Timing of both above earlier in intervention group Shorter length of stay in intervention group Family meeting in 62% of deaths in baseline group and 60% in intervention group with no difference in timings. Discussion of goals of care increased from 4% to 36% of patient days

Table 3.7. cont SUMMARY OF STUDIES DETERMINING WHEN TO CHANGE A PATIENT'S TREATMENT TO END OF LIFE CARE

Reference and country	Aim	Study design	Patient group and sample	Findings
Norton et al. (2003) United States	Authors examine and describe communication difficulties from the perspective of families who experienced conflict with clinicians regarding withdrawal of LST.	SSIV	74 family members who participated in the decision to withdraw LST 20 of whom reported conflict (27%)	Identification of unmet communication needs;- Timely information Honesty Clarity Need for the clinician to be informed Need for the clinician to listen
Terra, S.M. (2006) United States	Author examines the concept of futility Examines available predictive scoring systems Determines the applicability of these systems to their rural population	CNA	70 patients 40 who had died plus 30 randomly selected who had been discharged.	APACHE II scores calculated at time of admission are predictive of mortality in this population
Vigano et al (2000a) Canada	Authors explored clinical survivor predictors in patients with advanced carcinoma	PS	227 adult patients with terminal cancer of the lung breast or intestinal tract in one hospital.	64.8% of patients were still receiving cancer treatments in the terminal phase. 68.7% of terminal patients experienced moderate to severe fatigue 62.1% of terminal patients experienced anorexia 68.3% of terminal patients experienced impairment of well-being Variables more discriminant for worse survival in the univariate analysis ($P<0.01$) were lung cancer; liver metastases; more than five cancerous lesions; moderate to severe co-morbidities; cognitive impairment; weight loss; lower performance status; and abnormal blood test results.

Eol, End of Life; SSIV, semi-structured interviews; OBS, observation; LI, Low Intensity; AMC, Academic Medical Centre; HI, high intensity; LST, Life Sustaining Treatment; PAS, physician assisted suicide; VE, voluntary euthanasia; CS, cohort study; ICU, intensive care unit; PS, prospective study; MI myocardial infarction; CNA, Case note analysis; ED, emergency department; NA, narrative analysis; RN, Registered Nurse; DNR, do not resuscitate

3.5.2 Study Characteristics

Methods used in the quantitative studies identified for review were:

- Cohort study (Esteban et al (2001), Vigano et al (2000a))
- Survey (Frick et al 2003)
- Case note analysis (Hariharan et al (2003), Le Conte et al (2010), Mosenthal et al (2008) and Terra (2006)).

Methods used in the qualitative studies were

- semi-structured interviews (Barnato et al, 2012; McCallum et al, 2013; Norton et al, 2003)
- narrative analysis (McBride et al,2006; Barnato et al,2012)
- observation (Barnato et al,2012).

Location and participants

Of these eleven studies, five were conducted in the United States of America, two of these were qualitative and three quantitative. A further three of the studies were conducted in Europe, one in Australia, one in Canada and one in the Caribbean.

The characteristics of the participants in the studies also varied. Of the eleven papers identified eight used patients as their participants (Barnato et al 2012, Esteban et al 2001, Frick et al 2003, Hariharan et al 2003, Le Conte et al 2010, Mosenthal et al 2008, Terra 2006, Vigano et al, 2000a). Of these one was a qualitative study and also included interviews with staff (Bernato et al 2012).

Of the three remaining qualitative studies two used nursing staff as participants (McBride et al 2006, McCallum et al 2013) and the authors of the final study interviewed families who had been involved in the decision whether or not to withdraw life sustaining treatments (Norton et al, 2003).

The settings for the studies also varied slightly. Of the eight studies that selected patients as their participants six collected data in the Intensive Care Unit setting (Barnato et al, 2012 Esteban et al 2001, Frick et al 2003, Hariharan et al 2003, Mosenthal et al 2008 and Terra 2006), one the emergency department (Le Conte et al 2010) and one as monthly follow-up as oncology out-patients (Vigano et al, 2000a). The studies undertaken by Le Conte et al (2010) and Vigano et al (2000a) were deemed relevant to the review question as the settings were acute hospital based.

3.5.3 Risk of Bias

Bias occurs when either an unknown or unacknowledged error is created during the design of the study. This can occur at any phase (Pannucci et al, 2010). Therefore it is necessary that both qualitative and quantitative studies are reviewed in this context. The assessment of bias varies across methodologies as quantitative methodologies aim to produce generalisable research and qualitative methodologies aim to generate hypotheses for further investigation (Krefting, 1991). Whilst no design is exempt from bias some are more susceptible than others. In quantitative studies one of the main risks for bias is sample size; if the sample size is too small the results could be influenced by distorted measures caused by unusual characteristics of the participant group. This is less of an issue in qualitative

methodologies as small sample sizes are commonly used in order to generate theory for further research, rather than ensuring transferability (Gbrich,2007).

There are areas in all the studies reviewed that introduce an element of bias (see Table 3.8). Some of these potential bias areas will now be reviewed.

Table 3.8 Risks of bias

Author	**Type of bias**			
	Response	**Participant**	**Data collection/ reporting**	**Researcher**
Barnato et al (2012)			√	
Esteban et al (2001)			√	
Frick et al (2003)		√		
Hariharan et al (2003)			√	
Le Conte et al (2010)	√		√	
McBride et al (2006)			√	
Mc Cullum et al (2003)		√		√
Mosenthal et al (2008)			√	
Norton et al ((2003)		√	√	√
Terra et al (2006)		√	√	√
Vigano et al (2000a)		√		

Response bias

The first area of potential concern relates to the response rates of the research sites or participants in each study. Le Conte et al (2010) had a limited response rate with only 22.8% of all emergency departments approached agreeing to participate. This

could result in a skewing of the data as it is unknown how the patient case-mix in non-responding Emergency Departments might have differed. No details were provided of the characteristics of the Emergency Departments or patient case-mix, which would allow the reader to determine the relevance of this to the study results. This was not an issue identified as a limitation by the authors.

Participant selection bias

The possibility of bias caused by the participant selection process was identified as a potential concern in four of the studies reviewed.

Frick et al (2003) included participants with variable experience levels in their prospective daily prognostic judgement of a patient's eventual outcomes by Intensive Care Unit doctors and nurses. The experience levels of the nursing staff is clear and suggested that a reasonable level of experience was expected if they are to undertake these assessments (ICU certified or a minimum of 2 years postgraduate education (n=30)). The inclusion criteria for the medical team were less clear as convenience sampling was used. The most senior doctor on the unit that day made the decision resulting in ten doctors described as having variable levels of experience making this determination. This discrepancy in experience is not described further so this raises concerns that this potentially could introduce bias. This fact is not acknowledged as a limitation by the authors. This concern is exacerbated by the fact that so many different clinicians are making the judgement daily. This could also possibly skew the results as the opinions of the staff involved could differ greatly.

Terra (2006) gives no explanation for the inclusion and exclusion criteria she used in her study with only patients who died in the intensive care unit being included (n=70) plus 30 patients who had been discharged home (100 in total). This also risks selection bias as no rationale is provided for this decision.

Vigano et al (2000a) acknowledged that their comparatively small sample size (n=227) could have skewed their results as there would be uncertainty as to whether only those with the norm characteristics were being accessed. There are also concerns that the selection criteria for the participants is not robust in that there is little clinical evidence available with which to select the definition for “terminal” patients.

There are also potential concerns in this regard with the study undertaken by McCallum et al (2013). The first of these – small sample size - is acknowledged by the authors, however, the use of a single site was not identified as a limitation. Both of these factors could result in difficulties in reliably being able to draw inferences from the findings as either different participants or different sites could each have resulted in different findings. In effect, the results cannot be generalised because of these factors. There is also a lack of clarity about how the nurse participants initially were selected. The researchers identified a purposive sampling strategy but it is not clear what the criteria were for selection, which again could influence the findings.

Participant selection bias is also a potential concern in the study undertaken by Norton et al (2003). It is unclear how many participants were initially identified or how these were finally selected although we are informed that they had to be recently

bereaved and had been involved, in their perception, in conflict with clinicians regarding the withdrawal of treatment from a family member.

Data Collection/ Reporting Bias

There are also concerns relating to collection bias in the study undertaken by Barnato et al (2012) in that there is some discussion as to the roles of the various authors but there is a lack of clarity as to who performed the interviews. This could have an effect as different researchers could have differing attitudes that could affect the results. It is also stated that three people took field notes but there is a lack of clarity as to how this was managed. We are not informed whether there were any cross over times where more than one person was taking notes potentially resulting in duplication or whether there were set criteria to be observed.

The study undertaken by Hariharan et al (2003) has a potential risk of data collection bias in that it is not made clear who undertook the data collection and analysis.

The data collection in the study by Le Conte et al (2010) was undertaken by a senior physician on each site whose individual skills and experience are not reported. A definition of “senior” in this context is not provided. The likelihood of this bias was not reduced as no independent random checking of the data is reported. There is also the risk that bias may have been introduced as the data collector differed on each site. The data from this study could also have been affected by the fact that on review of the documentation required information was missing from the patient’s records in 3.7% of cases. This again could potentially change the final results of the study.

There are potential concerns regarding the study by Mc Bride et al (2006) in that one researcher undertook all the interviews and also undertook the analysing of the data from these. This could have resulted in the pre-conceptions of the interviewer colouring the findings. There is no account of use of a journal or note taking to counter this risk.

The study undertaken by Mosenthal et al (2008) also had the potential for data collection bias in that there is no rationale provided for the difference in the time periods covered for the comparisons (the second sample included an extra two months for data collection). There is no acknowledgement that this may have affected the results with the potential of a higher number of admissions in these last two months skewing the results.

In the study undertaken by Norton et al (2003) it is not clear who conducted the interviews, whether it was one researcher or several therefore, an assessment of potential bias is difficult to make. This is an issue which could affect the accuracy of the data collected making it difficult to be fully confident in the findings.

The study by Terra (2006) indicates some reporting bias. High APACHE II scores are identified by the researcher as being accurate predictors of death. The author provides a graph indicating the score distribution identifying the higher scores as providing a range for potential mortality. The author acknowledges that she had had no training in the use of the APACHE II Scoring system, which she was using as a tool. There is therefore the potential that the data could have been inaccurate due to inexperience. A further concern is that there would not appear to be any checking of

the data with the author being the sole extractor. There is also the concern that this tool has not been validated for this purpose.

It was identified in the study undertaken by Esteban et al (2001) that there was the potential for data reporting bias. One of the findings reported by the author was that an important factor in the decision to either withdraw or withhold treatment was the likelihood of the patient to leave hospital but the reader is provided with no evidence to support this statement.

Researcher Bias

A final area of potential bias was the risk of researcher bias. In the study undertaken by Terra (2006) the author acknowledges that her aim was to identify if a prognostic scoring system would be applicable in a community hospital. However, only one system was assessed in this context, the APACHE II Scoring system, which she was using as a tool. There is therefore the potential that the researcher may have had preconceptions concerning this that were not addressed.

The studies undertaken by McCallum et al (2003) and Norton et al (2003) both raised some concerns regarding potential researcher bias due to preconceptions. We are informed that an interview guide was designed for use in these studies but we are not informed as to what these prompts were and therefore there may be the potential for some bias in the design. A further concern is raised by the fact that the authors of both studies do not highlight this as a potential concern.

3.5.4 Synthesis of Data

Thematic analysis was used in order to synthesise the findings from both the qualitative and quantitative studies. Whilst this remains controversial, this is a method commonly used in mixed methods research (Mays et al., 2005) in order to identify themes. This method involved the identification of these themes in the studies and the summarising of them under thematic headings. Equal weight was given to these themes irrespective as to whether they were from qualitative or quantitative studies.

3.6 Findings

The review process undertaken resulted in the identification of five recurrent themes. Each of these themes consisted of sub-themes (see Table 3.9). These are presented in greater detail in this section. At the end of the section a critique is provided of changes in themes over time as reflected in the studies.

The first two themes, “Patient Observation” and “Knowledge of the Patient” relate to factors that may influence the decision-making process when recognising that a patient is irreversibly dying. It was evident from the papers reviewed that recognising irreversible dying was, in itself, a means to an end, prompting review of the care management plan for the patient. The themes “Communication”, “Attitudes of the Clinician” and “Use of a Tool” relate to factors that influence decisions when it has been identified that the patient has entered the dying phase.

Table 3.9 Themes identified in studies

Theme	*Sub-themes*	*Reference*
Patient Observation	Conscious level of the patient	Esteban et al (2001), Mosenthal et al (2008), Terra (2006)
	Pain	Le Conte et al (2010),McCallum et al (2013),
Knowledge of the Patient	Diagnosis	Barnato et al (2012),Esteban et al (2001),Frick et al (2003),Hariharan et al (2003), Le Conte et al (2010),Terra (2006), Vigano et al (2000a)
	Response to treatment	Barnato et al (2012),Le Conte et al (2010)
	Age	Frick et al (2003),Hariharan et al (2003), Le Conte et al (2010),Mosenthal et al (2008)
Communication	Multi-professional team working	Le Conte et al (2010), McCallum et al (2013)
	Lack of understanding amongst the family	Esteban et al (2001),Hariharan et al (2003), Le Conte et al (2010), McBride et al (2006),Mosenthal et al (2008), Norton et al (2003)
	Time the clinician has to spend with the family and patient	McBride et al (2006), McCallum et al (2013)
	Difficulty for clinicians when Breaking bad news	Barnato et al (2012), Hariharan et al (2003)
	Patient wishes	McBride et al (2006), McCallum et al (2013)
	Withdrawing treatment	Barnato et al (2012), Esteban et al (2001), Frick et al (2003) Hariharan et al (2003), Le Conte et al (2010), McCallum et al (2013), Mosenthal et al (2008), Terra (2006), Vigano et al (2000a)
Attitudes of the Clinician	Fear (including of litigation)	Barnato et al (2012), Hariharan et al (2003)
	Medical philosophy	Hariharan et al (2003), Norton et al (2003)
	Quality	Frick et al (2003), Le Conte et al (2010), McBride et al (2006), McCallum et al (2013)
Use of a Tool	Advance Care Plan	Barnato et al (2012), Le Conte et al (2010)
	SAPS 11	Esteban et al (2001), Frick et al (2003)
	APACHE 11	Hariharan et al (2003), Terra (2006)
	Karnofsky Performance Scale	Vigano et al (2000a)
	Edmunton Functional Assessment Tool	Vigano et al (2000a)
	Edmunton Symptom Assessment Tool	Vigano et al (2000a)

3.6.1 Patient Observation.

This first theme identified was the role of observing the patient when determining whether or not to change the focus of care. This theme was composed of two sub-themes, the conscious level of the patient and indicators of pain.

The conscious level of the patient was identified in three papers, all of which used quantitative methodologies (Esteban et al 2001; Mosenthal et al 2008; Terra 2006). They all used the Glasgow Coma Scale as a factor to determine the probable survival of a patient and stated that the lower score the less likely it is that the patient will survive. Mosenthal et al (2008) identified this as a standalone factor whilst the other two papers used an outcome prediction tool which included Glasgow Coma Scale measurement.

Two papers identified pain as a factor in the decision making process (Le Conte et al 2010; McCallum et al 2013). How pain was used as a factor to inform the decision-making process in these papers differed slightly with McCallum et al (2013) stating that pain relief is essential and that it is a common symptom in the patient who is dying and Le Conte et al (2010) expanding on this when they stated that the symptom of pain itself can indicate the need to limit any life supporting treatments as it can be an indicator of potential futility.

3.6.2 Knowledge of the Patient

The second theme related to how well the patient was known to the clinician. This theme was sub-divided into three sub-themes: diagnosis, response to treatment and age.

The effect of the patient's diagnosis when attempting to determine the timing of a change in the pattern of care was identified in seven of the studies reviewed. Le Conte et al (2010) stated that the patient's diagnosis can be the principle factor relating to either the withholding or the withdrawing of treatment and Esteban et al

(2001), Frick et al (2003) and Terra (2006) all stated that a diagnosis of a chronic life-limiting illness such as Chronic Obstructive Pulmonary Disease can make this decision easier. No mention was made in any of these papers as to whether the patient or their family were aware of the life limiting nature of their family member's diagnosis.

It was also recognised that a diagnosis of malignancy can be a factor that makes this decision easier (Barnato et al, 2012; Hariharan et al, 2003). Vigano et al (2000a) expanded on this, identifying in their study that if a patient had moderate to severe co-morbidities and also had been diagnosed as being terminally ill with cancer was a discriminant that suggested a worse survival prognosis ($P<0.01$).

The significance of the patient's response to treatment was identified by Barnato et al (2012) and Le Conte et al (2010). These studies had slightly differing focus; Barnato et al (2012) identifying during their interview process that any treatment given must be as a bridge to something, that is, treatment should lead to recovery. Le Conte et al (2010) drilled down into this identifying that in 59.8% of the decisions to withdraw/ withhold treatment in their study the response, or lack of it, to treatment in the first 24 hours was key.

The importance of the age of the patient was identified in four of the eleven studies, all of them using qualitative methodologies. Of these, three stated that age is a factor when clinicians are determining patterns of care provision (Hariharan et al, 2003; Le Conte et al, 2010; Mosenthal et al, 2008). They all identified that the younger patient is less likely to receive a "Do not resuscitate" order or have treatments either

withheld or withdrawn. Frick et al (2003) however, found in their study that age in itself is not a cause for concern when determining patterns of care as this factor did not cause any divergence of opinion between clinicians.

3.6.3 Communication

The third theme identified by the studies was the importance of clear communication. It appears that this theme was a constant for all authors and it contaoned six sub-themes: multi professional team working, lack of understanding amongst the family, time the clinician has to spend with the patient and their family, difficulties for clinicians when breaking bad news, patient wishes and withdrawing treatment.

Multi professional team working was identified in two of the studies reviewed. Le Conte et al (2010) found in an emergency department that in 19.9% of cases necessitating a decision to either withhold or withdraw treatment, this decision was made by a lone doctor. In all other cases there was consultation with other members of the team. McCallum et al (2013) also found that team working created a feeling of safety and security, which was a buffer to the distress that can affect teams when caring for the dying.

The understanding that the family have of the situation that they find themselves in was reported by six authors (Esteban et al, 2010; Hariharan et al, 2003; Le Conte et al, 2010; McBride et al, 2006; Mosenthal et al, 2008;Norton et al,2003). Norton et al (2003) identified that relatives feel that there is a lack of honesty from clinicians when communicating the need for end of life decisions with families. This was supported by the findings of Mosenthal et al (2008) who stated that early, facilitated

communications about a poor prognosis results in more discussion about the goals of care, thus resulting in more timely decision making around end of life care. This is complicated by the findings of McBride et al (2006) who found that frequently families did not understand the implications of the choices they were being asked to make relating to the withdrawing or withholding of treatment. The finding of Esteban et al (2010), that families are often not included in the decision making process (28.3%), was supported by Le Conte et al (2010) who however, identified that this proportion was closer to 41.6%. Hariharan et al (2003) also reminds us that families having unrealistic expectations that are not addressed regarding the prognosis of the patient also reduces the likelihood of inappropriate treatments being withdrawn or can cause them to be commenced inappropriately.

The time clinicians have to spend with the families was reported as a factor by two authors (McBride et al2006; McCallum et al, 2013). Both emphasised the role of the nurse in this: McBride et al (2006) found in their interviews with ICU nurses (n=21) that time is a requirement to ensure that families can be encouraged to accept the futility of aggressive treatment. This was emphasised by McCallum et al (2013) who, in their interviews with five ICU nurses, identified that nurses saw this as specifically part of their role when a family needs support in this type of decision making.

The difficulties that clinicians face when they are breaking bad news to families was reported by two researchers. Barnato et al (2012) found that clinicians would often attribute expectations to families based on stereotypical cultural issues, which were then not corroborated by either observation or interview. This may be a technique used in order to avoid talking honestly to families. Hariharan et al (2003) reported a

further potential avoidance technique in their study when they identified that multi professional team frequently recognised when further aggressive treatment would be futile but no effort was then made to change the focus of the care being provided. Once again, this would have entailed having these difficult discussions with families.

The importance of knowing the patient's wishes regarding their care was reported by McBride et al (2006). The nurses identified that having knowledge of the patient's wishes ensured that they could become a true advocate for that patient. McCallum et al (2013) expanded on this when they found that being able to respect a patient's wishes often provides nurses with a real sense of achievement and is part of preserving that patient's dignity.

The withdrawing or withholding of treatment from patients where further treatment is thought to be futile was reported in nine of the eleven studies. Terra (2006) reported that hospitals are beginning to accept the concept of futility and to transform that concept into clinical practice. However, one of the earliest studies reviewed identified that nurses tend to be more comfortable with this and are willing to consider the change of focus of care earlier than doctors (Frick, 2003). Several studies found that there are factors that can be used to assist with this kind of decision. Amongst these are the age of the patient, any advance directive, diagnosis and futility (Esteban et al, 2010; Le Conte et al, 2010; McCallum et al, 2008; Mosenthal et al, 2008). However, the study undertaken by Hariharan et al (2003) identified that even when it has been identified that further treatment is futile, teams still appear to be unwilling to withdraw treatment. This study was undertaken on a surgical intensive care unit and this may have affected the results of this study with surgery in particular having a

focus on cure. This finding was supported by the study undertaken by Vigano et al (2000a) who identified when recruiting for their study of terminally ill cancer patients that despite this diagnosis 64.8% of those recruited were still receiving cancer treatments. Finally, Bernato et al (2012) state that their study findings suggested that a time limited trial of life sustaining treatment can be helpful when taking families with you on the journey of acceptance of futility.

3.6.4 Attitudes of the Clinician

The fourth theme identified in the studies was that of the attitudes of the clinicians. This theme was made up of three sub-themes: fear, medical philosophy and quality.

The first of these was reported by Barnato et al (2012) in their mixed methods study. During the interview process they identified that clinicians were anxious that they would miss a reversible condition and therefore tended to continue with inappropriate treatments rather than address these concerns. As Hariharan et al (2003) identified, clinicians are reluctant to recognise futility because of fear of litigation. They state in their study that in nine cases there was reluctance to acknowledge futility because of this fear.

The medical philosophy of cure was identified by two of the studies reviewed. The findings of Norton et al (2003) during their twenty interviews with family members showed that families felt that they were not always told the truth by doctors because the doctor's themselves could not accept that the patient was dying. Hariharan et al (2003) expanded on this stating that the concept of an intensive care unit has raised expectations of survival amongst both clinicians and the general public. They also

found that in twelve cases the surgeons' were reluctant to accept the concept of futility largely because futility could be misconstrued as failure.

The role that quality played in determining the need to change the focus of a pattern of care was identified in four of the studies. McBride et al (2006) found in their 21 interviews with nurses that they considered that they have a role in encouraging families to reflect on the quality of life that the patient is enduring when they are considering the need to withdraw treatment. This may relate to the fact that nurses may be more likely to recognise medical futility when relating the prospect of withholding or withdrawing treatment to the patient's likely quality of life than are doctors (Frick et al, 2003; McCallum et al, 2013). However Le Conte et al (2010) also identified in their study that this factor was not strong enough to use as a standalone rationale for the withdrawal or withholding of treatment.

3.6.5 Tools that may assist judgement making when recognising irreversible dying

The final theme identified in the studies was the use of a tool in order to determine the timing of a change in focus of a pattern of care being provided. Six tools were identified in the studies reviewed:-

- Advance Directives
- Simplified Acute Physiology Score 11(SAPS 11)
- Acute Physiology and Chronic Health Evaluation 11 (APACHE 11)
- Karnofsky Performance Status
- Edmonton Functional Assessment Tool
- Edmonton Symptom Assessment Scale

Two of these tools related specifically to the assessment of the severity of a patients illness (SAPS11 and APACHE 11). Neither of these tools have been validated for use in the recognition of irreversible dying. The use of Advance Directives is also limited in its usefulness in this context as this simply provides the clinician with knowledge of the patient's wishes. This was supported by both Barnato et al (2012) and Le Conte et al (2010). Le Conte found that they were only taken into account by 1.9% of participants whereas Barnato et al (2012) found that even when the clinicians were aware of advance directives they were largely ignored.

The SAPS II tool was used in studies by Esteban et al, (2010) and Frick et al, (2003). This tool was designed for use specifically in the Intensive Care Unit. The SAPS II total score is the sum of scores of the worst value for each 12 physiological variables identified within the first 24 hours after ICU admission. The score is then converted into the probability of dying, that is, predicted mortality, by using the model equation. The study undertaken by Esteban et al (2010) used this tool within their study in determining how frequently life support was withheld or withdrawn from a patient being cared for in the intensive care setting. They reported that patients scoring higher on admission were those who would die even with active treatment (median 51 v 45). Frick et al (2003) earlier identified that clinicians were more likely to disagree when predicting patient outcomes where the SAPS II score was high.

The APACHE II tool was identified by two further studies (Hariharan et al, 2003; Terra, 2006). This tool was also developed for use in the intensive care setting in order to identify severity of illness and calculates twelve routine physiological measurements. Low APACHE II scores accurately predict survival but only very high

scores accurately predicted death. Both of these studies identified that a high score using this tool was a good predictor of futility. Hariharan et al (2003) confirmed this in their study results (mean 8.7 v 21.2). Terra (2006) provides a graph suggesting the same results but we are not provided with any supporting statistics in this paper.

Vigano et al (2000a) used three tools to assess prediction of clinical survival in their participant group of 227 cancer patients;

- Karnofsky Performance Status
- Edmonton Functional Assessment Tool
- Edmonton Symptom Assessment Scale

The Karnoksky Performance Status tool attempts to quantify cancer patient's well-being. It considers the patient's general well-being and their ability to function. This measure is used to determine whether they can receive chemotherapy, whether dose adjustment is necessary, and as a measure for the required intensity of palliative care rather than for determining life expectancy. The Edmonton Functional Assessment Tool is very similar in that it measures functional status including some symptoms, but also provides a judgement on the patient's functional performance. This assessment is also more a measure of illness than a tool to determine irreversible dying. The third tool, the Edmonton Symptom Assessment Tool, measures the type and severity of symptoms that the patient is exhibiting on assessment. The researchers found that one factor measured within these tools was relevant when determining a probable worse survival: that the patient was cognitively impaired ($p = <0.01$).

Finally, the studies were compared across time-lines. Of the five studies undertaken between 2000 and 2004 (Esteban et al, 2001; Frick et al, 2003; Hariharan et al, 2003; Norton et al, 2003; Vigano et al, 2000a), three used a quantitative methodology (Esteban et al, 2001; Frick et al, 2003; Hariharan et al, 2003). The four undertaken from 2008 onwards (Barnato et al, 2012; Le Conte et al, 2010; McCallum et al, 2013; Mosenthal et al,2008) were evenly split between these methodologies. The focus of the later studies appears to have shifted from the more measureable evidence to staff perception of concerns in this context.

A further area that has changed over the passage of time is that pre 2008 there was much more of a focus on use of tools (Frick et al 2003; Hariharan et al 2003; Terra et al, 2006). The studies undertaken post 2008 focus more on the withholding and withdrawing of treatments (Barnato et al 2012; Le Conte et al 2010; Mosenthal et al 2008).

3.7 Discussion

The eleven studies that were selected for inclusion in this review were all of high quality, and the variety of methodological approaches indicates the wide range of research in this area. However, the wide range of methodological and theoretical approaches also means that findings could not be combined using meta-synthesis. Instead thematic analysis was used as this is well suited to coping with the diverse types of evidence that were identified (Addington-Hall et al 2007). Findings were fairly consistent across all the studies.

This review adds to current knowledge by revealing several key themes and factors that clinicians use to determine that the patient may be irreversibly dying. This included direct patient observations that can be made, with judgements predicting outcome following these observations. This theme was identified by six of the eleven studies (Esteban et al, 2010; Le Conte et al, 2010, McCallum et al, 2013; Mosenthal et al, 2008; Terra, 2006; Vigano et al, 2000a). The fact that pain and conscious level of the patient can be indicators to the onset of the dying phase was also identified in the findings of the focus group discussions undertaken by van der Werff et al (2012). Pain in particular may be useful as a factor as this was identified as increasing towards the end of life (Bookbinder et al 2001; Forbes et al 2003; Levy, M.M., 2001; Lyness, J.M. 2004; Rutledge et al 2001b).

Knowledge of the patient was also identified as a key component. This was identified in seven of the eleven studies (Barnato et al, 2012; Esteban et al, 2010; Frick et al, 2003; Hariharan et al. 2003; Le Conte et al, 2010; Mosenthal et al, 2008; Terra, 2006). This was surprising in that only one of these studies related to the chronic setting (Terra, 2006); the others relating to the acute care setting which is less likely to identify the patient presenting with repeat admissions therefore less likely to have the opportunity to build relationships with the patient. However, the sub-themes identified here, “Diagnosis”, “Response to treatment”, and “Age”, relate to demographic data and treatment provision as opposed to relationship development.

The sub-theme “Age” was raised as a factor by three studies in the systematic review (Hariharan et al, 2003; Le Conte et al, 2010; Mosenthal et al, 2008). These authors all identified that the younger patient is less likely to receive a “Do not

resuscitate" order or have treatments either withheld or withdrawn. This finding is supported by Rutledge et al (2001a) who found that there is a survival disadvantage for the older patient with them being less likely to receive aggressive treatment.

Less surprisingly, communication issues were identified as a theme in each study reviewed. This concern was also highlighted by Lautrette et al (2006) when, in their systematic review of 8 studies, all identified that intensivists in particular needed to improve their skills when communicating with families. This may relate to the fact that death and dying are still a taboo subject to society and therefore these clinicians, as part of society, are uncomfortable initiating these conversations. This concern was supported by Leadbetter et al (2010) and The National Council for Palliative care (NCPC (2008) who stated that unless we are able to encourage society to talk about death and dying there is limited opportunity to improve the current services available. The NCPC (2008) also identified that doctors in particular have limited time when communicating bad news to patients and their families. This is an important factor as poor communication can result in the bereaved person's perception of a good death being compromised; that this perception was enhanced if there had been good communication between family and the health care professionals involved, as the family then had a full understanding of the inevitability of dying (Glavan et al 2008). Cooke (2007) also identified that there are risks that poor communication and understanding on the part of the health care professional can result in the patient's wishes not being observed citing the inability of clinicians to recognise the need to access an ambulance urgently when they identified that a patient wished to die at home, assuming that this did not classify as an acute need.

A second of the sub-themes under the classification of “Communication” identified in the systematic review, the withdrawing of treatment, was highlighted by Lyness (2004) as having the potential to distress families; particularly if they feel that being involved in the decision making process has left them feeling that they have caused the death by “pulling the switch”.

Within the theme “Attitudes of the Clinician” the area most consistently identified as a factor in this systematic review was the expected quality of life of the patient in the future (four of the eleven studies). The systematic review also indicated that medical philosophy of cure was less of a factor than anticipated. This is supported by the General Medical Council’s End of Life Guidelines which state that although doctors should aim to prolong life there is no obligation to do this irrespective of the consequences to the patient (General Medical Council (GMC) 2010). This finding may just relate to the studies meeting the inclusion criteria for this review and will require further exploration.

A further sub-theme identified by the studies was “Quality”. In the systematic review the findings of McBride et al (2006) suggests that nurses have a role when encouraging families to reflect on the quality of life that the patient is enduring when they are considering the need to withdraw treatment. This must be balanced against the findings of McCarthy et al (2010) who found there is confusion with relatives assuming that they have the right to make the decisions regarding a patient’s care plan.

Although use of a tool was identified as potentially being of use in this systematic review there was no consistency as to which tool was the most beneficial with seven studies identifying six different tools. However, it was identified by Reid et al (2013) that as patients became more ill some of these tools were less useful as the measures of some criterion such as appetite and depression become inappropriate and are therefore often not completed. This was supported by the Leadership Alliance for the Care of Dying People (2014) who state in their report that currently there is insufficient evidence to endorse any of the tools currently available for recognising the irreversible dying phase.

The findings in this review are applicable to both nurses and doctors who work with patients whose package of care may need reviewing as they may be irreversibly dying. These findings may also be generalisable as the studies reviewed covered various cultures. In addition, the countries where the studies were conducted have a diverse range of health care systems, from nationalised to private. Any cultural variables however, were not explored in this review.

3.8 Conclusions

The first objective of this systematic review was to:-

- identify any relevant primary research already undertaken which takes into consideration how clinicians determine that the appropriate time has been reached at which to review the focus of a treatment pattern in order to reflect the fact that the patient is now entering the last few days of life

Eleven studies were identified using a mix of qualitative and quantitative methodologies. Between them they identified five themes and twenty sub-themes as items taken into consideration by clinicians when they are reviewing patients with life-threatening illnesses. None of these related specifically to the recognition that a patient is now irreversibly dying possibly within the next few hours or days.

The second objective was to;-

- Identify whether this primary research also helps to determine how useful the factors identified are during the process of making these decisions and if these then prove to be a factor that is always present in the irreversibly dying patient.

This objective was achieved within four of the five themes; “Patient Observation”, “Knowledge of the Patient”, “Communication” and “Attitudes of the Clinician”. However, whilst seven authors discussed tools there was no consistency as to which was the most useful in the assessment of a patient’s probable survival with six differing tools being assessed. None of these tools have been validated for use in determining when a patient’s condition has become irreversible. These related more to the measurement of the severity of the illness that the patient was experiencing.

This review provides an evidence base for the development of the next phase of this study. All themes identified within this systematic review require further exploration in order to identify whether or not these are themes that clinicians use on a day to day basis or whether these are purely theoretically based.

The findings of this review will be discussed further in Chapter 8 and will be integrated with the findings from the interviews with clinicians (Chapter 6) and the Delphi Study (Chapter 7).

CHAPTER 4

METHODOLOGY

4.1 Introduction

The guidelines for the development of a complex intervention (MRC, 2008) point to the need to develop appropriate theory. This can be achieved by interviewing stakeholders. The aim of this chapter is to review various methodologies that may be used when attempting to identify factors that clinicians find useful or a barrier to recognising when a patient is irreversibly dying. Secondly, which methodology would be most appropriate in order to determine which of these factors should be considered for inclusion in an education package for clinicians? Initially a review of the risks and benefits of a qualitative approach will be undertaken.

4.2 Qualitative Research Approaches

Qualitative research can have a lot to offer in the field of health where the quality of the care provided is the major focus. Its methods can enrich the knowledge base of this area (Mays & Pope, 2000). In particular qualitative research tends to study things in their natural setting (Green et al 1998) attempting to make sense of issues through the meanings that people bring to them (Greenhalgh, 2003). It is a research approach that attempts to capture the complexities of the experiences of people and focuses on the meanings that people then attach to these experiences (Popay et al, 1998; Trinder et al, 2004). It tends to be underpinned by theoretical frameworks which provide a lens through which it is possible to view and interpret different phenomena (Higginbottom G, 2004). The aim of this style of research is to talk in depth to people allowing them to tell their own story thus giving us access to their view of the world rather than that of the researcher, and it also explores their

understanding of everyday practices, identifying ways it may be possible to improve these (Dees & Vernooij-Dassen, 2010). Qualitative interviewing in particular would appear to provide a method of exploring an aspect of life that the participant has experience of, and gaining an insight into its meaning for that person (Charmaz, 2003).

Qualitative data tends to consist largely of the words or actions of the participants recruited for the study. The aim of this methodology is to condense and organise these thoughts or actions in a manner which does not result in the loss of their initial meaning. This is a difficult task to perform and requires both creativity and imagination on the part of the researcher (Clarke, 1999).

It has also been suggested that qualitative methodologies can be very useful as a preliminary methodology prior to quantitative research (Pope et al, 1995) as the findings can provide a base line from which to develop hypotheses and research questions. Qualitative findings can also be combined with quantitative data (Savage 2000) to enhance understanding. In the context of the proposed study it may be possible that factors that either help or are a barrier to the determining of the need to change the focus of care to reflect the irreversible dying phase may be identified and a subsequent quantitative study could then measure the accuracy of these factors. There is also the possibility of this combination of a qualitative methodology with a quantitative approach will enhance the perspective of the phenomena being researched into in the proposed study.

There are many forms of methodologies available to use when considering qualitative research. The most commonly used are phenomenology, ethnography and grounded theory (Higginbottom, 2005). These will now be reviewed in order to assess their feasibility in the context of the proposed study.

4.2.1 Ethnography

Ethnography tends to focus largely on the study of the culture and any subcultures identified. It tends to concentrate on the social setting or culture within which the participants live and work and largely looks at how it is possible that behaviour can be influenced by these settings or cultures thus seeking to enhance our understanding of the real world (Serrant-Green, 2007). The aim of ethnographic research is usually to understand the participants' point of view within their cultural setting. This is underpinned by the belief that behaviour can only be understood when it is observed within its own context (Savage 2000), as this context itself will affect the behaviour exhibited.

One of the main issues identified when undertaking ethnographic research is that, although it supplies very rich data, this methodology can be labour intensive and therefore can have quite major cost implications (Savage, 2000) both in terms of time and finance. In order for ethnography to be effective it is necessary for the researcher to immerse themselves completely in the world that they are studying in order to gain a fuller understanding. This obviously can only occur following a reasonable time span. The researcher aims to observe the behaviour of the participant within his or her own area and records the interactions that take place

(CASP 1999). It is possible also to undertake interviews or review documents in order to enhance this immersion.

This methodology would be feasible on the basis that it uses a qualitative approach but this method of research is so highly labour intensive that it is unlikely to be suitable for the question identified. There are multiple concerns: first, that total immersion would take time to achieve and is undermined by the limited time available to complete this study and, second, that there would also be financial constraints. This method can also raise important ethical issues that would need to be addressed including informed consent. There may be a risk that obtaining informed consent would influence the study findings as the behaviours of the participants may be affected by this process as an increased awareness of observation of their behaviour develops. However, it would be unlikely that ethical approval would be given without the participants having a full understanding of the study. Further, immersion in practical terms is likely to focus on one of the sub-cultures of interest (e.g. a ward or group of wards) and might miss valuable insights from other areas.

A further concern would be that, although it would be possible to observe the behaviours of various clinicians when attempting to recognise whether or not a patient is dying, it would be very difficult to identify which factors they were using in order to enable this recognition. It may therefore be difficult to identify themes for exploring with any subsequent interviews in order to identify the rationale behind their decision making.

4.2.2 Phenomenology

Phenomenology differs from ethnography in that the researcher attempts to describe lived experiences whilst at the same time trying not to make assumptions about those experiences. Phenomenology is the study of the lived experience and the detailed description of these experiences as we live them. Although none of the phenomenological philosophers developed research methods as such, these philosophies remain the theoretical basis for much modern qualitative research (Fleming et al 2003). It is one of the methodologies that is frequently used by the nursing profession as their natural orientation towards the provision of holistic care provides a good background for phenomenological research. This style of research can emphasise the pre-understanding of the researcher, depending upon the approach used (Trinder et al, 2004). It tends to focus more on the individual's experiences rather than on that of any particular group. Thibodeau et al (1997) state that this type of research accepts that each individual's perception of reality is as true and valid as any other and it also tends to enlarge experience through attempting to understand it in the complexity of its context. It involves exploring in depth experience or texts in order to clarify the essence of the experience in question. This is also a methodology that can be useful when exploring phenomena about which there is limited data.

Edmund Husserl (1859-1938), who introduced the concept of classical phenomenology, saw meaning as being created by the mind through actions which have been directed towards objects using concepts, ideas and images which then form meanings for that individual (Grbich 2007). This style of phenomenology is heavily based in description. Heidegger (1889-1976) however, appears to have

broken away from the Husserlian style of phenomenology. He does not appear to agree with Husserl's view of the importance of description only, but focuses much more on understanding and interpretation of the data (Racher, 2003). His main concern was more about the nature of being and existence (Holloway et al 1996). Heidegger used the phrase "being in the world" in order to express how human beings exist or are involved in the world (van Manen, 1999). A key difference between Heideggerian and Husserlian approaches to phenomenology lies in the use of 'bracketing', Husserl developed the idea of bracketing in order to reduce bias on the part of the researcher. That is, the putting of brackets around the researcher's personal experiences of a phenomenon in order to enable clarity of vision of the essence of the phenomena that is being studied, an attempt at suspension of belief on the part of the researcher. However there is an extension to this as true bracketing is also about the researcher examining their own attitudes, beliefs and prejudices in order to bracket these out thus reducing the likelihood of influencing the findings (researcher bias). Although many researchers attempt this by using a journal to record their preconceptions and attitudes it is acknowledged that true bracketing is almost impossible to achieve. Heidegger also suggests that nothing can be reviewed or studied without taking into account who that person is in terms of life experiences and their background.

The Heideggerian school of phenomenology is seen as interpretive and therefore does not tend to advocate bracketing but tries to discover the meaning of the phenomenona. His purpose appears to go beyond the straight description of particular phenomenona and strongly advocates the use of hermeneutics founded on the view that lived experience needs to be interpreted (Racher et al 2003).

Both approaches to phenomenology have limitations. There is the possibility that the same research question asked in a different setting would come to different conclusions due to differing experiences of both the participants and the researcher. This methodology, like ethnography, can also be very heavily labour intensive and time consuming. This could potentially be an issue for the proposed study. Bracketing, whilst essential for Husserlian phenomenology, is acknowledged as being very difficult to achieve accurately for the researcher. There are also the ethical considerations that would need to be addressed such as informed consent and provision of support for the participants in case it should be required. The researcher's background is based in hospice nursing and therefore there is also the possibility that there could be preconceptions around the subject of the timely recognition of irreversible dying and the need to change the focus of care so therefore there is the risk that even with bracketing there is likely to be some influence on the data collection (such as who to seek out as participants) or the data analysis.

4.2.3 Grounded Theory

Grounded Theory is the final qualitative methodology to be considered for use in the proposed study. It is a methodology that was formally introduced by Glaser and Strauss in 1967 who argued that grounded theory is largely a "theory of resolving a main concern". This theory has much in common with ethnography in that it tends to use both participant observation and unstructured interviews as its most common methods of data collection (Byrne 2001). The main difference is that Grounded Theory argues that the data should come first and the theory will then emerge from the data, that is, the researcher tries to ignore their own preconceptions about the

findings to be expected from the study in order to avoid distorting these findings (Barbour, 2001). It is a methodology that sets out to explore what theory accounts for the research situation (Dick 2005). Its aim is to generate theory which is grounded in the data obtained (Kan et al, 2004). This means that the researcher would need to collect the data and from this identify a theory. By starting with this data obtained from the experiences of the participants the researcher can attend to how they construct their worlds (Wilson Scott, 2004). In practice therefore, the researcher starts by developing a preliminary set of interview questions aimed at opening up areas of potential significance to participants. The interview transcript is analysed and further questions are then identified for further exploration. The theory can then go on to be developed with the use of further interviews. This repeat of the data collection process is continued until saturation is achieved. That is, until no further new themes are being identified by the participants. In this form of research the collection and the analysis of this data need to be carried out in parallel. This ensures that the future course of the research can be shaped as it progresses dependant on the findings being made. This then is a methodology that would appear to seek meaning and develop explanations. It looks at processes and any barriers to services.

There are two potential approaches to grounded theory, constructivist or objectivist. The constructivist approach places emphasis on the participants' definitions of terms, situations and events attempting to identify any assumptions and implicit meanings formed by the participant whereas the objectivist approach is places greater emphasis on events, settings and behaviours (Charmaz, 2003).

The sampling strategy for this methodology is theoretical rather than purposive (Mays et al, 1995); the sampling technique is based on the concepts that have theoretical relevance to the evolving theory as opposed to being chosen on the basis of known characteristics or experiences. It demands concurrent data collection and analysis as identified earlier, so it is from this data that individuals who display the characteristics that are emerging can be recruited into the study (Higginbottom, 2004). Data collection in this methodology can be obtained from many sources including observation, interviews, documentation or meetings. This data is read and re-read in order to identify recurring themes, phrases or types of behaviour and then these are categorised (Wilson Scott, 2004). These categories are then further refined and reduced by grouping them together whilst also identifying additional themes or categories for further investigation (Pope et al, 2000). As the data is analysed it will suggest further groups to be sampled. It is essential that any analysis using the grounded theory approach should at least provide a detailed and saturated account of the data as opposed to a list of themes that appeared in the analysis.

The most common method of data collection for Grounded Theory is the undertaking of in-depth interviews with the identified participants. The aim is to elicit from the participants' their views on the subject in question. The interviewer drafts some possible ideas for questions but allows the interview to take the form of a conversation with ideas and issues emerging which can be followed up immediately. These ideas can then also be incorporated into subsequent interviews for further exploration (Charmaz, 2003). As explanations gradually emerge from the interviews the initial very open questions become more specifically probing (Dick, 2005).

This style of study requires an iterative approach which involves seeking meaning and developing explanations throughout the process of feed-back from the participants. It is a design involving a series of data collection interations, which are repeated until saturation occurs, and the research question has been answered (Grbich 2007). Key to the analysis in grounded theory is both the attempt to constantly challenge but also the development of new theoretical insights. In this methodology it is essential to pay close attention in particular to those cases that contest the majority of findings (negative cases) in order to achieve these theoretical insights. Unlike other methodologies, the analysis focuses down on the themes, narrowing the range of subjects in the interviews in order to develop a theoretical framework rather than as in most other methodologies, to open up and expand themes. There are a few limitations to this design particularly that of the researcher invariably approaching the topic with a set of preconceptions, which are very difficult to set aside increasing the risk of researcher bias.

This methodology, as with most qualitative research, can also be very time consuming and as such it can become very costly. It is impossible to predict when saturation would be achieved so it is difficult to predict how long the research will take. There is also the potential risk that following the collection of a set of data and subsequently analysing this, the researcher may still be unable to identify any significant theory.

The next area to be reviewed are potential quantitative approaches that could be used for this study.

4.3 Quantitative Research Approaches for gaining Consensus

Consensus methods have been used increasingly in the health setting in order to define levels of agreement in areas of contention (Fink et al 1984). There have been two main methodologies developed for gaining consensus through a quantitative approach, the most relevant approach when the data includes closed ended information (Cresswell et al 2007). Potentially, behaviour can be recorded using an observation "checklist" but, for this study, this would not help identify which factors are most useful to determine the need to review the pattern of care when a patient is irreversibly dying. If the researcher had a pre-prepared list to present there is the potential that an important factor to the clinicians could potentially be missed. Consensus methods, however, can also be seen by some as representing the lowest common denominator in a debate (Fink et al 1984).

4.3.1 Nominal Groups

The Nominal Group Technique was initially developed by Andre Delbecq and Andrew Van de Ven in 1968. They developed it as a technique they could use when attempting to enhance the efficiency and effectiveness of a planned programme in health services. They developed it as a purpose designed method of behavioural science that could be used when there was also the need for consensus within the group (Sink, 1983).

This methodology was developed in order to enable groups with either a specific interest or level of expertise in the area under consideration to generate and rank ideas. This structure needs to be very tightly controlled in order to reduce the effect of particularly dominant individuals (Green et al, 2004, p109). In order to achieve

consensus using this methodology each group member is requested to independently write their comments about the question being asked. Following this these are all listed and then the group discusses the comments raised and are asked to individually rank in importance the top ten factors that have been identified during the discussion. Those with the most votes are then listed and discussed and again ranked. This process continues until consensus has been reached by the group as to the most or least important factors (Fink et al, 1984). This methodology can be particularly useful in exploratory work (Gallagher et al, 1993) and has been described as a form of committee working where there are a range of alternative decisions available but with the advantage of a structured method to reduce frustrations (Horton, 2007). Gallagher et al (1993) also suggest that this is a methodology that can succeed in combining both the generation of new ideas but also can help with problem solving. They, once again, reiterate that this is a structured process which encourages the participation and involvement of every member of the group. Further, the nominal group process ensures that the quieter members of the group who may have gone unheard in the informal group are less likely to be dominated (Graffy et al 2008).

Although potentially this is a methodology that could be considered for the proposed study the concern would be relating to the selection of potential participants. This is such a specific question that the expertise and experience required amongst the participants would not be available in a single geographical location. As face to face meetings would be the norm for this methodology this would be unrealistic in this context due to logistical concerns.

4.3.2 Delphi Studies

The name of this methodology originates from the oracle of Delphi where the ancient Greeks were said to be able to forecast the future. It is a technique that was initially implemented by the Rand Corporation in America during the 1950s in research into defence (Williams, 1994). Since then this technique has gradually been developed and is now an established methodology in mainstream research.

Fink et al (1984) state that this methodology has a long history originating in 1948, and has been found to be of use particularly in the health care setting. It is a methodology which in particular, attempts to gain the opinion of experts in a certain field in a systematic manner (Loo et al, 2003; Okoli et al, 2004). As stated by Ludwig (2005) the Delphi technique relies on the understanding that it is probable that the experts in a field are likely to have the best idea as to what lies in the future in their setting.

Addington-Hall (2007) suggests that any methodology which includes a survey as a method is a process of asking people questions and then analysing these responses in a quantitative fashion using statistics. The main difference in the Delphi approach compared to some of the other methodologies is that, in general, the participants of this group never actually meet. The selection of these participants is undertaken on an individual basis; as a result none of the other participants are aware of who else has been approached. Okoli (2004) states that this can result in a lack of confrontation between experts whose opinions may vary. Williams (1994) reminds us that this can result in the encouraging of honest opinions free from any peer pressure. A questionnaire is sent to each participant for completion inviting views on

a specific topic. A summary of these views is compiled and sent back asking participants if their views remain the same taking into consideration the comments provided. This process is repeated until consensus is achieved. (Green et al, 2004, p109). Fink et al (1984) suggests that this process usually takes three or four rounds.

The analysis of the data gathered during a Delphi study is performed generally using statistical methods. Kirkwood et al (2003) suggests that commonly a combination of mean scores and ranking of each category is undertaken.

The sampling for a Delphi study is purposive in that the aim is to gain the opinion of experts in this field of work so it is important to define the word “expert”. Rudy (1996) suggests that one definition that can be used in this context is that of an expert being an “informed individual”. As stated by Okoli (2004) a Delphi Study does not rely on a statistical sample for its validity but is more about a group decision arrived at by qualified experts in the field of enquiry who have a deep understanding of the issue. Hasson et al (2000) reminds us however, that a weakness of this sampling method is that it is not possible to be fully assured that there is true representation within the participant group.

The advantages of this methodology are:

- Whilst each participant is able to express their view individually the researcher has the advantage of receiving information provided by the whole group

- As the questionnaires are either completed by post or by email there are fewer constraints regarding the geographical location of the potential participants
- The number of rounds required can be adjusted to the needs of the study, providing flexibility. There are no fixed numbers of rounds, these continue until the researcher identifies that a convergence of opinion has been achieved amongst the participants.

However, as Fink et al (1984) state, there are some limitations to this methodology. Firstly, fatigue amongst the participants is commonly reported. Often there is an increasing drop-out rate as the rounds continue. If this rate becomes too high there is the possibility that this may affect the validity of any findings as the non-responders may have had very different ideas that have now been missed (Addington-Hall, 2007). Secondly, the co-ordination of such large complex groups can be very complicated.

Sackman (1975) also suggested that there can be weaknesses in particular in the development of the questionnaire design and also issues with the identification of potential participants who can be considered as being experts in their field of work. This concern was also supported by Okoli et al (2004).

Having reviewed both quantitative and qualitative methodologies it is clear that each have something to offer and neither methodology would enable the aims and objectives of the study to be achieved fully. It was therefore decided to explore mixed method designs.

4.4 Mixed Methods Design

Mixed methods design involves the collection and analysis of data using a combination of qualitative and quantitative approaches in either a single study or in a linked series of studies (Cresswell et al 2007, p18). The principle behind this is that the combination of these two approaches results in an improved understanding of the research problem. Interest in the use of mixed methods in research was first evident in the 1950s. In the 1970s and 80s the debate continued as to whether it was feasible to combine qualitative and quantitative data with a lack of consensus of opinion at this time. Some stated that these two paradigms could not be mixed, whilst others felt that this combination was not an issue. More recently the focus has moved to the procedures or methods to follow when undertaking mixed methods research. There are three different and distinct occasions where the mixed methods approach tends to be used (Green et al 2004, p46). The first of these is when exploratory work is being undertaken, secondly, it can be undertaken following an initial research study in order to add depth to the original findings and thirdly it can be used in order to explore differing aspects of the same research question. Ingleton et al (2007) suggest that mixed methods are best used when attempting to open up a new field of study and that this will help us to understand relevant issues in the ever changing health context. They also imply that quantitative methodologies are only feasible when there is a clearly defined aim that is specific and measurable as the outcome of the study.

4.4.1 Issues in Mixed Methods

Problems may arise when using mixed methods. One of the issues identified by Crossley (2007, p205) was the difficulty in participant selection in health care

settings. She suggests that decisions need to be made early in a mixed methods design as to determine whether or not the same participants are to be recruited for both stages of the study. The benefit of recruiting the same participants for both stages would be that the data could be compared more easily but for this to be achievable the criteria for selection would need to be broad. A further potential barrier identified by Cresswell et al (2007, p10) is that the resource implications can be pronounced with the need to analyse two sets of data, one a qualitative assessment process and the second a quantitative one. This in itself can complicate the research making it comparatively difficult to present in a logical manner.

4.4.2 Rationale for Using Mixed Methods

As this proposed study has several aims and objectives, which is common with public health issues (Green et al, 2004) it was decided that using mixed methods was the best approach. This would ensure that each of the aims would be addressed by one or other methodology. The use of a qualitative approach initially would identify factors that the clinician either find to be a barrier or facilitator to the determining of the irreversible dying phase whereas a quantitative approach for phase 3 of the study would identify factors potentially useful to include in the development of an education package for the clinician. It is also possible that the second phase of the study may provide triangulation for the study by confirming the importance of factors identified in phase 1 (Ingleton et al, 2007, Green et al, 2004).

4.4.3 Rationale for use of Grounded Theory in the qualitative study

Choosing the correct methodology for a piece of research can be one of the most difficult problems facing a doctoral researcher (Jones et al. 2011). Having considered

various qualitative methodologies for this study, Grounded Theory is now presented as the methodology of choice for the phase of the study relating to the identification of facilitators and barriers to this process by the clinicians. This methodolgy offers a method that is detailed, robust and systematic yet also allows for some flexibility and freedom when responding to the findings. It is suitable for the investigation of complex and multifaceted phenomena and also for the exploration of socially based issues. It also has the advantage of there not being the need to have a preliminary hypothesis but gives the researcher the freedom to explore the area of interest and allow issues to emerge (Bryant, 2002). It also therefore, has the potential of reducing the influence of inaccurate preconceptions by the researcher on a piece of research by allowing the phenomena to emerge. It is a process that allows for the discovery of the phenomena that are of greatest interest to the participants. This proposed study does not start with a theory, there is the need to develop one and therefore the choice of Grounded Theory as the methodology to be used for this study would appear to be appropriate. The style chosen is the objectivist view point as this tends to be about settings and behaviours which is what is being explored in this study.

4.4.4 Rationale for Use of Delphi Study as the Quantitative Consensus Methodology

The most appropriate approach to be used for the third phase of this study is a Delphi methodology. This methodology can be characterised as a method for structuring a group communication process which allows the group to deal with complex problems (Linstone et al, 1975). It is based on a process for obtaining and analysing knowledge from this group of experts by means of a questionnaire, the results of these opinions being fed back to the group (Adler and Ziglio, 1996) facilitating the formation of a group judgment (Helmer, 1977). Jones et al (1995) and

Gilham (2000) identified that there are many benefits to this methodology which are relevant to this study amongst which are:

- low cost both in finances and in time
- the panel of experts can complete the questionnaire in their own time
- comparatively easy to get a lot of information quickly
- confidentiality can be more easily maintained

This methodology was designed to enable a rigorous query of experts in the field (Okoli, 2004) and will encourage processes for prioritising and consolidation resulting in potential consensus within the group (Ager et al 2007). This will be key to this phase of the study.

4.5 Summary

This chapter has reviewed five potential methodologies that could be considered in the context of the proposed study. The qualitative methodologies reviewed were Ethnography, Phenomenology and Grounded Theory whilst the quantitative consensus methodologies were Nominal Groups and Delphi Studies.

At present, there appears to be little research in the area of factors used by clinicians to help in the recognition that the patient may be irreversibly dying. Hence it would appear that a combined method could be used in order to achieve the research aims.

Phase 2 of the study will have no quantitatively measurable answer therefore this approach is unlikely to answer the question being posed, making it more appropriate

to use a qualitative methodology. This phase will therefore be undertaken using a Grounded Theory approach. This will help to identify the factors and topics clinicians feel are useful when recognising that a patient is irreversibly dying.

Phase 3 examines which of the factors identified by the clinicians are appropriate for inclusion in an education package. This is a more measurable aim and therefore a quantitative approach is appropriate. This phase will therefore be undertaken through a Delphi Study using a panel of experts to identify which of these themes and topics would be useful in this context.

CHAPTER 5

METHOD

5.1 Introduction

The main aim of the first section of this chapter is to describe the process followed when undertaking the interviews with clinicians in the various ward settings identified for the study. Following this the processes undertaken for the Delphi Study with a group of experts across the country is described.

5.2 Phase 2 Interviews

5.2.1 Setting and participants

The setting for this phase of the study was three acute clinical areas selected from the acute medical sector of a teaching hospital- the Stroke Unit, Elderly Care Unit and the Intensive Care Unit. The rationale for the choice of these wards was to enable comparison of responses across three areas with comparatively high death rates. This may be useful in identifying barriers or facilitators that clinicians perceive when they are attempting to recognise the patient who is irreversibly dying**.**

Although the sampling method for the Grounded Theory methodology is theoretical rather than purposive the ethics committee that reviewed this study required specific detail regarding the number, job role and workplace of each clinician the researcher was planning to interview. This resulted in the sampling method being purposive. Because of this requirement it was decided that from those who agreed to participate the most senior and most junior doctor and the two most senior and two most junior nurses from each unit would be interviewed. The most junior was identified by the lowest banding and then the most newly appointed and senior by highest banding

and then the longest serving. The rationale for this decision was that the study would enable comparison of responses not only across acute medical wards but also across experience levels, which may also indicate different barriers or facilitators. This will also enable cross checking of responses between staff of equal experience reducing the risk of misrepresentation of the findings resulting from one interview containing anomalies.

5.2.2 Study Procedures

The three wards approached consecutively were the Stroke Unit, the Care of the Elderly Unit and the Intensive Care Unit. It was decided to perform the interviews in this order as there were likely to be similarities in the responses between the first two units but there was the potential for different experiences on the Intensive Care Unit. If this third unit had been interviewed first the data from the interviews would have reflected this, leaving factors more pertinent to the Stroke Unit and Care of the Elderly Units potentially unexplored. The same processes were followed on each unit. The primary researcher approached the ward manager and asked for the numbers of medical and nursing staff (band 5 and above) who were currently working on that ward. The relevant number of letters requesting participants and the Participant Information Leaflets were then left in the ward staff room for clinicians in order to reduce the likelihood of their feeling pressurised to participate. This would also reduce the risk of identification of each individual by other members of their team as they would be unaware of who had contacted the researcher. It was also hoped that this would reduce the risk of coercion by senior members of staff on the wards. The letter asked them to contact the researcher within two weeks if they were interested in being involved in the study. The Participant Information Leaflet

acknowledged that it was possible that more people would agree to participate than were required for the study and therefore agreeing to participate may not result in being interviewed. A reply slip was enclosed with the invitation letter which requested information relating to role, banding and length of service in order to help the researcher to select the correct participants to interview.

At the initial meeting between the participant and the researcher a formal written consent process was undertaken. This explicitly stated that the participant was at liberty to withdraw at any stage during the study. The study itself involved an unstructured interview with the participants lasting between 30 and 40 minutes exploring the factors used in the recognition of the irreversible dying phase for them as an individual.

5.2.3 Recruitment and Inclusion/ Exclusion Criteria

The most senior and junior doctor and the two most senior and two most junior nurses on the three wards were selected from those agreeing to participate. Where the seniority levels were the same the decision was made by selecting the longest serving and most recently appointed members of staff respectively.

Inclusion criteria- all permanent medical staff and level 1 nursing staff band 5 and over on the three wards identified.

Exclusion criteria- Bank medical staff

Bank nursing staff

Trainee nursing staff

Staff who are known to have suffered bereavement within the last six months. (It was stated on the participant information sheet that if this has occurred they would not be eligible for the study.)

5.2.4 Interviews

All interviews were undertaken by the primary researcher. A topic guide was developed prior to the undertaking of the unstructured interviews (see Appendix B). A mutually agreed time and place was arranged with each participant for the interview to take place. The majority chose to have their interviews on the hospital premises either on or close to their respective wards. One participant requested to be interviewed at her home as she felt that there would be fewer interruptions there and one requested a meeting in a local coffee shop. These interviews were recorded, transcribed and anonymised. The transcription of the individual interviews was emailed to the interviewee to ensure that the written record was accurate. The experiences of the different staff were compared and contrasted and themes regarding similarities and differences noted, comparing and contrasting wards, clinical role and experience levels.

5.2.5 Data Collection

Reading and re-reading the transcripts enabled the researcher to identify recurring themes, phrases or behaviours. These themes were then coded and the subsequent interview questions were developed from the findings of this first set. These interviews were then expanded on as different factors were identified by the

interviewees and exploration of other factors identified stopped as it became clear that these themes had become saturated.

5.2.6 Data Management and Analysis

The data were analysed using the Grounded Theory approach. This is explicitly geared towards generating policy and practice orientated findings, and enables systematic comparisons to be made. It is a content analysis method, which involves summarising and classifying data within a thematic framework. This involved the researcher familiarising themselves with the transcripts (Wilson Scott 2004). Following this a thematic analysis was undertaken. The themes identified then become labels for codes. Indexing was the third step, where codes were applied to the whole data set. The data was then rearranged according to its thematic content (Pope et al 2000). It was hoped that practical strategies for improving the recognition of the need to change the focus of care being provided in order to reflect that the patient is irreversibly dying may be developed on the basis of this analysis. The identification of a need for further exploration of a factor raised in an interview arose from the analysis of the preceding interview (Charmaz 2003). Finally the analysis was interpreted by looking at relationships between the codes.

5.3 Phase 3 Delphi Study

5.3.1 Introduction

The third phase of the study was based on the findings of the analysis of the interviews (phase 2) combined with the findings of the initial literature review and the Systematic Review (phase 1). All of these had identified potential topics that may be

useful for inclusion in an education package which would help to enable clinicians recognise irreversible dying.

5.3.2 Setting and Participants

There was no requirement to have a physical setting for the Delphi study as the researchers contact with the participants was managed remotely.

Recruitment and Inclusion/ Exclusion Criteria

There is a lack of definition for the term “expert” when applied to Delphi Studies, resulting in a wide range of definitions (Keeney et al, 2001). For the purpose of this study it was decided to use the definition provided by Fink et al (1984) who suggest that an expert should be representative of their professional group at a level where their expertise would suggest that any comments are unlikely to be disputed, or be at a level of seniority in their organisation that the likelihood is that they have the power to instigate any actions required following any findings. A panel of experts was therefore identified by approaching the Secretariat of the National End of Life Care Programme who agreed to forward an e-mail on behalf of the researcher to all the End of Life Care Leads in England, Ireland and Wales. It was felt that this would be an appropriate group of experts to approach as they would frequently need to assist with the determining that the focus of a patient’s pattern of treatment needed changing in order to reflect that they are now irreversibly dying. If possible it was hoped that between 20 and 50 experts in end of life care would be recruited for this study.

The inclusion and exclusion criteria were as follows:-

- Inclusion- Clinicians who had managed a dying patient in the past two months or who are attached to the specialist palliative care setting

- Exclusion- Anyone who had been bereaved within the last 6 months.

The rationale for these criteria was that these clinicians are perceived as having the experience required but also there was the need to protect anyone who may be currently suffering emotionally.

The initial e-mail had attached to it the letter of invitation to participate, the Participant Information Sheet and the Questionnaire which also included the consent process (See Appendix D). Potential participants were asked to complete and return these electronically.

5.3.3 Study Procedures

The topics for inclusion in the first round questionnaire were identified by listing all the themes and sub-themes identified by the initial literature review, the systematic review and the interviews. These were then compared in order to identify where each topic had been acknowledged. In order to be included in the questionnaire it was required that the topic had been identified in two of the three areas.

The use of a tool in the questionnaire was omitted as there had been no consensus in the literature as to which tool would be useful and this had not been identified by any participants in the interview process. It was also identified during the systematic review that currently there are no validated tools for the recognition of the irreversible

dying phase. The age of the patient was also excluded as it was felt that this would not be useful for inclusion in an education package.

5.3.4 Data Collection

An e-mail was sent with an attachment containing the letter of invitation, the Patient Information Leaflet and Questionnaire which asked participants to rate factors for inclusion in an education programme for clinicians using a seven point Likert scale of 1-7, 1 being of no importance for inclusion and 7 being very important. This rating system was developed by Psychologist Rensis Likert (1932). At the end of each category there was also a free text box for comments.

. Participants were asked to complete and return these to the researcher by e-mail The questions themselves were divided into five broad topic areas which had been identified in the initial literature review, the systematic review or during the analysis of the interviews. These were:-

- Patient observation
- Knowledge of the patient
- Communication
- Experience of the clinician
- Attitudes of the clinician

In round two the questions were honed down becoming more specific and precise following the feedback received. Any comments received via the comments box were reviewed and any new topics identified were included in the round two questionnaires. Any factors and topics where consensus had been achieved were

listed on subsequent questionnaires and their mean score included for information only. Participants were informed that they were not required to rescore these.

This process was repeated until consensus was achieved (three rounds in total). Each time the questionnaire was sent out there was a time limit of two weeks given for the participants to respond. A reminder was sent seven days prior to the deadline.

For the third round, the mean score of any topics where consensus had not been reached in the previous round was also provided and participants were asked to re-rate the importance for inclusion in an education programme of that topic taking this information into consideration (Day et al 2005; Holey et al 2007; Powell 2003).

5.3.5 Data Management and Analysis

Participants were asked to rate each factor relating it to the importance of that factor being included in an education programme for clinicians. The responses were then analysed by the calculations of:-

- response rates
- level of agreement between participants for each factor identified (percentage)
- The mean of the ratings
- Standard deviation
- Inter-quartile range.

Hsu et al (2007) confirm that the majority of statistics used when analysing Delphi studies are those that measure central tendency such as mean, median, and mode

combined with measures of dispersion (inter-quartile range and standard deviation). Percentage rates have also been identified as a measure of consensus. 80% was the criteria identified by Hearnshaw et al (2001) as being a reliable statistic for assessing a topic as having achieved consensus although Boutron et al (2005) suggested that this could be as low as 40%. It was therefore decided that consensus would be judged as achieved if 80% of participants rated a topic at 6 & 7, that is, either important or very important. The scores of the questionnaires were collated in order to identify any consensus of opinions and the questionnaire was then refined on order to reflect this. This process was repeated until consensus was achieved, or it was clear this would not be achieved on each factor. Feedback to the panel was provided in the form of this revised questionnaire for comment. The researcher and the supervisors reviewed any contentious feedback before decisions were taken.

5.4 Ethical Issues

There were five main ethical considerations associated with this study:-

Confidentiality. This was ensured as far as practicable. However, it must be acknowledged that it was possible that some members of staff in phase 2 may have been identifiable by their use of idiomatic language. It was also possible that the administrative support would recognise the voices as they transcribed. This was acknowledged as a possibility to all prospective members of the study participant population prior to their consent to partake in the research being formalised. The tapes and the transcriptions from phase 2 of the study were stored in separate locked filing cabinets. All transcriptions were anonymised by the allocation of a combination of letters and numbers.

This was less of an issue for the Delphi study as each participant was known to the researcher only. Participants were not aware who the other participants were throughout the course of the study thus confidentiality was maintained.

Informed Consent. Written consent was obtained for both phases 2 and 3 of the study. It was essential that participants understood fully what was required from them. A detailed Participant Information Sheet was provided to all participants and the researcher was happy to answer any questions for both phases. All participants therefore were fully informed prior to formally consenting to participate.

Coercion. The greatest risk when recruiting on the wards for Phase 2 participants was that the primary researcher may have, at times, had patient conversations with staff from the participating wards. There was a potential therefore that the primary researcher could be known to some of the participants. This could result in recruitment issues as clinicians could feel obliged to participate or to answer the interview questions with what they think the researcher would want to hear rather than what was true for them. To help with this issue the researcher used one of the supervisors as a "critical friend" to assist with keeping the roles separated. Reflective practice was also used as a method of to identifying potential problems.

All participants in the Phase 3 Delphi study were volunteers and were recruited via a third party which may have helped to reduce the risk of participants feeling coerced. Although the initial email was sent out by the Secretariat of the National End of Life Care Programme to all End of Life Care Leads she was not aware of who did and did not respond to the researcher

Participant distress. It was acknowledged that undertaking this type of research may carry a psychological risk as the topic can be very emotionally charged (Seymour et al 1999). It was possible that some of the study population could have become distressed particularly during the Phase 2 interviews as these were dealing with a sensitive subject. Staff may be reflecting on situations which could cause distress if they feel that their practice could have been better. It was also possible that personal memories could be raised. Trained counselling staff were available as support for the participants if this was required. This would be provided totally confidentially between the counsellor and the individual. This support was available directly to the participant both through the local hospice and through the hospital's Occupational Health Service.

There were no significant risks to the participants of the Delphi Study in this context. There may possibly have been a burden in terms of time spent completing the questionnaire. There were no direct benefits to participants. However, they may have gained knowledge and improved their skills in the recognition of the irreversibly dying patient perhaps resulting in the identification of the need to change a focus of care in order to acknowledge that the patient may be dying by having the time to reflect on their experiences and thus enhance their practice.

Anonymity. This was maintained as far as was practicable. All transcribed interviews were anonymised using a combination of letters and numbers and were stored in filing cabinets separately from the tapes of the interviews. The only person with access to these cabinets was the primary researcher.

Permission to carry out this study was sought and obtained from Oxford University's Ethics Committee. Ethics approval was also sought and obtained from the local Research and Development Department for permission to perform research on a NHS site, and also from the Local Research Ethics Committee.

5.5 Summary

This chapter has provided a description of the processes that were followed during phases 2 (interviews) and phase 3 (Delphi) of this study. It has identified the ways in which participants were selected and described the settings for the interviews. The methods of data collection, data management and analysis were also described including the methods used in order to identify the topics included in the questionnaires. Finally ethical considerations for these two phases of the study were discussed.

CHAPTER 6

PHASE 2 INTERVIEW FINDINGS

6.1 Introduction

The objectives of the interviews were to:

1. identify and explore the factors that facilitate or prevent clinicians in the acute clinical areas to recognise whether or not the patient has entered the irreversible dying phase.

2. identify techniques that may be used to assist in the recognition of the irreversible dying phase thus improving predictive accuracy.

This chapter sets out the demographic information relating to the participants who were interviewed from the three wards; Stroke Unit, Care of the Elderly Unit and Intensive Care Unit. The factors and topics identified by these participants and conclusions drawn from these findings are then described.

6.2 Recruitment

In April 2010 staff on the Stroke Unit were approached. Recruitment was rapid and all interviews were completed during the month of May. All participants from this Unit were female (see Table 6.1).

Recruitment on the Care of the Elderly Unit followed on directly from the interviews on the Stroke Unit. Of this group five of the participants were female and one (the senior doctor) was male.

The final setting for recruitment was the Intensive Care Unit, which followed completion of the interviews on the Care of the Elderly Unit. Four nurses and two doctors were interviewed. Three nurses (all female) returned the reply slip stating that they were not willing to participate in this study; none of them supplied a reason for this decision.

The recruitment of medical participants took three months with the doctors requiring more in depth information prior to agreeing to participate.

Table 6.1: Demographic data of participants interviewed

Unit	**Role**	**Length of time in post (yrs)**			**Seniority**	**F/M**
		0-2	2-10	10-15		
Intensive Care Unit	Doctor			√	Senior	M
Intensive Care Unit	Doctor	√			Junior	M
Intensive Care Unit	Nurse			√	Senior	M
Intensive Care Unit	Nurse		√		Senior	F
Intensive Care Unit	Nurse		√		Junior	F
Intensive Care Unit	Nurse	√			Junior	F
Stroke Unit	Doctor	√			Senior	F
Stroke Unit	Doctor	√			Junior	F
Stroke Unit	Nurse			√	Senior	F
Stroke Unit	Nurse		√		Senior	F
Stroke Unit	Nurse		√		Junior	F
Stroke Unit	Nurse		√		Junior	F
Care of the Elderly Unit	Doctor			√	Senior	M
Care of the Elderly Unit	Doctor	√			Junior	F
Care of the Elderly Unit	Nurse			√	Senior	F
Care of the Elderly Unit	Nurse		√		Senior	F
Care of the Elderly Unit	Nurse	√			Junior	F
Care of the Elderly	Nurse	√			Junior	F

6.3 Themes emerging from the interviews

The aim of this study was to identify factors which help or hinder the clinician when they are attempting to recognise with accuracy when a patient is irreversibly dying. In

order to achieve this, for the purposes of the interview, it was suggested that when considering this issue, participants could

- consider a patient that they had cared for previously who then went on to die and the decision making process undertaken in that scenario.
- pretend that they were mentoring a junior member of staff and they were caring for a patient whose condition was changing. What were the factors/ topics that they would point out to this junior member of staff that made them consider that the patient was now likely to be entering the last few days or hours of their life?

The interviews were transcribed ad verbatim (see Appendix C) and the data was examined in order to identify themes and over-arching theoretical categories (Glaser et al, 1967).

In reporting the data, a standard format was used to ensure confidentiality was maintained for the participants: for example P1/SU/JN refers to Participant 1 working on the Stroke Unit as a junior nurse.

Table 6.2 Overview of Categories and Themes

CATEGORY	THEME	Quote
Patient observation	Level of consciousness of the patient	*"Just their consciousness level really" P1/SU/SN*
	Patients ability to carry out the activities of daily living	*or loss of ability to care for themselves." P10/CE/SD*
	Physical symptoms	*"all you are hearing is the mucus plug going up and own P3/SU/JN*
Knowledge of the patient	Predictability of disease trajectory	*"because with stroke you have no way of knowing when it's going to happen" P6/SU/SN*
	Patient records	*"what kind of treatment they'd had, and where we were heading with it. P9/CE/SN*
	Clinical test results	*"blood tests in terms of looking at particularly at renal function, P2/SU/SD*
	Rate of deterioration	*I think the most common thing is for someone to have deteriorated quickly."P11/CE/JD*
	Diagnosis	*The neuro ones tend to be a bit easier to spot, you know." P17/ITU/JD*
	Medical history	*"Um, the er, what they, their past medical history." P18/ITU/JD*
	Frequency of admissions	*"increased number of admissions." P10/CE/SD*
	Age of patient	*"I remember the resuscitation for that 13 year old girl, about an hour. And nobody wanted to stop". P11/CE/JD*
	Response to treatment	*"And then you've got people who aren't responding to, to maximal therapies." P16/ITU/SD*
Communication	Multi professional team working	*"I think it's essential that the team agrees that that is the course of action we're going to take." P3/SU/JN*
	Taboo subject for clinicians, patients and their carers	*I've never sort of been uncomfortable with death " P13/ITU/SN*
	Difficulties for clinicians when breaking bad news	*their loved one will get better um, and you know, the doctors can do something and that's not always the case then that's really hard." P12/CE/JN*
	Lack of understanding amongst the family	*"there's clearly a mismatch in terms of expectation. " P16/ITU/SD*
	Withdrawing treatment	*usually withdrawing treatment is one of the better options" P18/ITU/JN*
	Time the clinician has to spend with the patient and their family	*"you wouldn't necessarily pick up on it then as quickly as you might if you've got, you know, plenty of time" P9/CE/SN*
Experience	Qualifications of the clinician	*"I think it can, it's something that comes with experience." P8/CE/SN*
	Speciality working	*"most of us anaesthetists so we're all, most of us come from the same background" P17/ITU/JD*
	Previous personal and work experience	*I took what I learnt from my nursing to my family and what I learnt as a relative back to the ward." P6/SU/SN*
	Intuition of the clinician	*sometimes you get that gut feeling" P8/CE/SN*
	Seniority of the clinician	*"I think as a trainee, probably don'tl to question the boss." P17/ITU/JD*
Attitudes	Fear	*"I think we're all quite scared." P10/CE/SD*
	Acceptance	*"I mean knowing how important it is for doctors to have the humility to be able to accept."P11/CE/JD*
	Willpower	*"underlying all of that is the will of that person P4/SU/JN*
	Denial	*you've got a family that are absolutely adamant that they want everything done." P5/SU/JD*
	Medical philosophy of cure	*"Medicine's all about sort of keeping people going" P17/ITU/JD*
	Failure	*"I tell my student nurses that a dignified death is not about failing P9/CE/SN*
	Quality	*"Quality of life afterwards. P14/ITU/JN*

6.3.1 Patient Observation

An over-arching category identified was the factor labelled as “Patient Observation” (see table 6.2). The interviews were analysed further in order to identify the themes relating to this category. Three themes were identified within this category:

- Level of consciousness
- The ability to perform the activities of daily living
- The patient’s physical symptoms

Level of consciousness

The first theme identified in this category was the patient’s level of consciousness:

> *“Just their consciousness level really because obviously we are very GCS [Glasgow Coma Score] orientated here so we’re aware of neurological signs and deterioration so we probably go by that sort of first really.”* *P1/SU/SN*

It was clear that this was a theme that was highly relevant to the clinicians on the Stroke Unit. It was identified on this unit as being useful in determining that a patient may be dying by every participant interviewed, both across roles and across the levels of seniority:

> *“are they completely bed-bound, has their level of consciousness changed?”* *P5/SU/JD*

It was a theme that the Care of the Elderly Unit participants also identified with four of the six participants interviewed identifying this as a factor that was used to determine the need to change the focus of a pattern of care. However, only one participant from the Intensive Care Unit mentioned this theme and the perspective on this unit differed with the implication that a patient being conscious made it more difficult for them in this context:

"she was actually conscious and aware, and the family were aware. Um, we got to the point it was quite obvious that we'd escalated the treatment and we still weren't winning any ground." P13/ICU/SN

Activities of daily living

The ability to carry out the activities necessary for daily living was also identified early in the first interview on the Stroke Unit as a relevant theme:

"giving them any care or assistance that they needed because they couldn't do it for themselves" P1/SU/SN

Two participants on the Care of the Elderly Unit identified this theme, with participants 8 and 10 identifying that patients tended to need more help as they deteriorated and grew weaker and this could be a useful indicator that the patient may need reviewing as they may now be irreversibly dying and it may be necessary to consider a change in the focus of the patient's pattern of care:

"that somebody needs more assistance with eating and drinking because they're getting generally weaker." P8/CE/SN

"usual functional performance either cognitively or incontinence or loss of ability to care for themselves." P10/CE/SD

Physical symptoms

The final theme identified in this category was that of the physical symptoms that the patient displayed when clinicians are attempting to recognise when the patient is entering the last few days of life. This was initially identified as being useful factor during the second interview on the Stroke Unit and on further exploration on this unit this was corroborated by all following participants. The symptoms initially identified were wide ranging and included respiratory problems or a change in breathing

pattern, the patient's temperature, being unable to manage a nutritional diet, the colour of the patient's skin and reduced communication from the patient:

> *" I look at that person as a whole and the thing is, with stroke patients it's more apparent, it's either going to be an acute change because they develop an infection, so usually a pneumonia, and then they're physically, they fulfil the very unwell criteria* [of the Liverpool Care Pathway for the dying] *so they have a temperature." P2/SU/SD*

When explored in the following interview further symptoms were identified as having particular relevance. These included pain levels and thickened secretions:

> *"unable to clear the secretion so all you are hearing is the mucus plug going up and down" P3/SU/JN*

There were no further symptoms identified during the interviews on this unit. However, when this theme was pursued in the interviews undertaken with participants from the Care of the Elderly Unit a further factor was identified during the tenth interview which suggested that the condition of the skin of the patient could potentially be an indicator of impending death:

> *"Pressure areas, skin damage, is there a fever, um, whether they're um, generally oedematous" P10/CE/SD*

The final interview on this unit identified circulatory changes as a factor:

> *"the pulse being very weak or, or not palpable at all. Um, I think, I've seen a lot of times, you can see the patient's chest moving but you can't feel a pulse at all and I suppose that's because the blood pressure's getting so low that you know, you're still just about profusing to get your brain to be able to breathe but not to be able to really maintain a blood pressure that you can at all feel in the pulses. So I think if someone had all those things, those are the main things that I would look for." P12/CE/JD*

This theme was further pursued in the interviews undertaken on the Intensive Care Unit in order to determine whether the same symptoms were used here when recognising irreversible dying. Five of the six participants suggested that the patient's symptoms could indicate irreversible dying. Many of the symptoms identified were

the same as on the first two units but there was greater focus on recordable symptoms such as the patient's blood pressure in this setting. Many of the symptoms used on the other two units were inappropriate in this setting as the patient on the Intensive Care Unit were heavily sedated and therefore themes such as breathing patterns and colour were not considered to be useful indicators:

> *"You know, you can't get the blood pressure back up, I mean, we use noradrenaline a lot, assessing the blood pressure all the time."*
>
> *P14/ITU/JN*

6.3.2 Knowledge of the Patient

The next category to emerge was the effect that the extent of the clinician's knowledge of the patient had on this recognition. Nine themes were identified in relation to this over-arching category. These were:

- Predictability of the disease trajectory
- Patient records
- Clinical test results
- Rate of deterioration
- Diagnosis
- Medical history of the patient
- Frequency of admissions
- Age of the patient
- Response to treatment

Predictability of disease trajectory

This was identified during the first interview undertaken and subsequently by all participants on the Stroke Unit:

" picking up the fact that someone was well, OK one day and the next day they've deteriorated." *P2/SU/SD*

"When I've had the weekend off and then I've come in on the Monday morning I can see a definite change because I knew how they were previously" *P3/SU/JN*

It was also implied that admission to this unit as a result of an acute clinical event was in itself a factor that could complicate matters; potentially becoming a barrier:

"what I find with the acute stroke unit which I have to say, with the strokes, is that there is, because with stroke you have no way of knowing when it's going to happen, you can have families that will sit with you and say to you "but she was only gardening this morning" or "she was only in town shopping yesterday. Now she's had a stroke and she's dying"." *P6/SU/SN*

When this theme was explored further on the Care of the Elderly Unit it was identified by all the participants interviewed here also. A further issue was raised on this unit, the reliance on other people to help in this process, not necessarily health care professionals. One participant acknowledged the role of other patients who were sharing the room who would notice changes in their fellow patients' conditions:

"They certainly see deterioration. Most definitely. Um. And you do hear them say, oh, you know, you know, she's been off her breakfast now for the last, second day she hasn't eaten anything. She didn't eat anything yesterday." *P8/CE/SN*

A further participant on this unit suggested that when changes occur acutely it is more difficult for the family to accept that a patient may be dying. This in itself could be a barrier not necessarily to the recognition that this is the appropriate time to review the focus of a pattern of care but to the implementation of this change:

"I think the most common thing is for someone to have deteriorated quickly so someone, you know, the most common thing in this scenario that I'm talking about, the family being unhappy, they say things like, oh well, she was fine 2 weeks ago, she was fine. And um, they don't perhaps understand that, especially when you are elderly, patients do deteriorate much quicker than you're expecting doesn't mean that there's anything that you can fix just because it's quick."

P11/CE/JD

It was confirmed in the final interview on this unit that unpredictability of the disease trajectory could be a major barrier to the recognition of irreversible dying:

> *"you can have a, patients go up and down. You know, especially if they're there sort of longer term and um, you know they can be doing absolutely fine and then they just sort of drop off a cliff."*
>
> *P12/CE/JN*

This theme was pursued further on the Intensive Care Unit in order to determine whether any of the facilitators or barriers identified earlier were the same or whether there were variations related to setting. Four of the six participants identified this theme as a potential barrier. However, the emphasis differed from those of the other two units. All four of these interviews related the predictability of the disease trajectory to the withdrawal of treatment:

> *"And we explained to him that probably, almost as soon as I turned off the pumps she would go. And ….[name of a doctor[, who's a, he's a very clever doctor, he actually went up to her and he said, he explained to her, he said we can't help you anymore. You know, we're getting to the point, and how're you feeling. And she said no. So as soon as I switched the pumps, I mean she was gone within 5 minutes."*
>
> *P13/ITU/SN*

This was also supported by the doctors on this unit:

> *"So while we're doing bits and pieces of fiddling around, fix this, we'll do this, that and the other, we just need to step back and look at the situation. This patient, elderly, frail probably doesn't want this, probably scare them out of their mind, if their family probably don't want this um, and they have significant organ failure over a period of time, you know, maybe this isn't in the patient's best interests. But as I say, we're more detail driven so really it's take a step back."* *P17/ITU/JD*

Patient records

The next theme identified was the usefulness of using the patient's previous records when trying to recognise the irreversibly dying patient. This was initially identified in the second interview on the Stroke Unit but was then identified as a factor by all following participant interviews on this unit:

"and you also know that patient's medical history and what's happened to them recently that goes into diagnosing, you know, the last few days of life." *P2/SU/SD*

One participant on this unit implied that the effect that the patient's disease trajectory had on the family should be included in the patient records as this could also provide useful information:

"about how that person probably got into that bed, what they had been through, what disabilities they might have had, and what the family had been through. So I think a bit of background information" *P4/SU/JN*

When the interviews on the Care of the Elderly Unit were undertaken, it was identified that this was a theme that was not thought to be relevant by the first participant but when explored in the subsequent interviews was identified as a factor when determining whether or not a patient may be dying:

" I think I would want to know, you see first of all the patient's condition, um, what kind of treatment they'd had, um and where we were heading with it. You know, 'cos sometimes you've got a definite plan." *P9/CE/SN*

The next participant interviewed identified that there was the potential of aggressive treatment being prescribed inappropriately if current information about the patient was not available.

"Um, it depends on how much knowledge we have, If we knew anything about their um co-morbidities, if we know anything about their drug treatment then you've got a little bit of an idea of what they're capable of. Um, you tend if, the less, the less information the more aggressive you tend to be. And so you're, the old phrase of information being powerful, is, is, is well justified in these situations." *P10/CE/SD*

This theme was explored subsequently during the interviews on the Intensive Care Unit. All participants identified use of the patient's records as a factor of importance with the majority focused on the neurological monitoring of their patients, thus assessing the stability of their condition:

"nearly all of my patients are constantly monitored you know, with an arterial lines, you know, and they're, they're just wired up to the mains basically. Everything's there on screen and it's easier to look at the numbers and the patient on a constant basis" *P14/ITU/JN*

However, it was also acknowledged that having the full records of a patient was a benefit:

"that was on the basis of lots of information. Now I didn't necessarily have it in terms of my experience of him, but I had the notes, I had the rehabilitation doctor's notes, and had his renal physician's notes and I also had his family to er, speak to. Er, and so I think knowledge of the patient helps you er, enormously. I think the tragedy perhaps there was that why on earth was he sent up to us in the first place."
P16/ITU/SD

Clinical test results

This theme was identified by the second participant interviewed on the Stroke Unit in quite a broad context:

"blood tests in terms of looking at particularly at renal function, um, and looking for signs of infection because it could well be that that person is dying from their infection, that's, that's relevant. Um, And again, um, more specific, more tests to look at what, tests that would help to put together all that's going on with the patient so what you see clinically when you're examining them, um, blood tests might help to support what you can't measure despite being an inpatient. Um, I can't think that, unless, I mean their observations but other than that. I mean things like radiological investigations are useful to help with diagnosing what is perhaps causing a deterioration or what is causing that person to die." *P2/SU/SD*

Participants four and six on this unit also supported this theme but refined it further, relating it to the specific unit on which they were working:

"you might have a CT result that comes back and says the patients fine, OK, move on. But you might get a doctor, sit there looking quite sheepish and will say to you they've had a massive, massive stroke and you, you know when the doctors say to you that it's a massive stroke you sort of right away start thinking OK that usually means one half of the brain has gone and there's very little hope for survival. And usually you can sort of look at the CT result and then look at the patient and think, yes, it all tallies because a patient who has had a severe stroke is usually in a coma anyway. So you already kind of

guess that they've had a massive one but the CT scan can actually re-enforce that." *P6/SU/SD*

When this theme was explored on the Care of the Elderly Unit it appeared that it was considered to be a less useful factor with only one participant identifying it as helpful:

"try and establish what organ systems were um functional or dysfunctional." *P10/CE/SD*

This was also identified by two Intensive Care Unit participants:

"if they've got kidney failure, renal failure, their lungs are you know, just getting congested, then they're, they're in a terminal situation." *P13/ITU/SD*

" ICU is all about sort of numbers and things" *P17/ITU/JD*

Rate of deterioration

The fourth theme identified in this category was the relevance of the speed of the patient's deterioration. This was initially identified as a potential factor by the third participant interviewed:

"Yes. When I've had the weekend off and then I've come in on the Monday morning I can see a definite change because I knew how they were previously." *P3/SU/JN*

The participant referred to this theme on five separate occasions and therefore it would appear, rated it as being very valuable in this context. However, no further participants on the Stroke Unit identified this as a factor. When explored on the Care of the Elderly Unit it was found that this theme was potentially of more relevance in this setting with four of the six participants identifying it as a factor that they would take into consideration:

"I saw it in a lady yesterday. The lady, she, a couple of days she'd been going downhill, yesterday morning she was going downhill." *P7/CE/JN*

The seventh participant interviewed on this unit identified that acute deterioration can at times make it more difficult for the family to accept that death of their loved one may be imminent:

> *"I think the most common thing is for someone to have deteriorated quickly so someone, you know, the most common thing in this scenario that I'm talking about, the family being unhappy, they say things like, oh well, she was fine 2 weeks ago, she was fine. And um, they don't perhaps understand that, especially when you are elderly, patients do deteriorate much quicker than you're expecting doesn't mean that there's anything that you can fix just because it's quick."*
>
> *P11/CE/JD*

This theme was then explored further on the Intensive Care Unit. It emerged as a relevant factor for this setting but once again, in a different context relating more to the equipment used in this setting:

> *"And we explained to him that probably, almost as soon as I turned off the pumps she would go."* *P13/ITU/SN*

This suggestion was supported by a further participant interview but the penultimate participant interviewed suggested that if the deterioration was slow it could make it more difficult to determine if a change in focus of care to terminal was appropriate:

> *"And actually to step back and look at the bigger picture isn't always easy. So while we're doing bits and pieces of fiddling around, fix this, we'll do this, that and the other, we just need to step back and look at the situation. This patient, elderly, frail probably doesn't want this, probably scare them out of their mind, if their family probably don't want this um, and they have significant organ failure over a period of time, you know, maybe this isn't in the patient's best interests. But as I say, we're more detail driven so really it's take a step back, definitely."*
>
> *P17/ITU/JD*

Diagnosis

The fifth theme in this category was whether the patients' diagnosis was a facilitator or barrier to the recognition of the appropriate time at which to change the focus of a treatment programme. This theme was not identified as a factor during the first four

interviews. Participant 5 however, suggested that the more medical conditions a patient has, the more useful this factor becomes in the recognition process because the options available for treatment would become more limited:

> *"because of the limits when you're older which can be sort of more limited in that because an operation can be more difficult with more co-morbidities."* *P5/SU/JD*

This concept was supported in the following interview:

> *" you can have some pretty frail patients who've got co-morbid things with hearts and stuff going on anyway, but they have the stroke, and that sort of seals their fate."* *P6/SU/SN*

When this theme was further explored on the Care of the Elderly Unit it was not initially identified as a factor that was useful. The second interviewee suggested that co-morbidities was not the factor that was most useful in recognising irreversible dying; it was more the fact that the patient was diagnosed as having a terminal illness and the increased support that resulted from this for both the patient and the clinician. The impression was given that responsibility could be shared in this situation:

> *"Um, quite possibly cancer's easier. I feel that um, when I'm working with the patients, that almost if you have a diagnosis of cancer certainly you've got more support or it felt, it used to feel like a lot more support, a lot more resources you know, with the Macmillan service."* *P8/CE/SN*

However, this was the only participant who identified the diagnosis of cancer specifically as a factor. On further exploration in the following interviews the remaining participants all appeared to agree that multiple co-morbidities could be useful as had been initially identified on the Stroke Unit:

> *"they've come in with something like a chest infection and it's like well, you know, they've got a medical history as long as your arm and um, that's the sort of patient I'm thinking of where you'd look at them and think do, what are we actually going to do for this patient?"* *P12/CE/JN*

This theme was then explored further on the Intensive Care Unit where three of the participants identified this as an important theme. Two of these confirmed the views of those interviewed from the Stroke Unit, that if a patient had co-morbidities it was easier to accept that they were dying:

> *"sometimes you get people in and you think this is really unkind because they have been hypertensive, they've been immobile, they've got leg ulcers, they've got kidney failure, all kinds of problems that you know, sometimes the elderly accumulate and sometimes the not so elderly accumulate and you think, then, that what do we get at the end of it? And, how is that going to help. So that, that to some extent influences."* *P13/CE/SN*

But participant 17 reverted back to the concept that a specific single diagnosis enabled the identification of the irreversible dying phase. This time, relating it more to neurological illnesses rather than a cancer diagnosis. This may be because a patient diagnosed with cancer is less likely to be referred to the Intensive Care Unit:

> *" I think it depends on the pathology. The neuro ones tend to be a bit easier to spot, you know."* *P17/ITU/JD*

Medical history

The next theme identified as potentially influencing the recognition of irreversibly dying patient was the ability to obtain their medical history. This was not identified as a potential factor until the fifth interview was undertaken:

> *"The important thing is the diagnosis and the prognosis and what the treatment is going to look like."* *P5/SU/JD*

No further participants from the Stroke Unit identified this as a factor that would be useful in this context. When this theme was explored on the Care of the Elderly Unit only two participants identified it as a factor that they found useful. The first participant suggested that not having this information could result in the patient being treated much more aggressively and potentially inappropriately:

"Um, it depends on how much knowledge we have, If we knew anything about their um co-morbidities, if we know anything about their drug treatment then you've got a little bit of an idea of what they're capable of. Um, you tend if, the less, the less information the more aggressive you tend to be. And so you're, the old phrase of information being powerful" *P10/CE/SD*

The following participant interviewed also identified that information about a patient was important when making this determination:

"I would have thought about their medical history and what had gone on and tried to figure out what had caused the, the person to, to, to, worry me like that." *P11/CE/JD*

On further exploration of this factor on the Intensive Care Unit two further participants identified this as a factor they would use to recognise the irreversibly dying patient and the need to review the focus of a pattern of care provision. The first interviewee suggested that this theme was key and something that should always be considered wherever possible:

"The medical history is a good indicator. Someone with heart failure and then got a bit septic so you had to put them on invasive ventilation." *P13/ITU/SN*

This finding was supported by the final interviewee who also identified this factor as assisting the clinician in the recognition of the dying patient:

"Um, the er, what they, their past medical history." *P18/ITU/JD*

Frequency of admissions

The seventh factor identified in this category was the number of times a patient had been admitted in the recent past, with the likelihood that an increase in these figures could indicate that a patient may be coming towards the end of their lives. This was only identified in two interviews as a factor that should be taken into consideration, one of these on the Stroke Unit and the other on the Care of the Elderly Unit:

> *"you've got nurse to say how are they when somewhere like here you've got them for quite a long time or you've got people who come back again and again and they deteriorate and each admission they're a bit worse and often you have a long term sort of plan themselves so they sort of don't want any more than this, this and this to happen. I don't want treatment and you get to know them really well."*
>
> *P5/SU/JD*

Although this was not considered to be a factor in the next few interviews it was once again identified by participant 10:

> *"Um, then you add in other factors that um, that suggest this person has reached the last six months or last year of life um, increased number of admissions."* *P10/CE/SD*

No further participants identified this as a factor that they would consider to be either of benefit or a hindrance in the determination of a need to change from aggressive to palliative treatment modes. This may be because it is unlikely that the type of patient that they admit on these units would be regularly readmitted.

Age of the patient

The eighth theme, age of the patient, was not identified as factor in any of the interviews undertaken on the Stroke Unit. However, participant 7 from the Care of the Elderly Unit identified this as a factor requiring consideration:

> *"I just feel with the patients that we are having, and the age that they're having I feel as if they want to go. They've had their, I feel you know like, you know, they, they're all really old, they've had their, they've had their, their life and they think this is my time now. This is my time to go. But, like the younger, that kills me. You know, like when you see like a mother saying good-bye to their daughter."* *P7/CE/JN*

The following three participants did not identify this as a significant factor. Participant eleven however, related a personal experience in which the age of the patient was highlighted as a major factor emotionally for clinicians when accepting that a patient was dying:

" I mean, in resuscitation, you know, resuscitations that I've been in, for, for resuscitations that I've been to for elderly people, the ones that they sort of do not resuscitate or they haven't been done, hadn't been discussed and that hadn't been decided and you know the call goes out and people came maybe less than 10 minutes before people just stop and everyone knows, from the very beginning, you know, they take one look at the patient and you, you, you know that things aren't going to change and you aren't going to get them back and even if you do the, the patient's going to be too frail to, to ever really kind of, regain anything back. But, and, and the whole atmosphere is totally different and things you know, much easier, but then you get the, the younger patients and I remember the resuscitation for that 13 year old girl, about an hour. And nobody wanted to stop. Nobody wanted to stop at all. And we, we, we were all tried, you know, everything. Every single thing that we could think of but um, er, nobody, nobody could bear the thought, I mean, it was the hardest sort of thing in the world to sort of step back, especially when the mum was there. It was just, it was just awful. And so yes, like it's just two totally different things".P11/CE/JD

The first participant interviewed on the Intensive Care Unit did not indicate that the age of the patient was relevant. However, the following participant felt strongly that this was a factor of relevance when deciding on how aggressively to treat someone who may be dying:

"I think I'd be more inclined with somebody a little bit younger whose more robust, whose got a better constitution who may be that bit stronger to fight back and might possibly come out of it a little bit better than perhaps a little frail old lady in her 90s banging on with treatment you know." *P14/ITU/JN*

When this theme was explored further during the following interview the fact that a patient was young was identified as making it more difficult for clinicians to make this determination. It was suggested that it felt unnatural to recognise irreversible dying in younger people. This therefore was a factor that was perceived as a barrier to the decision to change to terminal care from a curative treatment pattern:

"When they're younger. I think that's a pretty difficult decision although I think that, you know, any, it's almost natural isn't it for somebody who is 86 and poorly to die but then if they're 19 or whatever and been in a car accident or something like that or anything that's happened to them I think it's a lot harder decision and I think it's a lot harder for doctors to make that decision." *P18/ITU/JN*

In total four of the six participants from the Intensive Care Unit who expressed the fact that this was an important issue for them suggested that this factor tended to be a barrier.

Response to treatment

The response of the patient to the treatment being provided was not identified as a factor in this process until it was raised by participant 10 on the Care of the Elderly Unit:

> *"you may well um, look at how well that person responds to simple measures such as somebody who comes in having collapsed in the street who is query conscious, clearly septic, but has got um, evidence of um, poor self care. Their, their albumin's low, they've got pressure sores whatever, you might well go down the route of giving them 24 hours of, of fluids and antibiotics and seeing if they perk up a bit and whether they, that improves the situation."* *P10/CE/SD*

On further exploration participant 11 felt this was not a factor of importance but participant 12 acknowledged that unless this factor was considered there was the risk that inappropriate, invasive treatments could be continued:

> *"That you're doing everything that you can for this patient and they're not responding to the treatment so at the end of the day you're just prolonging the inevitable really. That's the way I view it. Um, but obviously, it needs to be carefully laid out to the family members that you know, we've tried everything that we can, it's not working, there's nothing more that we can do."* *P12/CE/JN*

This theme was further explored on the Intensive Care Unit. Here, only one participant identified that this factor required consideration when attempting to recognise the irreversibly dying patient:

> *"And then you've got people who aren't responding to, to maximal therapies. Um, and I had that situation last weekend with a, a young man, 17 again, catastrophic head injury, who relatively unexpectedly to us had a, who arrested. And er, we resuscitated him, and we got a heart beat back, and we got a decent blood pressure back but spoke to his mum, got her in, and then it all slowed down again. And he clearly was dying then and er, boluses of adrenaline had no effect. So we see*

a number of, there's a spectrum for us isn't there? From somebody who is dead to somebody who will probably die if we withdraw treatment to somebody who's not responding to treatment. And to, the two cases that I've discussed where probably further treatment is inappropriate for them." *P16/ITU/SD*

6.3.3 Communication

The category of the role of communication in this context included six themes relating to the role of information provision and the understanding of this information in this situation. These were:

- Multi-professional team working
- Taboo subject
- Difficulties clinicians have when breaking bad news
- Lack of understanding
- Withdrawing or withholding treatment
- Time

.

Multi-professional team working

This theme was identified by all participants on the Stroke Unit:

"I don't know we have an MDT every Tuesday so that, you know, that is something that will be discussed at that as well." *P1/SU/SN*

On further exploration it became clear that decisions made with the full agreement of the team assisted the recognition process:

"as a team we may then, as a team, and that includes the person's family may decide not to do things. And only as a team, and with a team decision does that work. If someone in the team says no I'm not happy with this or actually I don't agree with it, then it can be very difficult. But as a team allowing, allowing someone to die because we're not doing what we can do that fits with their wishes, um, that makes it much better for the team." *P2/SU/SD*

The following participant expanded on this by implying that this kind of communication between team members can have an effect on the way that treatment options are then discussed with families:

> *"I think it's essential that the team agrees that that is the course of action we're going to take. And everybody is aware of that and by that, so we all sing from the same hymn sheet so that nobody's going to go in and talk about perhaps treatment or management of that patient um, when perhaps somebody else has said the patient's dying and we're looking at the palliative way of looking after that patient, TLC, rather than any further intervention for that patient. That way it's easier for staff and patients and relatives."* *P3/SU/JN*

This was not identified as important by either of the next two participants. Participant six, however, emphasised the role of the more junior nursing staff in identifying the need to change the focus of a treatment pattern for the dying patient:

> *"Because our doctors are very good on this ward. But I've noticed that they rely, it's almost as if they know that it's the nursing staff and the HCA's that are with that patient 24/7, and a lot of the doctors, before they make any definitive diagnosis or any definitive plans will actually say "What do you think?"* *P6/SU/SN*

This theme was pursued further on the Care of the Elderly Unit. The first participant in this setting identified that although the staff on this unit considered that they practised multi-professional working the ultimate decision making responsibility still lay solely with the senior medic on duty:

> *"come the end of the day it comes to the, you know, it's down to the consultant, it really comes down to the consultant."* *P7/CE/JN*

This was confirmed during the following two interviews. Participant eleven suggested that the benefits of multi-professional team working became apparent when decisions regarding a change in the focus of a pattern of care being provided when a patient was dying was complicated by the patient having multiple co-morbidities:

> *"It's a tremendous advantage to have multidisciplinary in-put particularly if you've got people with multiple pathology. Um, and also probably in handling the individuals requirements and expectations and the relatives requirements and expectations."* *P10/CE/JD*

On further exploration on the Intensive Care Unit this was not identified as a factor that was felt to be of much relevance. Little new information emerged in the following interviews relating to the importance of this theme but it was identified that there was a need for clinicians to communicate well with each other regarding decision making in this context:

> *"So I think in that context it is important that there is some kind of, of discussion around the decision that you're making. Um, you know with the surgeon or with the physician perhaps who's looking after them and the team. And that can extend to physios as well can't it or you know, other people who are, who are looking after them you know."* *P16/ITU/SD*

Participant 17 suggested that occasionally a challenge from another clinician can be of benefit when making this type of decision:

> *"it's better that too, if you have somebody who sort of takes a slightly um, er, different view. What it makes you do is sort of, you mightn't necessarily agree with them or change your view but it makes you think about how it is that you are actually come to that, come to that idea yourself and it might even strengthen your resolve to go on, I've thought about it, thanks for your in-put what have you but actually it made me even more, maybe."* *P17/ITU/JD*

The final participant appeared to be more cynical about whether or not multi-professional team working actually happened:

> *"I was going to say you can say what you feel but often it's nothing to do with you is it. Well, that's how I'm led to believe because that's how it works where I work. I don't know whether it's different anywhere else. But um, yes, I, I don't think that actually nurses opinions are taken into consideration a lot of the time which I think's completely ridiculous like, I suppose it does depend on what consultant's on but then also, it's like, we're the ones who have to deal with everything, they come and make the decisions, we're the one who like, implements it. Puts into place everything they say and then, at the end of the day, we're not really included in that process. We're just basically there to take obs. And do things like that and then report back and they make the decisions."* *P18/ITU/JN*

Taboo Subject

This theme was identified in the first interview held on the Stroke Unit as a factor of relevance in the context of this study. Initially it appeared that it was not considered to be of major importance as it was mentioned almost as an aside by this participant:

> *"Who wants to talk about death? And I think you know, people don't talk about death it's not a very, it's not a very nice subject in general, and people are afraid of dying aren't they because they don't know what happens afterwards I suppose."* *P1/SU/SN*

On exploring this further with the next participant it was found that there was the potential of this being a barrier to this recognition process:

> *"one of the things a junior doctor in particular or even sister finds difficult um talking to patients without interpretation um just, you know and, um, what choices there are such as resuscitation or future treatment and for a lot of people they have not thought about that and actually it's really important because management is I think it's important."* *P2/SU/SD*

Participant 3 identified that the increasing number of patients dying in hospitals has resulted in dying becoming a taboo subject for many people; home now not being considered to be the appropriate place of care.This could in itself be a barrier to the timely identification of the patient who may be dying:

> *"They need to be more aware of what the LCP is, and what death is. We are all so removed from people dying at home and dealing with death that even my generation have got this um, strange idea that um, it's all alright people aren't very logical about the process of the body closing down. People don't talk about it they don't see it."*
> *P3/SU/JN*

None of the following participants on the Stroke Unit considered this to be a relevant factor when determining whether or not a patient has reached the dying phase so it was explored further on the Care of the Elderly Unit.

On this unit five of the six participants identified that it was a factor that they would take into account. The only participant who did not identify this theme was a junior

nurse. The first participant interviewed confirmed the earlier findings but participant 10 suggested that there may be a connection between the fact that dying remains a taboo subject and the medical philosophy of cure that was still identified as being common amongst the medical teams:

> *"Well they find it a difficult subject to broach with others. They would be, they um, probably very upset if it wasn't broached with them if they were in the receiving end, but find it difficult to broach with others who, in whom they perhaps feel a, a responsibility to try and keep alive."*
>
> *P10/CE/SD*

This was supported by participant 11.

> *"doctors feel slightly awkward about um, talking to patients about death because they kind of feel a bit as if they've kind of you know, failed and they are worried about the reaction of the family, that the family are then going to you know, say why couldn't you have done more."*
>
> *P11/CE/JD*

Further exploration of this factor indicated that the acceptance of mortality may affect the way in which the clinician approaches the determining of the dying phase:

> *" I thought well dad was 82, he was active right up 'till the end and given a choice of how he'd want to go a quick flash of light and come off your bike is infinitely preferable. And I, and when my mother died I went to the funeral and I don't know whether, sometimes I wonder whether I'm sort of slightly freaked out but I'm , I've never sort of been uncomfortable with death and I don't know that's because I've had it sort of 2 or 3 close experiences and I think, made it, you know."*
>
> *P13/ITU/SN*

This was confirmed by participant 17. The final participant indicated that the fact that the subject of death and dying is taboo can have major implications for families and their ability to cope:

> *"When I finally got through to them and they just like, she would never have wanted this and it makes you feel awful because you just think you know, if you'd known that in the first place you wouldn't have brought them down to ICU and obviously it was the doctors decision and they thought at the time that they couldn't really stop and do nothing about it because this lady was waiting to have surgery the next day. But then she was too poorly to have the surgery and without the surgery she was going to die so it's just like completely catch 22. And then, when her family you just thought, God this is awful, like her family*

would have never had to see, like their last memories of her are being in ICU and being that poorly when you know, it didn't have to be like that but it's just one of those things unfortunately." P18/ITU/JN

Breaking Bad News

The third theme identified was that of the difficulty clinicians have when needing to break bad news either to patients or their families. This was identified as a factor during the third interview on the Stroke Unit:

"The acceptance that, you know, are they making the wrong decision. I think, you know you have clinical evidence but um, but it's always a hard thing to tell the patient." P3/SU/JD

Participant 5 confirmed this as an issue for clinicians but expanded on this suggesting that communication, when a patient is thought to be dying, can be left to junior staff. This can then result in giving the implication to families that the patient is no longer of importance to the senior clinicians:

"I think quite often once someone is on the Liverpool Care Pathway the consultants tend to walk past them on the ward round because there's nothing more they can do. And to some extent I do understand really because they have tight time schedules and they have to concentrate on those they can do something for. I feel sorry for the relatives because they are used to seeing the consultant every day and once the decision has been made they don't stop anymore and it's left to the junior doctors, and the consultants don't really stop anymore. I would, I make sure I go in quite a lot, I, I think that's what I would want in their case and I talk to the families and say she has given up". P5/SU/JD

This theme was explored further on the Care of the Elderly Unit. It was a theme which three of the six participants on this unit identified as a factor in their decision making process. The first participant identified that there could be the fear of the resulting behaviour of relatives in response to the bad news. This could result in the clinicians limiting their communication with the family. This in turn could then result in the need to change the focus of a pattern of care being identified but not implemented:

"And that was my opinion but come the end of the day she sort of snapped at me and she says "Well thank you very much I feel terrible now. I've got to, I've got to leave my three children and come and spend time with my mother". You know. And I went oh, I've, I've said something, I was sort of taken aback and I thought I've said something wrong where I was trying to be sort of there. But it sort of shows. She went off and I felt hurt. I went into the back, I cried my eyes out."

P7/CE/JN

The following participant confirmed these findings. Participant 12 however, related the difficulties of this situation to how accepting the relatives were when this type of conversation was required:

"If the family sort of understand and accept the gravity of the situation then from our perspective, it makes it easier in a way because you know they appreciate what's going on, and they understand what's going on. Um, and it can reduce the levels of false hope. Whereas if the family are of the mind- set that they, that their loved one will get better um, and you know, the doctors can do something and that's not always the case then that's really hard." *P12/CE/JN*

This theme was then explored further on the Intensive Care Unit as there is the potential for a very different perspective in this setting:

" if they've got kidney failure, renal failure, their lungs are you know, just getting congested, then they're, they're in a terminal situation and the the, the fine balance is getting the relatives to recognise that we're not sort of actually extending life but more we're prolonging death.."

P13/ITU/SN

This perception was confirmed in all the interviews where this theme was identified on this unit. During the final interview it was identified that, these conversations, once held with families, can be a relief for them:

"sometimes really hard to explain to um relatives that don't want um their relatives obviously to go on but in my experience most people don't want their, their relative to suffer or anything like that so usually withdrawing treatment is one of the better options rather than having them carry on on a machine and not be the person that they once were." *P18/ITU/JN*

Having reviewed this theme it was now necessary to identify whether there were any other themes identified by the participants as relevant when trying to determine whether a patient has entered the dying phase.

Lack of Understanding

Lack of understanding was a further theme raised for consideration, when the focus of a patient's care plan may need reviewing as the patient is irreversibly dying, by the fourth participant from the Stroke Unit. This nurse suggested that there could be concerns with families not understanding the process of dying and this could be a barrier to the recognition process:

> *"A 101 year old on our ward, and the family were told, the LCP was the kindest way, they agreed, and now they've rescinded it they want her, they think it is cruel that she is dying without anything to eat or drink, now where've they got that from."* *P4/SU/JN*

No further participants on the Stroke Unit indicated that this was a factor that could either help or hinder the determining of the dying phase. This theme was therefore explored further on the Care of the Elderly Unit in order to identify whether or not this was potentially a barrier to the recognition of the dying phase on this unit or whether this was perhaps a view confined to one participant.

The first two participants interviewed on the Care of the Elderly Unit both indicated that this was not a factor that they found relevant in these situations. The initial finding that this, however, was a potential barrier was supported by participant 9 who expanded on the initial findings suggesting that good communication skills between patients, relatives and clinicians would reduce the negative effect that this theme could have:

"I think if you've got, you know, doctors, nurses all agreeing that this is the best for the patient. And I think this is why we try and bring relatives in, so that they are fully aware of how poorly our patients are. Um, maybe sometimes we would use the word poorly rather than dying, that's definitely happened. Um, but then I suppose it's not quite so much of a shock then when that next step is being reached."

P9/CE/SN

This was supported by the following participant who re-enforced the need to ensure that relatives had a clear understanding of what was happening to their loved one:

"You, you have that discussion with the relatives that you're, that this person is very sick, they may not survive this, um, we'll only get some indication of whether it will or won't if we do x, y and z. Sadly, because of their previous health issues and whatever they're, they're not going to be a candidate for intensive care, for organ support, for ventilation. And if we're doing all the right things and they don't um, their heart stops and their breathing stops we're not going to get them back if we, if we attempt to aggressively resuscitate them, so let's give it a shot, see how they go, we'll meet again in 24 hours time and if they're still ticking along or looking better we'll continue, if they're not we'll simply be keeping them comfortable. You set that up ahead of time."

P1/CE/SD

This factor was not identified by any further participants on this unit.

The first interview undertaken on the Intensive Care Unit indicated that this was also a relevant factor in this setting as relatives needed to have realistic expectations. If this reality check was achieved it was implied that there was less likely to be avoidance of these difficult conversations by clinicians with the relatives, thus reducing the likelihood of a delay in the change of focus of a pattern of treatment:

"Then it was just, so I spoke to the husband and the consultant spoke to her and um, we told them that, you know, this was a hopeless situation." *P13/ITU/SN*

Neither of the following two participants indicated that this was a factor that they would take into account in this context. Participant 16, however, suggested that, at times, there can be issues when clinical departments give mixed messages to

patients and their carers. This can increase the misunderstandings held by the relatives:

> *"And I didn't have the discussion that the likelihood is he's…but there's clearly a mismatch in terms of expectation. The surgeon had told her he'd be out of hospital in 7-10 days! And, and I, those are some of the things we're fighting a little bit."* *P16/ITU/SD*

Participant 17 indicated that it was possible that allowing time for relatives to come to terms with the fact that the patient is dying can help the situation. This behaviour can result in the appropriate changes being made once the family has understood that there is a need for a change to the care plan:

> *"Sometimes they come in and they're quite belligerent about the treatment options that we want this and that done and the other and whatever. And then I think, when they've sat at the bedside for a week and realise that actually all has been done, things aren't going forward and that the best that we can get is that people who are older, the patient gets back to what their normal is which maybe wasn't great anyway. Then they sort of have an option and they weigh it up. So I think from that point of view er, a bit of time is useful for them to reflect on that I think."* *P17ITU/JD*

Withdrawing Treatment

The fifth theme identified within this category was the determining of the timing of the withdrawal of aggressive treatments. This was not identified on the Stroke Unit by any of the participants and nor was it identified on the Care of the Elderly Unit until the eighth interview undertaken:

> *"I think the time to stop treatment is very difficult. When someone's on IV antibiotics. The good old debate of the hydration um, I think the biggest barrier is actually talking to the patients themselves, it's people having that conversation, you know."* *P8/CE/SN*

On exploration it became clear that no further participants on this unit considered that this was a factor. During the interviews on the Intensive Care Unit however, it became clear that this could be a barrier to the change of focus being initiated, with

four of the six participants identifying it as an area of concern. Participant 14 suggested that, there was the possibility that treatment was continued inappropriately because of this factor:

> *" And is there any, any point sometimes in carrying on, excuse me, carrying on with treatment when there is no point. You know, surely we should just let them go with a bit of dignity sometimes. I think sometimes we just go a little bit too far. We carry on and try really, really, you know, try to bring them back when there is no point."*
>
> *P14/ITU/SN*

Participant 15 however, suggested that it was possible that being able to control the timing of a death could be of benefit to the family; allowing them time to come to terms with the situation:

> *" If it was 5 in the morning you thought, you knew that well, somebody blew their pupils, you could wait until 11 o'clock to have that conversation with the family. You wouldn't have to you know, speak to them straight away unless you know, they were really deteriorating."*
>
> *P15/ITU/SN*

Participant 17 suggested that this could result in issues for families with feelings of guilt on "giving up" on treatment and this also needs to be taken into consideration:

> *" 'cos you watch families and they're tortured about it all and I think they know probably that their family member wouldn't want just as much done but it would be difficult if it was your family member to say that's, we should stop."* *P1/ITU/JD*

This finding was confirmed by participant 18:

> *"and that's sometimes really hard to explain to um relatives that don't want um their relatives obviously to go on but in my experience most people don't want their, their relative to suffer or anything like that so usually withdrawing treatment is one of the better options rather than having them carry on on a machine and not be the person that they once were."* *P18/ITU/JN*

Time

This theme was not identified as a factor until participant 9 was interviewed. This clinician suggested that working on the Care of the Elderly Unit could result in tasks

being performed automatically without much reflection as to its appropriateness due to the busyness of this the unit. This could result in factors that would indicate that a patients' condition has changed being missed:

> *"Well, we've got 33 patients on the ward at the moment. Um, and I think if you, if you've got your proper numbers of staff on, then it's just about a copeable number. I think definitely, when we haven't got the right staff ratios on then I think care suffers, definitely. Um, and I think that's regardless of whether a patient was deteriorating or not. 'Cos you just physically haven't got, um, and then I think you do miss you know, those, those pointers that will tell you that a patient is deteriorating. Um, we always make sure that our turns get done. So we've got almost like your regiments that you go through in a shift but um, I think possibly then you wouldn't necessarily pick up on it then as quickly as you might if you've got, you know, plenty of time and less patients."* *P9/CE/SN*

Participant 11 expanded on this suggesting that the time of the week could also be a factor that could be a barrier to the identification of the patient whose needs have changed as reduced numbers of staff over some time periods results in less time for staff to be with their patients in order to assess them accurately:

> *" Um, because, er, when ,when someone's dying, when the nurses know they're dying I think that when they've got so many other things to do at the week-ends they may not have the opportunity to call, call the doctor about it and when they do the doctor might be caught up with you know, sort of a young, sick patient that you know, they've got to do lots of things with to, to, to sort of save their life, um, if I'm going to put it in a dramatic way, And, um, obviously, I mean, I would probably do the same. I, I wouldn't leave a young person um, that I thought that I could do something about and you know, fix them, to go and deal with someone who was dying because, I mean, you know, if, if, if it's literally that choice you, you would have to stay, you would have to stay with the one and not leave the one to, um, to deteriorate and, and that you'd lose anyway. And I think that over the week-ends, it, it can be that choice and obviously it shouldn't be, there obviously should be enough staffing levels all the time. But, very sadly, it, it, at the week-ends you do have to prioritise and patients who you don't think that you are going to be able to you know, fix can be down, can be down that priority list which is totally wrong but it, it's, um, because they cut staff so much."* *P11/CE/JD*

Participant 12 expanded on the comment made by the previous participant stating a further barrier to the process could be the lack of time resulting in choices having to

be made between caring for the dying patient or the prevention of an avoidable death:

> *"whenever I had an end of life patient um, I would try and give them the priority. Um, if I had a Health Care Assistant working with me I would say you know, just to keep an eye. Obviously it, it is difficult especially if the unit's really busy and you're needing to do things for patients that are going to live, um, and it is a toss up between the two but at the end of the day you're facilitating this person to have an, a pleasant death, as pleasant as possible, um, without pain, without distress and you know, you've got, you've got to offer the family the level of support that they need as well."* *P12/CE/JN*

Further exploration of this theme on the Intensive Care Unit indicated that it was less of a factor to the participants on this setting. Participant 14 however, accepted that it may be a factor needing to be taken into account when determining a patient's status when working on other units:

> *"I've got a friend who works on Stroke/ rehab and a friend who works for care of the elderly, and I can't imagine her, like I said, being able to look after these 20 patients all the time, especially if they're at risk of, then how do you know they're at risk of deteriorating?" P14/ITU/JN*

Participant 15 suggested that higher staffing levels available in the Intensive Care Unit meant that this factor rarely impinged here:

> *"because we're on the intensive care unit there's always a consultant on duty. And if it was, for instance, at night there's a very senior registrar. So, decisions aren't usually made at night like that really. But if somebody was actually deteriorating quite rapidly then they would obviously speak with the family and they would you know, they would 'phone the consultant at home."* *P15/ITU/SN*

6.3.4 Experience

The fourth category to be identified was the significance of any previous experiences the clinician may have had when recognising the dying patient. There were five themes identified in this category;

- the qualifications of the clinician

- working in speciality areas
- previous personal and work experiences,
- intuition
- seniority of the clinician.

Qualifications

This theme was identified by the second participant interviewed as a factor requiring consideration when clinicians are attempting to recognise the irreversibly dying patient

> *"Um, well I'd say, in my experience, um, juniors are very good at picking up changes. Um, and they are good at picking up the fact that someone was well, OK one day and the next day they've deteriorated. They are very good at picking up things like their temperatures changed or their blood pressure's doing this or their heart's doing this so, or they can't wake them up um.."* *P2/SU/SD*

No further participants on this unit felt that this was a relevant factor. Despite this it was felt that it would be useful to explore this theme further on the Care of the Elderly Unit in order to identify whether there were any differences in perception between these units. Five of the six participants on this second unit identified that this was a factor that had a bearing in this recognition process:

> *"I think it can, it's something that comes with experience, 'cos obviously you're not going to get it, well I say not, I didn't get it as a student myself. I didn't know. Um. In fact my observational skills weren't that brilliant and I couldn't really tell somebody was paler than the day before. I just couldn't remember what they were like the day before."* *P8/CE/SN*

This was reinforced by the following participant who was more explicit about the role that qualification had in this context:

> *"And, you know A… came over and had a chat with a couple of them, she was lovely. Um. Because they saw dying as it being wrong. And one thing I tell my student nurses when they first come on the ward is that a dignified death is not about failing and you know that they find*

quite difficult to understand. 'Cos we're an acute hospital so, well, should anybody be dying here?" *P9/CE/SN*

The final two participants who were interviewed on this unit both confirmed that being more junior could result in a delay in the determining of any need to change the focus of a pattern of care. This may relate to a lack of confidence:

"Um, er, sometimes, especially when you're young, I, I'm talking about doctors as well as nurses here, when you're sort of, just starting out, particularly students think, they kind of come up, they come up to you and they say oh, she's, she's, she's really unresponsive and, and sort of, get in you know, become quite worried about that and er, and don't necessarily think that something acute might have happened but don't necessarily think that that's part of, part of death." *P1/CE/JD*

"So I think a lot of times they're scared to make a decision. Um, but I, I can understand them you know. It's a scary place and a lot of junior doctors are quite young so you know, I don't think as a 25 year old I would have wanted to make that sort of decision." *P12/CE/JN*

This theme was explored further on the Intensive Care Unit. The first participant interviewed on this unit suggested that there was a potential issue in theoretical qualifications becoming a barrier to the practicalities of the role of the participant:

"And sometimes, it is very difficult because a lot of the youngest we've got tend, new staff nurses now, who've never done intensive care and they've been with us between 3 and 8 weeks, and so much of the basics. I mean, they go into university, they come out with a degree, but they can't you know, you want them to do a thorough assessment and sometimes I, I think I'm just being a crabby old bastard but you know, you've got to get this right." *P13/ITU/SN*

But participant 16 agreed with the participants from the Care of the Elderly Unit, that the more qualified the clinician was the more confident they became when making this type of decision:

"Now I felt happy enough to make decisions about, I felt happy to discharge patients home and one thing and another but you can understand why a 24 year old in their first or second job, who hasn't got the consultant with them, hasn't got a registrar with them feels very reluctant to make a decision in case it's the wrong one. And you can understand that, you know." *P16/ITU/SD*

Speciality working

The second factor identified was that of the speciality in which the clinician worked and its effect in this context. This factor was not identified until the third interview was undertaken. It was suggested by this participant that working with the same diagnosis, such as cancer, can aid in the recognition of the dying phase:

> *"perhaps, um, patients who have had some heart disease may always think that there is something else that can be done which is more acceptable than, you know, with cancer patients there isn't any more treatment."* *P3/SU/JN*

However, no further participants on this unit identified this as a factor. On exploration on the Care of the Elderly Unit no-one here indicated it was of relevance either. Further exploration of this theme on the Intensive Care Unit identified that speciality working was not a relevant factor until participant 17 was interviewed and suggested that this factor could potentially be a barrier. This participant raised the concern that working in a small, focused area had the potential to induce a tendency towards narrow thinking:

> *"most of us anaesthetists so we're all, most of us come from the same background or whatever. There's just a few of us who've seen other stuff so we're probably see things, we're probably skewed a little bit, we'd have to be. I mean it's skewed a little bit as a, as a result of all that so um, it probably makes it, there is probably less um, the feeling about whether or not to stop, whether or not to go on probably is fairly narrow because as a, as a trainee albeit I'm a consultant anaesthetist but I've, most of my ICU training's been here so I've been coloured by it all here."* *P17/ITU/JD*

Participant 18 remarked that this factor could be less about the speciality worked in and more about the frequency and numbers of deaths that occurred on that unit:

> *"Yes, I suppose it depends on what ward you work on doesn't it. Like, if you work on a ward that is more prone to having people die I think you would be better at it because you are more exposed to it and you would have better ways of affecting and dealing with that."*
> *P18/ITU/JN*

Previous personal and work experience

The next theme identified was that of the role that the personal and work experience of the clinician has in this context.

This theme was not identified by the participants as being of relevance until the final interview on the Stroke Unit. This participant suggested that personal and work experience were often inter-related and both were of relevance:

> *"And there's been a whole lot of death and dying and it's affecting me personally because about 4 years ago I lost 4 relatives in a year all of them to cancer and it was one every three months including my own dad. So I took what I learnt from, it was inter playable actually, I took what I learnt from my nursing to my family and what I learnt as a relative who went through it back to the ward." P6/SU/SN*

This theme was then explored further on the Care of the Elderly Unit where participant 7 suggested that work experiences in particular could result in the ability to identify the dying patient earlier:

> *"I know what the doctors, I know the doctors know a hell of a lot more than me, but through experience, I mean, if I think somebody should be on the LCP it will be one of the first things I'll say to the doctor. Doc, just have, can you just review it." P7/CE/JN*

Participant nine however, re-iterated the role of personal and work experiences inter-relating:

> *"Um. I mean, I knew my nan was dying but that's possibly, 'cos obviously of my background." P9/CE/SN*

The following two participants did not identify this as a factor of relevance but it was identified as being of relevance once again in the final interview on this unit (Care of the Elderly) where the participant suggested that experience enabled the recognition of when a patient may be entering the dying phase:

> *"'Cos you know, they're not always that, obviously, the, you know, they don't think they're ready to go but again, you can see a kind of vacancy and you can just recognise that the body has had enough*

um, when, you know, not just from numbers and results but the body's tired and it's had enough." *P12/CE/JN*

On exploring this theme further on the Intensive Care Unit the first three participants did not indicate that this was a factor that required consideration in this process. Participant 16 however, confirmed that the inter-relationship between personal and work life did potentially have an effect on this process:

"I think it's important because I think you know, maybe if you've seen your own parents, you know grow up and die or people close to you or you've worked in an environment where people, people die." *P16/ITU/SD*

Participant 17 suggested that having narrow experience could be a barrier when determining the need to change the focus of a pattern of care:

"So I think um, experience is, again you go down the, down the sort of tunneled vision route, the conditioned route or whatever but er, so you want to be really half way. People get a have a bit more faith, maybe a bit more thinking outside the box, maybe a bit more until you get a bit more, really conditioned and then you sort of go, oh, alright. So I don't know. So I think probably experience probably has a, where, where it would change is difficult." *P17/ITU/JD*

Participant 18 also suggested that experience from a variety of areas can be brought to bear in the process of determining whether the focus of a pattern of care requires changing and therefore could be seen as being a facilitator:

"they're all from different areas, so it's like one area does one thing and another, and then you bring them all together in one ICU where they're all from different backgrounds, they've all got different things." *P18/ITU/JN*

On analysis of the data obtained from these interviews it would appear that this could be an area of some relevance to the recognition of the need to change the focus of a pattern of care being provided to a patient in order to reflect the terminal nature of their condition even though it was not identified until approximately a third of the way through the interviews.

Intuition

The fourth theme identified was that of the role of the intuition of the clinician in the recognition of the dying patient. This theme was not raised until the last interview on the Stroke Unit:

> *"Or you can just have female intuition, nurses instinct, something, the patient could be sat talking to you but you can look at them thinking there's something, mmm, there's something not quite right here and something will lodge and you just keep an extra eye on that person and you might find like two hours later they go into cardiac arrest."*
> *P6/SU/SN*

On further exploration on the Care of the Elderly Unit it became clear that this was a factor considered of importance in this setting. It was identified by five of the six participants here that there sometimes was no clear rationale for this recognition:

> *"And it's one of those things, sometimes you get that gut feeling and you, and it is very difficult to explain 'cos the observations, clinical observations might still be fine."* *P8/CE/SN*

When this theme was explored further with the subsequent participant it was suggested that there could be a link between the experience levels and the intuition of the clinicians involved in the recognition process:

> *" Um, I don't really know just, it's a gut instinct. I can't describe it, you just, I think after twenty three years I know that something is not right with my patients. Um, more than the clinical, you know, those obs can tell you yes they've got an output but you also know that they are near to death."* *P9/CE/SN*

This was supported as a facilitator in the decision making process by the following interviews but participant 11 suggested that this was a skill that lay primarily with the nursing staff:

> *"Oh yes, I mean, whenever a nurse comes to me and says this patient's going to, going to pass away, I don't think they've ever been wrong."* *P11/CE/JD*

Having completed the interviews with the participants on the Care of the Elderly Unit it was decided to explore this theme further on the Intensive Care Unit. It was

identified that this was a theme that did not appear to resonate with this unit with none of these participants indicating this was of relevance.

Seniority

The final theme identified in this category was that of the role of the seniority of the clinician on this process. This factor was not identified until the final interview on the Care of the Elderly Unit:

> *"It's usually the younger doctors, the new doctors like we have to do this, this and this you know. They've come in with um, a stroke and this is the protocol to follow and it's like no, look at the patient. Yes, they've had a stroke um, but are they going to survive it? Um, so things like that. It is, a lot of times it is the doctor's experience. And like, if you just spoke to the Registrar usually on the unit that I came from, they'd be like yes, you know, they were usually quite, the calming influence."*
>
> *P12/CE/JN*

On further exploration of this factor on the Intensive Care Unit it was identified as a factor by the second participant from this unit:

> *"I mean I'm very inexperienced at the moment and I always look to the Sister or whoever's in charge in pretty much all the decisions I make and everything. So I certainly wouldn't, wouldn't like to be put in the situation where I'd missed something you know. So I, I'm really , I'm very, me, it's a very personal thing that I'd make absolutely sure I'd double checked everything. I'd hate to, I'd hate to miss something whereby the patient could have, you know, I might have missed it"*
>
> *P14/ITU/JN*

Participant 17 also identified that there was the possibility that the determining of the need to change the focus of a pattern of care and the implementation of this could be delayed due to the considerations of both hierarchy and experience:

> *"I think as a trainee, probably don't probably, we are probably conditioned not to question the boss."* *P17/ITU/JD*

6.3.5 Attitudes

The final category identified during the analysis of the interviews was that of the attitudes of both staff and patients. This category consisted of eight themes:

- Fear
- Acceptance
- Willpower
- Family conflict
- Denial
- Medical Philosophy of Cure
- Failure
- Quality

Fear

The initial theme identified in this category was the clinician's fear of getting the recognition of the irreversible dying phase wrong and the implications that this could have for the patient and their families. This was identified by the second and third participants who both suggested that a potential barrier was the doctors' fear of not always having the answer if they were challenged by patients or their families:

> *"I do wonder whether that's one of the barriers to doctors, raising it with patients that maybe their, they always believe it's something they can't do anything about and whether it's fear that they won't be able to answer the question. A question will come up that they can't answer um, whether the whole conversation will be so emotional it will be an unpleasant experience um, they don't want to upset the patient."*
>
> *P2/SU/SD*

When this was explored in more depth with participant 4 it became clear that there was also fear among the clinicians about the potential for litigation. It was suggested

that this could be a barrier to the timely implementation of a more appropriate plan of care:

> *"They are so worried about litigation, doing the wrong thing, because if they did the right thing they would know exactly what that person wanted when they got brought in on the stretcher."* *P4/SU/JN*

Participant six further stated that, as time goes on, this was becoming more of an issue for staff:

> *"There's so much more litigation coming into it now that sometimes, with the patients, you think why are you doing this to this particular patient. I had one consultant say to me "It's because if the patient died and it went to coroner's court and the coroner said that "the potassium levels weren't right and you didn't correct it," that you could actually then blame the doctor, that maybe had the potassium been corrected that the patient might have lived. And we're like yes, but for how much longer because that's a temporary measure. So yes so, I can't be critical on that score I suppose."* *P6/SU/SN*

Having completed the interviews on the Stroke Unit this theme was explored further on the Care of the Elderly Unit as it would be useful to identify whether or not this was a more generally accepted theme rather than one relating to a specific speciality. During the first interview on this unit it was identified that fear was also a factor here. However, this unit related this factor more to the junior staff having a fear of taking the responsibility for making this type of decision. This could also be a barrier to the implementation of a change in focus of a plan of care:

> *"And even, like even when like there senior house officers you know, they've, you know, I'll talk to the consultant about it."* *P7/CE/JN*

But participant 9 altered the focus of this theme when it was suggested that the patient's fear could be a factor when trying to determine the need for this change:

> *"I mean we've had ladies who've been genuinely scared as they were dying. We've had one lady recently, um, somebody sat with her all night just holding her hand because she, she was scared of dying."* *P9/CE/SN*

When discussing this theme the following participant reverted to the fear that clinicians had but also suggested that this responsibility is eased by working in the ward setting where the clinician has a team with which to share the responsibility:

> *"I think we're all quite scared, well hopefully we are questioning ourselves all the time but, I mean, that's partly why it's useful to be able to be open in a ward setting. It's easier in a ward setting whereas it's perhaps more difficult in a primary care setting if you're, if you're a sole practitioner."* *P10/CE/SD*

The final participant in this setting suggested that as the clinicians' experience increased their confidence in their decision making also improved, thus the fear lessened. This was a factor identified as facilitating the decision making process:

> *"I think a lot of them are scared to make a decision. Um, and I think it's experience and also you know, fear of litigation and everything. Because it's their decision, is it the right one, do they trust themselves enough to make that decision that this person is not going to receive treatment and therefore will likely die. Or you know, to put them on the Liverpool Care Pathway is acknowledging that this person is going to die and you're not going to do anything to stop it. So I think a lot of times they're scared to make a decision. Um, but I, I can understand them you know. It's a scary place and a lot of junior doctors are quite young so you know, I don't think as a 25 year old I would have wanted to make that sort of decision."* *P12/CE/JN*

On further exploration on the Intensive Care Unit participant 13 indicated that the fear of litigation was more of an issue for medical staff:

> *"And also I think that it's, it's more difficult for the doctor because they have more to lose. I mean, they are at the top end of the scale. So to them that's a loss. I mean it's a loss to the whole team but they feel their accountability very strongly."* *P13/ITU/SN*

Two of the subsequent interviews confirmed the previous finding: that there was a fear about potential litigation which could delay the treating of a patient as being in the dying phase of their life. Participant 17 however, went on to indicate that there was less of an issue with fear of litigation but more of an underlying fear of getting the timing wrong:

"I think there's more of a fear of just getting it wrong. I think I've heard that more than sort of this patient's not going to do and commencing the LCP and whatever, to send them up to the ward and whatever to, to pass away and then they don't, you know. And er, and it makes us all look a little silly. Um, I think that makes us look a bit silly. I think that the litigation thing is not much of an issue because the, if you, if they're here people are sort of dying now and maybe if, if, um, if families were you know, a bit more belligerent or whatever you know, about it um, threatening, not usually, don't threaten sort of litigation but sort of hostile then that might make you sort of more, treat more probably I would have thought, yes. But no, I don't think it's a major issue."

P17/ITU/JD

Acceptance

The second theme identified was the level of acceptance exhibited by the patient, their carer, the general public or the clinical staff of the inevitability of the death of the patient. This was initially identified during the third interview undertaken on the Stroke Unit:

" I think it's, it's socially more acceptable, has been historically, um, and perhaps, um, patients who have had some heart disease may always think that there is something else that can be done which is more acceptable than, you know, with cancer patients there isn't any more treatment." *P3/SU/JN*

No further participants on this unit indicated that this may be a significant factor. This theme was therefore explored further on the Care of the Elderly Unit in order to identify whether or not this related to one setting only. The third participant interviewed in this setting was the first to identify this as a relevant factor. The significance of how accepting the patient was of their condition was explored by this participant:

" I don't know whether it's them deciding, OK I'm ready to die now and just, whether that's them just being at peace with themselves or what's, what's acceptance of what's going to happen but once a patient has decided that they're ready to die, then they die quite quickly."

P9/CE/SN

Participant 11 agreed with this statement but suggested that there was a connection with the clinician's ability to accept that their patient was dying. If the clinician was unable to do this then there would be a delay in the patient receiving the appropriate care package:

> *"I mean knowing how important it is for doctors to have the humility to be able to accept death as well as some patients can. And, um, 'cos I remember, you know, with this patient she found it easier to talk about than we did, especially because we all liked her so much."*
>
> *P11/CE/JD*

The final participant on this unit identified that acceptance by the relatives that the patient is dying can also be a factor in this process, relating this to how acute the terminal illness had been for that patient and family:

> *"if the families don't want to accept that that's potentially what's going to happen. Um, and I've, I've seen it, you know, if it's an emergency admission and the person's suddenly become very unwell, whereas, I think if they have a chronic illness they kind of, they get used to the idea over a period of time. Whereas if it's a sudden illness um, then they're like well, they were fine last week you know, she was doing this last week, he was chopping wood, whatever, and um, because it's so sudden, they find it hard to cope with. But I think form a chronic point of view then generally they're like well, yes, they've gone longer than was expected or you know, they've fought hard and this is it now."*
>
> *P12/CE/JN*

These findings were also confirmed by participant 14 on the Intensive Care Unit:

> *"I have one particular patient um, where she was actually, we were withdrawing treatment from her, we were waiting for the organ donors team to set up, and the family kept saying to her go on, go, please go, you can go now."* *P14/ITU/JN*

No further participants on this unit indicated that this was a factor that was either useful or a hindrance to the recognition of the patient who is irreversibly dying.

Willpower

The fourth theme identified in this category was the role of the willpower that the patient exhibited during their illness.

This factor was initially identified by the fourth participant interviewed on the Stroke Unit. Here it was identified that a patient who appeared to be frail could surprise the clinician with their will to carry on living:

> *"Little frail ladies could on for a week or more or frail little thing could actually go that night, and somewhere underlying all of that is the will of that person, does that person want to do die because if they do they will be off that planet quicker than somebody who is fighting."*
>
> *P4/SU/JN*

The following interview confirmed this finding but expanded on it suggesting that it could also relate to the need the patient has to accomplish a task before they allow themselves to die:

> *"But actually I believe that people hold on to life and once they've sort of done, I believe that they want to say goodbye to someone, once they've done that then they're happy to die if you know what I mean."*
>
> *P5/SU/JD*

Participant six suggested that the reversal of this could also be true in that if a patient decided that they were going to die it could appear that they would do so whatever the health professional did:

> *"there is no logical reason why you should be dying now, you're fine, you could go on for another five years and it seems like all your best efforts are not going to help because they have, this person may have decided no, I'm going to die now, and they will. It's almost like you're doing it to spite me aren't you? But some of them will and you just think how can you do that? You know it's, it's, I just don't, I just don't understand it sometimes you know."* *P6/SU/SN*

Having completed the interviews on the Stroke Unit this theme was pursued on the Care of the Elderly Unit. Here participant 7 confirmed the findings from the previous

unit but suggested that there could also be a religious element relating to the need patients may have to confess their sins before dying:

> *" I do believe, you know, it's like it's three times, as much as three times it's happened in the last couple of months where once you'd got the padre in they've just, and the patient just slipped, it's like no…….just slipped."* *P7/CE/JN*

Participant 8 also suggested that patients who are less likely to "put up a fight" need to be identified as they potentially could need more support:

> *"I think, um, a patient who has lost the will-power is the patient as well who needs far more support, who won't really talk about it particularly um, who can't be bothered. Now, I'm not saying that you would then say oh we'll stop treatment on that one and not that on because that one can't be bothered. Um, I think you have to um, I'm a firm believer that patients can give up."* *P8/CE/SN*

This was further expanded upon by the participant 9 who suggested that various diagnoses may have an effect on the patient's will to live:

> *" Um, I think if you have a patient who is anxious or who is depressed then they appear to lose that will to fight so much quicker sometimes even more than your, your demented patient who is just spirited and cantankerous or whatever you like to call them. Um, but they have much more fight and yes, that changes."* *P9/CE/SN*

None of the following participants on this unit considered this to be a factor in this context.

On further exploration on the Intensive Care Unit this was identified as a factor by participant 14:

> *"So, yes, patient attitude does, they, this patient had decided that's it, I'm not going to live, I don't want to live like this and I'm not going to have any treatment and they did pass away."* *P14/ITU/JN*

This was the only participant on this unit who identified this theme. This would suggest that this may be of less relevance on the Intensive Care Unit. The over-all

analysis of these interviews would imply that this theme was considered to be a potential barrier to the recognition of irreversible dying.

Denial

The next factor in this category was identified by the fifth participant. This was the effect on this process that a family's non acceptance of the situation that they find themselves in could have. Denial was identified as a potential barrier to the timely recognition of dying and therefore potentially could cause a delay in the appropriate implementation of a change of focus to a plan of care:

> *"Yes. I mean if you've got a family that are absolutely adamant that they want everything done you tell them everything that's going on and you tell them why you don't think it's appropriate and you can't make them better and I think if they really want things done you sort of have to reach a compromise of what's actually reasonable to do, what's sort of in the best interests of the patient."* *P5/SU/JD*

The following participant interviewed confirmed this suggestion but expanded on it stating that this type of situation increased the stress for the clinician:

> *"some families can be quite in denial about what's going on. They don't want to hear you telling them that maybe mum, dad or whoever is actually now dying and that there's nothing more we can do on a medical level. And some of them are really like well, NO, I insist you do another CT scan and I insist you do this and you have to say "Look, a CT scan won't prove anything, it doesn't form part of treatment, so some relatives can make an already stressful situation much more stressful simply just because they just don't want to accept that their mum or their dad are dying."* *P6/SU/SN*

Although both of these participants indicated that this was a relevant theme no further participants agreed. It was noted that both of these participants worked on the Stroke Unit.

Medical Philosophy of Cure

The seventh theme identified in this category was the effect that the medical philosophy of cure and the death of a patient being perceived as a failure on the part of the doctor had on this recognition process. This theme was raised by the second participant interviewed on the Care of the Elderly Unit:

> *"I think er, the philosophy certainly for the medical teams is preserving life."* *P8/CE/SN*

The following participant confirmed that this was an issue primarily for the medical teams and in particular for those who are more junior:

> *"Yes, um, and probably with our, with junior doctors more than our consultants. Consultants will be much more realistic about what is, is achievable and also what is fair for our patients. Um, whereas I think junior doctors, they're, you know, they come out of med school, aren't they, and yes, we can save the world."* *P9/CE/SN*

This was re-iterated by the next participant, but participant 11 suggested that there was possibly a connection with the training that doctors receive still being focused on the cure of a patient:

> *"I think it's probably something, may be something that medical schools shy away from because they, you know, medical schools, medical students start out idealistic and thinking that they're not going into it to treat death but to keep people alive."* *P11/CE/JD*

Participant 12 confirmed that there is a perception of differing philosophies between the various clinical roles, and that this could be a barrier to the implementation of an appropriate treatment pattern of care for the dying patient:

> *"especially from a medical point of view um, think well you know, we can do this we can do that um, and I think yes, fine you can do all that and you'll probably prolong their life for x amount of time but what kind of a life is that person going to have. And I don't know, maybe nurses just see people, people more as people, as a rounder person who has a life and does this, that and the other, whereas doctors just think we have to save this patient."* *P12/CE/JN*

Having identified that this was a theme that staff on the Care of the Elderly Unit felt was relevant, further exploration as to its relevance in the Intensive Care Unit took place. It was clear that this was an area of concern in this setting and their perception was that this could be a major barrier in the recognition of irreversible dying and implementation of a change in treatment for patients:

> *"I mean they, they can't conceive failure. I think the hardest thing is, in the team is for a consultant to recognise that, you know, we've reached a sort of point at which nothing else is going to work" P13/ITU/SN*

This concern was confirmed by the following participant but participant 16 suggested that this philosophy of cure needs to be tempered by the need for a certain level of quality in the subsequent life of the patient:

> *"I don't sort of subscribe to the life at all costs necessarily because I don't think that's, that's appropriate. Um, and you know I think people have to have some sort of quality of life don't they? Um, and of course, nobody wants, nobody wants to die do they?" P16/ITU/SD*

Participant 17 expanded on this introducing the role that medical training has in this theme:

> *"Medicine's all about sort of keeping people going on or whatever. And maybe the actual actively saying this is, this is not in the patient's best interest, we should stop, is, is part of their medical care, health care or whatever. It's um, it's just the opposite of what we're so used to doing really you know. Just going on and on. And I think, um, when I was at medical school they asked us, gave us scenarios about people, what we would do as a sort of clinician to people who were you know, had fairly sort of limited ability whatever to keep going physically. And we were all, oh yes, we'll keep treating you know, keep going, keep going, keep going and so on. Er, and then they said what if you were the patient? And then oh no, I'd have stopped, I'd have stopped years ago, no way I want to be blah, blah, blah, you know. So it's a strange way that we have professionally versus our own sort of personal feelings about it all you know." P17/ITU/JD*

On further exploration of this theme with the final participant it was suggested that empathising with the patient could potentially help clinicians in this situation:

> *"And I think that I find that really hard to understand because I don't have that mentality because it's, it's maybe them, that's how they feel*

but then you have to think, and maybe it's because of my own feelings because I just think if that was me in the bed I wouldn't want that to be done to me so that, and I know that you're not meant to think like that in nursing, you're meant to have a completely neutral about things but then you could argue that doctors are not meant to think that we can let them die" *P18/ITU/JN*

Failure

The seventh theme was identified during the fourth interview undertaken on the Care of the Elderly Unit. This was the issue of the clinician feeling that they had failed if a patient died:

"And one thing I tell my student nurses when they first come on the ward is that a dignified death is not about failing and you know that they find quite difficult to understand. 'Cos we're an acute hospital so, well, should anybody be dying here?" *P9/CE/SN*

This was confirmed during the following interview. Participant 11 however, suggested that the feeling that they had failed can impede the clinicians' ability to communicate with the patient and their family and thus also delay the implementation of any planned changes of focus to a patients' pattern of treatment:

"doctors feel slightly awkward about um, talking to patients about death because they kind of feel a bit as if they've kind of you know, failed and they are worried about the reaction of the family, that the family are then going to you know, say why couldn't you have done more, why couldn't you have done this and they kind of feel guilt themselves" *P11/CE/JD*

On further exploration on the Intensive Care Unit participant 13 reverted to the fact that this could be a factor that related more to the medical teams:

"I mean they, they can't conceive failure. I think the hardest thing is, in the team is for a consultant to recognise that, you know, we've reached a sort of point at which nothing else is going to work" *P13/ITU/SN*

On undertaking further interviews in this setting only one further participant indicated that this was a factor that influenced them in their decision making and again confirmed that it was perceived as more of a medical issue:

"I think we probably, despite what we say and feel think it's a bit of a failure on our part, we haven't sort of fixed them er I think that's part of the sort of medical as in doctory sort of ethos is to sort of keep going you know. And a failure comes along and we want to fix that and another failure. I think we are very treatment driven here, that's just the nature of the job." *P17/ITU/JD*

Quality

The last theme identified as a factor in this category was raised by the last participant on the Care of the Elderly Unit. This factor was the role of the quality of the care being provided:

"should we not be thinking more palliative because if you're not going to achieve a, a good outcome or you know, the likelihood is they're not going to survive this episode of whatever, then I don't understand why you would perform a whole host of really invasive procedures a lot of the time, put them through that and then the outcome's going to still be the same at the end of it." *P12/CE/JN*

Participant 14 suggested that the effects of quality as a factor could be seen to be wider than just relating to the actual care provided to the patient but could also affect the relatives:

"Quality of life afterwards. Are they going to get quality of life afterwards? Is it, oh, I don't know, um, the relatives, you've got to think of the relatives, carrying on for the family, distressing them, prolonging things, making it worse for them. If you're going to bring somebody, not bring somebody back but stop them dying whatever, and the quality of life is that they're going to need 24 hour care from the family, they may have no mental capacity, they may you know, is it, is it worth it just to say that you've saved a life?" *P14/ITU/JN*

The following participant suggested that there is potentially a role for the assessment of the potential future quality of a patient's life to be a part of the process of deciding on the aggressiveness of the treatment to be given:

"I think they probably would, would make the decision if a patient was elderly and didn't, it just depends on what quality of life that patient had before they get that history you know, whether they were independent, what kind of, how they lived before so you know" *P15/ITU/SN*

Participant 16 expanded on this, suggesting that it could take the decision making out of the clinicians' hands as patients could have their own ideas as to what was acceptable, what was inappropriate or even felt that they had had enough:

> *"we had a lady who came in. In her 80s again, with an ischaemic leg, had the operation, had her leg off, and actually was getting better in terms of, but then didn't want to engage in the processes at all. Said I don't want any more treatment, you've taken my leg off, I can't drive anymore, I'm 85, leave me alone."* *P16/ITU/SD*

Having identified the factors that clinicians felt were either barriers or facilitators when attempting to recognise the irreversibly dying patient these findings were then compared across the clinical roles of the participants.

6.4 Comparing the Responses of the Medical and Nursing Participants

The aim of this section was to identify any similarities or differences in factors when the data from the interviews was analysed comparing the responses from the perspective of the professional role of the participant.

6.4.1 Categories and themes with data showing similarities across participant groups

When comparing the responses from the participants across roles, it was found that there were similarities in three of the over-arching categories (communication, experience, attitudes) and five of the themes contained within these (see table 6.3).

Table 6.3 Categories and themes with data showing similarities across participant groups

Category	Theme	Quote
Communication	Multi-professional team working	Nurse *"we have an MDT so that, is something that will be discussed at that as well."* Doctor *And only as a team, and with a team decision does that work.*
	Taboo subject for clinicians, patients and their carers	Nurse *people don't talk about death it's not a very nice subject in* Doctor *a difficult subject to broach with others.*
	Difficulties for clinicians when breaking bad news	Nurse *the fine balance is getting the relatives to recognise that we're not extending life but we're prolonging death."* Doctor *it's always a hard thing to tell the patient.*
Experience	Qualifications of the clinician	Nurse *I didn't get it as a student. In fact my observational skills weren't that brilliant.* *Doctor but you can understand why a 24 year old who hasn't got the consultant with them,feels very reluctant to make a decision in case it's the wrong one.*
Attitudes	Failure	Nurse *I tell my student nurses when they first come on the ward is that a dignified death is not about failing.* Doctor *doctors feel awkward about talking to patients about death because they feel as if they've failed.*

The category "Communication" indicated similarities in three themes.

Multi-professional team working in this context was identified as a positive factor by both clinical roles. Eleven of the seventeen participants who identified this factor were nurses and the remainder doctors. The focus of this theme for both the medical and nursing participants was that this type of decision was easier to make if consensus was achieved within the team. The nurses responses also included the importance of including families in the decision making process. This was not specifically identified as useful by the doctors.

The second theme (taboo subject) was identified as a relevant factor by eleven participants: seven nurses and four doctors. The focus of this theme was the difficulties faced by clinicians when breaking bad news to the dying patient and their families. The data indicated that was a concern for both the nursing and medical staff (nurses=7; doctors=3). There is the potential that this is such a concern because of fear of the reaction that they, as clinicians, may be about to face particularly from families and carers.

When the data concerning the category “Experience” was compared only one theme emerged as having similarities across the roles, the qualification of the clinician. It was clear when comparing the data that there were no major differences in the importance that the roles placed on this theme when determining the need for a change of focus in a patient’s treatment plan. Four nurses and four doctors identified this factor as being of relevance.

The final category, “Attitudes”, also only revealed one theme where the participants irrespective of role, indicated agreement: the role of failure. When comparing the data relating to this theme across the participant groups there appeared to be little difference of opinion between doctors and nurses with two nurses and three doctors identifying it as a factor they felt to be of relevance. The difference was more apparent when context was considered. The doctors identified it as a concern for them and a potential barrier but the concerns raised by the nurses were for their colleagues; the doctors.

6.4.2 Categories and themes with data showing differences across participant groups

The data was explored further in order to identify any categories and themes where the role of the participant indicated differences of opinion. Differences in the responses in themes were identified within all five categories see Table 6.4).

The first category explored was “Patient Observation”. When the data was compared across the responses within the theme of the patient’s level of consciousness half of the nurses interviewed identified this as a factor but only a third of the doctors. Where the doctors did identify this theme the focus was similar to the nurses, how difficult it was to rouse the patient. It is possible that the increased importance given to this theme by nurses may relate to the nurses having more contact with the patient.

Table 6.4 Categories and themes showing differences across participant groups

Category	Theme	Quotes
Patient Observation	Level of consciousness of the patient	Nurse *we are very GCS orientated here signs.* Doctor *has their level of consciousness changed?*
	Patient's ability to carry out the activities of daily living	Nurse *"giving them any care or assistance that they needed because they couldn't do it for themselves*
Knowledge of the Patient	Predictability of disease trajectory	Nurse *with stroke you have no way of knowing when it's going to happen* Doctor *elderly patients deteriorate much quicker than you're expecting*
	Patient records	Nurse *how that person got into that bed, what they had been through, what disabilities they have* Doctor *what's happened to them recently*
	Clinical test results	Nurse "*Look at the Ct results and then look at the patient and think, yes, it all tallies* Doctor *blood tests in terms of looking at particularly at renal function*
	Rate of deterioration	Nurse *I've had the weekend off and then I've come in on the Monday morning I can see a definite change* Doctor *they say things like, oh well, she was fine 2 weeks ago, she was fine*
	Diagnosis	Nurse *patients who've got co-morbid thingsbut they have the stroke, and that sort of seals their fate* Doctor *The neuro ones tend to be a bit easier to spot*
	Medical history	Nurse *The medical history is a good indicator* Doctor *it depends on how much knowledge we have, If we knew anything about their um co-morbidities*
	Frequency of admission	Nurse - None Doctor *you've got people who come back again and again and they deteriorate and each admission they're a bit worse*
	Response to treatment	Nurse- *they're not responding to the treatment so at the end of the day you're just prolonging the inevitable* Doctor- *how well that person responds to simple measures*
Communication	Lack of understanding amongst the family	Nurse- *we try and bring relatives in, so that they are fully aware of how poorly our patients are* Doctor- *The surgeon had told her he'd be out of hospital in 7-10 days! And,those are the things we're fighting a little bit.*
	Withdrawing treatment	Nurse - *The good old debate of the hydration. the biggest barrier* Doctor-*you watch families and they're tortured about it all and I think they know that their family member wouldn't want it*
	Time the clinician has to spend with the patient and their family	Nurse- *then you wouldn't necessarily pick up on it as quickly as you might if you've got plenty of time* Doctor- *the doctor might be caught up with a young, sick patient that they've got to do lots of things to, to save their life*
Experience	Previous personal and work experience	Nurse- *I took what I learnt from my nursing to my family and what I learnt as a relative back to the ward* Doctor- *you've worked in an environment where people die*
	Intuition of the clinician	Nurse- *it's a gut instinct* Doctor- *whenever a nurse says this patient's going to, going to pass away, I don't think they've ever been wrong*
Attitudes	Acceptance	Nurse- *patients who have heart disease may think there is something else that can be done which is less acceptable than with cancer patients there isn't any more treatment* Doctor- *this patient found it easier to talk about than we did*
	Willpower	Nurse- *does that person want to do die because if they do they will be off that planet quicker* Doctor- *I believe that people hold on to life*
	Medical philosophy of cure	Nurse- *they can't conceive failure* Doctor- *Medicine's all about keeping people going*
	Quality	Nurse- *Quality of life afterwards* Doctor-*In her 80s with an ischaemic leg, had her leg off, and actually was getting better, but then didn't want to engage in the processes at all. Said I don't want any more treatment*

In the second topic in this category - the patient's ability to carry out the activities of daily living - it was identified that two of the three participants indicating this theme were nurses. Again, this may be a factor of more important to nurses as they have more contact with the patient.

When the category "Knowledge of the Patient" was explored eight of the themes identified indicated responses from the medical participants differing from those of the nurses. The first of these was the "Predictability of disease trajectory".

When compared across participant roles it was identified that this was a potential barrier to recognising irreversible dying by all doctors interviewed and ten of the twelve nurses. The focus between the roles however, differed with doctors expressing concerns when a patient deteriorated unexpectedly. This was acknowledged by some nurse participants but their focus related more to the relief they felt when a patient died if the perception was that the death had taken longer than predicted and felt drawn out.

The second theme related to the significance of the "Patient records". The two participants not identifying this as a factor were nurses and therefore there is the potential that this could be a factor more useful to the medical staff. This may be because nurses traditionally tend not to use the patient's medical records on a regular basis. In the settings used for data collection, nursing records tend to be kept separately and to relate more to day to day practical care provision.

The next theme explored - the relevance of any clinical test results - indicated that this was not of importance to the nurse participants with only three nurses mentioning this theme whereas half of the doctors identified it as a facilitator in this decision making process.

Rate of deterioration was also identified as a theme where there were differences between the responses of the nurse when compared to those of the medical participants. The nurse participants prioritised this theme with six of the eight participants who identified this being nursing staff. This again may relate to direct patient contact time.

The analysis of the next theme - the effect that a patient's diagnosis has on the decision-making process - indicated that this was a factor that was more likely to be considered by the doctors than by the nurses. Five of the six doctors interviewed identified this as a factor but less than half of the nurses interviewed mentioned this as a factor to take into consideration when determining the irreversible dying phase.

The sixth theme identified was the patient's medical history. Four of the six doctors interviewed identified this as a factor, whereas only one nurse suggested that it was a factor requiring consideration.

The usefulness of the frequency of admissions was explored next. Both of the participants who identified this as a factor were doctors. This may relate to access to the patient's medical records where it would be easiest to identify this theme. Nurses traditionally commence new documentation for each admission and therefore unless

specifically looked for, frequency of admission may not be easily identifiable and therefore less likely to be used as a factor in the recognition of the irreversibly dying patient and of the need to change the focus of a pattern of care.

The final theme in this category, the relevance given to the way in which the patient responded to treatment, was then explored in the context of the clinical role of the interviewee. This identified that the medical participants considered it more useful with two of the three participants identifying this theme being doctors.

The third category “Communication” was then explored in this context. The first theme identified within this category was “Lack of understanding amongst the family”. When the data from the interviews was compared across the roles there appeared to be limited correlation. An equal number of doctors compared to nurses identified this as factor that they would take into consideration when determining the need to change a pattern of treatment provision. However, the context for this differed with the nursing participants focussing on their concerns relating to the families of the patient whereas the doctors focus was on a lack of understanding within the multi-professional team.

When the theme “Withdrawing treatment” was explored it emerged that more nurses (n=4) than doctors (n=1) considered this to be a factor of relevance. The focus also differed with the nurse participants expressing concerns about the withdrawal of fluids and nutrition. The focus of the doctor related to ensuring that the family understood what was happening and why.

The final theme in this third category, “Time the clinician has to spend with the patient and their family”, was then compared across the roles of the participants. This theme was identified as important by the nurse participants with four of the five participants identifying this theme being nurses. They identified that having time to spend with patients helped with the recognition process but there were concerns that there may be competing demands for their attention when choosing between the patient who had a chance for survival and the patient who was irreversibly dying.

The fourth category was then explored and two themes were identified as having differences in the responses when the medical participants were compared to those of the nurses. The first of these was “Previous personal and work experience”. Five of the seven participants identifying this factor were nursing staff. The only participants to identify this factor on both the Stroke and Care of the Elderly Units were nurses but two of the three identifying it on the Intensive Care Unit were doctors.

The data from the second theme in this category, the role of the intuition of the clinician, was then analysed in this context. This indicated that there were clear differences within the responses with nurses appearing to value this theme more highly (five of the six participants). The medical participant who identified this suggested that it was a nursing skill rather than a medical one.

“Acceptance” was the first theme explored in the category of “Attitudes”. On comparing this data across the two roles it was identified as a factor more frequently by the nurses. Once again the reason for valuing it varied with the doctor’s focus

being on whether or not the patient accepted their condition whereas the nurses commented on the ability of staff to accept the patient's condition.

The next theme in this category, the willpower that the patient exhibits, was the next to be explored. When comparing the interviews across roles all bar one of the participants identifying this topic were nursing staff. Once again, there is the possibility that this could relate to the fact that the nurses role tends to be much more "hands on".

The data from the interviews when the theme "medical philosophy of cure" was explored indicated that this was a concern for both roles. Ten of the eighteen participants identified this topic. Of these seven were nurses and three doctors. A senior doctor stated that there was possibly a connection with the training that doctors currently receive still being very focused on the cure of a patient. The nurses identified the fact that medical teams can still perceive death as failure with the resulting barrier to a change in a care plan.

The final theme identified as containing differences in the data when medical and nursing participants were compared was how "quality" affected this process. This was a factor identified more frequently by nurses than doctors with three of the four identifying this theme being nursing staff.

6.5 Analysis of Data Comparing Responses between Senior and Junior Participants.

The aim of this section was to identify any similarities or differences between responses when considered from the perspective of the seniority of the participant.

6.5.1 Categories and themes where there were similarities of response across participant groups.

When comparing the responses from the participants across levels of seniority, it was found that there were similarities in all of the over-arching categories and fifteen of the themes contained within these (see table 6.5).

Table 6.5 Categories and themes with data indicating similarities of response across participant groups

Category	Theme	Quotes
Patient Observation	Level of consciousness of the patient	Senior- *Just their consciousness level* Junior- *has their level of consciousness changed*
	Physical symptoms	Senior- *they develop an infection, so usually a pneumonia* Junior- *unable to clear the secretion*
Knowledge of the Patient	Predictability of disease trajectory	Senior- *with stroke you have no way of knowing when it's going to happen* Junior- *someone to have deteriorated quickly*
	Patient records	Senior- *sometimes you've got a definite plan* Junior- *patients are constantly monitored*
	Medical history	Senior- *If we knew anything about their co-morbidities* Junior- *thought about their medical history*
Communication	Multi-professional team working	Senior- *we have an MDT every Tuesday* Junior- *it's essential that the team agrees*
	Taboo subject for clinicians, patients and their carers	Senior- *people don't talk about death* Junior- *People don't talk about it*
	Withdrawing treatment	Senior- *the time to stop treatment is very difficult* Junior- *it would be difficult if it was your family member*
	Time the clinician has to spend with the patient and their family	Senior- *you wouldn't pick up on it as quickly as you might if you've got time* Junior- *they may not have the opportunity to call the doctor*
Experience	Previous personal and work experience	Senior- *you've worked in an environment where people die* Junior- *through experience*
	Intuition of the clinician	Senior- *nurses instinct* Junior- *whenever a nurse comes to me and says this patient's going to, going to pass away, I don't think they've ever been wrong*
Attitudes	Denial	Senior- *some families can be quite in denial* Junior- *absolutely adamant that they want everything done*
	Medical philosophy of cure	Senior- *the philosophy y for the medical teams is preserving life.* Junior- *medical students start out idealistic thinking to keep people alive*
	Failure	Senior- *death is not about failing* Junior- *feel as if they've failed*
	Quality	Senior- *quality of life* Junior- *Quality of life afterwards*
	Willpower	Senior- *there is no logical reason why you should be dying now* Junior- *the will of that person*

The first category reviewed was “Patient Observation”. Two themes were identified as having similar responses by both senior and junior staff. The first was the “level of consciousness of the patient”. There were no clear thematic differences identified between responses in this theme. It was also identified that there were no discernible differences when exploring the data regarding symptoms that the patient exhibits. This would suggest that these factors are useful to all of the participants irrespective of levels of seniority.

The second category explored in this context was “Knowledge of the Patient”. It was identified that three of the themes indicated similarities between the perceptions of the junior and senior staff when describing factors of significance to them in this context

The first theme identified in this category, the predictability of the disease trajectory indicated that the seniority of the clinician made little difference to the importance allocated to this as a factor. Eight junior and eight senior staff indicated it as a topic that they would use in this process.

The second theme identified the relevance of considering the patient’s medical records. This again indicated that there appeared to be no difference as to the level of importance clinicians gave this theme with, half being junior and half senior. However there were differences in the context used for this factor. The senior participants focussed on the previous medical history of the patient, potentially identifying factors that may indicate futility. The focus of the junior participants was on the monitoring of the patient and identifying any changes in this way.

The final theme identified in this category, the role that the patient's medical history was explored next. There once again appeared to be limited differences of opinion when compared across levels of seniority with three of the five identifying this factor being junior participants.

When explored, the data relating to the category "Communication" identified four themes as having similarities when compared across levels of seniority. The first of these identified was multi-professional team working. It appeared that this factor was valued equally by the senior and junior participants with eight of the seventeen participants identifying this theme being senior staff and nine junior. However, on analysing the context in which the participants placed this theme it was clear the there was frustration for the junior staff who indicated that although staff considered that they worked as a team any decisions could only be taken by senior staff and this could result in a delay in the implementation of a more appropriate focus to the care plan of the patient.

The second and third themes in this category, the fact that dying is still a taboo subject in this society and withdrawal of treatment, appeared to have no differences when explored across the levels of seniority of the participant.

The final theme in this category was "Time that the clinician has to spend with the patient and their family". When compared across the interviews there appeared to be little difference of opinion as to its value with slightly more junior staff (n=3) to senior staff (n=2) identifying this theme. However, junior staff were concerned that they did not have enough time to spend with the dying patient because of the

busyness of the ward and competing demands for their time. The senior staff were more concerned about the potential for delay in changes to a care plan because decisions were not being taken out of hours.

The fourth category, “Experience” revealed two further themes where there were similarities in the responses when compared across levels of seniority. The theme of previous experiences, both personal and work related, indicated few differences of opinion with four of those identifying it as a factor being junior and three being senior. When reviewing the transcriptions there were few differences in the context reported however, one of the more junior interviewees suggested that if you do not have these experiences to bolster your decision making there is the possibility that changes may not be made due to a lack of self confidence.

The second theme in this category, the role of intuition of the clinician, was analysed next in this context. When considering the data identified, this theme indicated little difference of opinion with three of the participants identifying this theme being junior and three senior. Both senior and junior staff felt that intuition developed alongside experience levels when comparisons could be made of the condition of a patient to that of a similar patient cared for previously.

The final category “Attitudes” was identified as containing four themes where there were similarities between the responses. The first of these was “denial”. This was identified as a potential barrier by both the senior and junior participants. The context given for this factor was also the same. It was focussed on the difficulties raised when family were denying the inevitability of the situation. The theme of the “medical

philosophy of cure" also did not indicate any differences when seniority of position was considered with the same proportions of senior and junior staff identifying this theme. The third theme in this category, the risk clinicians faced of being considered as a failure when reviewed was identified by two junior participants and three senior. The next theme, the willpower that the patient exhibits also indicated few differences in the responses with four identifying this theme being senior staff and three being junior. Both senior and junior staff held the same focus regarding willpower at opposite ends of the spectrum suggesting that a patients' willpower can either result in their "refusing" to die until they have achieved a certain goal or "deciding" to die even when there is no clinical evidence that they should die so quickly. The final theme in this section was the effect that quality had in the determining irreversible dying. When the data was reviewed in this context it was clear that there were no differences relating to the experience levels of the clinicians with two of the four participants identifying this theme being the more junior staff interviewed and two senior. The focus across these interviews was also the same with discussion of a poor quality of life for the patient linked to the prolonging of death.

6.5.2 Categories and themes where there were differences between the responses of participants groups.

When comparing the responses from the participants across levels of seniority, it was found that there were differences in four of the five over-arching categories. "Attitudes" was the only category where none of the themes indicated differences dependant on levels of seniority. There were twelve themes contained within these (see table 6.6). The category containing the majority of these was "Knowledge of the Patient".

The category “Patient Observation” revealed only one theme where there were differences in the responses of the participants according to their levels of seniority, the patient’s ability to carry out the activities of daily living. All three participants identifying this as useful were senior staff.

Table 6.6 Categories and themes with data indicating differing responses between participant groups

Category	Theme	Quotes
Patient Observation	Patient's ability to carry out the activities of daily living.	Senior- *loss of ability to care for themselves* Junior- None
Knowledge of the Patient	Clinical test results	Senior- *blood tests* Junior- *all about numbers*
	Rate of deterioration	Senior- *as soon as I turned off the pumps she would go* Junior- *I can see a definite change because I knew how they were previously*
	Diagnosis	Senior- *if you have a diagnosis of cancer* Junior- *The neuro ones tend to be easier to spot*
	Frequency of admission	Senior- *increased number of admissions* Junior- None
	Age of the patient	Senior- *It's harder to discuss with someone in their 20s.* Junior- *they're all really old*
	Response to treatment	Senior- *how well that person responds* Junior- *there's nothing more that we can do*
Communication	Difficulties for clinicians when breaking bad news	Senior- *getting the relatives to recognise that we're prolonging death* Junior- *it's always hard to tell the patient*
	Lack of understanding amongst the family	Senior- *we try and bring relatives in* Junior- *Sometimes they come in and they're quite belligerent*
Experience	Qualifications of the clinician	Senior- *I felt happy to make decisions* Junior- *It's a scary place*
	Speciality working	Senior-*If a patient's had a severe stroke there's no hope of survival.* Junior- *most of us come from the same background*
	Seniority of the clinician	Senior- None Junior- *I'm very inexperienced at the moment and I always look tor whoever's in charge pretty much all the decisions*

The second category explored, the knowledge clinicians may have regarding the patient, was then analysed across the levels of seniority. This identified six themes where there were differences in the responses. The first of these was the relevance of the patient's clinical test results to this process. There were five senior staff but only one junior who considered this to be a theme of importance. These six participants all made comments suggesting that looking at the quantitative information provided by these tests could be very useful in this situation. The theme "Rate at which the patient is deteriorating" also indicated differences between the importance allocated to it as a factor in the recognition of irreversible dying by the different levels of seniority with five of the eight who identified this factor being junior. The next theme indicating differing responses was the effect that a patient's diagnosis may have on the decision-making process. There was apparent relevance when relating this to the experience levels of the clinician with approximately two-thirds of senior staff identifying this factor but just over a third of junior staff. The context for both, however, was the determining of the appropriate care plan. The theme "Frequency of admissions" was only identified as a factor when recognising irreversible dying by two participants, both of them senior staff.

The reporting of the relevance of the age of the patient was addressed next in this context. When considering the data across the levels of experience of the participants it was identified that there were differences as to the importance of this factor relating to the seniority of the participant with five junior staff identifying this factor and only one senior.

The final theme in this category, the relevance given to the way in which the patient responded to a treatment pattern was then explored. It was identified that two of the three participants who identified this were senior participants. It must be acknowledged however, that as only three participants identified this as a factor that needed consideration in this context this finding must be considered with caution.

The third category was “Communication”. There were two themes identified here where the responses differed when analysed across levels of seniority, the first being the difficulties clinicians face when breaking bad news. When the data here was explored it indicated that this may be an area where staff become more comfortable with communicating about death and dying as they gain experience. Seven of the ten interviews where this was identified as a factor were with the junior staff. Their consistent message was that this was an area that caused them concern and was seen as a barrier to the implementation of a change in the focus of a care plan.

The second theme identified was the role that a “Lack of understanding amongst the family” may have in this process. It would appear that being more senior increases the likelihood of this factor being significant with four of the six participants who reported this being more senior staff. All comments related to issues where the families did not fully understand the implications of the illness their loved one was suffering from and therefore not recognising the likely outcome.

The final category where differences in the responses were identified was “Experience”. This category had three themes where differences in response relating to the seniority of the participant were identified. The first of these related to the

qualifications of the clinician. The data indicated that there was potential significance when the seniority of the clinicians was taken into account. The more senior staff identified this theme (six out of the eight) as relevant when recognising irreversible dying. The most common context was the ability to look back and reflect on the development of clinical skills. One junior participant suggested that as you became more qualified you developed in confidence and the ability to accept situations.

The second theme in this category, the issue of working within a speciality was then explored. Two of the three participants who identified this theme were the more junior staff. There were two main contexts raised in this theme, the risk of becoming so focussed on a speciality that other co-morbidities could be ignored and secondly, as the clinician specialises the likelihood is that signs and symptoms are less likely to be missed.

The final theme, “Seniority”, in this category was then analysed. This was identified as a factor by three participants. All three were junior staff. When explored further as to the context of this theme it was clear that all participants indicated that with seniority came an increase in confidence in the ability to make these decisions.

6.6 Analysis of relationships of categories and themes between Units

Having reviewed the data across both the role and seniority levels of the participants the final comparison to be made was between the different unit settings in order to identify any differences or similarities.

6.6.1 Categories and themes with data indicating similarities across participant groups

When comparing the responses from the participants across areas of work, it was identified that there were similarities in three of the over-arching categories and seven of the themes contained within these (see table 6.7).

Table 6.7 Categories and themes with data indicating similarities across participant response

Category	Theme
Knowledge of the Patient	Predictability of disease trajectory
	Patient records
	Rate of deterioration
Communication	Breaking bad news
Attitudes	Fear
	Willpower

The first category reviewed was “Knowledge of the Patient”. Three themes within this category were identified as having similar responses across units, the first being the predictability of the disease trajectory. Similarities were identified between the Stroke and Care of the Elderly Units. When the responses from the Intensive Care Unit were analysed there was a slant towards concerns around the withdrawing of treatment and switching off of machinery. It was also highlighted by the staff on this unit that there was the potential for ensuring that the timing of a death could be arranged in order to suit the family once the decision to withdraw treatment had been made. This was a factor that staff on this Unit found positive but raises the concern that there may be the situation where a patient’s death is prolonged unnecessarily.

Following this the second theme, patient records, identified that there were again, similarities in the responses between the Stroke Unit and the Care of the Elderly Unit with the focus being on the treatment and care the patient had received in the past. However, needs in the Intensive Care Unit differed with the focus being on the recordings of data from the life support machinery as being a factor in the decision making process.

The final theme in this category, the rate of the patient's deterioration, was identified as a factor by only one participant on the Stroke Unit. This in itself is not surprising as this as a stroke is an acute event in itself but contrary to this, nearly equal numbers identified this theme as one of the factors that could be useful in the determining in the need for a change in a pattern of care by the participants from the Care of the Elderly and the Intensive Care Units.

The second category where there were similarities in the responses between sites was "Communication". The theme identified here was the difficulties clinicians face when breaking bad news. This theme indicated that this was a factor that caused anxiety for the clinicians on the Intensive Care Unit in particular with five of the ten participants identifying it as a factor with the remaining five being split between the other two units (Stroke Unit =2, Care of the Elderly Unit = 3). It would appear that the emphasis on the Intensive Care Unit was as a result of the decision being complicated by the need to explain withdrawal of treatment. This was seen to cause confusion for families when determining the need to change the focus of a care plan.

The final category where there were similarities between the responses was “Attitudes”. There were only two themes within this category where similarities were found, the first was “Fear”. This was identified by four of the participants on each unit but each in a differing context. Those from the Stroke Unit suggested that a potential barrier to this process was the fear the doctors may have about not always knowing the answer when challenged by patients or their families. On the Care of the Elderly Unit too, this was an area that the participants felt could be a barrier to the determining of the need to change the focus of a pattern of care. The four participants on the Intensive Care Unit focussed on the fear of litigation as an issue in particular for the medical staff.

The second theme, the willpower that the patient exhibits was identified by seven participants, three from the Stroke Unit, three from the Care of the Elderly Unit and one from the Intensive Care.

6.6.2 Categories and themes with data indicating differences across participant groups

When comparing the responses from the participants across areas of work, it was identified that there were differences in the responses when responses were compared across areas of work in all of the over-arching categories and fourteen of the themes contained within these (see table 6.9).

Table 6.8 Categories and themes with data indicating differences across participant groups

Category	Theme
Patient Observation	Level of consciousness of the patient
	Patient's ability to carry out the ativities of daily living
Knowledge of the Patient	Diagnosis
	Age
Communication	Multi-professional team working
	Taboo subject for clinicians, patients and their carers
	Lack of understanding amongst the family
	Withdrawal of treatment
Experience	Intuition of the clinician
Attitudes	Acceptance
	Denial
	Medical philosophy of cure
	Failure
	Quality

The first category explored was "Patient Observation" and the first theme identified was the conscious level of the patient. All the staff on the Stroke Unit identified this theme as being important but on the Care of the Elderly Unit it appeared to be of less importance with four of the six participants identifying it. The major difference was identified in the interviews from the Intensive Care Unit with only the one participant mentioning this as a factor requiring consideration. This may be due to the patients on this unit generally being fully sedated and therefore this would be a factor of less relevance whereas, for the other two units, this would be a clear indicator of a change in the condition of the patient.

The second theme in this category, the ability of the patient to carry out the activities of daily living, was then explored. This factor was identified by one participant on the

Stroke Unit, two on the Care of the Elderly Unit and none from the Intensive Care Unit.

Two themes were identified in the category “knowledge of the Patient”, diagnosis and age. The effect that a patient’s diagnosis may have on the decision-making process regarding the appropriate time at which to change the focus of a pattern of care was identified as important particularly on the Care of the Elderly Unit with half of the participants identifying this factor working on this unit. However, one participant on the Intensive Care Unit reverted to the idea that a specific diagnosis enabled the identification of the dying phase, this time relating it more to neurological illnesses rather than cancer.

The age of the patient was not identified as a factor by any participants on the Stroke Unit. However, it was identified on the Care of the Elderly Unit as a factor with the patient being more elderly making it emotionally easier for the clinician to state that a patient is dying. In total four of the six participants who expressed the fact that this was an important factor for them when recognising irreversible dying were from the Intensive Care Unit. The theme from these interviews suggested that this factor tended to be a barrier in this process.

Three themes were identified in the category “Communication”. The first of these was the fact that dying remains a taboo subject in society as a whole. This theme was identified by three participants on the Stroke Unit, five on the Care of the Elderly Unit and three on the Intensive Care Unit. However, the context for this finding differed in the interviews from the Stroke Unit where it was suggested that this factor

was a barrier when trying to change the focus of a pattern of care in that it could result in a lack of honest communication with the patient and family. The majority of interviews described a feeling of discomfort when trying to initiate conversations about dying with families. When the data was explored on the Care of the Elderly and the Intensive Care Units the context related to clinician avoidance of consideration of their own mortality.

The next theme identified was lack of understanding. This factor was identified by one participant from the Stroke Unit two from the Care of the Elderly Unit and three from the Intensive Care Unit. All participants had the same focus. They all related this to a lack of understanding on the part of the families of the futility of continuing aggressive treatment.

The final theme identified in this category was the role that withdrawal of treatment had in the decision making process. This theme was not identified on the Stroke Unit and only by one participant on the Care of the Elderly Unit. On exploration on the Intensive Care Unit it became clear that this could be a barrier to the change in a care plan being initiated, with four of the six participants identifying it as a potential issue.

Only one theme was identified in the category “Experience” where differences between the responses were apparent when considered across site of working and this was the intuition of the clinician. This theme was not raised until the last interview on the Stroke Unit. On exploration on the Care of the Elderly Unit it became clear that this was a factor considered important by all the participants here with five

of the six interviewed in this setting raising this as a factor. On the Intensive Care Unit however, this was a theme that was not considered to be a factor when recognising irreversible dying.

The final category explored was that of the attitudes that people have relating to this topic. The first theme in this category, the level of acceptance exhibited by those concerned in this recognition process was the next area to be analysed. This theme was identified by five participants in total. One from the Stroke Unit suggested that the understanding of the public may affect this theme, with the majority of the public seeing cancer as a death sentence and therefore easier to accept as life limiting. Three of the interviews on the Care of the Elderly Unit supported this finding. The majority of these participants citing family levels of acceptance of the situation being key. Only one participant from the Intensive Care setting felt this was of significance, stating that clinicians can have problems accepting futility.

The next theme was that of denial. This was identified by the final two participants interviewed on the Stroke Unit. Although both of these participants appeared to feel that this was a relevant theme no other participants on any of the wards agreed. This could relate to death being more expected on the Care of the Elderly and Intensive Care Units. Both participants suggested that this related more to the relative's denial of the inevitable rather than the patient and their wish to continue inappropriate aggressive treatments.

The theme of the medical philosophy of cure was identified by ten participants, none of these worked on the Stroke Unit. The five participants on the Care of the Elderly

Unit identified that this was potentially a barrier to the recognising irreversible dying. In the Intensive Care setting it was clear that this was an area of great concern. Their perception also was that this was a potential barrier to the decision making process.

The theme “Failure” was identified by a total of five participants, three on the Care of the Elderly Unit and two on the Intensive Care Unit. Once again, this was not identified as a factor by the participants on the Stroke Unit. The focus from the two units identifying this factor varied. The interviews from the Care of the Elderly Unit described the need to take responsibility for these types of decisions and rationalised this with seniority and experience levels whereas the interviews from the Intensive Care Unit focussed on the feeling of inadequacy experienced by the clinician when a patient died.

The final theme in this category was “quality”. This theme was not raised until the last interview undertaken on the Care of the Elderly Unit and then by three further participants on the Intensive Care Unit. The context for this for the participant from the Care of the Elderly Unit was the perceived reduction to a patient’s quality of life when invasive treatments are continued inappropriately. The context on the Intensive Care Unit shifted subtly with the perception of how the patient regarded their quality of life being emphasised. This unit also focussed on the potential lengthening of the dying process as opposed to the patient having quality time.

6.7 Summary and Conclusions

The findings from these interviews have identified factors that clinicians consider to be facilitators or barriers to the recognition of irreversible dying. They have also

identified factors where there is uncertainty amongst the participants as to their importance in this context.

The facilitators which helped identification were:-

Patient Observation	level of consciousness of the patient
	Patient's ability to carry out the activities of daily living
	Physical symptoms
Knowledge of the Patient	Predictability of disease trajectory
	Patient records
	Rate of deterioration
	Medical history
Communication	Multi-professional working
Attitudes	Quality

Although there was general agreement regarding the above, when physical symptoms was explored there was no consensus as to which specific symptoms were most useful.

The main factors that were a barrier to recognising dying were:-

Knowledge of the patient	Frequency of admission
	Response to treatment
Attitudes	Fear

The theme fear related mainly to fear of litigation if this recognition was inaccurate.

There were several themes identified where it was difficult to interpret whether they are useful in this context or not. These were:-

Knowledge of the Patient	Clinical test results
	Diagnosis
	Age
Communication	Time the clinician has to spend with the patient and their family
Experience	Qualifications of the clinician
	Speciality working
	Intuition of the clinician
	Seniority of the clinician
Attitudes	Acceptance
	Willpower
	Failure

There were also differences noted when the transcriptions from the Intensive Care Unit were compared to the other two units. The most important facilitator for this unit would be the expected quality of life for the patient; the main barriers being the age of the patient and the difficulties regarding the withdrawal of treatment. Many of the factors for the Stroke and Care of the Elderly Units appeared to be less relevant for this unit. These were:-

- Patient's ability to carry out the activities of daily living
- Level of consciousness of the patient
- Rate of deterioration
- Intuition of the clinician

- Acceptance
- Willpower
- Denial

The theme that appears to be emerging from these findings is that clinicians have a fear of getting the timing of this recognition wrong due to the decision making process being so complex. This is exacerbated by fear of missing the treatable.

These findings suggest that many clinicians may lack confidence in determining when the time is appropriate to change the focus of a pattern of treatment from aggressive to a more palliative approach. They have concerns that they may be making the wrong decision. This is intensified by concerns regarding the implications of this for patients and their families. This could be improved by the development of a relevant education package combining many of the themes that have been identified during the analysis of these interviews.

It will also be necessary to take into account the needs of the clinicians working in the Intensive Care Unit as these differ and may require the development of a specific package.

These categories and themes will now be reviewed in order to achieve some consensus regarding which should be considered for inclusion in an education package to assist clinicians to develop these skills. In order to achieve consensus about topics to be included a Delphi Study was undertaken. This is described in Chapter 7.

CHAPTER 7

PHASE 2 (DELPHI) FINDINGS

7.1 Introduction

This chapter describes the development of the questionnaire used in the Delphi Study and the resulting findings. The factors for inclusion in round 1 were identified by combining the findings of the interviews with those of both the literature review and the systematic literature review. This process provides content validity of the questionnaire as it provides some triangulation helping to increase the transferability of the findings.

7.2 Round 1

7.2.1 Factors and topics included in the questionnaire

The categories and themes identified during phase 2 of this study (interviews) were used as the framework for developing the topics to be contained in the Round 1 questionnaire of the Delphi study. The process of mapping these themes against the literature (Lit), the findings from the Systematic Review (SR) and interviews (Int) is provided at Table 7.1. This process assisted in the grouping of these various factors and topics. In order to be included in the questionnaire each factor must have been identified in a minimum of two of the three processes.

Table 7.1 Factors and topics for inclusion in round 1 questionnaire

Patient Observation

Topic	Include	Lit	SR	Int
Conscious level of the patient	√	√	√	√
Patient's ability to carry out the activities of daily living	√	√	x	√
Pain	√	√	√	√
Breathing pattern changes	√	√	x	√
Anorexia and cachexia	√	√	x	√
Blood pressure, pulse, temperature	√	√	x	√
Colour of the patient	√	√	x	√
Short lived improvement	x	√	x	x
Increasing weakness	x	√	x	x
Delerium	x	√	x	x
Restlessness	x	√	x	x

Knowledge of the Patient

Topic	Include	Lit	SR	Int
Predictability of the disease trajectory	√	√	x	√
Patient records	√	x	x	√
Diagnosis	√	√	√	√
Clinical test results e.g blood tests, scans	√	√	x	√
Rate of deterioration	√	√	x	√
Medical history	√	√	x	√
Response to treatment	√	x	√	√
Frequency of admission	x	x	x	√
Age	x	x	√	√

Communication

Topic	Include	Lit	SR	Int
MDT Working	√	x	√	√
Taboo subject for clinicians, patients and their carers	√	√	x	√
Lack of understanding amongst the family	√	√	√	√
Time the clinician has to spend with the family and patient	√	x	√	√
Difficulty for clinicians when Breaking bad news	√	√	√	√
Patient wishes	x	x	√	x
Withdrawing treatment	√	x	√	√

Experience of the Clinician

Topic	Include	Lit	SR	Int
Area of work of the clinician	√	√	x	√
Intuition of the clinician	√	√	x	√
Seniority of the clinician	√	√	x	√
Previous experiences (both personal and work related) of the clinician.	√	√	x	√
Qualification of the clinician	√	√	x	√

Attitudes of the Clinician

Topic	Include	Lit	SR	Int
Fear (including of litigation)	√	√	√	√
Acceptance	√	x	x	√
Medical philosophy	√	√	√	√
Willpower	√	x	x	√
Failure	√	√	x	√
Quality	√	x	√	√
Denial	x	x	x	√

Miscellaneous

Topic	Include	Lit	SR	Int
Use of a tool	x	√	√	x

Lit, Literature; SR, Systematic Review; Int, Interviews

Two exceptions were made to this decision: in the factor “Attitudes of the Clinician” it was decided to include both of the topics “Acceptance” and “Willpower”. Although both these factors had only been identified in the interview process, both topics recurred in multiple interviews across settings.

The role of denial, also identified as a factor, was excluded from the questionnaire as it only emerged from two interviews undertaken

The initial literature review and the systematic review both highlighted the usefulness of a tool when trying to recognise the patient who is irreversibly dying. It was decided that this also would not be included in the questionnaire as many of the topics measured within these tools were covered in the topics already being included in the questionnaire (conscious levels, anorexia and cachexia) and also because none of the tools identified had been validated for use in this context.

Once the questionnaire topics had been finalised, three members of the local hospice clinical staff (nurses Band 5 and above (n= 2) and medical consultant (n= 1)) were asked to read through the questionnaire and comment on the clarity of questions and any potential ambiguities identified (see Appendix D) as suggested by Gillham (2000). No areas of concern were identified during this process.

7.2.2 Participant Demographics

The initial email was sent out by the Secretariat of the National End of Life Care Programme to the End of Life Care Leads across England, Ireland and Wales. Within the first few days there had been a response from ten clinicians who indicated

a willingness to participate in this study. There were no further responses by the end of the fortnight, so a further invitation email was sent out. This resulted in two further members of this group agreeing to participate. One of these contacted the researcher directly by telephone for further information about the study; specifically clarification was requested regarding the approach to be taken when considering the questions in the questionnaire: whether to rate according to which factors and topics the participant would use when assessing a patient or those the participant considered would be important to include in an education package for clinicians. It was re-iterated that it was intended that the focus was to be the factors and topics that would be considered useful in an education package. It was reinforced that the study related to the identification of those factors and topics that clinicians felt warranted inclusion in this package, not whether it was an important factor for them as an individual clinician when faced with this type of decision making.

Over the following two weeks a further 12 participants completed and returned consent forms and the questionnaires. At this point round 1 of the Delphi Study was closed and the completed questionnaires analysed.

The demographics for the participants in this stage of the Delphi study can be found in Table 7.2.

In order to preserve the anonymity of each of the participants the geographical location of their place of work has been grouped into the NHS Commissioning Board regions.

Table 7.2 Participant Demographics for the Delphi Study Expert panel

		Location of work		Role		Age		Gender		Round		
No	**Work setting**	**By NHS Commissioning Board region**	**Grade**	**Nurse**	**Doctor**	**50+**	**36-50**	**M**	**F**	**1**	**2**	**3**
1	Hospice	North	Band 6	Nurse		50+			F	√	√	√
2	Hospital	London	Band 8	Nurse			36-50		F	√	√	x
3	Hospital	North	Band 8a	Nurse			36-50		F	√	x	√
4	Hospital	North	Band 8b	Nurse		50+			F	√	x	√
5	Specialist Palliative Care Unit	Midlands and East	Associate Specialist		Doctor		36-50		F	√	√	x
6	Hospital	South	Band 8	Nurse			36-50		F	√	√	√
7	Community and Hospital	London	Band 8c	Nurse			36-50		F	√	x	√
8	Hospice and Hospital	Midlands and East	Consultant		Doctor		36-50		F	√	√	x
9	Hospice and Hospital	Ireland	Band 8a	Nurse		50+			F	√	x	x
10	Hospital	South	Band 8b	Nurse		50+			F	√	√	√
11	Hospital	North	Band 8b	Nurse			36-50	M		√	√	x
12	Cancer Centre	North	Band 7	Nurse			36-50		F	√	√	√
13	Cancer Centre	South	Band 8b	Nurse			36-50	M		√	x	x
14	Community and Hospital	South	Consultant		Doctor		36-50		F	√	√	√
15	Hospital and Hospice	South	Consultant		Doctor	50+		M		√	√	√
16	Hospital	South	Band 7	Nurse			36-50		F	√	√	√
17	Hospital and Community	North	Consultant		Doctor		36-50	M		√	√	√
18	Hospital	South	Consultant		Doctor		36-50	M		√	√	√
19	Hospice and Community	South	Band 8b	Nurse			36-50		F	√	x	x
20	Hospital	London	Consultant		Doctor		36-50		F	√	x	√
21	Hospital	North	Band 7	Nurse			36-50		F	√	x	x
22	Hospital	South	Associate Specialist		Doctor	50+			F	√	√	√
23	Hospital	South	Consultant		Doctor		36-50		F	√	x	x
24	Hospital	South	Band 8b	Nurse			36-50		F	√	x	x
25	Community	London	Band 8c	Nurse			36-50		F	x	√	√
26	Hospital	Midlands and East	Consultant		Doctor	50+			F	x	√	√
27	Hospital	Midlands and East	Band 8b	Nurse			36-50		F	x	√	x
				17	**10**	**7**	**20**	**5**	**22**	**24**	**17**	**16**

The majority of clinicians who responded to the email worked in the hospital setting (19/24). The remaining five worked in palliative care units or hospices.

The geographical spread was broad. The majority of responses (45.73%) were from the south of the country, 29.15% from the north and smaller numbers from London (n=3) and Ireland (n=1).

7.2.3 Analysis of Round 1 Questionnaire

Participants were asked to score each topic on a Likert scale ranging from 0 (being of no importance) to 7 (being very important for inclusion) as shown in Table 7.3.

Table 7.3 Example of Likert scale question

Topic	1 Not important	2	3	4	5	6	7 Very important
Withdrawing treatment							

The percentage of participants scoring each topic was calculated as stated earlier (see section 5.3.5) as a measure of level of agreement between the participants for each topic.

The mean of each factor was calculated along with the standard deviation of the mean and also the inter-quartile range (IQR). The data was also presented as Box and Whisker plots as this would help identify if the results were being skewed by any outliers. This ensured that both dispersion as well as consensus were measured.

7.2.4 Patient Observation

There was only one topic in this factor where the percentage score allocated by the participants to scores 6 and 7 was a minimum of 80% (see Table 7.4). This was the breathing pattern changes that the patient exhibited.

This topic was identified as important for inclusion having 95.83% of participants scoring it at 6 or 7. This importance was enhanced by a SD of ≤1 and an IQR of 1 indicating consensus.

Table 7.4 Analysis of "Patient Observation" Round 1

Topic	% 6&7	Mean	S.D.	IQR
Patient Observation				
Conscious level of the patient	66.66	5.87	1.23	2
Patient's ability to carry out the Activities of Daily Living	37.5	4.95	1.32	3
Pain	37.5	4.71	1.47	4
Breathing pattern changes	95.83	6.46	0.76	1
Anorexia and cachexia	37.5	4.75	1.17	2
Blood pressure, pulse, temperature	20.83	3.96	1.30	2
Colour of the patient	29.16	5.21	1.05	1

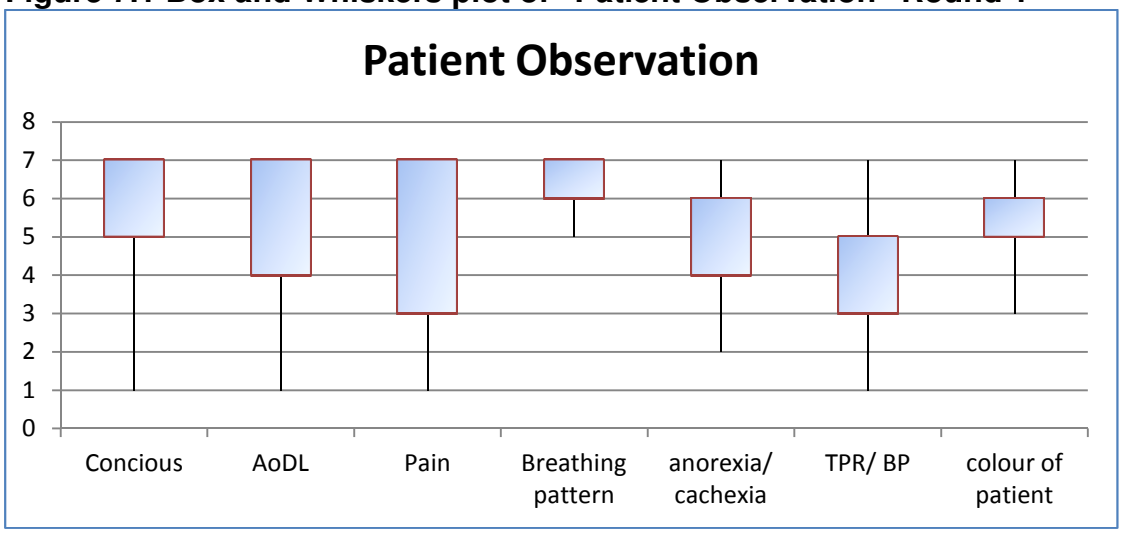
The only other topic with a low IQR was the colour of the patient (see Table 7.4). Although the IQR was the same as the topic achieving consensus this was related to the fact that a high proportion of participants had scored this factor at 5 (n= 12). Therefore although the data was not widely dispersed as identified in the Box and Whisker Plot (see Figure 7.1) a form of consensus had been achieved in that this topic was seen as being neither extremely important nor of no importance at all by the majority of the panel.

When this topic was analysed further across the roles of the Delphi participants it was clear that both doctors (88.89%, SD 0.77 and IQR 1) and nurses felt that this was a significant factor but with nurses placing more emphasis on its importance (100%, SD 0.51 and IQR 1). This may relate to the fact that nurses tend to have day to day physical contact with the patient and therefore this may be a factor that they are more likely to recognise.

The data across this factor was re-checked to ensure that it was not being skewed by one participant having differing views to the others on the panel as there appeared to be a consistent outlier. It was identified that the low scoring outliers had

been provided by two participants, both nurses and both working in the hospital setting.

Figure 7.1 Box and Whiskers plot of "Patient Observation" Round 1



7.2.5 Knowledge of the patient

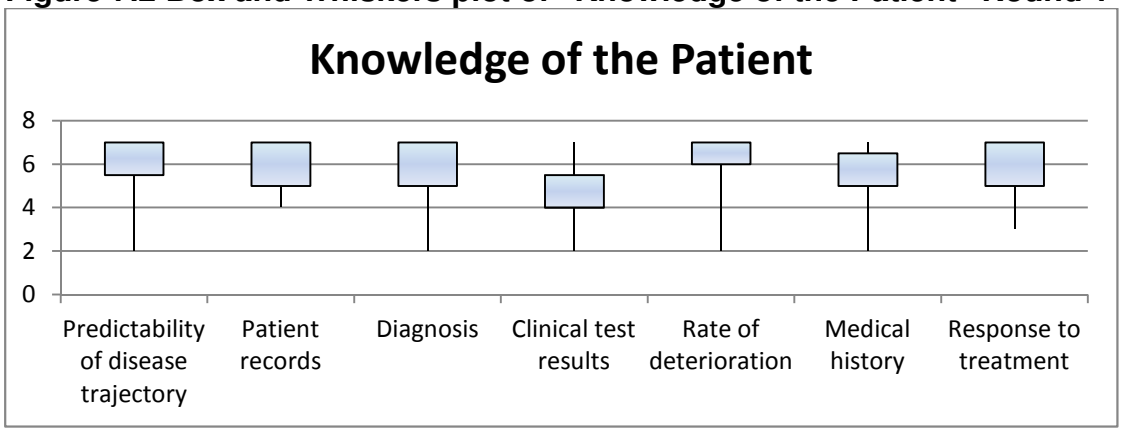
Only one topic was identified within the factor "Knowledge of the patient" by the panel of experts as being useful in an education package aiming at helping clinicians to recognise irreversible dying (see Table 7.5). This was the rate at which the patient's condition deteriorated. This topic scored 91.66% and once again had an IQR of 1 which increases its likely usefulness in this context. The SD of this factor however was 1.58 showing that there is the potential here for the significance of this finding to be reduced. In order to ensure that there was no skew of the data a review of the Box and Whisker plot identified that although the SD was 1.58 there was an outlier which accounted for this (see Figure 7.2).

Table 7.5 Analysis of "Knowledge of the Patient" Round 1

Topic	% 6&7	Mean	S.D.	IQR
Knowledge of the Patient				
Predictability of the disease trajectory	75	5.96	0.87	1.5
Patient records	54.16	5.71	1.01	2
Diagnosis	62.5	5.75	1.15	2
Clinical test results e.g blood tests, scans	25	4.54	1.20	1.5
Rate of deterioration	91.66	6.29	1.58	1
Medical history	62.5	5.46	1.21	1.5
Response to treatment	62.5	5.67	1.36	2

When the data was explored across the roles of the clinicians it was clear that rate of deterioration was an important topic to both roles but fractionally more so to doctors. The figures may be skewed with the SD identifying outliers in both roles (doctors 1.58, nurses 1.06). Once this was re-checked this seemed unlikely with five different participants scoring 2 on the five different topics containing outliers. Predictability of disease trajectory was also of significance to the doctors (88.89%, SD 0.75, IQR 1).

Figure 7.2 Box and Whiskers plot of "Knowledge of the Patient" Round 1



Despite the weaknesses identified, as the percentage of participants indicating that this was an important factor for inclusion in an education package was so high, it was decided that the factor "Rate of Deterioration" had achieved consensus.

7.2.6 Communication

On analysis of this factor it was clear that this area resonated with the panel as to its relevance for inclusion. Three of the six themes achieved consensus in this first round (see Table 7.5) these being

- Multi-professional team working
- Time the clinician has to spend with the family and patient
- Withdrawing treatment

All of these topics scored 87.57% and had an IQR of 1. The SD of these three topics were also all ≤1suggesting that they were of importance to the panel.

Table 7.6 Analysis of "Communication" Round 1

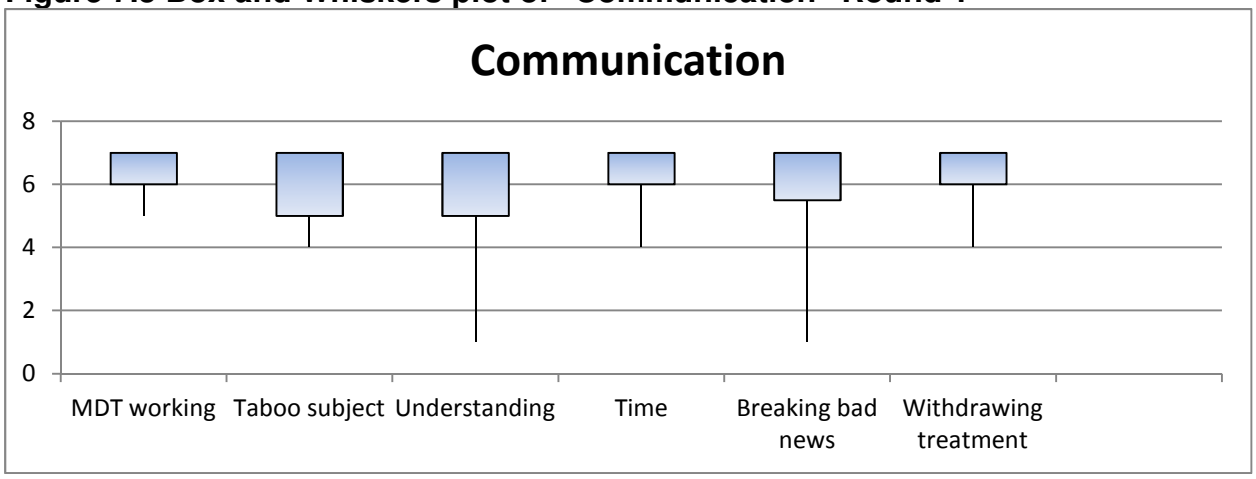
Topic	% 6&7	Mean	S.D.	IQR
Communication				
MPT Working	87.57	6.37	0.81	1
Taboo subject for clinicians, patients and their carers	66.66	6	1.01	2
Lack of understanding amongst the family	70.83	5.91	1.17	2
Time the clinician has to spend with the family and patient	87.57	6.21	0.99	1
Difficulty for clinicians when breaking bad news	75	5.92	1.16	1.5
Withdrawing treatment	87.57	6.39	0.87	1

The Box and Whisker plot indicates that the data for two of these topics was skewed by outliers with SD of ≥ 1 and an IQR of ≤ 1 these were:-

- Lack of understanding amongst the family
- Difficulty for clinicians when breaking bad news

On re-checking the data it was identified that the outlier for both of these topics was one medical participant working in the acute sector.

Figure 7.3 Box and Whiskers plot of "Communication" Round 1



On considering the data across roles the findings from the nursing participants closely mirrored the over-all analysis. The doctors on the panel however, considered these topics to be less key in an education package with consensus only being achieved for one topic, the withdrawing of treatment (88.89%, SD 0.76, IQR 1).

It was clear that the expert panel felt that these three topics warranted inclusion in an education package relating to this area.

7.2.7 Experience of the Clinician

The next area that the panel rated were the topics included in the factor "Experience of the Clinician".

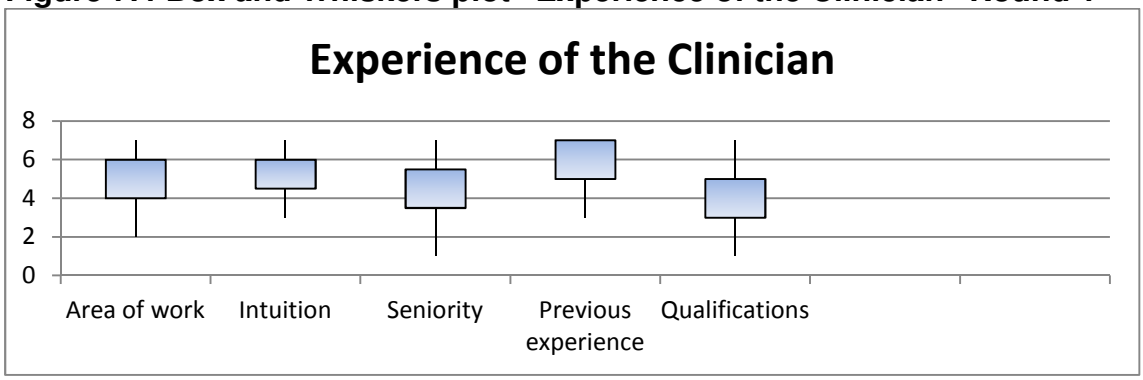
The expert panel did not identify this theme as being of use in this context with all of the topics having a SD and IQR of ≥ 1 (see table 7.7). Even when considered across roles that there was no consensus suggesting that these topics were important to include in an education package.

Table 7.7 Analysis of "Experience of the Clinician" Round 1

Topic	% 6&7	Mean	S.D.	IQR
Experience of the clinician				
Area of work of the clinician	41.66	4.92	1.25	2
Intuition of the clinician	50	5.37	1.24	1.5
Seniority of the clinician	24	4.04	1.28	2
Previous experiences (both personal and work related) of the clinician.	58.33	5.71	1.16	2
Qualification of the clinician	12.5	4.04	1.17	2

When the data was transferred into a Box and Whiskers plot (see Figure 7.4) it was clear that although the percentage scores were not high and the data was widespread for each topic there was some consensus around the middle scores of the Likert scale and it was therefore decided to retain this category in the next round.

Figure 7.4 Box and Whiskers plot "Experience of the Clinician" Round 1



7.2.8 Attitudes of the Clinician

The final topics to be analysed were those grouped under the factor "Attitudes of the Clinicians".

One topic in this factor achieved consensus, the role that quality had in this context (see Table 7.8). This topic appeared to be important for inclusion with 95% of the panel scoring it at 6 or 7 on the Likert scale and it also had a low IQR (1) and SD.

When the data was transferred into a Box and Whisker plot (see Figure 7.5) there was only one significant outlier and this was in the topic “failure”. This was identified as being from a nurse participant working in the acute hospital setting.

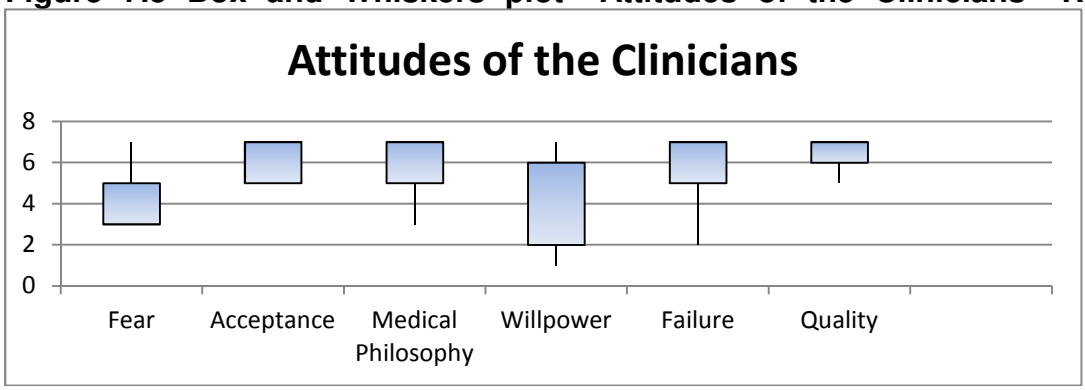
When this was factor was analysed across the role of the participant it became clear that none of the doctors thought this was an important area with none scoring any topics as important for inclusion in an education package. The nurses reflected the overall findings but with increased consensus indicated by a SD of 0.59.

Table 7.8 Analysis of “Attitudes of the Clinician” Round 1

Topic	% 6&7	Mean	S.D.	IQR
Attitudes of the clinicians				
Fear (including of litigation)	60.86	5.74	1.06	2
Acceptance	73.91	6.09	0.99	2
Medical philosophy	72.72	5.95	0.99	2
Willpower	31.57	4.16	1.37	4
Failure	60.86	5.64	1.18	2
Quality	95	6.4	0.74	1

The decision was made to accept that consensus has been achieved for the topic “quality”. All remaining topics would be retained for round 2.

Figure 7.5 Box and Whiskers plot “Attitudes of the Clinicians” Round 1.



7.2.9 Summary of findings of round 1

In this first round five factors were rated by the expert panel. These had been sub-divided into 31 topics. Consensus was achieved in six topics that they should be included in an education package. The remaining 25 topics would be carried forward into round 2. The factor containing the majority of topics to achieve consensus was that of “Communication”. The only factor where none of the topics achieved consensus was “Experience of the Clinician”

7.3 Round 2

7.3.1 Factors and Topics Included in the Second Questionnaire

All factors and topics that had not achieved consensus in the first round were included in round 2 of this Delphi Study (n=25). The comments provided by the participants on each factor in the responses to the first questionnaire were then taken into consideration.

There were no comments made regarding any difficulties with the rating system by any of the participants of this round but there were several further topics within each factor that different participants felt warranted inclusion for rating (n=22). It was decided to include all topics mentioned as they may prove to be important to the experts (see Table 7.9). It was noted that there was no consensus between the participants regarding these new topics with each being identified by a single participant.

The factor “age of the patient” (Knowledge of the Patient) had been excluded from round 1 during the development of the questionnaire as there was limited reference

to this topic in the systematic review and the interviews and it was not thought to be relevant to education but as it had now been identified as a potential factor by experts in the field it was felt that it should be included at this stage.

It was also suggested that some of the topics included in the original questionnaire needed to be broken down further as the participants were being asked to rate multiple topics as one (two topics now becoming five). One participant suggested that in the factor labelled “Patient Observation” anorexia and cachexia and blood pressure, pulse and temperature should all be separated out in order to help identify which of these factors was of most relevance. In the factor labelled “Attitudes of the Clinician” it was suggested by a different participant that the topics “Fear”, “Acceptance”, “Medical Philosophy”, “Willpower” and “Death” should be expanded on to improve clarity (See Table 7.9). The questionnaire was then adjusted to reflect the suggestions made regarding all 50 topics now identified.

Table 7.9 Factors and topics included in Round 2 Questionnaire

Factor	Topic
Patient Observation	Conscious level of the patient
	Patient's ability to carry out the activities of daily living
	Pain
Split out	Anorexia
	Cachexia
Split out	Blood pressure
	Pulse
	Temperature
	Colour of the patient
New	Body tone
	Gastric absorption
	Terminal agitation
Knowledge of the Patient	Predictability of disease trajectory
	Patient records
	Diagnosis
	Clinical test results e.g. blood tests, scans
	Medical history
	Response to treatment
New	Previous resuscitation decisions
	Advance care plans
	Patient's own knowledge of imminent death
	Age of patient
	Treatment options the patient wants to try have run out
	Exclusion of reversible causes
Communication	Taboo subject for clinicians, patients and their carers
	Lack of understanding amongst the family
	Difficulty for clinicians when breaking bad news
New	Family preferences and wishes
	Patient preferences and wishes
	Uncertainty
	Consistent communication with families- not raising false hope
	Requests for suicide/ euthanasia
Experience of the Clinician	Area of work of the clinician
	Intuition of the clinician
	Seniority of the clinician
	Previous experiences (both personal and work related) of the clinician
	Qualification of the clinician
New	Frequency of dealing with the dying patient
	Perceived seniority being a barrier to MDT working
Attitudes of the Clinician	Fear that they will not know the answer to questions asked or that family pressures could lead to litigation
Definitions expanded	Acceptance that the patient is dying
	Medical philosophy of cure
	Willpower of the patient to reach a target
	Death being seen as failure
New	Culture of the patient
	Spiritual issues for the patient
	The importance of hope to the patient
	Religion
	Willingness to champion patient wishes
	Courage to challenge systems

7.3.2 Round 2 Participants

The second round of the questionnaire was then sent out to the 24 participants who had responded to round 1. Fifteen participants returned the questionnaire within the two week time frame, two of these being participants who had not taken part in the first round. It was possible that clinicians approached for round 1 had passed the questionnaire on to their colleagues, perhaps thinking that it was more pertinent to their roles. The email was re-sent removing from the group address those who had either already completed and returned the questionnaire or notified the researcher that they wished to be withdrawn from the study. This resulted in a further two participants responding, one of these also being a new participant.

Of these new participants one came from London and the other two from the Midlands and East region. Two were nurses and in the 36-50 age bracket. Two worked in the hospital setting supporting the concept that this is the area where there has been most interest shown in this study. Eight of the non-responders to this second round worked in the hospital setting (see Table 7.2).

There were ten participants who responded in the first round and who did not respond to the second, of these seven were nurses and the only male to drop out at this stage was one of these. This would possibly suggests that doctors still feel that the recognition of the irreversibly dying patient rests with them but also some awareness that they are uncertain of how to achieve this with any accuracy.

Of the ten participants who chose to withdraw from the study three contacted the primary researcher in order to clarify their reasons for non-participation. The rationale for withdrawal provided were:-

- A change in role and therefore no longer working in end of life care making it inappropriate to continue
- Resignation from post
- Struggling with the rating system

Changing the rating system was considered but as no other participants had expressed concerns it was decided not to at this stage although there is the potential that some of the other non-responders may have been challenged by this.

7.3.3 Analysis of Round 2 Questionnaires

Once the questionnaires from this round had been returned the data obtained was once again transferred into a table in order to help identify the percentage of participants scoring at points 6 and 7 on the Likert scale. It was also decided to check for consensus at scores 1 and 2 which would indicate consensus that this factor or topic would not be of use in an education package. Following this the mean, standard deviation and the inter-quartile range were also calculated as a means of identifying both the consensus of the scores and their dispersion.

The participant response rate was 58.33% (n =14/24) of which three were new. Thus the final number of participants included in the analysis of round 2 was 17.

7.3.4 Patient Observation

The first factor to be analysed was the factor "Patient Observation" (see Table 7.10).

Only one topic in this factor achieved consensus with 82.35% of the expert panel scoring its significance at 6 or 7 on the Likert scale. This finding was further supported by the fact that the IQR was 0 and the SD ≥ 1 indicating that the data was not widespread thus demonstrating consensus.

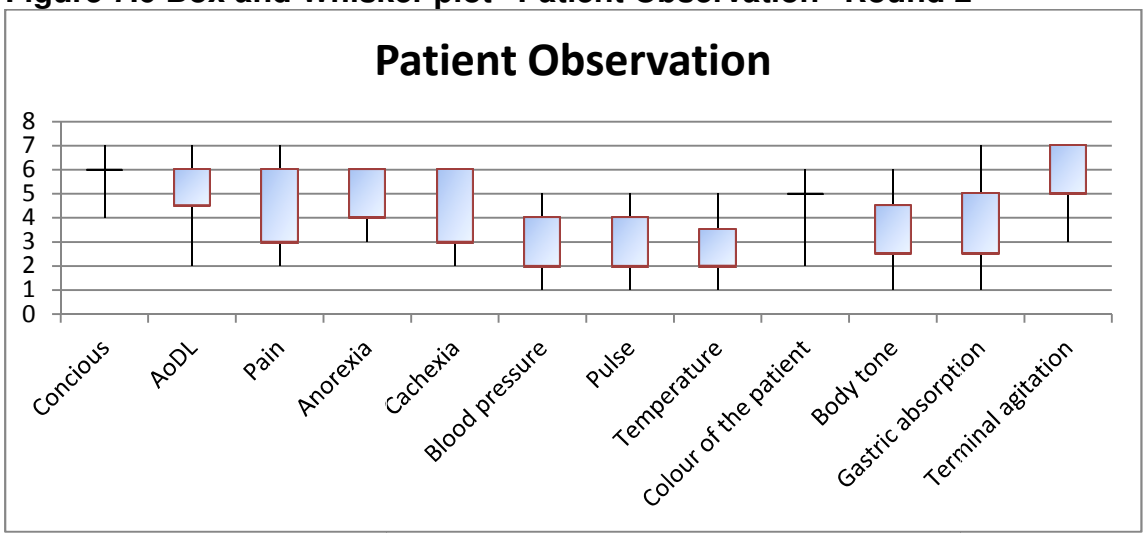
Table7.10 Analysis of "Patient Observation" Round 2

Topic	% 6&7	% 1&2	Mean	S.D.	IQR
Patient Observation					
Conscious level of the patient	82.35	0	5.94	0.60	0
Patient's ability to carry out the Activities of Daily Living	41.17	5.88	5.06	1.10	1.5
Pain	29.41	11.76	4.18	1.04	3
Anorexia	29.41	0	4.82	0.58	2
Cachexia	29.41	5.88	4.41	0.82	3
Blood pressure	0	41.18	2.82	0.79	2
Pulse	0	41.18	2.76	0.80	2
Temperature	0	47.05	2.65	0.81	1.5
Colour of the patient	17.64	5.88	4.88	0.80	0
Body tone	5.88	23.52	3.53	1.04	2
Gastric absorption	5.88	23.52	3.53	1.21	2.5
Terminal agitation	58.82	0	5.76	0.89	2

It was clear that none of the participants felt that the topics blood pressure, pulse or temperature would be useful in an education package with none of the participants scoring it at 6 or 7 and the IQR being 2. The SD however, was below 1 suggesting that although there was no consensus apparent for inclusion in an education package in this context there was some consensus in that the large majority of participants scored it at the same level with few outliers skewing the data. This was supported when the data was transported into a Box and Whisker plot (see Figure 7.6).

In general this appears to be a factor where there is considerable disagreement between the participants as to the importance of topics for inclusion in this education package with a wide range of scores within the data indicating limited consensus.

Figure 7.6 Box and Whisker plot "Patient Observation" Round 2



When the data was analysed with reference to the role of the participant it was clear that there were differing priorities; the doctors identifying the conscious level of the patient as significant (87.5%, SD 0.71 and IQR 0) whereas the nurses suggested that for their role, the relevance of terminal agitation was more important for inclusion in the education package (88.88%, SD 0.32 and IQR 1).

Consensus on conscious level of the patient was accepted as being achieved.

7.3.5 Knowledge of the patient

On analysis of this factor only two topics achieved consensus amongst the panel as to importance for inclusion in an education package (see Table 7.11). These were:-

- Predictability of disease trajectory (82.35%)

- Exclusion of reversible causes (100%)

In round 1, 75% of the participants indicated that the predictability of the disease trajectory was an important factor for inclusion in an education package. This percentage increased to 82.35% in round 2 thus achieving consensus. This is accounted for by the fact that all three new participants to this round scored it highly where only one participant who had scored it highly in round 1 had withdrawn from the study. It was also clear that this was a factor that the doctors in particular valued (87.5% v 77.77%).

Table 7.11 Analysis of "Knowledge of the Patient" Round 2

Topic	% 6&7	% 1&2	Mean	S.D.	IQR
Knowledge of the patient					
Predictability of the disease trajectory	82.35	0	5.88	0.36	0
Patient records	58.82	0	5.53	0.84	1
Diagnosis	17.65	82.35	2.59	1.85	0.5
Clinical test results e.g blood tests, scans	35.29	0	4.94	0.65	2
Medical history	17.65	82.35	2.53	1.44	1
Response to treatment	70.58	11.76	5.53	0.97	0.5
Previous resuscitation decisions	41.17	5.88	5.12	1.01	2
Advance care plans	64.70	17.65	5.29	1.15	3.5
Patient's own knowledge of imminent death	58.82	5.88	5.47	1.03	2.5
Age of patient	5.88	35.29	3.44	1.08	3
Treatment options the patient wants to try have run out	35.29	11.76	4.56	1.42	2.5
Exclusion of reversible causes	100	0	6.59	0.17	1

Exclusion of reversible causes had not been included in the first questionnaire but had been identified by the experts for inclusion in round 2. On analysis, it was clear that this was a topic that was regarded to be of importance by the panel with immediate consensus being achieved.

The significance of these percentages was enhanced by low SD and IQR for both of these factors (see Table 7.11).

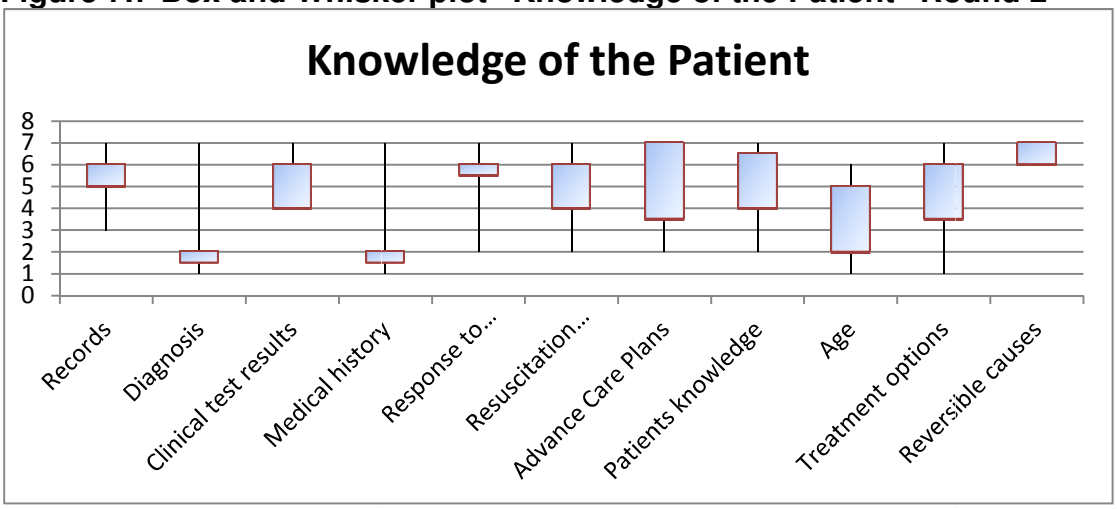
Two further topics achieved consensus at points 1& 2 on the Likert scale signifying that these are not necessary in an education package. These were:

- Diagnosis
- Medical History

Five topics in this factor ("Previous resuscitation decisions", "Advance care plans", "Patient's own knowledge of imminent death" and "Age of the patient") were identified as having limited importance for inclusion in an education package all having a SD of ≤ 1 and IQRs of between 2 and 3 suggesting a wide range of scores across the data and thus a potential skewing of the results by outliers. This was confirmed when the data was transferred to a Box and Whisker plot (see Figure 7.7). These topics had all been identified as potential areas to be assessed for importance of inclusion in an education package in the comments from participants in round 1 of the study.

The data for some of the topics within this factor was potentially skewed as three of the topics to be scored by the panel ("Clinical test results", "Age of the patient" and "Treatment options the patient wants to try have run out") were omitted each by one nurse participant. This may have been an accidental omission as no comments were made regarding these topics by these participants.

Figure 7.7 Box and Whisker plot "Knowledge of the Patient" Round 2



The translation of the data into the Box and Whisker plot (see Figure 7.7) clarified the fact that there were outliers in particular in whether diagnosis or medical history warranted inclusion in an education package although consensus had been achieved.

When the data was analysed across roles of the experts the doctor's analysis related closely to the over-all findings except for "Response to treatment" which they rated highly (87.5%, SD 0.53 and IQR 0). The nurses however, suggested that inclusion of the use of "Advance care plans" (88.88%, SD 0.29, IQR 1) would be more useful.

Of the three outlying participants that scored "Diagnosis" highly one was a doctor and two nurses. "Medical history" was again scored as being not relevant for inclusion by two nurses and one doctor, this time a different doctor however, these were the same nurse participants. On checking the demographic data it was found that both these nurses worked in the same hospital and therefore there was the potential that there had been some conferring when rating these topics.

In summary, of the topics identified in the comments from the expert panel of round 1 for this factor, only one achieved consensus for inclusion ("Exclusion of reversible causes"). Four topics from this factor achieved consensus for exclusion from an education package and therefore would not be carried through to the next round leaving eight for rating in round 3.

7.3.6 Communication

The third factor to be analysed was that of the importance that the panel of experts allocated to the factor "Communication" when deciding what needed including in an education package for clinicians to aid with the recognition of irreversible dying.

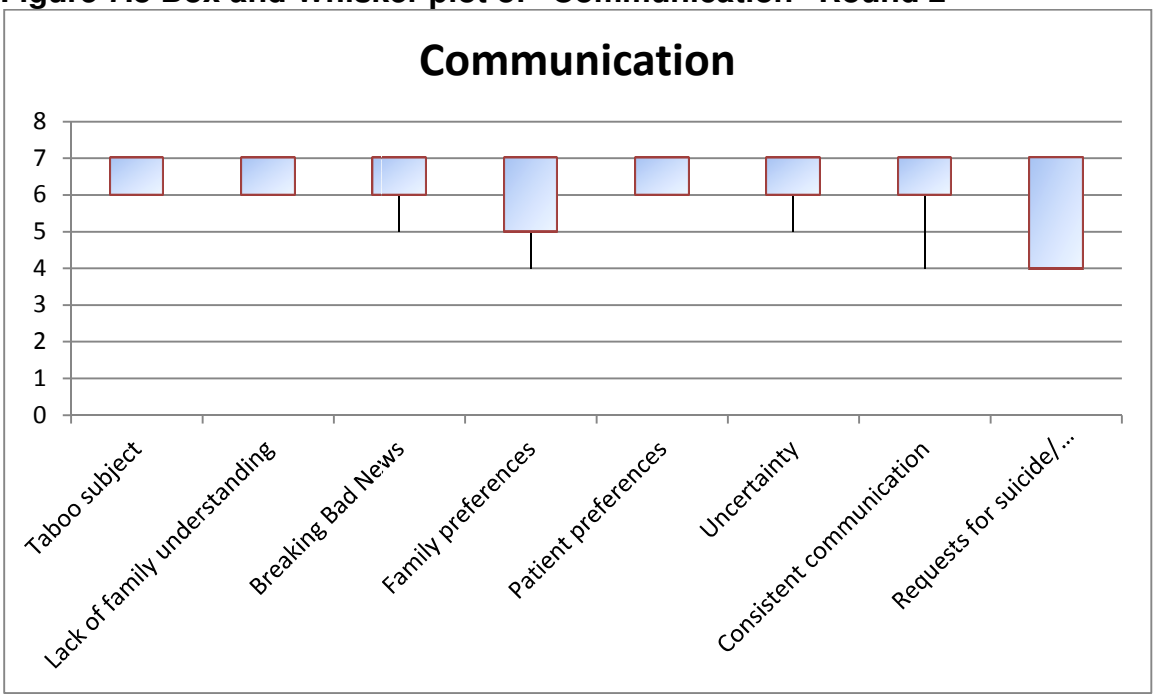
It was clear that this was a factor that the panel considered important with only two of the topics rated not achieving consensus that they were not important to include, these being the role of "Family preferences and wishes" and "Requests for either suicide or euthanasia" (see Table 7.12).

Table 7.12 Analysis of "Communication" Round 2

Topic	% 6&7	% 1&2	Mean	S.D.	IQR
Communication					
Taboo subject for clinicians, patients and their carers	100	0	6.59	0.17	1
Lack of understanding amongst the family	100	0	6.41	0.17	1
Difficulty for clinicians when breaking bad news	94.12	0	6.41	0.40	1
Family preferences and wishes	58.82	0	5.76	0.58	2
Patient preferences and wishes	100	0	6.53	0.17	1
Uncertainty	94.12	0	6.41	0.40	1
Consistent communication with families- not raising false hope	94.12	0	6.47	0.64	1
Requests for suicide/ euthanasia	41.17	0	5.29	0.56	3

Both of these factors had an IQR of ≤ 2 but the standard deviation for both was low suggesting that there was a wider spread of data across these two topics. This was confirmed when the data was transferred to a Box and Whisker plot (see Figure 7.8).

Figure 7.8 Box and Whisker plot of "Communication" Round 2



When the data relating to these factors was explored across the roles of the participants it became clear that doctors and nurses considered these to be equally important with the same six factors being indicated as being of benefit in an education package as in the over-all analysis. The six factors achieving consensus were therefore excluded from the next round of the questionnaire.

7.3.7 Experience of the Clinician

How the varying levels of "Experience of the Clinician" were valued by the experts in this context was the next factor analysed.

Table 7.13 Analysis of "Experience of the Clinician" Round 2

Topic	% 6&7	% 1&2	Mean	S.D.	IQR
Experience of the clinician					
Area of work of the clinician	17.65	82.35	2.35	1.14	1
Intuition of the clinician	0	0	5.23	0.80	1
Seniority of the clinician	5.88	88.23	2	1.114	1
Previous experiences (both personal and work related) of the clinician.	0	0	5.12	0.79	1.5
Qualification of the clinician	11.76	11.78	3.88	0.79	2
Frequency of dealing with the dying patient	0	0	5.37	0.58	1
Perceived seniority being a barrier to MDT collaboration	0	0	4.70	0.56	2.5

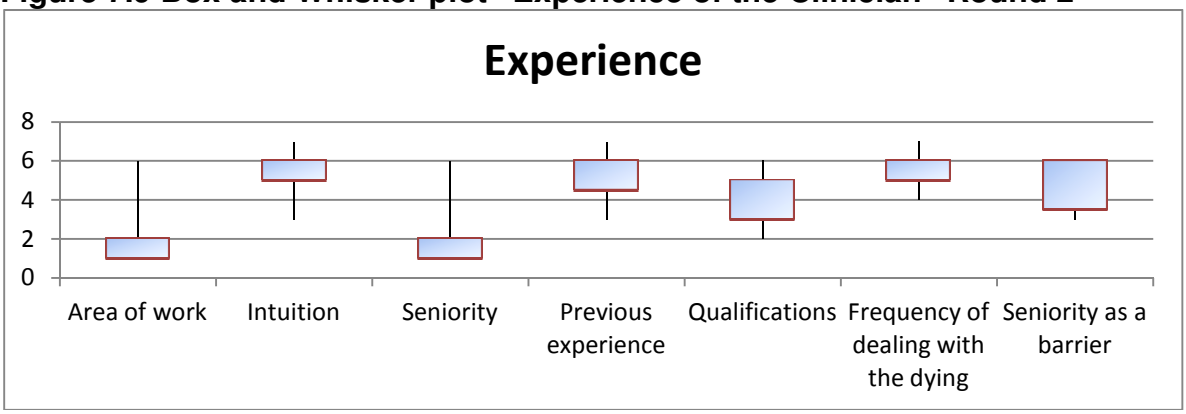
Unlike the factor communication, the panel appeared to suggest that this factor may have less of a role in an education package with a very small percentage of clinicians rating any of the topics in this group at 6 or 7 on the Likert scale (see Table 7.13). Two topics were rated at 1 or 2 by over 80% of the participants indicating that these would not be useful in an education package. Both of these topics had outliers as can be seen in the Box and Whisker plot (see Figure 7.9). In total there were three outliers in the topic "Area of work of the clinician". All of these were responses from nurses, two working in the hospital setting. One of these participants was an outlier in both topics and was the only outlier in the topic "Seniority of the clinician".

One topic in this factor was not ratred by one participant ("Frequency of dealing with the dying patient") with no comment made as to why. It may have been an error or a topic that this doctor had difficulty in rating regarding its usefulness in an education package. This may potentially have skewed the data.

However, the IQR for four factors suggested that the data was not particularly widespread and the SD for three of these topics was ≥ 1 again indicating some consensus amongst the participants as not rating this highly as needing either

inclusion in or exclusion from an education package. This was clarified by transferring the data to a Box and Whisker plot (see Figure 7.9).

Figure 7.9 Box and Whisker plot "Experience of the Clinician" Round 2



When this factor was analysed across the role of the participants there appeared to be few differences between the opinions of the doctors and nurses regarding the limited importance they considered this area to be for inclusion.

Having completed the analysis it was decided to remove the two topics achieving consensus as not being important for inclusion in an education package leaving five topics to be rated in the third round.

7.3.8 Attitudes of the Clinicians

Finally the factor of the "Attitudes of the Clinicians" involved in this process was analysed. Two topics in this factor were identified as having achieved consensus with percentage scores above 80%, a SD≥ 1 and IQR of 1. These were "Acceptance" and "Medical philosophy of cure" (see Table 7.14) It was also noted that although the SD and IQR of the topic of spiritual issues were both 1 or below the

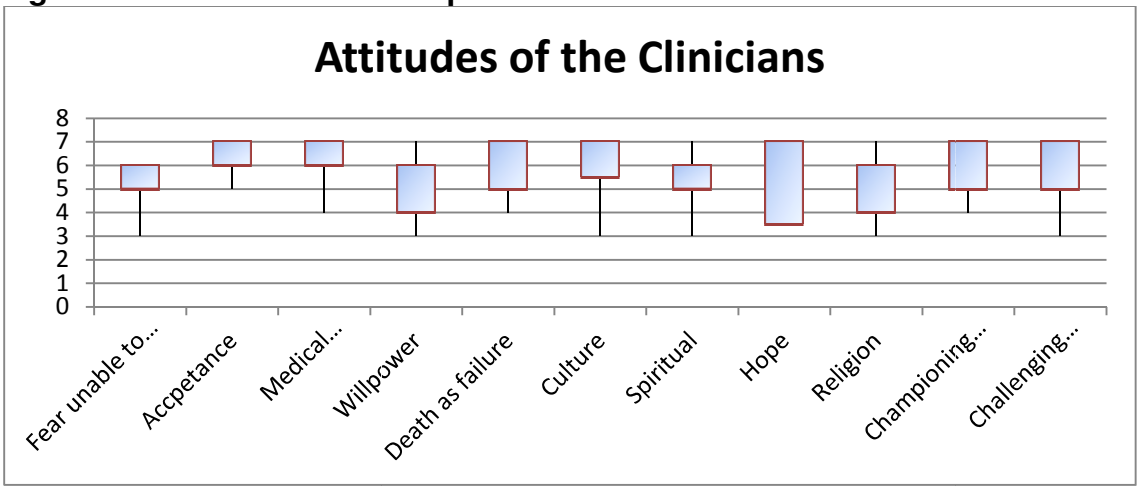
data was skewed by outliers at either end of the data range as identified when the data was transferred into a Box and Whisker plot (see Figure 7.10).

Table 7.14 Analysis of "Attitudes of the Clinician" Round 2

Topic	% 6&7	% 1&2	Mean	S.D.	IQR
Attitudes of the clinicians					
Fear that they will not know the answer to questions asked or that family pressure could lead to litigation.	64.70	0	5.59	0.79	1
Acceptance	94.11	0	6.35	0.39	1
Medical philosophy of cure	82.35	0	6.06	0.62	1
Willpower of the patient to reach a target	41.17	0	4.94	0.79	2
Death being seen as failure	70.58	0	6	0.61	2
Culture of the patient	76.47	0	5.94	0.81	1.5
Spiritual issues for the patient	52.94	0	5.41	0.82	1
The importance of hope to the patient	76.47	0	5.88	0.59	0.5
Religion	35.29	0	4.82	0.79	2
Willingness to champion patient wishes	64.70	0	5.76	0.57	2
Courage to challenge systems	70.58	0	6	0.96	2

In the data relating to the importance of hope to the patient it was clear that although there appears to be a wide range of scores these were spread equally throughout the participants resulting in no outliers.

Figure 7.10 Box and Whisker plot of "Attitudes of the Clinician" Round 2



When considered across roles there was consensus between the doctors and nurses regarding the topic the importance of the patient accepting the fact that they

are dying. However, the doctor's responses also suggested that for them, both the issue of the medical philosophy of cure and the importance of hope to the patient were significant whereas for the nurses, having the courage to challenge systems was more highly rated.

7.3.9 Summary of Findings of Round 2

At the end of round 2, 15 out of the 50 topics in the questionnaire had achieved consensus that they should be considered for inclusion in an education package so these were excluded from round 3 of the Delphi Study. The remaining 35 topics were retained for rating in round 3.

Once again, the factor "Communication" achieved the majority of consensuses with six topics achieving this. All factors being rated contained a minimum of one topic where consensus had been achieved.

7.4 Round 3

7.4.1 Factors and topics included in the Round 3 Questionnaire

The 35 topics within the five factors that did not achieve consensus in round 2 were included in the round 3 questionnaire. No additional comments or suggestions were provided for inclusion by the expert panel completing this round so the final questionnaire consisted of these 35 topics (see Table 7.15).

Table 7.15 Factors and topics included in Round 3

Factor	Topic
Patient observation	Patient's ability to carry out the activities of daily living
	Pain
	Anorexia
	Cachexia
	Blood pressure
	Pulse
	Temperature
	Colour of the patient
	Body tone
	Gastric absorption
	Terminal agitation
Knowledge of the patient	Patient records
	Clinical test results e.g. blood tests, scans
	Response to treatment
	Previous resuscitation decisions
	Advance Care Plans
	Patient's own knowledge of imminent death
	Age of patient
	Treatment options the patient wants to try have run out
Communication	Family preferences and wishes
	Requests for suicide/ euthanasia
Experience of the clinician	Intuition of the clinician
	Previous experiences (both personal and work related) of the clinician
	Qualification of the clinician
	Frequency of dealing with the dying patient
	Perceived seniority being a barrier to MDT working
Attitudes of the clinician	Fear that they will not know the answer to questions asked or that family pressures could lead to litigation
	Willpower of the patient to reach a target
	Death being seen as failure
	Culture of the patient
	Spiritual issues for the patient
	The importance of hope to the patient
	Religion
	Willingness to champion patient wishes
	Courage to challenge systems

The questionnaire was re-designed prior re-sending it as there was the possibility of the panel anticipating the factors and topics (see Appendix E). With the questionnaire in this round, the panel was supplied with the mean score of each topic from round 2 and was asked to take this into consideration whilst they were re-rating. The layout was also altered so that there was less likelihood of the participants completing it by rote.

7.4.2 Round 3 Participants

Ten participants returned the round 3 questionnaire within the time frame specified. The email was re-sent removing from the group address those who had already completed and returned this round, extending the response period by a further seven days. This resulted in a further six participants responding.

All ten participants that had returned the questionnaire promptly had taken part in all three rounds of the study. Work location appeared to be key to the interest levels shown with 80% of these immediate responders working in the hospital setting. When considered across role it was found that this may have also affected interest levels with 50% of participating doctors replying to all questionnaires whilst only 28.76% of nurses responded to all three rounds. The only two geographic locations of the initial immediate responders were the North (n=3) and South (n=7) areas. (See Table 7.2)

When explored across all 16 responding participants it was identified that four participants who had taken part in round 1 but not in round 2 had once again participated in this final round. All of these participants worked in the hospital setting, two from London and two from the North, three of them nurses and one a doctor. No reason was given for non-contribution to round 2.

These findings again appear to confirm that this subject was of particular interest to those working in the hospital setting with 81.25% (n=13) of participants located there. When considered as a percentage the split between clinical role initially appears to be reasonably even (56.25% nurses and 43.75% doctors) but when the fact that

there are fewer doctor participants than nurses is taken into account it becomes clear that this appears to be an area that proportionally, doctors are concerned about with 70% of the total of participating doctors responding to this final round.

When reviewed across geographical area it was noted that there appeared to be a higher response rate from those working in the South of the country (42.75%, n=7). None of these participants worked in the same geographical area. They were spread from Dorset to Kent.

When the data regarding non-responders to this round was examined it was found that ten previous participants had chosen not to respond to the third round. Of these six had only responded to the first round. No specific reason was provided to the researcher other than the one participant who had expressed concerns regarding the rating of the questionnaire. There is the potential that this was more of a concern amongst the participants than was recognised earlier. It is also possible that this may relate to either sickness or annual leave as four participants had responded to both rounds 1 and 2.

Seven of these non-responders worked in the hospital setting and five of these had only responded to round 1. As this was identified earlier as a work setting who appeared to have particular interest in this area this was unexpected but when role was also taken into consideration it became clear that five of the six working in the hospital setting who did not respond were nurses once again indicating that the concern relating to this topic is more focussed on the medical role.

7.4.3 Analysis of Round 3 Questionnaires

The percentage response rate of the total of participants was 59% (16/27) thus the dropout rate was 41% in total over the three rounds. However, of the sixteen responders to this third round 56.25% had completed all three rounds (n=9), 18.75% had responded to rounds 1 and 3 (n=3) and 12.50% to rounds 2 and 3 (n=2). This would suggest that there was a high level of interest amongst the participants in this subject.

7.4.4 Patient Observation

The first factor in round 3 to be analysed was that relating to the relevance that the role of observing the patient may have in this context.

When the percentage of those scoring the importance of these topics as 6 or 7 on the Likert scale was analysed it was clear that none of the remaining topics were considered as being of particular importance for inclusion in an education package.

Table 7.16 Analysis of "Patient Observation" Round 3

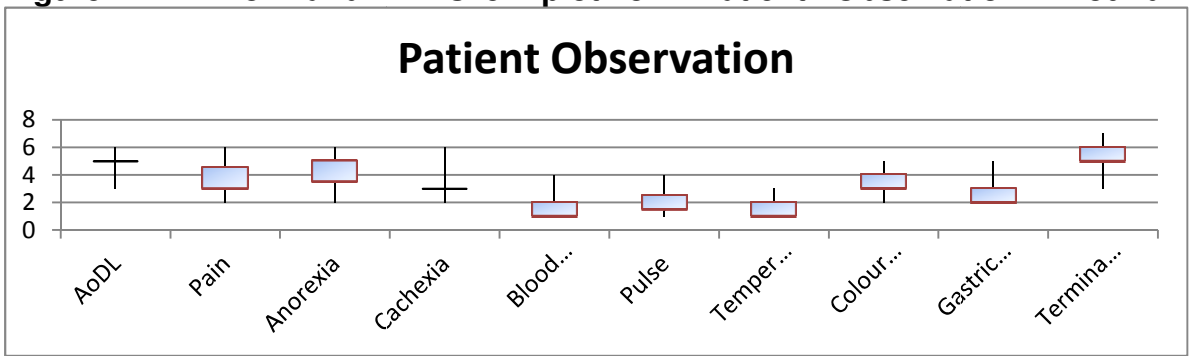
Topic	% 6&7	%1&2	Mean	S.D.	IQR
Patient Observation					
Patient's ability to carry out the Activities of Daily Living	18.75	0	4.87	0.68	0
Pain	6.25	18.75	3.87	1.05	1.5
Anorexia	6.25	6.25	5.37	1.59	1.5
Cachexia	6.25	6.25	3.81	0.95	1
Blood pressure	0	87.5	1.89	0.78	1
Pulse	0	87.5	2	0.87	1
Temperature	0	81.25	1.80	0.73	1
Colour of the patient	0	18.75	3.25	0.83	1
Body tone	0	31.25	1.47	1.65	1.5
Gastric absorption	0	43.75	2.75	0.82	1
Terminal agitation	43.75	0	5	1	1

However, when the percentages rating at 1 or 2 for importance that is, of no importance for inclusion in an education programme, it was clear that there were three factors considered to be of little relevance (see Table 7.16), these being

- Blood pressure
- Pulse
- Temperature.

This finding was supported by all these factors having a SD of less than 1 and an IQR of 1 suggesting that the data was centralised around the lower scores with no major outliers (see Figure 7.11).

Figure 7.11 Box and Whisker plot of "Patient Observation" Round 3



There were four other topics where a SD of ≥1 was accompanied by an IQR of 1 or less. These were:-

- The patient's ability to carry out activities of daily living
- Cachexia
- Colour of the patient
- Gastric absorption

These indicted some consensus that these topics may be moderately important but would not be amongst the top priorities for inclusion in this package.

When this category was analysed across role of the participant it was clear that this was a factor that nurses felt was of more relevance to them with only two factors having an IQR ≤1 (body tone and gastric absorption) and all having a standard deviation of 1 or less. This may relate to the fact that nurses tend to have more day to day contact and therefore patient observation for them is key to this process of recognition. Although there was no consensus regarding what it was important to include it was clear that the nurses dismissed the use of blood pressure or pulse with 87.5% scoring these factors as being of no relevance in an education programme.

7.4.5 Knowledge of the Patient

When percentages were analysed across this factor it was clear that there was a lack of consensus in either the high or low scoring categories indicating a lack of consensus amongst the experts as to whether these factors were either highly important or of no importance (see Table 7.17).

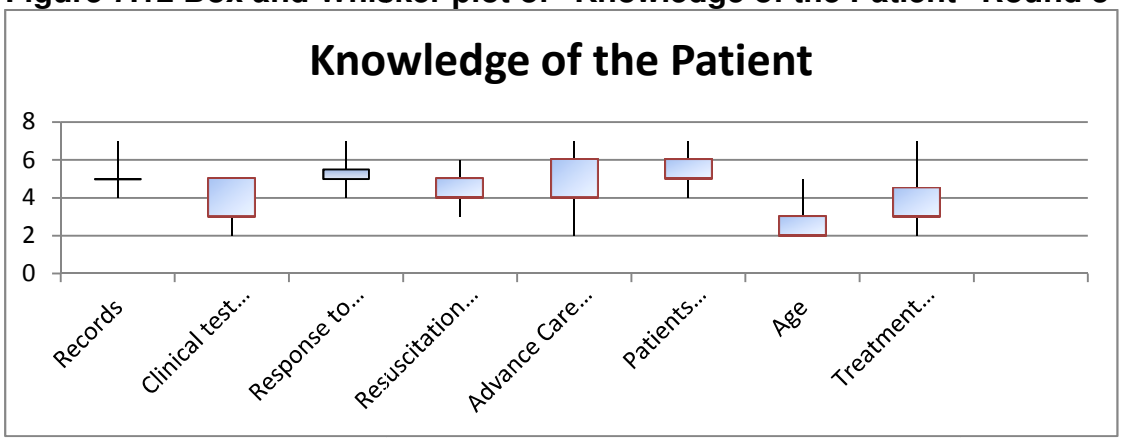
Table 7.17 Analysis of "Knowledge of the Patient" Round 3

Topic	% 6&7	%1&2	Mean	S.D.	IQR
Knowledge of the patient					
Patient records	33.33	0	5.25	0.66	0.5
Clinical test results e.g blood tests, scans	0	18.75	3.81	1.08	2
Response to treatment	18.75	0	4.69	0.97	0
Previous resuscitation decisions	12.50	0	4.56	0.79	1
Advance care plans	31.25	6.25	4.81	1.24	2
Patients own knowledge of imminent death	31.25	0	5.19	0.81	1
Age of patient	0	43.75	2.69	0.66	1
Treatment options the patient wants to try have run out	12.50	18.75	3.75	1.35	1.5

When the SD and IQR were calculated it was identified that the above suggestion, that these factors were neither important for inclusion or exclusion in an education package was supported. The panel indicated that the topics contained in this factor

would not be their top priorities for inclusion when educating clinicians in this context (see Table 7.17).

Figure 7.12 Box and Whisker plot of "Knowledge of the Patient" Round 3



When this data was transferred into a Box and Whisker plot for ease of reading only two topics had any major outliers (see Figure 7.12).

The topic "Advance Care Plans" had outliers at both ends of the scale one rating it at two and the other at seven. This may be accounted for by the role of the participant with the nurse valuing it highly whilst the doctor indicating that this topic was of little relevance.

The second topic with outliers was "when treatment options the patient wants to try have run out". Three participants rated this at 2, two of them nurses and one a doctor. The only participant rating this topic at seven was a nurse.

When this factor was analysed as a whole across the clinical role of the participant no major differences of opinion were noted with the majority of the scoring being

centralised and therefore no topics achieving consensus for inclusion in or exclusion from an education package.

7.4.6 Communication

By this third round there were only two topics remaining in the factor of communication where consensus had not already been achieved, these were the preferences and wishes of the families and any requests for euthanasia or mention of suicide by the patient. This fact on its own would indicate that communication issues should be the central focus of any education package developed as a result of this study.

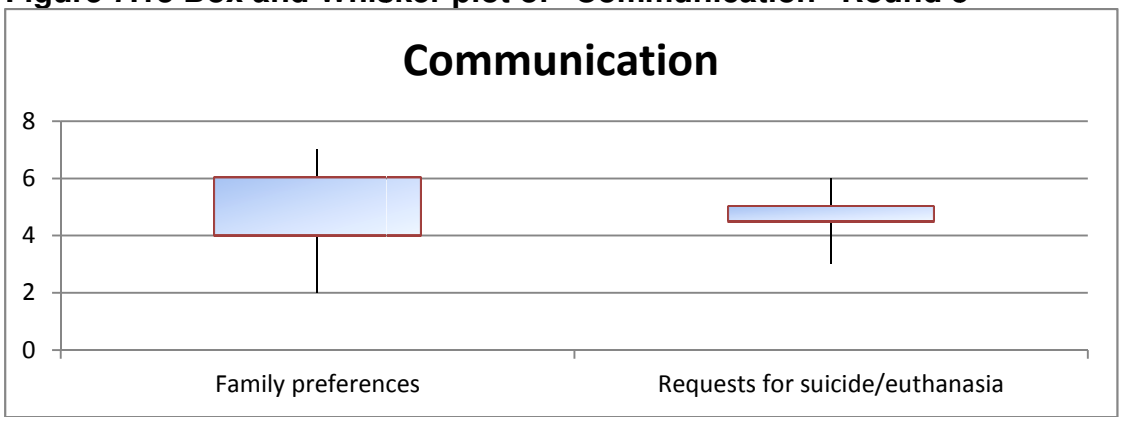
When these two last topics were analysed it was clear that, as with the previous category, there was no consensus as to the importance of the inclusion or exclusion of these in an education package. This was once again confirmed when the SD and IQR scores were taken into account which indicated that these two topics were not the top priority for inclusion in an education package (see Table 7.18).

Table 7.18 Analysis of "Communication" Round 3

Topic	%6&7	%1&2	Mean	S.D.	IQR
Communication					
Family preferences and wishes	12.50	6.25	4.81	1.29	2
Requests for suicide/euthanasia	6.25	6.25	4.31	1.04	0.5

When the data was transferred to a Box and Whisker Plot for ease of reading it was clear that the data for the topic "Family preferences" was widespread. One outlier rated it at 2 and one scored it at seven. One of these was a nurse and one a doctor, the doctor being the participant giving the lower score (see Figure 7.13).

Figure 7.13 Box and Whisker plot of "Communication" Round 3



When the data was analysed across the roles of the panel it appeared that the nurses tended to be centralised when rating these topics whereas the doctor's data was more widespread with both of these topics having an IQR of 2 and SD of≥ 1. This may relate once again to the fact that the nursing staff tend to have more day to day contact with both patients and their families.

7.4.7 Experience of the Clinician

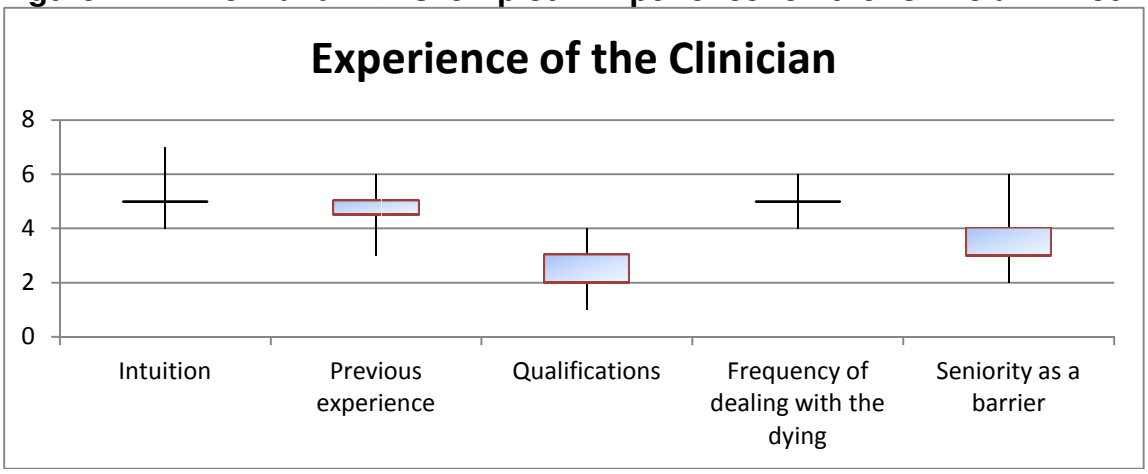
The fourth factor analysed was that of the relevance of including the experience of the clinician as a topic in an education package. The statistics indicated that this was a factor that the experts did not feel strongly about when considering an education package with the majority of the experts rating the topics as being neither very important nor of no relevance at all (see Table 7.19). This is confirmed by the fact that the SD were all below 1 and only 1 IQR was above 1 and yet the percentages for scoring 1&2 or 6&7 were very low.

Table 7.19 Analysis of "Experience of the Clinician" Round 3

Topic	% 6&7	%1&2	Mean	SD	IQR
Experience of the Clinician					
Intuition of the clinician	12.50	0	5.12	0.59	0
Previous experiences (both personal and work related) of the clinician.	6.25	0	4.75	0.65	0.5
Qualification of the clinician	0	43.75	2.81	0.95	2
Frequency of dealing with the dying patient	12.50	0	5.06	0.43	0
Perceived seniority being a barrier to MDT collaboration.	6.25	12.50	3.69	0.97	1

This was seen clearly when the data was transferred into a Box and Whiskers Plot (see Figure 7.14).

Figure 7.14 Box and Whisker plot "Experience of the Clinician" Round 3



When this category was analysed across the role of the participant it became clear that once again there were few differences of opinion between the two clinical roles regarding their perception of its importance for inclusion. The rating for intuition (which is traditionally seen as an aspect of nursing) was similar between both doctors (mean= 4.43, SD=0.85, IQR=0) and nurses (mean=5.11, SD=0.81, IQR=0).

7.4.8 Attitudes of the Clinicians

The final factor analysed was whether the attitudes of the clinician involved in this decision making process warranted inclusion in this education programme.

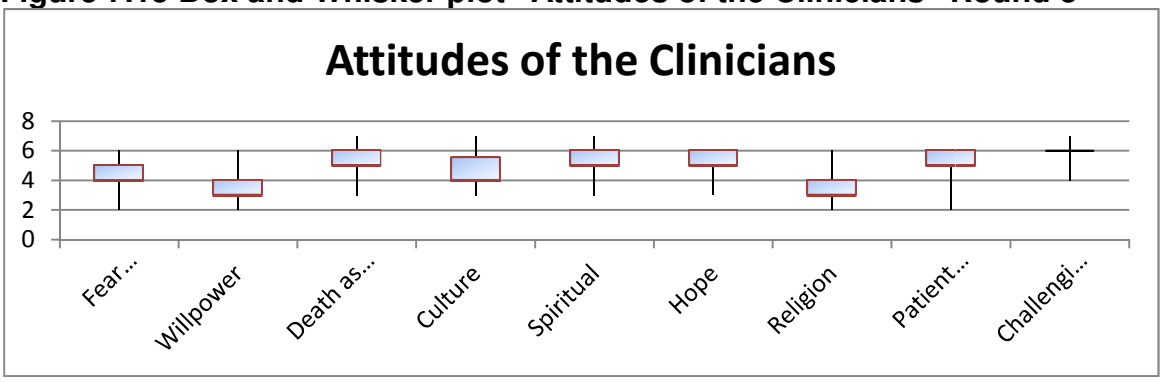
On calculation of the percentages allocating a score of 6&7 it was clear that the experts identified that support for the clinician in the challenging of current systems was a topic that should be included in this education programme (see Table 7.20). This could imply that current systems do not support clinicians in the timely recognition of the dying patient.

Table 7.20 Analysis of "Attitudes of the Clinicians" Round 3

Topic	% 6&7	%1&2	Mean	SD	IQR
Attitudes of the Clinicians					
Fear that they will not know the answers to questions asked or that family pressure could lead to litigation	18.75	6.25	4.62	1.11	1
Willpower of the patient to reach a target	6.25	6.25	3.94	0.95	1.5
Death being seen as failure	68.75	0	5.56	1.11	1
Culture of the patient	25	0	4.94	1.03	1
Spiritual issues for the patient	31.25	0	5.12	0.96	1
The importance of hope to the patient	31.25	0	5.12	0.93	1
Religion	6.25	6.25	3.81	0.88	1
Willingness to champion patient wishes	37.5	6.25	5.06	1.03	1
Courage to challenge systems	81.25	0	5.75	0.75	0

There were three further topics identified that had an IQR of 1 combined with a SD of ≥1; spiritual issues, hope and religion. These three topics all displayed central tendencies within the data but this related to these factors being scored in the middle ranges of the Likert scale by the expert panel (see Figure 7.15).

Figure 7.15 Box and Whisker plot "Attitudes of the Clinicians" Round 3



When the topic "Courage to challenge systems" was analysed across the roles of the experts it was clear that although consensus had been achieved this was largely because of the importance that nursing staff put on this factor (88% rating at 6&7).The doctors were consistent in their rating but with a smaller percentage rating it at this level. It is possible that this may relate to nurses feeling less empowered in the current processes potentially causing frustration with current systems.

7.5 Topics identified by the expert panel for Exclusion from an Education Package

Having reviewed the topics that achieved consensus from the panel of experts that it was important to include them in an education package; those that were excluded are now explored.

Initially, the topics identified in the various phases of the study (literature review, systematic literature review or the interviews) but which were then excluded from the education package by the panel of experts will be reviewed.

7.5.1 Topics excluded from the initial questionnaire

There was one topic identified in the factor “Patient Observation” that was excluded from the initial questionnaire. This topic was the role that the patient being dysphagic had on this recognition process. This topic had been identified by Vigano et al ((2000b) in the initial literature review but in no other phases of this study. Vigano et al (2000b) found that there was a correlation between length of survival and dysphagia which indicated a poor survival prospect. This could indicate that this is not a topic considered useful for inclusion in an education package by either theorists or practitioners. The fact that this was not identified on the wards as either a barrier or a facilitator in the recognition of the dying phase may also relate to the type of patient being cared there. Patients admitted to the Stroke Unit would frequently have swallowing problems, whereas on the Intensive Care Unit patients are usually heavily sedated so this topic would not be useful in either of these settings. The only unit where this factor may have been of use would have been the Care of the Elderly Unit but even there, it is more probable that the patients would become anorexic or cachexic rather than dysphagic.

The next topic excluded from the Delphi study related to the factor “Knowledge of the Patient”. This topic was the importance of including the frequency of admissions as a subject in an education package assisting clinicians to recognise dying. This topic was not identified as being relevant in any of the literature reviewed and by only two of the participants interviewed. This may indicate that this topic was not important either in theory or in practice and therefore was also excluded.

The fourth factor where topics were excluded from the initial questionnaire was that of “Attitudes of the Clinicians”. This factor contained one topic that was excluded. This was the role of denial in an education package. This topic was not identified in any of the literature reviewed suggesting that denial may not be considered as influential by the academic world. However, only two participants interviewed identified this topic during the interviews. This would suggest that neither theory nor practice identified this area as being valuable in this context. This was confirmed by the Delphi study with this topic not being identified as warranting inclusion in an education package.

There were seven tools identified within the literature reviewed. These were:

- Advance Directives (Barnato et al2012; Le Conte et al, 2010)
- SAPS II (Esteban et al, 2001; Frick et al, 2003),
- APACHE II (Hariharan et al, 2003; Terra, 2006),
- Karnovsky Performance Scale (Glare et al, 2003; Vigano et al, 2000a)),
- Palliative Progress Index (Morita et al, 2001)
- Edmonton Functional Assessment Tool (Vigano et al, 2000a).
- Edmonton Symptom Assessment Scale (Vigano et al, 2000a).

These were all excluded from the initial questionnaire as the use of a tool was not identified in the subsequent interviews. Many of the assessments made using these tools are self assessments to be undertaken by the patient and therefore it is unlikely that they would be useful for determining the need to change focus for the last days of life as the patient is unlikely to be able to complete these. On further examination it was clear that many of the factors identified potentially for inclusion in an education

package were included in many of these tools such as level of consciousness, ability to perform the activities of daily living and many of the physical symptoms.

No tools were identified as being of use during the interview process so either clinicians are unaware of them or are aware of them and do not find them useful. It could indicate another potential gap between theory and practice with multiple tools being developed but not used in the care setting. This would be an area that could benefit from further research. This is a finding that is supported by Leadership Alliance for the Care of Dying People (2014) who also reviewed various prognostic tools in their advice following the withdrawal of the Liverpool Care Pathway for the Dying. They were unable to identify any tool that had a sufficient evidence base for use for the last few hours/ days of life.

7.5.2 Excluded from the factor “Patient Observation” by the panel of experts

There were three topics in this factor where consensus was achieved that the topic identified would not be useful in an education package. These were three of the vital signs temperature, pulse and blood pressure.

These topics had been identified as topics for inclusion in the initial literature review (Gbenga, 2009; Morrow, 2009). They each indicated that hypotension in particular was indicative of a shortened life expectancy.

These topics were also identified in the interview process with the patient’s blood pressure being indicated as the most important of the three. This was particularly evident with the participants from the Intensive Care Unit. This finding that could be

anticipated as, due to the complexity of the conditions being treated on this unit, the majority of these patients have to be fully sedated resulting in their assessment by clinicians relying heavily on technology.

Initially the panel of experts seemed undecided when rating these three topics. They identified that the factors required splitting as some were more important than the others. However, they came to the consensus that none of these were important for inclusion in this package during round 3 of the questionnaire.

This could indicate that there may be some confusion regarding these topics both for the experts and the clinicians who are attempting to make these determinations. It may therefore be more important to address those issues regarded as important by both clinicians and theorists and await further research findings regarding the importance of a patient's vital signs in this determination before these topics are included in an education package.

7.5.3 Excluded from the factor "Knowledge of the patient" by the panel of experts

The next factor where topics were identified as not being important for inclusion in an education package was "Knowledge of the Patient". The two topics identified here were the relevance of the patient's diagnosis and their medical history.

The patient's diagnosis was identified as a topic in the Systematic Literature Review (Barnato et al, 2012; Esteban et al, 2001; Frick et al, 2003; Hariharan et al, 2003; Le Conte et al, 2010 and Terra, 2006; Vigano et al, 2000a). It was also clear from the interviews that the clinicians on the floor rated this as a valuable topic when

attempting to recognise the need to change the focus of a pattern of care to palliative with nearly two thirds of those interviewed identifying this factor. It was clear that the clinicians from the Intensive Care Unit in particular valued this topic. This would support the finding that the needs relating to education on this unit may be specific to them. This may relate to the fact that this unit does not specialise in one disease group unlike those on the Stroke Unit and even on the Care of the Elderly Unit where patients are suffering from chronic illnesses that could largely be predicted. However, by round 2 of the Delphi Study the panel of experts had indicated that this was not an important topic for inclusion in the education package. This may support the fact that the questionnaire was being rated as to the importance of this topic when considering an education package as opposed to a topic that clinicians may find useful when attempting to recognise the patient who is irreversibly dying.

The second topic, the patient's medical history, was also judged to be unnecessary to include in an education package. It was not identified as a topic that would be useful in any of the literature reviewed. However, approximately one third of the clinicians interviewed in Phase 2 of this study indicated that it was useful in this recognition process and so it had been included in the initial questionnaire. The panel of experts however, did not rate it highly. This may indicate that clinicians could be relying on a topic to assist in this process that neither the current evidence base nor the experts would support as being useful. This could indicate that as experience develops this becomes a less useful factor in this process.

7.5.4 Excluded from the factor “Experience of the Clinician” by the panel of experts

The final factor where topics were identified for exclusion from an education package was the factor of the “Experience of the Clinician”. The two topics identified were the area in which the clinician works and their level of seniority.

The topic of the area in which the clinician works was not raised in any of the literature reviewed but was identified during the interview process. This was an area where those working in the Intensive Care Unit prioritised this topic more highly than the other units. This may again relate to the type of patients treated on this unit. In this setting, patients are admitted with a variety of diagnoses whereas the other two settings have more predictable disease trajectories resulting in their being able to predict more accurately potential outcomes. It is also possible that staff in these settings were not conscious that they were using this topic as it had become second nature and therefore they did not recognise this as useful. The panel of experts identified that this topic was not of importance in this context. It is possible that the experts did not recognise the importance of this topic for those clinicians working on the Intensive Care Unit as it is unlikely that they are based on this unit.

The final factor, “Level of Seniority” was the last to be reviewed. This factor was identified initially in the initial literature review by Mallory et al (2006) who stated that as the practical experiences of the clinician increases they develop greater feelings of acceptance and tend to be more open with their communication exhibiting less anxiety about caring for the dying patient. This topic was also identified in the interview process by three participants, 2 of these were nurses and one was a doctor

working on the Intensive Care Unit. This suggested that there may be ambivalence relating to the relevance of this topic.

Once the decision was made to include the fact that that consensus was achieved if 80% or more of the participants scored the Likert scale at points 1 or 2 (that is, of no importance for inclusion in an education package) it was identified that this topic should be excluded from the education package.

7.6 Topics identified as not achieving consensus for inclusion or exclusion from an Education Package by the panel of experts

This following section will review the topics that were identified through the literature, interviews or the panel of experts and included as potential topics in the questionnaire but did not achieve consensus by the expert panel either for inclusion or exclusion from an education package.

In total 60 topics were identified for the panel of experts to rate as to their relevance for inclusion in this education package aimed at improving the ability of clinicians to recognise irreversible dying. Of these 31 topics did not achieve consensus regarding definitive inclusion or exclusion from this package (see Appendix F).

Only one of the topics where consensus was not achieved within the theme “Patient Observation” had been identified initially in the Systematic Review. This was the role that an increase in the patient’s pain had on thisrecognition process. But neither the interviewees on the three acute clinical areas nor the panel of experts rated this topic as either a factor to take into consideration or as warranting inclusion in an education

package. This could imply that there may be a gap between theory and practice with none of those involved practically in this recognition process identifying it as important.

Five of the topics (patient's ability to carry out the activities of daily living, pain, anorexia, cachexia and colour of the patient) were identified during the initial literature review. This enhanced the importance of a more systematic methodology of literature review ensuring that the most robust and accurate of information was obtained for review.

Only one of these five topics was identified during the interview process, the patient's ability to carry out the activities of daily living. This may also indicate a potential gap between theory and practice but the likelihood of this is reduced in that the panel of experts did not rate this factor as important for inclusion either. There is the potential that this is a topic used on the wards where they have not necessarily undertaken any specific end of life care training. It is possible that further research in this area could provide some clarity here.

Of the eight topics not achieving consensus within this theme three had been identified as needing inclusion in the questionnaire by the expert panel. These were the topics of body tone, gastric absorption and terminal agitation. None of these areas had been identified within other phases of the study and once identified it was noted that the experts themselves could not achieve consensus regarding their importance in education. This may highlight a concern regarding palliative care in particular in that there is limited research evidence available regarding practice.

Therefore there is the potential that pockets of practice may vary across locations as services develop according to local needs as a result of limited centralisation of information.

One topic within the factor “Knowledge of the Patient” identified during the systematic literature review failed to achieve consensus (response to treatment) and only one from the initial literature review (clinical test results). This indicated that the literature available appeared to be robust with the majority of topics identified using this methodology achieving consensus. Both of these topics and also that of “patient records” were identified in the interviews which would increase the validity of their not being necessary to included in the education package as theory and practice appear to match.

The remaining five factors not achieving consensus were all identified for inclusion by the panel of experts during the three rounds of the questionnaire (previous resuscitation decisions, advance care plans, patient’s own knowledge of their imminent death, age of the patient and treatment options the patient wants to try have run out). This would indicate that there could be a lack of consensus amongst the experts as to what is important for inclusion in an education package supporting the concept that palliative care experts practice in small select communities which may not communicate effectively between themselves. This would be eased if more research was available ensuring an evidence base and which would result in improved consistency across the country.

The next factor reviewed was that of the role of “Communication”. It was clear that all clinicians considered this to be important for inclusion in an education package with nine of the eleven topics identified achieving consensus for inclusion. The two factors not achieving consensus for either inclusion or exclusion were “family preferences and wishes” and “requests for euthanasia /suicide”. Neither of these topics had been identified in the literature nor the subsequent interviews. However, the panel of experts identified them as topics warranting inclusion for consideration in round 2 of the questionnaire. In this round it was clear that the nursing staff considered the role of family wishes to be more important than did the doctors (77.77% v 37.5%). This may relate to the fact that nursing staff are likely to have more day to day contact with the families and therefore would be more aware of their preferences. However, by round 3 the level of importance at which the experts rated this topic had dropped with both sets of clinicians; only 44.44% of the nurses rating it as important (0% as not important at all) and 14.28% of the doctors (14.28% as not important at all). This may relate to the fact that by round 3 these were the only two topics remaining for rating in this factor so the experts may have been more focussed when considering them. There is also the possibility that having rated these topics in previous rounds they had had time to reflect more deeply and therefore decided that it was not as important as they had initially indicated.

In the factor “Experience of the Clinician” there were five topics identified as not achieving consensus for either inclusion in or exclusion from this education package. This factor differed in that three of these five topics were identified in the literature but not in the interviews or by the panel of experts. These were the role of “intuition of the clinician”, “Previous experiences (both personal and work related) of the

clinician" and "The qualifications of the clinician". This could indicate that there is a gap between theory and practice which requires further exploration.

The remaining two topics not achieving any consensus were the importance of including the "frequency of dealing with the dying patient" and "perceived seniority being a barrier to MDT working" in an education package. Both of these were again identified only by the panel of experts. "Frequency of dealing with the dying" was a topic rated more highly by the nurses than the doctors in round two (55.55% v 25%). The expert's ratings dropped in round three with none of the doctors rating it as important and only 11.11% of the nurses. There is the potential that some of the scores in round three were influenced by the fact that the mean score from the previous round was provided to the panel. It must also be acknowledged that there may be a gap between the topics that the experts' rate as important opposed to those the generalist indicated as important. This may also need to be addressed with further research and education.

It was anticipated by the researcher that perceived hierarchical concerns would be a topic raised by clinicians relating in particular to professional issues. It had not been anticipated that clinicians would indicate that personal experiences such as the loss of a family member would be useful as a topic. This area may benefit from further research as this may be a factor that identifies those more likely to enter the caring professions. It was also noticed that clinicians tended to pull away from the identification of useful factors and topics in order to discuss their feelings (largely the nurses). This could relate to either their profession or that the majority were female and more comfortable talking about feelings.

The final factor addressed was that of the “Attitudes of the Clinician”. Here eight of the twelve topics identified did not achieve consensus as to whether or not they would be useful in an education package aimed at assisting clinicians to recognise irreversible dying. These were:-

- Fear that they (the clinician) would not know the answer to questions asked or that family pressure could lead to litigation
- Willpower of the patient to reach a target
- Death being seen as failure
- Culture of the patient
- Spiritual issues for the patient
- The importance of hope to the patient
- Religion
- Willingness to champion patient wishes.

The first three of these were identified as potential topics during the interview process. “Fear” and “death being seen as failure” were also identified in the initial literature review and “fear” in the systematic literature review. However, when the experts were asked to rate these topics they could not achieve consensus as to their importance for either inclusion or exclusion. This also indicated that there may be gaps between the literature, the generalists on the floor engaged in this practice and the experts. This may need to be addressed with further research and education.

The final five topics were all identified as needing inclusion in round two of the questionnaire for rating by the panel of experts. Once again the panel could not achieve consensus. This confirms that pockets of practice may vary widely as a

result of palliative care developing locally in order to reflect the needs of the closer community but lacking an evidence base resulting in a lack of consistency of care provision.

There appeared to be some consensus between doctors and nurses regarding “culture of the patient”, “spiritual issues for the patient” and “the importance of hope to the patient” in that the ratings were very similar. Both “religion” and “willingness to champion the patient’s wishes” were rated more highly by nurses in both round one and two. This may again relate to the fact that nurses spend more time with their patients and therefore may be able to see them as individuals whereas there is a possibility that doctors prioritise a diagnosis or illness that requires treatment.

7.7 Summary

The first round of the Delphi questionnaire contained 31 topics. These were categorised under five headings (factors). These factors and topics had been identified by combining the findings of the literature review, systematic literature review and the interviews.

The first round resulted in consensus in six topics which were divided between four of the five factors. The only factor where there was no consensus about any of the topics contained within it in this round was that of “Experience of the Clinician”. The factor where the majority of the topics reached consensus was that relating to the importance of communication skills in this education package.

The total number of factors remained at five for rating in the second round questionnaire. Following inclusion of the topics identified by the experts in the comments returned within each factor (n=22) during round 1, the total number of topics was now increased to 50 for round 2. This round resulted in consensus in fifteen topics spread across all five factors, once again, the majority coming from within the factor “Communication” (n=6) reinforcing its importance. Four topics were identified as having no relevance in an education package by the panel of experts.

The third round questionnaire contained 35 topics all carried forward from round 2 with no new factors or topics being suggested by the panel. This final round resulted in consensus in four further topics. Three of these were identified as having no relevance for inclusion in this education package. These topics were the temperature, pulse and blood pressure of the patient

In total therefore 18 topics sub-divided between four of the five factors were identified by the expert panel for inclusion in an education package designed to help clinicians recognise when a patient may have reached the irreversible dying stage (see Table 7.21).

Table 7.21 Topics Achieving Consensus for inclusion in an Education Package

Factor	Topic
Patient Observation	Breathing pattern changes
	Level of consciousness of the patient
Knowledge of the Patient	Rate of deterioration
	Predictability of disease trajectory
	Exclusion of reversible causes
Communication	Multi professional team working
	Time the clinician has to spend with the family and patient
	Withdrawing treatment
	Taboo subject for clinicians patients, and their carer
	Lack of understanding among family members
	Difficulty for clinicians when breaking bad news
	Patient preferences and wishes
	Uncertainty
	Consistent communication with families- not raising false hope
Attitudes of the Clinician	Quality
	Acceptance that the patient is dying
	Medical philosophy of cure
	Courage to challenge systems

CHAPTER 8

DISCUSSION

8.1 Introduction

Having presented the findings of each of the three phases of this study separately, the combined findings are discussed in this chapter in relation to the original aims and objectives of the study.

First, the aims and objectives of this thesis will be re-visited as a convenient reminder for the reader. Following this the development of a theoretical model will be presented. The factors identified in the systematic review and by the clinicians interviewed as either helpful or as barriers to the recognition of irreversible dying will be translated into this model and will be discussed in more depth. Any new factors arising from the Delphi study and identified as either being of use or not of use in an education package will also be included in this translation. The aim will be to identify where the development of a complex intervention may result in changes in these behaviour of clinicians thus improving the recognition of the irreversibly dying patient (MRC, 2008).

These factors will be reviewed subsequently in order to identify whether any would be of use in this education package and will be contextualised in relation to the existing literature (See section 8.5). This section will also identify areas where education may not be the solution.

8.2 Review of Aims and Objectives

The aim of this study was to explore factors that either facilitate or are a barrier to

clinicians when they are attempting to recognise whether or not a patient is entering the irreversible dying phase. Following this the study would then attempt to identify which of these factors would be useful to include in an education package designed to help clinicians with the process of recognising the irreversible dying phase. These aims were addressed by exploring three objectives. These were:

a) To identify and explore the factors which facilitate or prevent clinicians in the acute medical hospital setting to determine whether or not the patient has entered the irreversible dying phase.

b) To identify techniques that may be utilised to assist in the determining of this dying phase thus improving predictive accuracy.

c) To identify which of the factors identified by the clinicians in the acute medical hospital setting and the currently available literature would be useful for inclusion in an education programme designed to help clinicians to recognise the irreversibly dying patient.

These aims and objectives have been addressed in three distinct phases of investigation.

- Phase 1- a systematic review.
- Phase 2 - a process of 18 interviews with key clinicians in the acute medical setting using grounded theory principles for analysis.
- Phase 3 – a Delphi study in order to provide confirmation of which of the factors identified would be useful in an education package.

Having re-visited the aims and objectives of this study the following section describes the development of a theoretical model in order to clarify where there is the potential for the development of a complex intervention aimed at affecting the behaviour of clinicians engaged in this process.

8.3 Development of a Theoretical Model

A theoretical model is a theory which has been designed to explain an entire situation or behaviour. The notion is that eventually this model would be able to predict that behaviour. The theoretical model developed for the purpose of this study was based on the social cognitive theory developed by Albert Bandura in1977 which had an emphasis on the acquisition of social behaviours. This theory was expanded upon and renamed Social Cognitive Theory (prior to this it had been known as a Social Learning Theory) in order to emphasise the important role that cognition plays in performing behaviours (Bandura 1986). This theory is a behavioural prediction theory that places emphasis on what people think and its consequent effect on their behaviour (Redding et al 2000). It suggests that behaviours can be explained in terms of three key concepts which continuously interact. That is, a change in one concept will affect the other two. As stated by NICE (2007) factors such as birth, parental income, prejudice or discrimination can all impact on behaviours and these therefore also needed to be taken into account within the model developed.

The over-arching theory emerging from the interviews was that clinicians have a fear of getting the timing of the recognition of the irreversible dying phase wrong and therefore fear they may withdraw or withhold treatment inappropriately. The model chosen seems feasible as this over-arching theory could potentially relate to each

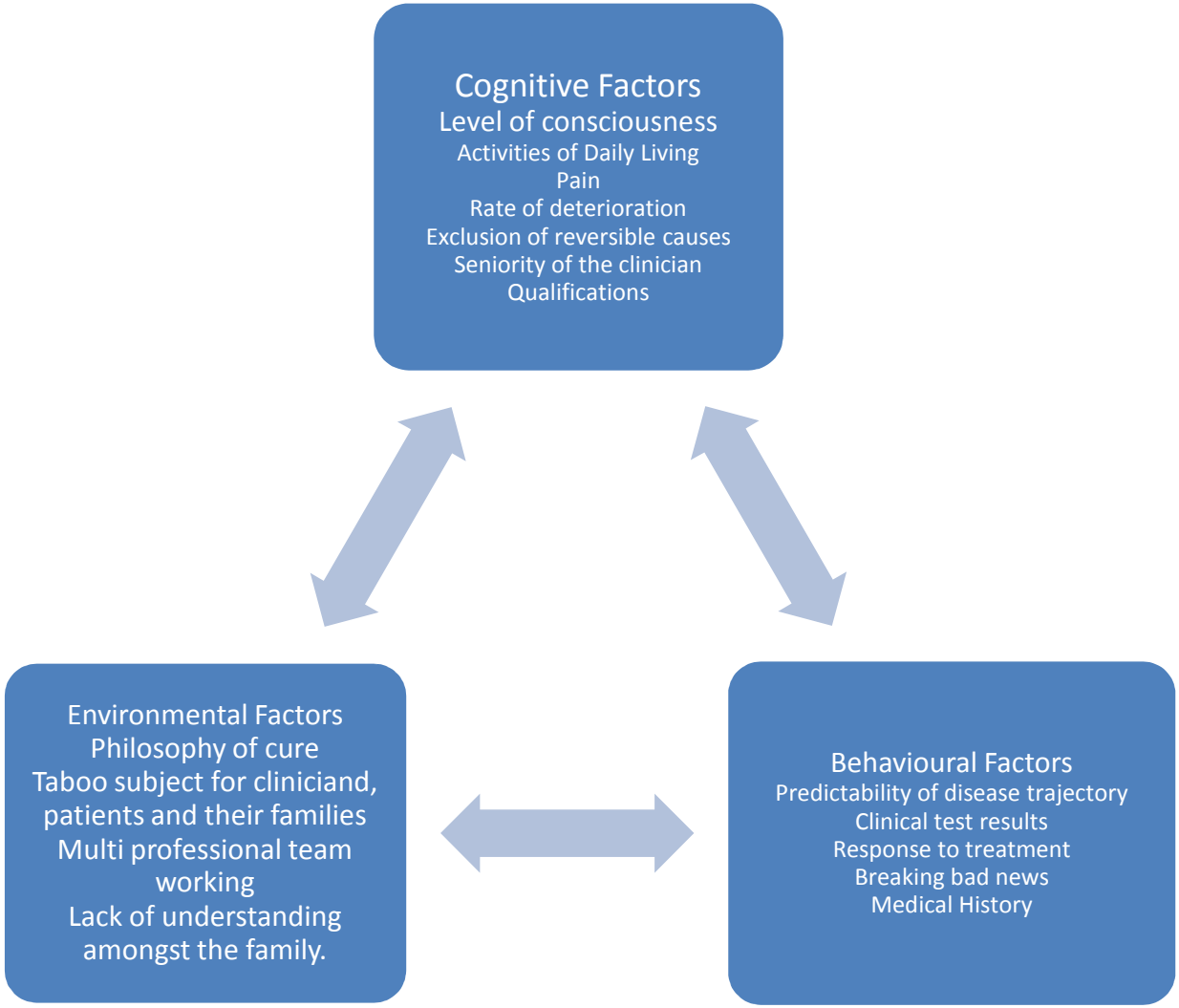
factor identified. There is a possibility that the individual clinicians' perception is that that they do not have the skills required to identify the patient who is irreversibly dying, that they may have observed other clinicians struggle with this recognition process which then has an impact on their levels of confidence when faced with this situation and this is then further compromised by the fact that society finds this a topic difficult to discuss. This is impacted further in particular in the health care setting where the philosophy which is prevalent is one where death is considered to be a failure.

The three concepts combined in this model were

- cognitive factors (personal factors). This relates to the internal factors relating to the individual and how they then perceive their efficacy (knowledge, attitudes, experience and expectations)
- behavioural factors – how the witnessing of a behaviour can result in a change in the behaviour of the individual (practice, emotional coping strategies, skills)
- environmental factors- aspects of the setting that may affect the individual's ability to perform the behaviour (societal attitudes and culture of the workplace).

A theoretical model of how health care professionals may recognise the irreversible dying phase is presented at Figure 8.1.

Figure 8.1 Theoretical model of how health care professionals recognise the irreversible dying phase



The themes and factors identified in the study were translated into this theoretical model by identifying the way in which the topics identified by the study would affect the behaviour of the clinicians.

8.3.1 Factors identified in the study

Four main themes were initially identified through the process of the systematic review. “Patient Observation” and “Knowledge of the Patient” were both identified as facilitators in this recognition process whereas “Communication” and “Attitudes of the Clinician” were identified as being facilitators when positive but also the potential to be barriers when they were negative. The findings of the interviews in phase 2 of the study complimented and built on these findings expanding on the theme “Attitudes of the Clinician” in particular, placing an equal emphasis on the attitudes of the patient and their families rather than only the clinician. These interviews also identified a fifth theme, “Experience of the Clinician”.

The factors identified by the systematic literature review and those from the interviews were then translated into the theoretical model alongside those factors identified during the Delphi study. The aim of this process was to encapsulate the findings of this study (see Table 8.1).

Table 8.1 Translation of factors into the theoretical model

Cognitive Factors	
Patient Observation	Conscious level of the patient
	Patient's ability to carry out the activities of daily living
	Pain
	Anorexia
	Changes in breathing pattern
	Blood pressure
	Pulse
	Temperature
Knowledge of the patient	Age of patient
	Rate of the patient's deterioration
	Exclusion of reversible causes
	Diagnosis
Communication	Withholding or withdrawing treatment
Experience of the Clinician	Area of work of the clinician
	Seniority of the clinician
	Previous experiences (both personal and work related) of the clinician
	Qualification of the clinician
Attitudes of the Clinician	Fear that they will not know the answer to questions asked or that family pressures could lead to litigation
	Acceptance that the patient is dying
	Death being seen as failure
	Quality
Behavioural Factors	
Knowledge of the patient	Predictability of disease trajectory
	Patient records
	Diagnosis
	Clinical test results e.g. blood tests, scans
	Medical history
	Response to treatment
Communication	Difficulty for clinicians when breaking bad news
	Uncertainty
	Time the clinician has to spend with the patient and their family
Environmental Factors	
Communication	Multi professional team working
	Taboo subject for clinicians, patients and their carers
	Lack of understanding amongst the family
	Patient preferences and wishes
	Consistent communication with families- not raising false hope
Attitudes of the clinician	Medical philosophy of cure
	Willpower of the patient to reach a target
	The importance of hope to the patient

8.3.2 Translation of topics into "Cognitive Factors"

The first factor to be addressed was the cognitive element of this theoretical model, that is, the factors relating to the individual clinician.

Topics translated into the "Cognitive Factor" within the theme "Patient Observation"

This factor relates to the internal components of the individual involved in recognising the irreversibly dying patient, that is, their knowledge, skills, experience and expectations. All topics identified within this theme were considered to translate into this cognitive factor. The topics included direct patient observations that can be made, with judgements predicting outcome following these observations.

The conscious level of the patient was identified as a potential indicator of the onset of the dying phase by Barham (2002), Eychmuller et al (2012), Gbenga (2009), Hwang et al (2013), Jack et al (2003) and Morrow (2009). This was supported in the findings of the focus group discussions undertaken by van der Werff et al (2012). The findings of the interviews undertaken during this study also supported this. It was a factor identified within all settings, by both roles interviewed and both senior and junior staff. All participants interviewed on the Stroke Unit identified this as being useful and four of the six participants on the Care of the Elderly Unit. This may have related to the fact that the majority of patients cared for in the Care of the Elderly setting have chronic illnesses accompanied by longer trajectories so there may be a slower "slipping away" rather than an acute event (Lyness, 2004). Esteban et al (2001) used the measurement of conscious level in order to identify whether or not there was an association with the implementation of a "Do not resuscitate" order and found no connection, that is, the patients who were largely unresponsive were no more likely to receive one of these orders than those who were conscious. This was

contradicted by both Mosenthal et al (2008) and Terra (2006) who both used tools (SAPS II and APACHE II) in their studies which include the assessment of a patient's consciousness level in order to assess the likelihood of a patient's survival. When these findings were compared to the findings from the Delphi study there was some contradiction with only 66% of the participants scoring it at 6 or 7 in the first round. In the second round this figure rose to 82.35% thus achieving consensus that this factor warranted inclusion in an education package. This change in scoring pattern was accounted for by the fact that the majority of those who had chosen not to complete round 2 but had completed round 1 had scored this factor as of some importance only and two of the three new participants in the second round had scored it at 7 on the Likert scale. This did not seem to relate to care setting as one of these participants worked in the community and the other in the hospital. There is the potential that if the behaviour of clinicians could be affected here by an education package there could be improved recognition of irreversible dying

Symptom management has been identified as key to good care at the end of life (Raijmakers et al, 2012). The fact that pain can also be an indicator to the onset of the dying phase was identified in the findings of the focus group discussions undertaken by van der Werff et al (2012). Pain in particular has been identified as increasing towards the end of life (Bookbinder et al 2001; Forbes et al 2003; Levy, M.M., 2001; Lyness, J.M. 2004; Rutledge et al 2001b). There may be the added concern that patients may not receive adequate relief from pain at the end of their lives (Valente, 2004). As pain is a common symptom in the dying patient it is essential that good pain relief is provided (McCallum et al, 2013). Le Conte et

al (2010) expanded on this stating that the symptom of pain itself can indicate the need to limit any life supporting treatments as it can be an indicator of potential futility. The prevalence of this symptom could potentially be useful in anticipating the final days of life and used to prepare families for the inevitable (Kehl, 2013). The importance of pain as a factor was supported by the interview process with participants from the Stroke Unit and the Care of the Elderly Unit identifying this as a factor to be taken into consideration. However, this was not mentioned during the interviews on the Intensive Care Unit. Although the literature and interviews support the idea that this is an important factor requiring consideration when recognising the patient who is irreversibly dying the panel of experts were unable to confirm this, being unable to determine whether this was either useful or not for inclusion in an education package addressing this concern. If this factor is to be influenced therefore a different process will need to be developed

Participants from two of the three units where interviews were undertaken (Stroke Unit and Care of the Elderly Unit) identified that the patient no longer being able to carry out the activities of daily living was potentially an indicator that a patient may be entering the last few days of life. This finding was supported by Vigano et al (2000b) in their systematic review of 22 studies which identified that there was a value in the performance status of the patient being amongst the prognostic factors for determining the probable length of survival for the terminally ill. This was related to relatives in particular witnessing and reporting this lessening of ability (Hubbard et al, 2012; Lyness, 2004). This can also be a measure that patients themselves use to measure their illness (Calvin, 2004). However, this factor was not identified on the Intensive Care Unit as being of use or a barrier

and the panel of experts were also unable to come to a consensus of opinion on the need to include this factor in an education package so this will also require a different methodology if behaviours are to be affected..

A change in the patient's breathing pattern has been identified as a factor useful in recognising when dying was imminent (Barham, 2002; Echymuller et al, 2012; Kennnedy et al 2014; McGaughey et al, 2009; Moneymaker, 2005; Plonk & Arnold, 2005; Vigano et al, 2000b) and was also identified as a factor by the interview participants on all three units although it appeared from these that doctors found this topic more useful than did the nursing staff. The expert panel also considered this to be a factor of importance for inclusion in an education package and was the only factor within this theme where consensus was achieved within the first round of the Delphi. This therefore could be an area where changes could be made.

Anorexia was identified as being a potential factor that could be a facilitator in the recognition of the irreversible dying phase (Barham, 2002; Echymuller et al, 2012; Gbenga, 2009; Morrow, 2009, Plonk et al, 2005; Vigano et al, 2000b; Yun et al, 2001). This was supported by the findings of the interviews with one third of the participants interviewed identifying this factor. A decrease in appetite and a change in the sense of taste were the rationale suggested by van der Werff et al ((2012) for this phenomena. However the panel of experts were unable to come to a consensus regarding whether or not these factors should or should not be included in the education package.

Temperature, pulse and blood pressure were all identified as potential factors that could indicate that a patient may be dying (Gbenga, 2009; Hwang et al, 2013; McGaughey et al, 2009; Morrow, 2009; Moneymaker, 2005; van der Werff, 2012). However, there was limited support for this finding in the interview phase of this study with only two participants identifying these factors; both doctors. The panel of experts agreed that these factors would not be useful in an education package in round 3 of the questionnaire.

Topics translated into the "Cognitive Factor" within the theme "Knowledge of the patient"

The theme "Knowledge of the Patient" contained four topics that translated into the cognitive factor of this theoretical model. These were the age of the patient, the exclusion of reversible causes, diagnosis and the rate at which the patient is deteriorating.

The "Age" of the patient was identified as a topic that can affect this decision making process; the younger patient being less likely to receive a "Do not resuscitate" order or have treatments either withheld or withdrawn (Hariharan et al, 2003; Le Conte et al, 2010; Mosenthal et al, 2008). This finding was supported by Rutledge et al (2001a) who found that there is a survival disadvantage for the older patient with them being less likely to receive aggressive treatment. One third of the participants interviewed identified the age of the patient as a factor in their recognition process expressing reluctance to "give up" on the younger patient. This factor had not initially been included in the questionnaire but it was identified in the comments received back from the first round participants and

therefore was included in round 2. However, consensus was not achieved regarding whether or not this factor would be useful in an education package.

Even though the patient has a right to receive treatment he or she does not have the right to demand inappropriate treatment (Gavrin, 2007). However, it is also important to ensure that a medical judgement has been made to ensure the deterioration in the patient's condition has not been caused by a potentially reversible factor (LACD, 2014; Luce, 2010). The exclusion of reversible causes was not identified in the findings of phase 2 (interviews) of the study therefore it was not included as a topic in the questionnaire. It was identified as a potential topic for inclusion in an education package in the comments received back from this first round. The panel of experts achieved consensus that it was important that the exclusion of reversible causes should be included in an education package in the second round and, subsequently, changes could be made to clinicians' behaviour.

The effect of the patient's diagnosis when attempting to determine the timing of a change in the pattern of care was identified during the systematic review as a potential factor (Barnato et al 2012; Esteban et al 2001, Frick et al, 2003; Hariharan et al, 2003; Le Conte et al, 2010; Terra 2006). This was supported by the participants interviewed with more than half of them identifying this as a factor in recognising the irreversible dying phase. It was recognised that a diagnosis of malignancy can make this decision easier (Barnato et al, 2012; Hariharan et al, 2003). There is also the potential that a cancer diagnosis prompts health care professionals to consider whether death is imminent where this may be more

problematic in other life limiting conditions (Kennedy et al, 2014). The Delphi study finding however, suggests that, despite these findings, this factor is less important when considering education in this context with consensus to this being achieved in round 2.

The rate at which the condition of a patient is deteriorating can be seen as an indicator of survival as opposed to an absolute measure of survival (Bennett et al, 2000). Approximately one third of those interviewed confirmed this finding with three quarters of these being in nursing roles. This may relate to the time that nurses spend in close contact with their patients. This finding was confirmed by the panel of experts as an important topic to include in an education package which may therefore improve the clinician's ability to recognise of the irreversibly dying patient.

Topics translated into the "Cognitive Factor" within the theme "Communication"

The third theme identified, "Communication", contained only one factor relating to the cognitive section of the theoretical model, that of withdrawing or withholding treatment. This factor was identified as requiring careful consideration when attempting to recognise the irreversible dying phase (Barnato et al, 2012; Esteban et al, 2001; Frick et al, 2003; Hariharan et al, 2003; Le Conte et al, 2010; McCallum et al, 2013; Mosenthal et al, 2008; Terra, 2006; Walker et al, 2010) and was highlighted by Lyness (2004) as having the potential to distress families; particularly if it was considered that being involved in the decision making process left them feeling that they had been the cause of the death by "pulling the switch". There is also the potential that families may believe that they have more

authority in the decision making processes relating to end of life care than is the case (McCarthy et al, 2012). However, contrary to this, it was also identified that families may be pushed into making inappropriate recommendations in response to the clinician's inability to accept the inevitable if the clinician perceives death as failure (Weiser et al, 2011). This was also raised as an important factor by four of the six participants interviewed the Intensive Care Unit. However, only one other participant identified this factor, from the Care of the Elderly Unit. The focus of these interviews was related to the withholding or withdrawal of medical treatment. The withholding or withdrawal of hydration and nutrition was not identified in the analysis of the interviews although this concern has been high-lighted (DoH, 2014). Because of the frequency of identification in the literature this factor was included in the first round of the questionnaire and its importance was confirmed when consensus was achieved within the panel during the first round regarding its importance for inclusion in an education package. This also, may be an area where education could have an impact on behaviour.

Topics translated into the "Cognitive Factor" within the theme "Experience of the Clinician"

The importance of the competence and experience levels of the clinician was the third theme identified during the interview process where topics were translated into the cognitive factor of the theoretical model. As this over-arching theme suggests, "Experience of the Clinician" with all factors within it, related to the competence of the clinician. The factors related to area of work, seniority, qualifications and previous personal and work related experience were all identified in the findings of the analysis of the interviews.

Working alongside a more senior clinician who has already had the experience was considered useful and can help nurture attitudinal development of junior staff (Mallory et al, 2006) but it is recognised that even doctors who have experienced training in end of life care still have difficulty in recognising accurately the patient who is irreversible dying (Tanneberger et al, 2002). The clinical estimation of an end of life prognosis required a greater level of experience combined with specific end of life care training (Tanneburger et al, 2002).

Previous personal experience with death and dying can be of value when working in the clinical setting and attempting to recognise the irreversible dying phase. Mallory et al (2006) also argues attitudes of nurses caring for the dying can be improved with clinical experience of caring for the dying.

All three of these factors were identified in the findings of the interviews with particular focus noted on the role of the qualification of the clinician with nearly half of those interviewed identifying this as important to them.

The panel of experts when asked to rate these factors for importance of inclusion in the education package indicated that area of work and levels of seniority were not important in this context. This may relate to the probability that these factors cannot be changed by education itself. They also could not achieve consensus regarding the importance of inclusion in an education package of the remaining two factors.

Topics translated into the "Cognitive Factor" within the theme "Attitudes of the Clinician"

The final theme addressed in this first factor was the "Attitudes of the Clinician". Four factors from this theme relate to the cognitive factor of the theoretical model. All of these factors ("Fear", "Acceptance", "Death as failure" and "Quality") were identified in the findings from the interviews undertaken in phase 2 of this study.

The factor most frequently identified during the interviews was "Fear" with two thirds of the participants identifying this as relevant when recognising irreversible dying. Clinicians can be anxious that they could miss a reversible condition and therefore tend to continue with inappropriate treatments rather than address these concerns (Barnato et al, 2012). As Hariharan et al (2003) identified, clinicians are also reluctant to recognise futility because of fear of litigation. This was supported by the findings of the interviews with two thirds of the participants identifying this potential barrier. However, when the results of the Delphi study were analysed "Fear" was one of the factors where there was no consensus regarding inclusion or exclusion from an education package.

This was mirrored in the findings relating to the factor "Death as Failure". This may be an important finding in that there is the potential that if it is considered a failure when a patient dies important decisions regarding treatment provision will not be made (Rousseau, 2001). Hariharan et al (2003) expanded on this stating that the concept of an intensive care unit has raised expectations of survival amongst both clinicians and the general public and there is reluctance to accept the concept of futility largely because futility could be misconstrued as failure.

This was identified in over a quarter of the interviews as a potential barrier but the panel of experts did not consider this factor to be either important or unimportant for inclusion in an education package.

“Acceptance” and “Quality were also identified as factors during the interview process. Both factors were considered to be important for inclusion by the panel of experts with “Quality” achieving consensus of its importance in round 1 and “Acceptance” in round 2. Acceptance of the situation can be key factor and can lead to a good death (Leadbetter et al, 2010). This may reflect the importance of health care professionals accepting their own mortality as being a keystone to the acceptance of the death of others (Rousseau, 2001). The factor “Quality” when the interviews were analysed, related to the quality of life that could be expected by the patient if aggressive treatment continued. This factor is one that the general public has identified as important (McCarthy et al, 2010). Nurses have a role when encouraging families to reflect on the quality of life that the patient is enduring when they are considering the need to withdraw treatment (McBride et al, 2006). This must be balanced against the findings of McCarthy et al (2010) who found there is confusion with relatives incorrectly assuming that they have the right to make the decisions regarding a patient’s care plan.

Having reviewed the factors that comprised the “Cognitive factor” of this theoretical model, those relating to the “Behavioural factor” will now be explored.

8.3.3 Translation of topics into “Behavioural Factors”

This factor relates in particular to the behaviours exhibited by the individual clinician, their practice, coping strategies and skills. When the factors identified in the systematic review, interview findings or by the panel of experts were translated into the theoretical model, fourteen topics within three of the themes were identified. The first theme to be explored is “Knowledge of the Patient”.

Topics translated into the “Behavioural Factor” within the theme “Knowledge of the patient”

This theme contained six topics relating to the skills, self-efficacy and practice of the individual. These were:

- Predictability of the disease trajectory
- Diagnosis
- Medical history
- Patient records
- Clinical test results
- Response to treatment

The predictability of the disease trajectory was identified as a useful factor in the recognition of the irreversible dying phase in the findings of the interviews. The predictability of the trajectory when considering non-cancer diagnoses is likely to be marked by peaks and troughs in the patient’s condition (Leadbetter et al, 2010). Even these acute exacerbations are not always indicative of imminent death (Hubbard et al, 2012). This topic was confirmed as important by the panel

of experts as they reached consensus that this was an important topic to include in an education package.

The factors “Diagnosis” and “Medical History” were also identified as factors that were useful in the recognition of the dying patient by the participants interviewed. Le Conte et al (2010) stated that the patient’s diagnosis can be the principle factor to be taken into consideration in relation to either the withholding or the withdrawing of treatment. A diagnosis of a chronic life-limiting illness such as Chronic Obstructive Pulmonary Disease can make this recognition easier (Esteban et al, 2001; Frick et al, 2003; Terra, 2006). It has been identified that a diagnosis of malignancy can make this recognition easier still (Barnato et al, 2012; Hariharan et al, 2003). Vigano et al (2000a) expanded on this, identifying in their study that if a patient had moderate to severe co-morbidities and also had been diagnosed as being terminally ill with cancer this was a discriminant that suggested a worse survival prognosis. However, this can result in the risk that in this situation of the care of patients becoming fragmented due to multiple speciality professional involvement (National Council for Palliative Care, 2008). However, when the panel of experts were asked to rate this topic for importance of inclusion in an education package they achieved consensus that it should not be included. This does not necessarily indicate that this was excluded because it was not an important factor in this process, but that the panel identified that it would not be useful to include in an education programme.

Three further factors were identified during the interview process; “Patient records”, “Clinical test results” and “Response to treatment”. The role of the

patient's response to treatment was identified by both Barnato et al (2012) and Le Conte et al (2010). Barnato et al (2012) suggested that any treatment given must be as a bridge to something, that is, treatment should lead to recovery whereas Le Conte et al (2010) identified that response to treatment within the first 24hours of it being initiated was a factor in the decision to withdraw/ withhold treatment. However, when the expert panel was asked to rate these factors for inclusion in an education package they were ambivalent as to its relevance.

Topics translated into the "Behavioural Factor" within the theme "Communication".

The second theme containing topics relevant to the factor "Behaviour" in this theoretical model was "Communication". Three relevant topics were identified within this theme; "Difficulty for clinicians when breaking bad news", "Uncertainty" and "Time that the clinician has to spend with the patient and their family".

It is important that patients and their families remain informed as disease progresses in order to maintain the partnership between the health care professionals, the patient and their family (Lyness, 2004; LACDP, 2014) and therefore the ability to break bad news well becomes key. Lautrette et al (2006) identified that intensivists in particular needed to improve their skills when communicating with families. The ability of the clinician to break bad news effectively, and have the confidence to do this, was identified as a factor in over half of the interviews undertaken and crossed all sites. When the expert panel was asked to rate this factor for importance they confirmed that this was an important factor in the recognition (and subsequent implementation of appropriate

care) of the irreversible dying phase. Consensus to this was achieved at the end of round 2.

“Uncertainty” was not identified as a specific theme during the interview process but was an implication behind many of the themes. There is the potential that the pattern of over-estimation life expectancy by doctors (Chow et al, 2001; Christakis et al, 2000; Ellershaw et al, 2003b; Glare et al, 2003; Murray et al, 2005; Roberts, 2005; Tanneberger et al, 2002) could relate to this (Rutledge et al, 2001b). This factor was raised by the expert panel in the comments provided at the end of round 1. However, no consensus was achieved regarding either its importance or lack of importance during the subsequent rounds.

The time clinicians have to spend with patients and their families was reported by two authors (McBride et al 2006; McCallum et al, 2013). Both emphasised the role of the nurse: McBride et al (2006) stated that, for nurses in particular, time is a requirement to ensure that families can be encouraged to accept the futility of aggressive treatment. This was re-emphasised by McCallum et al (2013) who identified that nurses saw this as part of their role when a family needs support in this type of decision making. Doctors in particular have limited time when communicating bad news to patients and their families (NCPC, 2008; Puntillo et al, 2006). This is an important factor as inappropriately rushed communication can then result in the bereaved person’s perception of a good death being compromised; that this perception was enhanced if there had been good communication between family and the health care professionals involved, as the family then had a full understanding of the inevitability of dying (Glavan et al

2008). This factor was identified as being a facilitator when time was available but also as a potential barrier if time was insufficient by approximately one third of the clinicians interviewed suggesting that they also valued this factor. This was confirmed by the Delphi study when this topic achieved consensus in the first round.

Having considered the factors relating to the behavioural factor element of this theoretical framework finally those relating to the environment will be considered.

8.3.4 Translation of topics into “Environmental Factors”

The factors relating to the environment factor of the theoretical model are those that may affect the social norm of clinicians when trying to recognise the irreversibly dying patient. It also related to any control held by the clinician in influencing others in order to change this environment.

Two themes were identified containing topics relating to this specific factor; “Communication” and “Attitudes of the Clinician”.

Topics translated into the “Environmental Factor” from within the theme “Communication”.

The relevant factors relating to “Communication” were the first to be translated into this model. These were identified as:

- Multi professional team working
- Taboo subject for clinicians, patients and their families
- Lack of understanding amongst the family

- The patient's preferences and wishes
- Consistent communication with families ensuring that false hope is not raised

The factors "Multi professional team working", "Lack of understanding among the family" and "Taboo subject" were all factors identified during the interview process. In particular working as a multi professional team was identified as a facilitator by all except one participant, that being a nurse from the Intensive Care Unit. Working as a team in this way encourages the use of multiple resources enhancing the service available (Myers Schim et al, 2007). However, it has been identified that, in some areas, nurses can feel unsupported and their opinions not respected (Puntillo et al, 2006). It is key that nurses should participate in the decision making process relating to the recognition of the dying patient as they can alert others to broader considerations other than the purely physical (Shotton, 2000).

The fact that death and dying is a taboo subject within this society was identified by nearly two thirds of the clinicians interviewed as a potential barrier to this recognition process, nearly half of these working on the Care of the Elderly Unit. Unless we are able to encourage society to talk about death and dying there is limited opportunity to improve the services currently available (Leadbetter et al, 2010; The National Council for Palliative care (NCPC), 2008).

The understanding that the family have of the situation they find themselves in was a factor identified by approximately a third of the participants interviewed.

They identified that this factor could be either a barrier or a facilitator in recognising dying. The implication being that, if the family fully understood the futility of implementing aggressive treatment it was easier to withhold or withdraw this treatment. This finding was complicated by the findings of McBride et al (2006) who found that frequently families did not understand the implications of the choices they were being asked to make relating to the withdrawing or withholding of treatment. There is also the possibility that families can have unrealistic expectations that are not addressed regarding the prognosis of the patient. Unless this lack of understanding is addressed there is the likelihood of treatments either being withdrawn inappropriately or even started inappropriately (Hariharan et al, 2003). This is further complicated by the fact that if families are informed that the patient is dying their expectation is that this will happen imminently and therefore there is a requirement for clear information provision regarding clinical uncertainty (DoH, 2013)

When the Delphi panel were asked to rate these factors they were all identified as being important to include in an education package.

Neither of the factors “Patient preferences and wishes” nor “Consistent communication with families in order that false hope is not raised” were identified as relevant factors in the findings from the interviews. However, it is important that the patient’s wishes regarding their care is known as this ensures that the clinician is enabled to become a true advocate (LACDP, 2014; McBride et al, 2006). Having the knowledge of, and then being able to respect, a patient’s wishes often provides nurses with a real sense of achievement and is part of

preserving that patient's dignity (McCallum et al, 2013). The relevance of this factor was confirmed by the Delphi panel when consensus was achieved that both of these factors should be included in an education package aimed at enabling the recognition of the irreversible dying phase.

Topics translated into the "Environmental Factor" from within the theme "Attitudes of the Clinician".

Within the theme "Attitudes of the Clinician" the area most consistently identified as a factor in the interviews was the effect that the medical philosophy of cure of the unit had on this recognition process with over half of the participants identifying this as a potential barrier to recognising irreversible dying. None of these participants worked on the Stroke Unit; but only one participant working in the Intensive Care Unit did not identify this factor. The concept of an intensive care unit has raised expectations of survival amongst both clinicians and the general public with surgeons in particular being reluctant to accept the concept of futility largely because futility could be misconstrued as failure (Hariharan et al, 2003; Weiser et al, 2011). There is also the potential of burdensome treatments continuing inappropriately even when the patient has not requested this (Valente, 2004). This is supported by the General Medical Council's Guidelines which state that although doctors should aim to prolong life there is no obligation to do this irrespective of the consequences to the patient (General Medical Council (GMC) 2010; Leadbetter et al, 2010). The importance of this factor was confirmed by the panel of experts who achieved consensus that this should be included in an education package.

A further factor translated into this section of the theoretical model was identified during the interview process and this was the willpower that the patient exhibited; that patients could be determined to reach an objective and would do so even when clinicians had assessed this as being unachievable. This was a factor identified by nearly half of the participants' interviews, only one of these working on the Intensive Care Unit. It was not identified as a potential factor in any of the literature reviewed. However, when the Delphi panel were asked to rate this for the importance of inclusion in an education package no consensus was achieved.

Hope is highly individualised and is shaped by the person's values (Davison et al, 2006). It can provide meaning and motivation for the dying patient (Duhamel et al, 2003) but a loss of this hope has been identified as an indicator of a desire to hasten death in the terminally ill patient (Leung, 2007). Avoidance of information provision can be a strategy used by patients and their families in order to preserve hope (Clayton et al, 2007) but honest discussion about death and futility does not abolish hope but modifies its interpretation (Rousseau, 2001). This opportunity can be blocked when clinicians and families collude in order to foster a patient's optimism (Routledge et al, 2001b). This factor, however, was only identified by one of the clinicians interviewed, a junior nurse working on the Stroke Unit. However, the panel of experts identified this topic as potentially requiring inclusion in an education package in the comments received back from the first round of the Delphi. Once included in the questionnaire however, the panel could not achieve consensus regarding its importance in this context.

8.4 Techniques identified that may be used to assist in the recognition of the dying phase.

When the second objective of this study was explored there were no clear techniques identified in the literature, by the clinicians interviewed or by the panel of experts which would be considered useful in this context. That is, there appeared to be no systematic procedure that could be followed in order to complete this complex process accurately. The literature did identify potential tools (Esteban et al, 2001; Frick et al, 2003; Hariharan et al, 2003; Terra, 2006; Vigano et al, 2000a) that may be useful in this context but there was no consistency as to which tool was the most beneficial. Currently there is insufficient evidence to endorse any of these for use in recognising the irreversible dying phase (LACDP, 2014). However, it has long been recognised that there is the need to improve end of life decision making particularly in the intensive care setting with the aim of reducing the prolonging of dying (Connors et al, 1995). With this in mind the APACHE 11 tool was developed. Although designed to identify the seriousness of a patient's illness it was found that when a patient scored highly using this tool there was increased likelihood of their dying. However, it has also been identified that the accuracy of this prediction varied with the diagnosis (Waters et al, 1990; Ridley, S, 1998). Knaus (2002) also raised the concern that some clinicians were reluctant to use this tool as they felt that it reduced their sense of control and even potentially questioned the quality of decisions that they made. This has resulted in the score not being used to assist in the recognition of irreversible dying. This is also complicated by the fact that there are occasionally patients who survive despite all the odds therefore making it more difficult for the clinician to accept futility.

8.5 Factors identified for Inclusion in an Education Package

The third objective of this study was to identify any factors that would be useful to include in an education package designed to up-skill clinicians in the recognition of irreversible dying. Currently there is limited training available to ensure that health care professionals are comfortable when dealing with any issues related to death and dying (Levy, 2001). Research has confirmed that it is unlikely that skill will improve with experience alone; and it has been statistically proven that there is significant improvement in practice post training (Wilkinson et al, 2002).

As stated earlier in this chapter (see section 8.3) there was potential within this theoretical model for each of the factors to inter-relate and inter-act with each other. Therefore if one area was affected in any way this would have an effect on the remaining two factors. There was potential for each of the factors in this theoretical model to be affected in some way by the development of a complex intervention with a focus on education to assist clinicians to recognise the irreversible dying phase. If this proved to be effective it could result in changes in practice and behaviour due to increased understanding and skills. The education package would need to be in the form of a complex intervention as it would need to contain several interacting components (MRC, 2008) covering a range of possible outcomes and also targeting a variable population. As identified by the MRC (2008) a range of outcome measures would be required in this context as there could be no single outcome that would indicate the usefulness of this package.

There were 18 factors identified by the panel of experts where consensus regarding the importance of their being included in an education package was achieved (see Table 8.2).

Table 8.2 Topics Achieving Consensus for inclusion in an education package arranged within the theoretical model

Factor	Topic	Cognitive	Behavioural	Environmental
Patient Observation	Breathing pattern changes	√		
	Level of consciousness	√		
Knowledge of the Patient	Rate of deterioration		√	
	Predictability of disease trajectory		√	
	Exclusion of reversible causes	√		
Communication	Multi-professional team working			√
	Time the clinician has to spend with the family and patient			√
	Withdrawing treatment	√		
	Taboo subject for clinicians patients, and their carer			√
	Lack of understanding among family members			√
	Difficulty for clinicians when breaking bad news		√	
	Patient preferences and wishes			√
	Uncertainty		√	
	Consistent communication with families- not raising false hope			√
Attitudes of the Clinician	Quality	√		
	Acceptance that the patient is dying	√		
	Medical philosophy of cure			√
	Courage to challenge systems		√	

It was clear that medical training in palliative care in particular is not considered to be consistent or adequate across the country (DoH, 2014; Leadbetter et al, 2010). Leadbetter et al (2010) identified that this is a concern that is wider spread than one profession, with training needs in care of the dying being a basic requirement for the multi professional team if issues relating to end-of-life were to be addressed. The authors raised the concern that if palliative care was seen as a speciality there is the potential that health care professionals would not recognise that this was an area that should relate to the care all health care professionals provide in all settings as a general care workforce. It is therefore important that when an education package or complex intervention is being developed it addresses the topics that are relevant to all staff working with the dying (NCPC, 2008). However, currently, there would appear to be limited evidence available of existing knowledge and understanding which would enable changes in practice aimed at optimising care provision (Bookbinder, et al, 2001). It was clear that training in the provision of end-of-life care affected all health care professionals whatever their role and whichever setting they worked in. Despite this most of this training is currently provided to doctors or nurses in separate sessions rather than bringing the two professions together so that they may learn from each other (Myers Schim et al, 2007; LACDP, 2014). The development of any education package could be designed to improve this.

Using the theoretical framework and translating the topics where consensus was achieved into the framework has enabled the identification of areas that could be reached through education. Some of these factors, specifically those identified by the panel of experts could clearly be developed into an education package

(changes in breathing pattern, level of consciousness, rate of deterioration, predictability of disease trajectory, exclusion of reversible causes, withdrawal or withholding of treatment, the importance of consistency in the message being communicated and quality issues). The development of a complex intervention involving experiential workshops using different case studies covering the multi professional team may be a possible way forward

Having stated the importance of the development of a complex intervention focussing an education package aimed at improving the ability of the clinician to recognise irreversible dying it is also acknowledged that some of the factors identified in the literature by the participants interviewed, and confirmed as important for inclusion in an education package by the panel of experts, related more to shifting the culture and philosophy of both the health care setting and the wider community (multi professional team working, time to spend with the patient and their families, taboo subject within this society, lack of understanding among family members, the difficulties for clinicians when breaking bad news, patient preferences and wishes, acceptance of the futility of further aggressive treatment, medical philosophy of cure and the courage to challenge the current systems in place). Change of culture and philosophy are problematic areas in which to effect change effectively. In order to achieve this shift there would be a need to understand the barriers and facilitators to this change and any factors that are maintaining current behaviours (MRC, 2008). Further research may be required into these areas in order to identify a strategy designed to affect this change.

There is a strong desire within the National Health Service to provide the best possible quality of care but there are challenges to be faced in achieving this relating to unclear goals and overlapping priorities that can distract attention (Dixon-Woods et al, 2013). Staff can occasionally struggle to provide care effectively as poor organisational and poor information systems disempower them from initiating improvements (Dixon-Woods et al, 2013) leaving them with the perception that they are unvalued. Approximately one third of National Health Service organisations use a culture assessment tool (NICE, 2009). The aim of this is to improve their clinical governance (NICE, 2009). These tools have also identified that there tended to be a failure to consider the perspective of the patient when planning for change and then assessing its impact within these organisations. There is the added difficulty relating to the perception of the drivers for a change in culture, with the frequent perception of staff being that these changes are driven more by government targets and external agencies than by the need to improve the quality of care provision (NICE, 2009). There may be a discrepancy between the views of those staff at the more senior levels and those providing the care on the floor with the more senior staff being more positive about the culture of an organisation than the more junior staff; this being a particularly negative factor amongst nursing staff (The King's Fund, 2014).

One of the factors most frequently cited as an obstacle to the provision of quality care by staff was the lack of opportunity for training and development (Chartered Institute of Personnel and Development, 2013). More specifically there is the need to shift the culture, particularly held within medicine away from cure to doing the right thing for the individual (Puntillo et al, 2006). An inroad into this concern

could be made by addressing early in the training of doctors and nurses the inclusion of an emphasis on palliative care (Christakis et al, 2000; Tanneberger et al, 2002).

17 of the 31 factors (54.8%) identified as not achieving consensus for either inclusion or exclusion in this education package were factors identified for consideration by the expert panel. This could be a cause for concern as it may indicate that specialist palliative care providers do not have much evidence on which to base their practice and therefore there may be limited consensus amongst the experts as to what is useful or a barrier in this context as practice has developed reflecting local needs and this does not necessarily reflect what is happening in practice with the generalists on the floor who are providing the care.

8.6 Limitations to this study

There are various limitations to this study. These will now be described and attributed the appropriate phase of the study undertaken.

8.6.1 Limitations to the Systematic Review

There were several limitations relating to the Systematic Review specifically. The first of these was the fact that the year 2000 was chosen as the cut off point for the literature search. Although the rationale for the date chosen was clear there is the possibility that relevant important studies that may have been undertaken prior to this will have been missed due to this date choice and thus, important data may have been missed.

A second limitation to this phase of the study was that the studies identified for appraisal in this systematic review consisted of a wide range of participants including patients, doctors, nurses and their families. This, at times, restricted the ability of the researcher to make meaningful comparisons across this wide range of data.

A further concern was the probability of researcher bias. As the researcher has been based in the hospice setting for the last 25 years and also has a clinical background it is probable that there were preconceptions being held by the researcher which may have unintentionally affected which of the studies were selected. The risk of this was reduced by the use of an independent tool with which to appraise the studies and also by having a second checker appraise the studies independently.

Finally, the majority of the studies chosen for appraisal in the systematic review had small sample sizes which will have reduced their generalisability to other areas as the results and findings may have been skewed by a group that does not reflect the norm.

8.6.2 Limitations to the interview phase

The first limitation identified which affected this phase of the study was that of the participant sampling method. The proposal had initially been to employ Grounded Theory as the methodology for this phase of the study. Unfortunately, the ethics committee were unable to accept this as a sampling method and therefore it was decided to use purposive sampling in order to identify potential participants.

Although this meant that it was not possible to use the Grounded Theory methodology in full the principles of this methodology were still used for the analysis of the data. This participant selection issue may have in fact benefitted the study as it allowed for comparison across roles, levels of seniority and work place which may not have occurred if the sampling method had been theoretical.

There is also the limitation that the interviews undertaken during this phase of the study were restricted to doctors and nurses whereas many other clinicians work with the dying patient (E.g. Physiotherapist, Social Worker) all who may have had relevant in-put into this study which has now been missed.

The decision to choose the local district general hospital as the site from where to select the participants was also a limitation to this phase of the study in that all participants worked in the same district general hospital all be it on differing units. This could have resulted in the study being less generalisable as practice could have varied across different hospitals and this will not have been identifiable in the data.

There may also have been limitations introduced during the development of the topic guide used for the interviews. Areas such as culture were not identified for inclusion as a potential issue in the recognition of the irreversibly dying patient. This resulted in this area not being explored. This then resulted in potentially not identifying any cultural barriers to this recognition process for clinicians. This was exacerbated by the limited sampling frame of the participants. However, when this topic was identified as a potential barrier by the panel of experts at the end of

round 1, they then could not agree on its relevance for either inclusion in or exclusion from an education programme.

The interviews themselves also may have been affected by researcher bias in that the researcher may have been influenced by her previous experience as a clinician working in the hospice setting which may have introduced bias into the interviews and their analysis. The risk of this was reduced by the researcher maintaining a journal and also using her supervisors as “critical friends”.

8.6.3 Limitations to the Delphi phase

With hindsight, there is the potential that the participant selection for this phase of the study may have resulted in the loss of useful data in that theoretical experts were used for this phase. The definition used for this phase of the study resulted in the identification of participants who were theoretically the experts but may not all have been working on the ward on a daily basis. It may have been more useful to define “expert” as those clinicians who are facing this recognition process on a daily basis, that is, the generalist working on the ward setting. There is the potential that the experiences of these two groups differ widely and the findings may have differed as a result.

A further limitation to the Delphi study is that by using the Secretariat of the National End of Life Programme to send out the initial invitations, although ensuring

confidentiality resulted in the researcher being unaware of the total number of invitations that were initially sent out to participants. This resulted therefore in the

inability to accurately measure the drop-out rate as there was no baseline measure. This rate could only be accounted for following the responses to rounds 2 and 3.

Another limitation to be identified in this phase was the title of the questionnaire. The title given to it was “What factors assist clinicians to determine dying in an acute hospital? That is, the same title as the thesis as a whole. What the participants were being asked to rate was what factors would be useful to include in an education package for clinicians to help enable them to recognise the patient who is irreversibly dying. This in itself was probably the cause of a large part of the confusion that clinicians expressed when unsure what they were meant to be rating.

8.7 Summary

This chapter has reminded the reader of the aims and objectives of this study. It then addressed the development of a theoretical model as recommended by the MRC Guidelines (2008) when the objective is to develop a complex intervention. The model chosen was based on the social cognitive theory and consisted of three concepts, cognitive, behavioural and environmental factors all of which constantly inter-relate resulting in changes in behaviour. The findings from phases 1, 2 and 3 of the study were then translated into this model. As identified in section 8.3.2, the belief is that if one of the factors from this theoretical model is altered this will then affect the other two. A discussion was then undertaken in order to identify where an education package could affect each of the three factors identified in this theoretical model.

Translating the factors identified into this model also indicated that there were some factors that may require a different approach as they depend upon a change in culture rather than a complex education intervention.

Finally, the three phases of this study were reviewed in order to identify their limitations.

Chapter 9 will now develop the conclusions arising from this study.

CHAPTER 9

CONCLUSIONS AND RECOMMENDATIONS

9.1 Introduction

This chapter builds on the discussion presented in the previous chapter. It will identify the original contributions that this study has made relating to the knowledge available to help clinicians when they attempt to recognise the irreversible dying phase. It will also consider what implications the findings from this study may have for the practice of clinicians and provide recommendations for future clinical practice, education, policy and further research. Section 9.4 will focus on a reflection of how effective the processes of the study undertaken were and how the researcher themselves may have affected the findings

9.2 Areas where this study contributes

Published literature has identified that the recognition of the patient who is irreversibly dying is an issue that has troubled clinicians (Chow et al 2001; Christakis et al 2000; Vigano et al 2000a) and that this recognition process is complex. Issues include unrealistic expectations of society, lack of support at the community level, medical practitioners' fear of litigation and increasing specialisation in single organ illnesses when the majority of patients who are actively dying will have multi organ failure and probably will have been diagnosed with multiple co-morbidities (Hillman, 2010). The findings from this study suggest that many clinicians lack confidence in recognising the irreversible dying phase. They appear to have concerns about making the wrong decision, exacerbated by the ramifications of this error for patients and their families. The identification of these concerns will enable steps to be taken to address them.

This study is original in the exploration of the factors clinicians identify as useful in assisting in the recognition process and which of these factors could then be useful in an education programme. The theoretical model developed summarises the factors identified by the literature and interview findings. This study provides an evidence base for the development of a complex intervention based on an education package (MRC, 2008) but it also identifies factors that will need to be addressed in a broader context as they relate to cultural issues. It can be used to stimulate discussion by health care professionals in their own settings relating to the recognition of dying. In particular, the need to address the philosophy and culture of the health care setting and also that of the broader community has been confirmed. Whilst concerns relating to the medical philosophy of cure is well documented (Hariharan et al, 2003; Leadbetter et al, 2010; Norton et al, 2003) the influence of societal culture is less widely addressed in the literature.

9.3 Recommendations for practice, education, policy and research

Four distinct areas have been identified where the findings from this study may have implications. These are clinical practice, education, policy and research.

9.3.1 Recommendations for Clinical Practice

Engaging with staff and ensuring they have vision and enthusiasm for the promotion of good quality care provision for the dying patient is key to the provision of appropriate care. The aim of this study has been to identify factors that clinicians find useful or a barrier to the recognition of the irreversibly dying patient but also to identify which of these it would be useful to include in a complex intervention in the form of an education package. The theme that

emerged from these findings is that clinicians have a fear of getting the timing of this recognition wrong because the decision making process is complex and this complexity is exacerbated by fear of missing the treatable.

There is evidence of studies where the views of the clinician relating to the recognition of dying have been explored (Barnato et al, 2012; McBride et al, 2006; McCallum et al, 2013) but this is the first study which has focussed on the last few days or hours of life and where the findings from the participants have informed the development of a theoretical model in order to identify methods of supporting clinicians when faced with this process.

One area where practice could be affected is by ensuring clinicians are aware of some of the topics identified during the course of this study and encouraging them to take these into consideration when they are reviewing a patient who appears to be deteriorating and may potentially be entering the last few days of life.

It was identified in this study that by encouraging clinicians to use their observational skills such as the consideration of the breathing pattern, how rapid is it, how shallow, are there secretions present, and also the conscious level of the patient. By doing this they may improve their ability to recognise the irreversibly dying patient. These factors however, would be less useful in the intensive care setting as many of the patients here are sedated in order to be mechanically ventilated and therefore these topics would not be appropriate.

Clinicians should also be reminded of the need to check the patient records carefully ensuring that they have all the up to date information available with which to make this decision. The clinician needs to take into consideration in particular, the rate at which the patient is deteriorating, the predictability of the disease trajectory of the illness with which the patient has been diagnosed and whether or not there are any reversible causes identifiable for the deterioration. These areas would need to be reviewed prior to making the decision that the patient is irreversibly dying.

It was also identified that a potential barrier to the recognition of these patients was a possible avoidance of difficult and potentially distressing conversations by the clinicians. It is important that clinicians acknowledge this potential barrier and make an effort to address it. This will be difficult to achieve in that death and dying are still very much taboo subjects in society, even amongst clinicians. They will need to be encouraged to consider this topic and to discuss it amongst themselves. Once they are able to acknowledge this avoidance there is the potential for it to be addressed in a meaningful manner. Clinicians also need to acknowledge the potential barrier caused by any philosophy of health care being purely about saving lives and not including the provision of good deaths. By acknowledging this there is the potential that the behaviour of staff may alter. In order to achieve this there may be the need to enhance the skills that clinicians currently have when they are undertaking difficult and sensitive conversations.

Finally, the role of clear communication must be accepted as a key topic in the practice of clinicians when they are working with the dying patient. This

incorporates the communication between teams, between team members, between team members and the patient and also between team members and the patient's family. If this communication is clear it results in everyone working together towards the same end rather than potentially the care becoming fragmented as teams work towards different goals. If communication between the clinician and the patient and family in particular is ambiguous this can result in a lack of understanding relating to the futility of carrying on treatment and prolonging the dying phase. This can potentially result in antagonism between groups due to a lack of clarity and understanding.

However, clinicians also need to be reminded that these are not topics that should be used as absolute measures for recognising the irreversibly dying patient in their own right but are topics it may be useful to take into consideration when reviewing a patient who is deteriorating and are probably more precise when used in combinations.

One possible approach to addressing these findings is the development of a complex intervention in the form of an education package. This could be designed to reflect the theoretical model introduced earlier as if one of the factors was addressed in this way this would affect the other two factors thus potentially altering the behaviour of the clinicians when they consider whether or not a patient may be irreversibly dying. Once developed this package could be used to improve the skills and confidence of the clinicians involved in this process. It may also provide them with the confidence to communicate bad news and to address topics that are currently considered taboo (Leadbetter et al, 2010; Levy, 2001;

NCPC, 2008). Recently advanced communication skills training was well resourced for specialist care staff. As a result of this study it would be recommended that this was once again resourced and widened to include staff in all settings. The majority of barriers identified related to concerns relating to communication skills which could be addressed in this package (NCPC, 2008). This could result in more appropriate treatment for the patient and reduced frustration for the clinician.

9.3.2 Recommendations for education and training

The second area where there are potential recommendations arising from the findings of this study is that of education. This study has identified that there are several areas where there is a possible gap between theory and practice with factors identified by the literature or the panel of experts as being useful not being identified by the clinicians and vice versa. Some of these factors could also be addressed by the development of this complex intervention. Initially however, it would be imperative to identify what competencies for clinicians are already available in care of the dying and the contents of these programmes in order to reduce the risk of duplication.

This study also demonstrates that the skill sets vary between the clinical roles of doctors and nursing staff. In order to address this factor, as suggested by the theoretical model, it is recommended here that the package is developed with this in mind and is developed as a multi professional course, encouraging the various team members to discuss these differences enabling the recognition of these

differing skills and valuing both their similarities and differences. This could result in a more holistic assessment of the patient being undertaken.

With the theoretical model in mind there is the potential that the complex intervention could focus on cognitive factors such as the physical observation of the patient combined with those which were identified as behavioural, particularly those relating to communication. If these two areas were addressed within this complex intervention there is the potential for the confidence of the clinician to grow in this context which will then affect environmental factors as the clinicians become more comfortable discussing death and dying.

It was identified that the needs of the staff in the Intensive Care setting vary from the other two settings. It is recommended that a core set of modules is developed particularly relating to communication skills and then “bolt on” modules that are speciality specific are also developed.

Organisations caring for the dying patient should be obliged to ensure staff are competent (DoH, 2014). Therefore the final recommendation here would be that training in the recognition and appropriate care of the dying patient should not only be part of a compulsory induction process but should also be a continuing competency requirement.

9.3.3 Recommendations for Policy

The third area identified where recommendations can be made is that of policy. The findings from this study could be included in the evaluation of the evidence

informing the development of any guidelines drawn up by the National Institute for Excellence (2004) regarding the care of the dying adult. This in its turn could inform policy decisions. The current document (NICE, 2004), addresses the patient dying of cancer but there is the potential for this to be broadened to include any dying patient. Although NICE (2004) acknowledge the need for specialists to access advanced communication skills and training, the care provided to the dying patient will often be provided by generalist staff. Currently their needs in training and education in this context do not appear to be being addressed. Therefore the recommendation is that advanced communication skills training be extended to all health care professionals dealing with the dying patient. This again is an area the theoretical model identified where education would potentially affect the behaviour of clinicians.

A broader recommendation that is identified in this context is the need to address issues of philosophy and culture contained in the environmental factor of the model both in the health care setting but also in the wider context of society as a whole. Topics explored in the this area of the theoretical model indicated that education would not address all the factors identified but a broader approach would be required to address cultural changes needed relating to areas such as the medical philosophy of cure and the encouraging of clinicians to challenge systems both of which are currently seen as barriers to the provision of appropriate care. The wider societal issues such as death being a taboo subject will also need to be addressed. Any future revision of the End of Life Care Strategy (DoH, 2008) should include the need for these areas to be addressed both within the health community but also in society as a whole.

9.3.4 Recommendations for Research

The MRC Guidance for Developing and Evaluating Complex Interventions (2008) describes the process for the development of any complex intervention. This study has identified the evidence base on which to ground the development of this intervention. This was then re-enforced by the development of the theoretical model where it was identified that by addressing any of the three factors, behavioural, cognitive or environmental the other two factors would also be affected resulting in a change of behaviour of the clinician. This would then result in the development of the confidence of the clinician in the recognition of the irreversibly dying patient thus ensuring that appropriate care is provided.

This study has high-lighted that there is a paucity of robust research available in palliative care in general and end of life care in particular which clinicians can use as evidence on which they can base their decision making. This concern was initially raised as by the DoH (2008) who identified that there was limited evidence available on which they could base recommendations in their strategy for care at the end of life for cancer patients. More recently the Leadership Alliance for the Care of Dying People (2014) identified that recognising dying is a priority if decisions and plans are to be made in accordance with the patient's wishes. They also acknowledged that there was still limited active research being undertaken in this area. They also stated that it was important that patients in the last few hours or days of life be recognised and their care reviewed; that this is one of the key duties and responsibilities of health and care staff. Currently there is limited education provision and little research available to enable clinicians to do this.

The fact that there is currently very little robust evidence available for clinicians to access has resulted in there being multiple areas where practice has developed locally. This study provides evidence that even the experts have difficulty achieving consensus perhaps due to this.

As stated in chapter 1, the aims of this study were to explore factors that help or hinder a clinician when attempting to determine whether or not a patient is entering the irreversible dying phase and to seek consensus on which of these factors would be useful to include in an education programme to help with this process. This has been achieved. Further stages are now needed to develop this intervention, evaluate it and then convert this into practice. Therefore further work is required to:

- Identify what competencies are already available for clinicians relating to the recognition and care of the irreversibly dying patient. Areas to be considered in this context would be the Royal College of Physicians, the Nursing and Midwifery Council and also disease specific guidelines. The findings of this study should be compared to the training currently provided and any gaps identified and focussed on in this complex intervention.
- Develop an understanding of the possible effects of the education package as identified in the theoretical model by testing through focus groups, surveys or small observational studies varying components of the education package in order to identify their effects.
- Design a complex intervention. This will need to be based on the theoretical model presented in Chapter 8. If the factors identified relating to the competency of the clinician are included in this intervention there is the

possibility that this will increase the confidence of the individual which will in turn affect their attitudes and experiences. This may then impact on the environmental factors where, as their confidence develops, they will become more likely to question any philosophy of cure attitudes, acknowledging futility and in turn ,begin to address this taboo subject

- Once designed, undertake a pilot of the education package by health care professionals in order to refine the contents.
- Evaluate this pilot identifying those topics of the theoretical model which responded in particular to education
- Design a main trial in order to evaluate the complex intervention.
- Re-visit the complex intervention in a separate study in order to assess the true effectiveness of this intervention

A further area that will require research was identified as an area of limitation in this study. This was the effect that culture has on this process. The cultural attitudes of everyone concerned in this context will have an effect on their response to futility and irreversible dying. The cultural attitudes of clinicians, patients and their families needs to be explored in depth in order to identify further potential barriers or facilitators to this recognition process.

9.4 Reflections on the Study

The three phases of this study, the systematic review, unstructured interviews analysed using the Grounded Theory approach and the Delphi study enabled the aims and objectives of the study to be largely met. By identifying the theoretical evidence available in the literature and then establishing how this converts into

practice and finally gaining an expert consensus on the topic, a greater understanding of what clinicians find useful in the recognition of the irreversibly dying patient and the potential need to review the focus of a pattern of care was developed. Ultimately, the findings of the study as a whole have resulted in the identification of themes and factors that it would be beneficial to include in a complex intervention in the form of an education package relating to this. It has also identified other factors that will need to be addressed in a wider societal and cultural manner.

Reflections on the processes

Through the development of the initial literature review and the systematic review, an evidence base regarding how, in theory, clinicians recognise that a patient may be irreversibly dying was established. The evidence indicated that potentially there may be tools to help with this process but on further exploration these tools related to patients with a longer term prognosis of weeks to months rather than to the last few days of life and measured severity of an illness rather than recognition that a patient may be irreversibly dying. None of these had been validated for use when assessing whether a patient has entered the last few days of life.

The literature frequently identified that this is an area where clinicians are notoriously inaccurate and that there is currently limited research evidence available related to the themes and factors to take into consideration when attempting to recognise the patient who is irreversibly dying.

It had been anticipated prior to the commencement of the study that it might be difficult to recruit participants for the interview phase of this study. There were concerns that this could be a particular issue on the Intensive Care Unit. However, it was clear that that the nurses in this setting in particular were keen to participate. The recruitment of doctors however, was more problematic. Only one of the four consultants based in the Intensive Care Unit responded and only one junior doctor out of a potential twelve working on that unit at that time. However, this was also identified as an issue on the Care of the Elderly Unit. There is the possibility that this related largely to poor timing by the researcher with these wards both being approached over the period where the majority of staff take annual leave.

A further concern identified related to the transcribing of the interviews undertaken in phase 2 of the study. There was the potential for issues relating to confidentiality in that the transcribers may have had telephone conversations with some of the staff interviewed. A further method used to reduce this risk was when interviewing, the researcher took care not to mention the name of the participant. If finances had allowed an external transcriber would have been employed in order to reduce this risk further.

Interviewing staff on the wards had both positive and negative factors attached to it. On the positive side staff who agreed to participate had a genuine interest in the subject matter and were very engaged and co-operative. However there were issues in the choice of place of interview in that staff were at times distracted as they were aware that their colleagues were covering for them. There is the

potential that this could have resulted in a lack of focus possibly resulting in a loss of important data as the thread of the conversation was lost or attempts were made by the participants to hurry the process. It also had the drawback of constant interruptions from other members of staff when the area chosen for the interviews was close to the ward. On the occasion where the participant requested to be interviewed in a coffee shop, the issues related to the lack of privacy and the amount of background noise.

The use of a topic guide in the interview process was useful in that factors that needed to be further explored were less likely to be missed. Allowing participants to explore the topic using this guide resulted in a wealth of data.

On analysing the interviews, those undertaken with the medical participants tended to be longer in duration. These were also more focussed on clinical factors with measureable outcomes. There appeared to be a tendency to avoid any discussion relating to emotions and feelings. This may relate to the style of teaching doctors receive which focuses largely on facts and quantitative issues and much less on intangible qualitative information.

When phase 3 was reflected upon there were some limitations here regarding the sample selection process. In addition to the recruitment via the National End of Life Care Programme, a snowball sampling method could have been used in order to identify experts in the field by other health professionals. To a small extent this may have happened informally. However, in any study where participants are self-selecting, it is most likely the case that they have a particular

interest in the topic. While this is not major limitation, particularly given the nature of the Delphi method to gain a consensus opinion from experts in the area, it does mean that a wide range of experiences may not have been identified.

The topics and design of the initial round 1 Delphi questionnaire could potentially have been more robust with exclusion of the findings of the initial literature review. The factors identified in this first review came from literature that did not necessarily include primary research and was therefore less evidence based and may potentially have weakened the questionnaire. This could have resulted in more of a focus on factors that were more important for consideration in this context.

Reflecting on whether it would have been better to use the median score rather than the mean in order to measure the level of consensus within the Delphi it would appear that little would have been gained by this as the mean score of 15 out of 18 topics achieving consensus for inclusion in an education package was between 6 and 7. The lowest score of those achieving consensus in the remaining three topics identified was 5.75. This topic was contained in the factor “”Attitudes of the Clinician” and was the topic “courage to challenge systems”. When compared to the percentage this topic only just achieved consensus with that measure also (81.25%).

Having reflected on the study it would appear that the methodologies chosen were appropriate in that the themes and factors that clinicians find useful or barriers to the recognition of the dying phase in practice were identified. These

were then reviewed by the panel of experts for usefulness of inclusion in an education package. In hindsight however, perhaps the focus of the entire study should have been on either the identification of the factors that clinicians find useful or barriers to the recognition of the dying patient or which specific factors would be useful in an education package for clinicians designed to help with the recognition of irreversible dying. This would have allowed for a more focused comparison with the relevant literature in the systematic review and during the analysis of the interviews. This would also have provided clarity for Delphi participants as to which of these two aspects they were expected to focus on when rating each of the topics.

Researcher as an instrument.

The findings of the systematic review indicated a lack of evidence based literature regarding how health professionals know when to change the focus of a pattern of care provision to reflect that the patient is irreversibly dying. This clarified that further investigation was required in order to identify potential themes and factors clinicians found useful when faced with this recognition process.

An area of concern identified was the possible bias of the researcher in this context as a result of having a clinical background and being hospice based and therefore holding strong opinions on this subject. The use of a journal to help bracketing was helpful at times, encouraging a reflective process raising awareness of potential issues and conflicts. However, at times it was impossible to be completely impartial and this may have affected the findings within the

interview process in particular. A further concern was that the principle researcher undertook both the interviews and then the analysis of these interviews. Ideally two different people would have undertaken these roles in order to reduce this potential bias. However, undertaking both of these roles did result in the researcher being totally immersed in the data. The interview process was also much more time consuming than had actually been allowed for which increased the pressure on the researcher when analysing the interviews.

A further complication was the lack of experience the researcher had in undertaking interviews. With the advantages of hindsight and having analysed the transcripts of these interviews it became clear that there were themes that with careful probing would have been useful to explore further with the participants. The focus of the researcher was largely concentrated on the questions to be asked rather than listening to and engaging with the responses that it is possible that data may have been lost. This would have explored their thoughts relating to the facilitators and barriers to the recognition of the irreversible dying phase more fully.

The researcher was also concentrating on ensuring that anything said by the researcher did not affect the responses of the interviewee and this potentially also resulted in lack of in depth exploration.

9.5 Study Conclusions

This study aimed to identify and explore factors that help or hinder a clinician when attempting to recognise whether or not a patient is entering the irreversible

dying phase and then to seek consensus on which of these factors would be useful to include in a complex intervention in the form of an education programme to help up skill clinicians in the process of recognising the dying phase. The theme that emerged was that clinicians have a fear of getting the timing of this recognition wrong because the decision making process is so complex and this is exacerbated by fear of missing the treatable.

The findings and the theoretical model that have resulted from this study highlight the complexity of this recognition process and the fear that clinicians have of being wrong in their decision making. The findings of this study confirm that clinicians find the recognition that a patient is dying a difficult area to assess with great certainty. There would appear to be a deep concern about getting it right in order to reduce distress for the patients and carers.

The theoretical model helped to organise the role that the different topics within the five over-arching themes (“Patient Observation”; “Knowledge of the Patient”; “Communication”; “Experience of the Clinician”; “Attitudes of the Clinician”) have and identify how they relate to this recognition process.

The reliance of doctors on tangible evidence appeared to complement the more intuitive nursing factors that were identified and it is possible that due to these preferred styles working together may assist in the process as there could be a wider, more holistic view of the patient. An education package where both groups of professionals attend together could result in the clinicians learning to recognise each other’s strengths and to use them when reviewing the patient thus

improving the likelihood of their being identified and therefore the care provision being appropriate.

This three phase study has identified factors that clinicians feel are barriers or facilitators in the recognition of the patient who is irreversibly dying. It has also identified which of these factors would be useful for inclusion in a complex intervention for clinicians in order to improve their practice in this area. There has also been confirmation of the impact that the cultural attitude to death and dying of society as a whole has on this process. This study can now be used as the evidence base for the next stages of development of a complex intervention in the form of an education package, testing through focus groups, surveys or small observational studies varying components in order to identify their effects, pilot of an education package and the design of a main trial in order to evaluate the complex intervention.

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APPENDIX A

SEARCH STRATEGY SAMPLE

Journals@Ovid Full Text <January 24, 2013> (updates since 2013-01-23) - (18 records) Search has not been executed against Database Embase <1996 to 2013 Week 03> due to lack of updates since last alert execution Search has not been executed against Database Ovid MEDLINE(R) without Revisions <1996 to January Week 3 2013> due to lack of updates since last alert execution

Results Generated From: Journals@Ovid Full Text <October 03, 2013> (updates since 2013-10-02) - (no records) Search has not been executed against Database Embase <1996 to 2013 Week 39> due to lack of updates since last alert execution Search has not been executed against Database Ovid MEDLINE(R) without Revisions <1996 to September Week 4 2013> due to lack of updates since last alert execution

Undertaken 14/09/13

Database	Search Term	View Results	
CINAHL	(health AND care AND professional).ti,ab	10315	Apply Limits
CINAHL	clinician.ti,ab	8354	Apply Limits
CINAHL	nurses.ti,ab	138750	Apply Limits
CINAHL	doctors.ti,ab	12101	Apply Limits
CINAHL	1-4.ti,ab	2294	Apply Limits
CINAHL	behaviour.ti,ab	16018	Apply Limits
CINAHL	approach.ti,ab	88085	Apply Limits
CINAHL	(decision AND making).ti,ab	20774	Apply Limits
CINAHL	6-8.ti,ab	1224	Apply Limits
CINAHL	recognise.ti,ab	1539	Apply Limits
CINAHL	determine.ti,ab	100602	Apply Limits
CINAHL	factors.ti,ab	141295	Apply Limits
CINAHL	techniques.ti,ab	36604	Apply Limits
CINAHL	10-13.ti,ab	327	Apply Limits
CINAHL	palliative.ti,ab	14197	Apply Limits
CINAHL	(end AND of AND life).ti,ab	11707	Apply Limits
CINAHL	dying.ti,ab	7880	Apply Limits
CINAHL	futility.ti,ab	457	Apply Limits
CINAHL	(terminally AND ill).ti,ab	2259	Apply Limits
CINAHL	prognosis.ti,ab	12895	Apply Limits
CINAHL	15-20.ti,ab	627	Apply Limits
CINAHL	5 and 9 and 14 and 21	0	Apply Limits

#	Search History	Results
1	Health Care Professional and (recognise or determine) and (dying or palliative or end of life)	10510
2	limit 1 to abstracts	9705
3	limit 2 to "middle aged (45 plus years)" [Limit not valid in Journals@Ovid; records were retained]	9705
4	limit 3 to humans [Limit not valid in Journals@Ovid; records were retained]	9705
5	limit 4 to english language [Limit not valid in Journals@Ovid; records were re! tained]	9705
6	limit 5 to human [Limit not valid in Journals@Ovid; records were retained]	9705
7	limit 6 to aged <65+ years> [Limit not valid in Journals@Ovid; records were retained]	9705
8	limit 7 to yr="1990 -Current"	9612
9	limit 8 to updaterange="ovft(20131002155356-20131003012624]"	0

Results Generated From: Journals@Ovid Full Text <March 10, 2014> (updates since 2014-03-06) - (no records) Search has not been executed against Database Embase <1996 to 2014 Week 10> due to lack of updates since last alert execution Search has not been executed against Database Ovid MEDLINE(R) without Revisions <1996 to February Week 4 2014> due to lack of updates since last alert execution

#	Search History	Results
1	Health Care Professional and (recognise or determine) and (dying or palliative or end of life)	10174
2	limit 1 to abstracts	9331
3	limit 2 to "middle aged (45 plus years)" [Limit not valid in Journals@Ovid; records were retained]	9331
4	limit 3 to humans [Limit not valid in Journals@Ovid; records were retained]	9331
5	limit 4 to english language [Limit not valid in Journals@Ovid; records were re! tained]	9331
6	limit 5 to human [Limit not valid in Journals@Ovid; records were retained]	9331
7	limit 6 to aged <65+ years> [Limit not valid in Journals@Ovid; records were retained]	9331
8	limit 7 to yr="1990 -Current"	9238
9	limit 8 to updaterange="ovft(20140306231732-20140310020842]"	0

Results Generated From: Journals@Ovid Full Text <April 28, 2014> (updates since 2014-04-24) - (no records) Search has not been executed against Database Embase <1996 to 2014 Week 17> due to lack of updates since last alert execution Search has not been executed against Database Ovid MEDLINE(R) without Revisions <1996 to April Week 3 2014> due to lack of updates since last alert execution

#	Search History	Results
1	Health Care Professional and (recognise or determine) and (dying or palliative or end of life)	10312
2	limit 1 to abstracts	9455
3	limit 2 to "middle aged (45 plus years)" [Limit not valid in Journals@Ovid; records were retained]	9455
4	limit 3 to humans [Limit not valid in Journals@Ovid; records were retained]	9455
5	limit 4 to english language [Limit not valid in Journals@Ovid; records were re! tained]	9455
6	limit 5 to human [Limit not valid in Journals@Ovid; records were retained]	9455
7	limit 6 to aged <65+ years> [Limit not valid in Journals@Ovid; records were retained]	9455
8	limit 7 to yr="1990 -Current"	9356
9	limit 8 to updaterange="ovft(20140424225244-20140428054242]"	0

Results Generated From: Journals@Ovid Full Text <May 20, 2014> (updates since 2014-05-19) - (no records) Search has not been executed against Database Embase <1996 to 2014 Week 20> due to lack of updates since last alert execution Search has not been executed against Database Ovid MEDLINE(R) without Revisions <1996 to May Week 1 2014> due to lack of updates since last alert execution

#	Search History	Results
1	Health Care Professional and (recognise or determine) and (dying or palliative or end of life)	10371
2	limit 1 to abstracts	9507
3	limit 2 to "middle aged (45 plus years)" [Limit not valid in Journals@Ovid; records were retained]	9507
4	limit 3 to humans [Limit not valid in Journals@Ovid; records were retained]	9507
5	limit 4 to english language [Limit not valid in Journals@Ovid; records were re! tained]	9507
6	limit 5 to human [Limit not valid in Journals@Ovid; records were retained]	9507
7	limit 6 to aged <65+ years> [Limit not valid in Journals@Ovid; records were retained]	9507
8	limit 7 to yr="1990 -Current"	9408
9	limit 8 to updaterange="ovft(20140519103935-20140520032008]"	0

APPENDIX B
TOPIC GUIDE FOR INTERVIEWS

What do you think about this as a subject? Do you think it is important?

How long have you been caring for the dying?

What strikes you in particular when caring for the dying?

If it helps you may like to think about a particular patient

1. What factors are helpful when you are trying to decide whether a patient will die in the next few days?

2. In your experience what things get in the way of identifying the dying phase?

Probes for above 2 questions:-skill mix, work load, age, time of day, MDT working, medical history, clinical test results, family dynamics, experience, symptoms

3. What difference does it make if you know the patient well?

New member of staff, how and what would you teach them?

Speciality	With drawing treatment	Taboo subject
Staff expectations	Fear of being wrong	Training
Lack of time	Taking away hope	

Is there anything else you would like to add?

APPENDIX C
SAMPLE INTERVIEW (PARTICIPANT 17)

What do you think of identifying dying as a subject, do you think it's important or is it one that 5the government's actually over-emphasising?

Er. I mean it's clearly very important. I think we're good at handling um, life but not so good at handling death. More particularly, because as a society, we're not particularly good at it either professionally. It makes us all a bit squeamish no matter how much we get used to it we still are a little bit squeamish about it all. Um. Is government over-emphasising it? Um, I don't know actually. I haven't seen an awful lot from the government about it.

I suppose I was thinking along the lines of the Darzi report.

OK. Right. Well.

End of Life Care Strategy and saying that people aren't talking about it enough and Advance Care Planning

Well I think we probably, we probably should talk about it a bit more. It's very, it's so very unusual as far as I can see that anyone has made any intimation other than I don't want to be this that and the other to their family. I don't know whether or not it's because Plymouth's a bit of a blue collar town. Certainly I've worked in other places and there is a bit more um, autonomy but not anything unique, I worked in the States as well, not anything like the States. People there are a bit more used to it I suppose. It's still um, as though we're on the shop floor if we've got issues to raise with family. Er, some people just have lack of insight of how unwell you have to be to get into intensive care. So, um, I think it's important though we probably could do better. Um, I think at least everybody's a little squeamish no matter how good we think we are.

Why do you think that is? What is it that causes that?

It's probably just um, I don't know whether or not it's an inbuilt fear of ones own mortality or whether or not we just um. It's emotional instead of medicine. Medicine's all about sort of keeping people going on or whatever. And maybe the actual actively saying this is, this is not in the patient's best interest, we should stop, is, is part of their medical care, health care or whatever. It's um, it's just the opposite of what we're so used to doing really you know. Just going on and on. And I think, um, when I was at medical school they asked us, gave us scenarios about people, what we would do as a sort of clinician to people who were you know, had fairly sort of limited ability whatever to keep going physically. And we were all, oh yes, we'll keep treating you know, keep going, keep going, keep going and so on. Er, and then they said what if you were the patient? And then oh no, I'd have stopped, I'd have stopped years ago, no way I want to be blah, blah, blah, you know. So it's a strange way that we have professionally versus our own sort of personal feelings about it all you know. And I, I think that probably the dread is that we become too much the other way and I think that's what it

probably is. It's the slippery slope argument. People don't want to start going down that or else we end up in a world where we don't try just as much as we probably could in some circumstances. Mmm.

Is there anything about it being a difficult subject to raise generally because we just don't talk about it as a society?

Well I think you're right. I mean I , I come from an Irish Catholic background and I've been to more funerals than I've been to any weddings or anything else. I mean, we, as a society, or, as in at home, it's part of…..people talk about having a good death and stuff like that and having a good funeral. Er, and individuals talk about what a good send off, I mean, it's sort of a bit more, 'cos it's a bit more faith based society, it's a bit more um, accepted I suppose as just this is, whether, whereas here, in England, in, in Britain I think we probably don't talk about it as much. There's a little more um, er, um, buttoned down about it I suppose. That's my general feeling talking to, not professionally, talking to other people, you know. So, um, we probably don't talk about it as much, and there isn't this sort of, the idea of it being part of, an extension of life um, er, maybe it's because families just aren't as nuclear as they are in other societies. But, as I say, from a, from a personal point of view it, it was just that from so high I was going to funerals of great grandparents and god knows who and you know, that was the normal thing. Anybody died in the village we went to their funeral, it was just that was the way we did it. Um, society here is, is less er, how would you describe it? Um, ie I'm seen as a sort of outsider although I've been in England for fifteen years whatever it is. It's slightly um, different feel to it. Not now but, better, worse whatever, there's less emphasis on, on, on death as part of life I think. Really. And I think it's, whatever, a lot of people who come through the doors from a professional point of view, they, they haven't had the opportunity to, to talk about it maybe, and the last thing you want to do is when they're acutely unwell is for them to come in and then the family have to have some sort of discussion about themselves and invariably they're going to err on the side of caution and say no we want everything done. 'Cos that's actually the easiest, the default setting, is that we will continue to push forward. There's no, um, it would be very difficult at that stage I think, 'cos you watch families and they're tortured about it all and I think they know probably that their family member wouldn't want just as much done but it would be difficult if it was your family member to say that's, we should stop. And I think it's, so there isn't the background in society being discussed, it's not discussed in families and then of course, in the emergency setting, boom, 'cos the default setting is the, the inertia, you just keep going down that path you know.

Yes.

And I think it's only after maybe, if somebody had a catastrophic sort of injury or what have you, it's a few days that they're here at the bedside and I think you can almost see a sort of sea change in them. Sometimes they come in and they're quite belligerent about the treatment options that we want this and that done and the other and whatever. And then I think, when they've sat at the bedside for a week and realise that actually all has been done, things aren't going forward and that the best that we can get is that people who are older, the patient gets back to

what their normal is which maybe wasn't great anyway. Then they sort of have an option and they weigh it up. So I think from that point of view er, a bit of time is useful for them to reflect on that I think. And I do see that professionally.

And is that something that is usually available in this setting?

Well. I think the family still have the, have the, they're labouring under a sort of um, I think the, they think they're there to make the decisions and I don't think they fully realise that the decisions are made sort of around them, that their assent is sought for things not their consent. Um, and I think once that, once you just say that actually you don't have to make, you as a family member don't have to make the decision, the people who are looking after your family member have made the decision and the decision is x, y and z. You see a lot of relief then actually so people are they, you know, clearly we try to sort of bring them along, involve them in the discussion but tell them that you don't have to make the decision, we very much make it from a professional point of view. Are you OK with that? And invariably they are which is good, as far as I can see anyway.

Yes. You've never had a case where they've actually not agreed and….

Um. I suppose I probably, 'cos I'm not, I wouldn't be the sort of final arbiter, that would be the consultant looking after the patient, maybe there have been cases in the past and it's um, I'm the sort of filler between the real decision making and the family. You've got a sort of whole myriad of doctors to sort of sieve out the sort of the bad feeling and maybe that sort of overarches it, I'm not sure. Um, I, I can't think of any to be honest. I think once it's been, I mean there's sometimes differences of opinion within the family, but in terms of actual withdrawal of treatment, because I think probably we don't do it very quickly, I think that probably we maybe could be a little bit more proactive in instigating it. I think people get the opportunity to sort of reflect and whatever and then have a few discussions with, er, you know, the, the senior doctors whatever, I think.

Do you work as a multi disciplinary team or is it very medically led?

Very medically led. Yes. Er, I think that's um…..

How does that affect the decision making process?

Mmmm.

Or does it?

Long pause.

I think, um, how does it affect it?

Long pause.

Not only are we all, is it mainly to retain the, it's all sort of, there's various parameters of doctors but we're all sort of, most of us anaesthetists so we're all,

most of us come from the same background or whatever. There's just a few of us who've seen other stuff so we're probably see things, we're probably skewed a little bit, we'd have to be. I mean it's skewed a little bit as a, as a result of all that so um, it probably makes it, there is probably less um, the feeling about whether or not to stop, whether or not to go on probably is fairly narrow because as a, as a trainee albeit I'm a consultant anaesthetist but I've, most of my ICU training's been here so I've been coloured by it all here so when the boss goes oh I think this is all a bit, I'm already thinking it because we've been through the same process. So what, sorry I'm rambling. What I'm trying to say is we, we are all cut from the same cloth and as a result there isn't an awful lot of discussion. I mean, if there were other professionals there probably would be significantly more discussion about things.

Do you think that's good or bad?

Er, I think it's always, it's better that too, if you have somebody who sort of takes a slightly um, er, different view. What it makes you do is sort of, you mightn't necessarily agree with them or change your view but it makes you think about how it is that you are actually come to that, come to that idea yourself and it might even strengthen your resolve to go on, I've thought about it, thanks for your in-put what have you but actually it made me even more, maybe.

Yes.

Um. I don't think I've ever witnessed an opportunity or time when we've gone the boss has said I think we should probably stop and then somebody go oh, but what about such and such and then they go oh on, actually you're right, let's go, let's continue. I don't think that happens. Um, when it comes to the sort of final decision maybe the process, maybe all that has been taken into account, so maybe that's the opportunity for people to voice their own opinions if the, if the general sort of withdrawal of care. I think as a trainee, probably don't probably, we are probably conditioned not to question the boss because it's all part of the training thing, is that you're, oh, yes, that's settles that because it's not unreasonable or whatever and you tend not to question I think and again I think that's because we're all, not just all doctors, we're all the same, that sort of trained doctor, so I think it probably would be different if you were a physician, surgeon, anaesthetist, GP you know, that's the whole spectrum of just doctors you know. And then you've got other people as well that would be significantly different. Um, we're all anaesthetists so it's a little narrow.

Mmm.

So I think we probably don't, we probably don't um, deviate from this sort of the norm that much.

You mentioned experience levels and seniority. Does that have any effect on actually identifying dying?

Long pause.

Yes, I think so, yes. I mean I, I think it has to. I mean, some people, um, who, who haven't done the, haven't seen that many of those, what we would think of as those heart sink patients come through that we know that they're in a bad way and have a very poor quality of life or whatever and acute deterioration now. They mightn't know that what we've seen over a week or two is basically them crumble and succumb. They mightn't have seen that and therefore they might have a bit more um, of a view that. You know, we should, should keep going and do as much as we can whatever. So I think um, experience is, again you go down the, down the sort of tunnelled vision route, the conditioned route or whatever but er, so you want to be really half way. People get a have a bit more faith, maybe a bit more thinking outside the box, maybe a bit more until you get a bit more, really conditioned and then you sort of go, oh, alright. So I don't know. So I think probably experience probably has a, where, where it would change is difficult.

If you were looking after a patient and you think they are changing. What are the kinds of things that indicate to you that someone is changing and is now entering that dying phase?

It's really difficult. Um. 'Cos um, I mean, um it's diff……, it's different when we um, have a, I think it depends on the pathology. The neuro ones tend to be a bit easier to spot, you know. Um, er, the other sort of people that we have are the intractable heart failure whatever, there's always something else that you can try sort of change and what have you, you know. the other sort of people that we have are the intractable heart failure whatever, there's always something else that you can try sort of change and what have you, you know. The intractable intracranial pressure rises that we can't fix and then I think it's easier to say that this patient is clearly, even, despite our best efforts, is, is going to succumb. They are dying if you like, in front of us despite our best efforts. And that's easy to spot. What I think is significantly harder to spot are the people that sort of slowly deteriorate um, and it's difficult to rewind to a week or two before their admission and say I see it probably isn't appropriate for you, I think that would be difficult because a slow decline, a little bit of organ failure, a little bit of this and a bit of that and a lung infection and there was another infection whatever superimposed on top. And then they sort of generally feel ill and then all of a sudden you suddenly realise they've had organ failure for a week and this has failed, this has failed, this has failed and then, all of a sudden you start to think, actually things are not going well, you're not sort of looking for serious or significant but small or incremental deteriorations in health because as we go round each time, we go round twice, three times a day, we're looking at details actually. And actually to step back and look at the bigger picture isn't always easy. So while we're doing bits and pieces of fiddling around, fix this, we'll do this, that and the other, we just need to step back and look at the situation. This patient, elderly, frail probably doesn't want this, probably scare them out of there mind, if their family probably don't want this um, and they have significant organ failure over a period of time, you know, maybe this isn't in the patient's best interests. But as I say, we're more detail driven so really it's take a step back, definitely.

Yes. Is there anything you actually look for in the patient? Without necessarily knowing their history.

Um. We are very, er, ageist. Um, markedly so I think. First thing when you ring the boss is I've got a 60 year old or I've got an 85 year old and that I think, before the, you know, 'cos, I'm, I get phone calls and that's your, you are instantly thinking is the age. So I think that's the one thing we are probably over focussed on 'cos we get a lot of 60 year olds and we get a lot of 80 year olds and vice versa. Um, other things we look for um, as I say I work with the neuro which are a slightly different bunch. Um, the er, what they, their past medical history and definitely what they're functionally like, I think that's a thing that anaesthetics is good at, having done a bit of medicine, medicine is less good at but anaesthetics or ICU is good at saying I know we have heart failure, you are rheumatoid and you are this and you are that and what have you. They'll ask can you climb a flight of stairs, do you go to the shops, do you go out of the house, are you house-bound, are you sort of wheelchair bound, are you breathless at rest? These questions that we probably don't ask, or that we don't ask as much in medicine. We are reasonably good in ICU and I think it's because we have to sort of somehow come up with some way of rationing what is quite a precious resource. Not the doctors but the actual bed space. We've a 28 bedded unit for a 1,200 bedded hospital and there's probably 28 of the sickest patients we could actually do something for in the hospital in ICU. That's not an ego thing about we can fix them or whatever, it's just most of the sickest patients should probably be in ICU and therefore you have to look at a way of somehow rationalising who gets in and who doesn't. As I say, we are not very good at that. Um, age and functional ability and maybe your pathology as well but if, all other things being equal those two would be the ones would that I would say I look at the most.

Yes. Yes.

And it's, sometimes it's really difficult when you get called in the middle of the night. Somebody's come in, brought in by ambulance or whatever, and they're in a bit of a state, they're 75 or whatever. There's no relatives, GPs, friends to ask what is this patient like, I mean, you sometimes just have to crack on and the next day the bits and pieces of the jig-saw sort of come in place and you realise that this patient probably would, 12 or 24 hours earlier probably wouldn't have been a great candidate for overly aggressive treatment.

Does that then make it difficult to withdraw?

Yes, once you've started, once you've started I think it is. Because not only do you, have you, do you know what I mean, you've made a space for them and there's space available for them and they're on the appropriate sort of regimes and stuff and the family have also been or their friends whatever have been involved and whatever and you know when they, it's difficult after 12hours for us to sort of, you know we admitted the patient in the middle of the night and your relative or your friend or whatever, actually I don't think they're for us, they're sort of one for us you know. And I'm withdrawing and you know, and in the end that makes it more difficult. What I know with the senior clinicians say is that sometimes if they are humming and hawing about whether or not someone is going to do or not they'll bring them down and give them you know, 48 hours sort of aggressive treatment so they, at the end of that 48 hours say to the family. Look, you know, they've done well, or they haven't done well. We, sort of,

aggressively treated them for 48 hours or so and this will mean either they will recover and we will continue or this means they are unlikely to recover and use that as a sort of, instead of just having an open door policy just giving them 48 hours or so and see which way they'll turn. And that helps you, it involves the families, you say look, this is what we're doing, we're going to give your relative, friend whoever um, 48 hours of treatment and see what happens to them. It also helps prepare them for, if you're getting the most sort of treatment you can get and they're still not improving, they're clearly deteriorating or after 48 hours it then makes decisions about sort of end of life care significantly easier for them if you, if you demonstrate the fact that you've had a reasonable go, you know. We've given them a go. You hear people say um, how they haven't done and it, it strengthens our hand, it doesn't make, we're not aiming to, to withdraw on people but it um, but it enables us to, with a reasonably clear conscience, to say look we've had a reasonable go here and we're not winning. Let's review our options. And one of the options might be, tell you what, let's just stop. Um, the 48 hours tends to be longer. We get to the 48 hours and it's still there but it's, I think that's more of a detail thing, everyone gets stuck in with the details and the numbers and what have you. And they mightn't just take a step back. I think it's improved now with the way the, because it's inevitably the senior um, person making the decisions ultimately. There's 5 loads of opinions or whatever, there'll be an opinion gathering process potentially. Albeit as I say we all tend to, just with the hierarchical structure, and the fact we're all anaesthetists, tend to sing from the same song sheet. There's not an awful lot of ethical discussion goes on on the ward rounds which is not a good thing. The boss will make the decision no matter what is said I suppose um, but, um, there used to be change over willy- nilly, the consultants now, you get a consultant for three or four days in a row so at least they have a reasonable chance to see people on a regular basis, see whether or not there's any clear um, trend one way or another and that is, if the net result is that they think this is not in the patient's best interest, we think this is, it gives them, having seen them for three or four days, it gives them opportunity to say actually I think it's probably time.

What were the issues before when they were seeing different consultants each day?

Well. People, people were less keen to er, to, to withdraw I think. That' s fairly, um, fairly clear from… Again, I have to say I have no evidence but I think if you spoke to the senior clinicians they would say the same thing as well, that they, if you, you know, if you're just sort of minding the shop for 24 hours or whatever or overnight or whatever for, it's, it's very difficult because you haven't had discussions, you haven't seen with your own eyes any deterioration or failure to improve. You haven't seen, you haven't spoken to the family. Maybe, whilst we're trying to hand over sort of as much as possible maybe you haven't got the full details and it makes decision making, particularly if it's sort of affecting life or death, it sounds very grandiose but, it, it makes it quite difficult. And the default setting will always be keep going and that's… As I say I think the change of work patterns of the consultant body, I think that's sort of meant that there's more um, er, oversight, so they can see within three or four days any potential, so it works quite well. But I, the er, you know, if there's a night time consultant on they won't, it's very unlikely unless it's barn door obvious that somebody's not going to do,

they're very unlikely to withdraw unless that's um, part of the hand over that they've had that, that the day time person for instance, has thought, you know, things are not going so well, I think we might need to withdraw, then they might be happier to, to actively withdraw.

A couple of interviews ago um, one person mentioned a fear of litigation as an issue. Do you feel that?

Um. Not that much. Now I don't know, working, I think if you, if you work in ICU, people do die a lot. I think there's more of a fear of just getting it wrong. I think I've heard that more than sort of this patient's not going to do and commencing the LCP and whatever, to send them up to the ward and whatever to, to pass away and then they don't, you know. And er, and it makes us all look a little silly. Um, I think that makes us look a bit silly. I think that the litigation thing is not much of an issue because the, if you, if they're here people are sort of dying now and maybe if, if, um, if families were you know, a bit more belligerent or whatever you know, about it um, threatening, not usually, don't threaten sort of litigation but sort of hostile then that might make you sort of more, treat more probably I would have thought, yes. But no, I don't think it's a major issue.

No. I don't think I've got anything else in particular that I want to ask. Is there anything that you think that we've not talked about that actually is a factor in trying to identify dying? Whether it's the plus or the negative, a specific barrier or a specific positive?

Er. I don't um, I think um, some people maybe, some clinicians you know, might be more um, er, I think it's a personality driven thing they might be more keen to say no it's actually, no this is crazy, or we should keep going, keep going, keep going. And I, I think that um, I don't know where I, I, us, not that I make these decisions, where I am on that spectrum I'm not sure but, but I could certainly, having worked here and knowing quite a lot of the senior guys for the last ten years or whatever I could spot the ones who are more pro, do you know what I mean.

Yes.

I know from experience that, you know, so yes, it's a personality driven thing. I don't know where, I'm pretty certain it's not evidence based because as I say we're awful at predicting who will do and who won't do and the only way we really have is giving them a bit of a go and see if they'll do or not.. Things that we use as predictors of outcome aren't particularly accurate you know, um, um, and we've proven that to ourselves time and time again. But um, no I think that's probably about it really er, I think it's a personality thing, I think most people will err on the side of caution, I think we probably don't talk about it very much, I think we probably, despite what we say and feel think it's a bit of a failure on our part, we haven't sort of fixed them er I think that's part of the sort of medical as in doctory sort of ethos is to sort of keep going you know. And a failure comes along and we want to fix that and another failure. I think we are very treatment driven here, that's just the nature of the job. ICU is all about sort of numbers and things so we in terms of oversight and over-view it's difficult, um. I think it's almost

exclusively medical in its decision making process. We, not actively, but I think it tends to be the case we exclude the um, nursing staff. I think probably um, and sometimes afterwards when decisions are made the nurses go oh yes, thanks, or oh good, you know we sort of, they're almost sort of hoping or expecting that that's going to be the outcome. They don't, I don't know why, it tends not to be, certainly in this unit, there tends not to be as much of input from them unless they obviously feel quite strongly about it all. Senior nurses or whatever it is I don't know whether or not we have a particularly autocratic working system here. It's a friendly bunch but I don't think we, I'm not sure, I've seen other places where people are a bit more vocal. Um, we probably don't involve the relatives as much but we certainly would do and try our best if we are sort of thinking of withdrawing or whatever. Um, we try our best to communicate with them but um, so I think that's all I really want to say, you know, um. I don't know if that's of any use at all.

That is. That's lovely. Thank you.

We're probably not very good at it, I don't know. Difficult isn't it?

I don't think anybody is at the moment. We're not as good as we think we are.

I think that's exactly right. At least the LCP thing gives everyone, when people have seen people on it. I think at least it removes some of the um, barriers to actually starting people on it. Some of it will be oh, I don't know, on the top of your mind you know it's symptom control and the LCP's quite good as a package and you can say this is what we're going to do you know. And because it's almost universally accepted now it seems to be a reasonable way for people. They don't always die but mainly they will die in comfort and peaceful whatever. So I think that's probably a reasonable thing. Interestingly, we don't have it here on the unit. Um, we don't have an actual written pathway but we use some of the elements from the LCP here because it's mainly community based or certainly not ICU based. That's part of the thing that I'm going to do over the next few months. I might well look at actually, can we, 'cos I know some other units do have actually ICU based LCP type pathways. I think we might well move towards that, at least looking at it anyway. I know other friends who have the same sort of senior trainee levels as me out in different places so there are opportunities to talk about it. I know some units are quite good, quite robust ICU based care pathways. We're a little bit less despite the size of this place. We're a big ICU, it's less er, regimented for whatever reason. Alright? Is that OK?

That's lovely, thank you very much indeed

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APPENDIX D
DELPHI QUESTIONNAIRE ROUND 1

What factors assist clinicians to determining dying in an acute hospital? Round 1 of a Delphi Study.

Please complete the following consent form prior to completing the questionnaire
Name of Researcher: Mrs J.F. Dee

Please note that if you have any unanswered questions about this study then you should NOT complete this form. Please contact the researcher if you wish to discuss any issues.

Please tick all boxes

1	I confirm that I have read and understood the information sheet dated dd/mm/yy for the above study and have had the opportunity to ask questions and have had these answered satisfactorily.	
2	I confirm that I have had the opportunity to discuss the study with the researcher. I do not have any further questions about the study.	
3	I understand that the information collected during this study will remain strictly confidential. I understand that relevant data collected during the study may be looked at by individuals from the Research Sponsor, for the purpose of audit and monitoring, and where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my data.	
4	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
5	I agree to partake in the above study.	
6	If I withdraw from the study I understand that you will destroy all identifiable information, but will use the data collected up to my withdrawal	

Demographic information

Male ☐ Female ☐ Age 20-35 ☐ 36-50 ☐ 50+ ☐

Doctor ☐ Grade Nurse ☐ Geographical location

Preferred e-mail contact address

Thank you for deciding to take part, all of the information you provide will be treated with strict confidentiality. This survey should take you no longer than 15 minutes to complete.

Please rate the following criteria for their importance for inclusion in an education programme for clinicians to help them determine when a patient is entering the last few days of life.

A) Patient Observation

Topic	**1 Not important**	**2**	**3**	**4**	**5**	**6**	**7 Very important**
Conscious level of the patient							
Patient's ability to carry out the activities of daily living							
Please rate the following physical symptoms individually							
Pain							
Breathing pattern changes							
Anorexia and cachexia							
Blood pressure, pulse, temperature							
Colour of the patient							
Comments							

B) Knowledge of the Patient

Topic	1 Not important	2	3	4	5	6	7 Very important
Predictability of the disease trajectory							
Patient records							
Diagnosis							
Clinical test results e.g blood tests, scans							
Rate of deterioration							
Medical history							
Response to treatment							
Comments							

C) Communication

Topic	1 Not important	2	3	4	5	6	7 Very important
MDT Working							
Taboo subject for clinicians, patients and their carers							
Lack of understanding amongst the family							
Time the clinician has to spend with the family and patient							
Difficulty for clinicians when Breaking bad news							
Withdrawing treatment							
Comments							

D) Experience of the Clinician

Topic	1 Not important	2	3	4	5	6	7 Very important
Area of work of the clinician							
Intuition of the clinician							
Seniority of the clinician							
Previous experiences (both personal and work related) of the clinician.							
Qualification of the clinician							
Comments							

E) Attitudes of the Clinicians

Topic	1 Not important	2	3	4	5	6	7 Very important
Fear (including of litigation)							
Acceptance							
Medical philosophy							
Willpower							
Failure							
Quality							
Comments							

Are there any other criteria that you consider important or that we have missed and should now include at this stage?
Thank you for participating in this study. Please could you now e-mail this document to Frankie.dee@stlukes-hospice.org.uk I will contact you again soon with the second round of this study

APPENDIX E
DELPHI QUESTIONNAIRE ROUND 3

What factors assist clinicians to determine dying in an acute hospital? Delphi Study Round 3

This is the final round of this study and I would like to thank you for taking part. From the responses provided there are still a number of statements which have not achieved consensus. These statements are presented on the following pages, with the mean score from round 2; would you please re-rate these according to your view of their importance for inclusion in an education package for clinicians to help them determine when a patient is entering the last few days of life.

Example

Patient Observation		1 Not important	2	3	4	5	6	7 Very important
Pain	Mean from round 2				4.18			
	Your score			√				

All of the information you have provided will be treated with strict confidentiality. This survey should take you no longer than 15 minutes to complete.

How important is it to include the following topic in an education package for clinicians to help them determine when a patient is entering the last few days of life?

Patient Observation		1 Not important	2	3	4	5	6	7 Very important
Patient's ability to carry out the activities of daily living	Mean from round 2					5.06		
	Your score							
Pain	Mean from round 2				4.18			
	Your score							
Anorexia	Mean from round 2				4.82			
	Your score							
Cachexia	Mean from round 2				4.41			
	Your score							
Blood pressure	Mean from round 2		2.82					
	Your score							
Pulse	Mean from round 2		2.76					
	Your score							
Temperature	Mean from round 2		2.65					
	Your score							
Colour of the patient	Mean from round 2			3.53				
	Your score							
Body tone	Mean from round 2			3.53				
Gastric absorption	Mean from round 2			3.53				
	Your score							
Terminal agitation	Mean from round 2					5.76		
	Your score							
Knowledge of the patient								
Patient records	Mean from round 2					5.53		
	Your score							
Clinical test results eg. Blood tests, scans	Mean from round 2				4.94			
	Your score							

Response to treatment	Mean from round 2					5.53		
	Your score							
Previous resuscitation decisions	Mean from round 2					5.12		
	Your score							
Advance care plans	Mean from round 2					5.29		
	Your score							
Patient's own knowledge of imminent death	Mean from round 2					5.47		
	Your score							
Age of patient	Mean from round 2			3.44				
	Your score							
Treatment options the patient wants to try have run out	Mean from round 2				4.56			
	Your score							
Communication								
Family preferences and wishes	Mean from round 2					5.76		
	Your score							
Requests for euthanasia/ suicide	Mean from round 2					5.29		
	Your score							
Experience of Clinician								
Intuition of the clinician	Mean from round 2					5.23		
	Your score							
Previous experiences (both personal and work related of the clinician	Mean from round 2					5.12		
	Your score							
Qualification of the clinician	Mean from round 2			3.88				
	Your mean							
Frequency of dealing with the dying patient	Mean from round 2					5.37		
	Your mean							
Perceived seniority being a barrier to MDT collaboration	Mean from round 2				4.70			
	Your mean							
Attitudes of the Clinician								
Fear that they will not know the answer to questions asked or that family pressure could lead to litigation	Mean from round 2					5.59		
	Your score							

Willpower of the patient to reach a target	Mean from round 2				4.94			
	Your score							
Death being seen as failure	Mean from round 2						6	
	Your score							
Culture of the patient	Mean from round 2					5.94		
	Your score							
Spiritual issues for the patient	Mean from round 2					5.41		
	Your score							
The importance of hope to the patient	Mean from round 2					5.88		
	Your score							
Religion	Mean from round 2				4.82			
	Your score							
Willingness to champion patient wishes	Mean from round 2					5.76		
	Your score							
Courage to challenge systems	Mean from round 2						6	
	Your score							

Statements for which consensus was achieved in Rounds 1 and 2 either at scores 1&2 or 6&7

A. Patient observation:
Breathing pattern changes
Conscious level

B. Knowledge of the patient:
Rate of deterioration
Predictability of disease trajectory
Diagnosis
Medical history
Exclusion of reversible causes

C. Communication:
MDT working
Time the clinician has to spend with the family and patient
Withdrawing treatment
Taboo subject for clinicians, patients and their carers
Lack of understanding amongst the family
Difficulty for clinicians breaking bad news
Patient preferences and wishes
Uncertainty
Consistent communication with families- not raising false hope

D. Experience of the clinician
Area of work of the clinician
Seniority of the clinician

E. Attitude of clinicians
Quality
Acceptance that the patient is dying
Medical philosophy of cure

APPENDIX F
Topics not achieving consensus that they warranted inclusion in an education package

In total 60 topics were identified by phases 1 and 2 of the study for the panel of experts to score as to their relevance for inclusion in this education package. Of these 31 topics did not achieve consensus regarding definitive inclusion or exclusion from this proposed package, eight in the factor:-

"Patient Observation"

- Patient's ability to carry out the activities of daily living
- Pain
- Anorexia
- Cachexia
- Colour of the patient
- Body tone
- Gastric absorption
- Terminal agitation

Eight in "Knowledge of the Patient"

- Patient records
- Clinical test results
- Response to treatment
- Previous resuscitation decisions
- Advance care plans
- Patient's own knowledge of their imminent death
- Age of the patient
- Treatment options the patient wants to try have run out.

Two in "Communication"

- Family wishes and preferences
- Requests for euthanasia/ suicide

Five in "Experience of the Clinician"

- Intuition of the clinician
- Previous experiences (both personal and work related of the clinician)
- Qualification of the clinician
- Frequency of dealing with the dying patient
- Perceived seniority being a barrier to multi-disciplinary team collaboration

and eight in "Attitudes of the Clinician"

- Fear that they (the clinician) will not know the answer to questions asked or that family pressure could lead to litigation
- Willpower of the patient to reach a target
- Death being seen as failure
- Culture of the patient
- Spiritual issues for the patient
- The importance of hope to the patient
- Religion

Willingness to champion p