1. Project details

1.1 Investigator details

Lead investigator: Julie Ellis
Primary supervisor: Professor ***
Second supervisor: Professor ***

1.2 Project title: Family Practices during Life-threatening Illness

1.3 University of Sheffield URMS sponsor reference: *****

1.4 NRES reference number: ********

1.5 Version and date: Version *, **/**/**

2. Research question

Overall aim of project

The aim of this project is to explore how everyday family life carries on, when someone in the family has a life-threatening or terminal illness.
This will mean asking the following research questions:

1. How is everyday family life experienced at different points over the illness process?

2. How do people maintain relationships and identities within families following the diagnosis of a life-threatening/terminal illness of a family member? Are they likely to change – and how might people understand this?

3. Is hospice space significant for family members as a setting for everyday family life during the latter stages of an illness trajectory? And if so how? Here the Chief Investigator will be looking at the physical space, at the way people express their feelings and at what hospice space might symbolise for people.

The first 2 research questions will be addressed by conducting repeat in-depth interviews with patients and members of their close family. These participants will be recruited from a hospice day unit. Research question 3 will be answered by observing patients and their visiting families on the hospice inpatient unit. The participant observation will run concurrently with the interview phases of the research. The Chief Investigator will be spending 2-3 days a week, over a period of 7 months getting involved in life on the ward to get more insight into the way life-threatening illness might affect everyday, routine aspects of family life.

3. **Nature of research**

The proposal research is original and will fulfil the requirements for the degree of Doctor of Philosophy in the Department of Sociological Studies, at the University of Sheffield.
4. Background

4.1 Introduction to area of proposed research

The motivation to design and conduct the proposed research has in part stemmed from the Chief Investigator’s voluntary experience at a hospice where whilst spending time on the inpatient ward she became interested in the significance of what was being communicated between patient and relative and how families managed to carry on and ‘be’ a family during this time. It became apparent to the Chief Investigator that personal and familial identities were somehow being renegotiated during this period and that this observation resonated with ideas within the bereavement literature where it is argued that grief can involve retrospective renegotiations of memories via narrative reconstruction (Walter, 1996; Arnason, 2000) – or in other words bereaved people tell stories about the person who has died and their relationship with them to help them make sense of their loss. Indeed some participants the Chief Investigator interviewed for a previous small-scale project about the social construction of bereavement experiences, drew on the last stages of someone’s life to contextualise, understand and tell the story of their grief; indicating that happenings and relations just prior to death were significant for the experience of bereavement.

It was from these preliminary personal and theoretical thoughts that the proposed project came into focus (see Seymour, 1999 for a similar instance). These contributed to the decision to examine in-depth, a period of time for families when the death of a member is a real possibility, with the resulting data having the potential to provide a platform for future work on how this time might shape and affect bereavement experiences.

Since its initial conception the project has developed and shifted its focus as the Chief Investigator has reviewed relevant literature to refine and direct the main research aims. The proposed research has been influenced by important anthropological (for instance Seremetakis, 1991) and sociological work (for
instance, Exley, 1999) in the area of death and dying, and uses theoretical insights gained from cultural studies pertaining to the study of everyday life (Moran, 2005; Highmore, 2002) to inform its focus on the very mundane aspects of being in a family and ‘doing’ family life at a time when someone has a life-threatening illness.

It has also been influenced by narrative approaches to research (Chase, 2005) and a growing trend within health research to draw on the principles and ideas of story-telling as a way to communicate and negotiate illness experiences (Grinyer, 2006; Frank, 2002; 1995). Bury (2001) argues that by listening to chronically ill patients’ narratives, one can discern how ‘illness constitutes a major instance of biographical disruption’ in which the relations between body, mind and everyday life are threatened (2001: 264). So too, McNamara (2001) suggests that ‘the diagnosis of cancer constitutes a major existential threat and sufferers are prompted to revaluate their lives and dreams’ (2001:34). Both these statements raise the related question of how the diagnosis impacts upon individual family members, their everyday lives and the biography of the ‘family’ itself. In addition Mead’s (1934) assertion that we experience our sense of self in relation to those around us prompts further questions regarding how illness not only affects the sufferer but also the people closest too them, and what their narratives about living with this knowledge day-to-day might reveal. While Glaser and Strauss’ (1965a, 1968) earlier work explored the degree of openness with which dying people and their families communicated, more recent work on family as the outcome of ‘practices’ (how family life gets ‘done’) (Morgan, 1996) and on the relationship between narrative and ontological security (one’s sense of place in the world) (Giddens, 1991) provides a theoretical context for revisiting these questions and focusing upon the everyday, lived experience of being a ‘family’ and ‘doing’ family life at this time. The research proposes to explore how families and their individual members accommodate the ontological insecurity (Giddens, 1991)
posed by the threat of death, along with their continuing engagement with previous social roles, relationships, modes of living and identities.

### 4.2 Justification for proposed research

The World Health Organisation (WHO) begins its definition of palliative care by saying that it is ‘...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness...' (WHO, 2005). During The Birmingham International Workshop on Supportive, Palliative, and End-Of-Life Care Research which was held in 2005, leading researchers in the field identified ten areas where they felt there was an urgent need for research and further exploration; one of these areas was family and informal care-giving (Addington-Hall, 2007). As gaining a greater understanding of how families are affected by life-threatening illness is currently one of the key challenges facing palliative care, the proposed research will make an important contribution to meeting this challenge. In particular it will generate data to help practitioners better understand what is meaningful about everyday family life for patients and their relatives, so that service provision can work with a more informed understanding of family life during this time. It is important to have a broader and deeper understanding of what being in a family and having a family life means to those negotiating a life-threatening illness, before palliative care practitioners can set about the task of improving quality of life (as is stipulated in the aforementioned WHO definition) of which family life is a central aspect.

Thus, the proposed research offers an opportunity to generate novel data and new perspectives by considering dynamic developments in family sociology and theories of relatedness and intimacy (Jamieson, 1998; Bernardes, 1997; Morgan, 1996; Finch and Mason, 1993), in the context of palliative care and its associated empirical and theoretical ideas. It is anticipated that it will offer a fresh perspective on families dealing with life-threatening illness by asking questions about and seeking to

observe the more mundane aspects of family life at this time. This will provide a context for considering the processes involved in the creation and maintenance of diverse family lives during life-threatening illness, and draw upon the idea of ‘family’ as ‘a quality rather than a thing’ (Morgan, 1996:186). From this perspective it will challenge taken-for-granted assumptions about ‘the’ family as an a priori, given entity and raise important questions about the concept of ‘family’ that service providers have in mind, when they are developing tools for ‘coping’ and ways of meeting ‘needs’ for families. In addition the proposed research will have a focus which is different to the concerns that appear to dominate the literature in this area. For instance, essentially assumptive ideas around family functionality which tend to identify with families as ‘systems’ and are concerned with determining their coping strategies and needs (Rolland, 1999), are undoubtedly important. However this is perhaps not the whole story that families want to tell about their lives at this time- as it is anticipated that this proposed research will demonstrate.

Therefore while the ethos of the Hospice Movement places the patient within a familial or wider social context, with support needs which extend beyond medical provision and symptom control (du Boulay, 1984) the proposed study will make apparent the intimate voices and implicit actions involved in processes of (re-) negotiating familial relationships and of living as part of a family day-to-day at this time. It will also do this without assuming these will automatically be framed in terms of ‘needs’ and ways to ‘cope’. The novel data will inform the provision of services to families, providing a more evidence-based account of what is meaningful to those families in terms of the everyday, more mundane and therefore perhaps overlooked aspects of their day-to-day lives. As such, the proposed study has the potential to enable palliative care staff to realise holistic care goals more comprehensively and social work staff to provide support for all family members as they experience the illness process of a relative. In addition, the work could potentially raise issues surrounding the management of grief, which may
then inform the provision of bereavement care. It will also provide useful insight for practitioners delivering hospice services to people in their own homes, where considering the implications of life-threatening illness for everyday family life are especially pertinent.

5. Plan of the investigation

5.1 Overall methodology

Phenomenological approaches to research provide a methodological framework which is ‘sensitive enough to allow subjective experiences to be elicited with compassion, whilst at the same time conforming to expectations and principles of scientific rigour’ (Seymour and Clark, 1998:127). It is a particularly appropriate approach to take in the proposed research not only because it enables the researcher to explore meanings, values and feelings, but also because it involves qualitative methods of data collection which are ‘minimally intrusive’ and as is stated in the quote above, they allow the researcher to gather data compassionately (Seymour and Clark, 1998:127). This is very important for ethical reasons in a study like the one which is being proposed because of the potential vulnerability of the participants, and the circumstances they are facing.

Qualitative methods are particularly suited to conducting research with vulnerable groups because they allow the participant to have a voice and they have an inherent flexibility which is conducive for ethical research practice (Liamputtong, 2007). For example, in-depth interviews elicit personal narratives from respondents rather than opposing a rigid interview structure upon them (Seymour and Clark, 1998) and have an analytical approach to data collection and analysis which considers that ‘it is possible to make inferences about experience from verbal accounts’ (Payne, 2007:140). Whilst participant observation can be used to ‘capture naturally occurring events with minimum research interference’ and has an
analytical approach, which involves interpreting meanings in the human action that is observed

Qualitative research methods are also appropriate in research which aims to explore social processes
(Bryman, 2001). Therefore they are applicable in the proposed study where the focus is upon experience
with a temporal dimension – the illness process- and also because they will facilitate the exploration of
‘the processes by which families create, sustain, and discuss their own family realities’ (Daly, 1992:4).
Furthermore it is argued that there is a ‘fit between qualitative research and characteristics of families’
and that these methods provide a holistic picture of families and family life because there they can reveal
‘the individual and collective phenomenological experiences of family members’ (Daly, 1992:4).
Therefore for all the above reasons a phenomenological, qualitative methodological approach will be
taken.

5.2 Design: study design and justification

Overall approach

Methods which will generate primary data are the most appropriate for this research. To capture the
immediacy of people’s stories about their experiences of living day-to-day in a family where someone
has a life-threatening illness, the Chief Investigator needs to use an approach which will provide access
to the meanings participants attach to being in that situation in the here-and-now. The project also has a
temporal focus in the sense that it will try to capture how these meanings alter and experiences change
for families over the illness process. Therefore three separate interviews will be conducted over a five
month period so the data generated reflects a more sustained picture of family life at this time and not
just a ‘snapshot’. Whilst observation on the hospice ward will allow the research to explore what family
life is like towards the end of the illness process, when someone is in the terminal phases of their life.

The research approach consists of the following activities:

- Repeat in-depth interviews with hospice day care patients and family members
- My Family Story timelines (past, present and future) and People in my Family ecomaps (and additional exercises for children aged 9-12 and young people aged 13-16).
- Telephone contact
- Periods of participant observation on inpatient ward.

By using a mixture of approaches to capture people’s accounts as they talk about their experiences, and also observing how family life is played out in a particular setting which is directly linked to the illness, the research can explore how everyday family life is carried on at this time. It can do this on an individual level by capturing the experiences of individual family members as they share their stories, and it can also gain an insight into the shared biography of a particular family by considering the individual narratives as a whole, and by observing families interacting together and talking about their experiences collectively in the hospice ward setting.

Repeat in-depth interviews

Primary data collection will consist of 3 interviews conducted over a period of 5 months, each taking place approximately 6-8 weeks apart. Generally it is anticipated that these sessions will be conducted with individuals, although Morris (2001) points out that many participants in her study on the needs of cancer patients and their carers, requested to be interviewed in a joint context. Therefore the Chief Investigator has mentioned in the participant information sheets that if families prefer, joint or even small group interviews can be arranged. These sessions will be approached in the same way as individual interviews, details of which follow.
In-depth interviewing is appropriate for finding out about people’s everyday family lives because individuals themselves can provide the deepest, most comprehensive insight. Asking people to tell their stories about, and reflect upon their family life at different points over the illness journey, will allow the research to capture feelings and experiences infused with a sense of immediacy, and to understand something about the process and fluidity of family practices across this time (Morgan, 1996). Topic guides which have been informed by an examination of the literature will help the Chief Investigator in conducting the interviews. However because of the methodological approach to be taken, the research is essentially participant-centred and the Chief Investigator has developed schedules that incorporate flexibility to allow the participant to take some of the lead in the interviews. As Riessman (2003) has suggested narrative research approaches are designed to elicit participant’s stories about their lives with minimal interference or directing on the researcher’s part. What people choose to share and how they choose to share it can be extremely important for the overall analytical picture in qualitative research projects (Reissman, 2003). Thus it is proposed that not all areas outlined on the aforementioned topic guides will necessarily be covered, and additional topics may be discussed as participants talk about their lives and take the interview in unexpected directions. Also it is anticipated that a continued engagement with current literature will point to further important issues that should be included in the interview guide, whilst the Chief Investigator’s participatory observation experience on the ward, will lead to the development of further ideas to be explored in the interviews.

**Interview 1**

The initial interview will incorporate participatory components that will help to facilitate the Chief Investigator to get some background information on the families she is working with, and which will also assist in guiding the conversation at the initial meeting. Owing to the fact that this is a potentiality sensitive area of research the Chief Investigator believes inviting the participant to tell the story of their
family in their own words and time, signifies something of her genuine interest in learning about the
family, and that this would be an appropriate way of ‘breaking the ice’ and building the foundations of
the research relationship. In the first instance participants will be invited to tell the researcher their
‘family story’ in 3 phases; the past, present and future. The participants will be invited to plot specific
events and things of significance which pertain to their story on the ‘my family story’ timelines
(appendix 1). Using timelines in research has worked successfully in projects with children and young
people (James, 2005). Though it is something that would be appropriate to use with any age-group to
facilitate conversation, whilst participatory methods in general are used extensively and creatively in
family research undertaken at one of the country’s leading centres for family based research – the
Morgan Centre at the University of Manchester. To ensure that rich, detailed data is gathered there are a
series of prompts and questions the Chief Investigator can draw upon to accompany this exercise
(appendix 2). It is proposed that this activity will provide the Chief Investigator with an understanding
of what meanings participants attach to being in their family and what the shared history of that family is
about from their perspective. The timeline which refers specifically to the future opens up the
opportunity for participants to discuss the implications of the life-threatening illness, and it will allow
the Chief Investigator to ascertain early on, how open the family is with regard to acknowledging the
possibility that the suffer amongst them might die. She will therefore be able to better ensure that she
works sensitively with this knowledge and can lessen the likelihood of causing distress to participants.
Below is an illustration of a completed timeline:

(2002) We moved to here
(1976) Harry was born
(1993) Jess moved away
In addition to the timelines the participant will be invited to complete a ‘people in my family’ ecomap to plot relational family dynamics from the participant’s perspective (appendix 3). The map places the participant at the centre and then other family members are mapped onto the diagram strategically to signify the participant’s sense of closeness to them. This technique has been used in other family related studies and specifically in the context of terminal illness (Ray and Street, 2007). The maps can be completed either before a participant begins to tell their family story, or as and when a family character is introduced into the story. This diagrammatic exploration will allow the Chief Investigator to become familiar with the family structure and the resulting representation will provide a useful context and future reference point throughout the research process.

It is possible for both the aforementioned tasks to be carried out verbally and without making a visual representation of what is talked about, if participants prefer.

**Interviews 2 and 3**

The aim of these 2 further interviews is to encourage the participant to describe their experiences of doing everyday family life, day-to-day at this time. The Chief Investigator may follow up on some of the issues which were discussed during the first interview. However she will mainly be concerned with encouraging participants to convey what is current and immediate in their day-to-day lives and how this may have changed, or be changing, in relation to the life-threatening illness. The Chief Investigator will use a topic guide with key questions which are informed by the project’s main research questions to loosely guide the sessions and encourage participants to talk about their lives in response to these broad questions and in relation to the various topic areas listed e.g. leisure time and paid work (appendix 4).
The responses which the Chief Investigator gains from the first five interviews which are conducted will be reviewed closely and any amendments made to the activities and topic guides where necessary. If any changes are made to the study proposal, these will be submitted to the ethics committee for approval.

**Post-death interviews**

Although the Chief Investigator does not mention in the participant information sheets the issue of continued participation in the event of the ill person’s death for sensitivity reasons, it is proposed that should a family member wish to continue in the project under these circumstances that the Chief Investigator would act in accordance with the person’s wishes, reiterating that they can change their mind at any point. Due to the unpredictability of disease it is impossible to say how likely this event will be, although the day care recruitment team (see below) have been asked to consider patients physical symptoms when recruiting to avoid placing undue strain upon a particularly poorly patient. Conducting interviews after a death will still generate data that is relevant and informative with regard to the project’s aims, because the absence of that person from the family will give an even more projected perspective of the consequences of a life-threatening illness for family life. The Chief Investigator also feels that to completely withdraw from a family when someone still very much wants to reflect on the death as part of their story, might cause them distress. In particular if they interpret this action to imply that their story is no longer important.

**Children and young people**

Primary data collection will consist of 2 interviews to take place over a 5 month period; typically these will occur 3-4 months apart. These sessions will incorporate a greater participatory element than the adult sessions because using ‘structured activities’ within the interview context can aid children to express their ideas and to talk about their experiences in a way which might feel more meaningful for them (Mauthner, 1997). This is not to suggest that children’s abilities are considered as lesser, or that
research with them requires ‘special’ methods to be adopted (Christensen and James, 2000). A child-centred approach to research requires the researcher to utilise research strategies that recognise children’s agency and allow them to use the different skills they are more used to deploying in their day-to-day lives (James, 1999). Accordingly the strengths of traditional methods such as interviewing will allow the proposed research to capture the meanings and experiential aspects of children’s lives within families, whilst the additional activities involved enhance their ability to participate in the research process (James, 1999). There will be activities scheduled for both interviews. In interview 1, both children aged 9-12 and young people aged 13-16 will complete the same activities as they have been specifically designed to apply usefully for both age groups. In the second interview the activity will be slightly different for the two age groups, but it is essentially designed to explore the same issues. In addition to the activities and after they have been completed, the Chief Investigator will invite the participant to do some form of craft activity or perhaps play a board game, whilst she asks them questions about their everyday family life at the time, and how it carries on in the context of life-threatening illness. This will happen for the latter part of both interviews 1 and 2 and an interview guide consisting of some broad questions will be used to prompt the Chief Investigator during this time (appendix 5). It is intended that having something else to focus on at the same time as talking about research related issues, will facilitate an informal atmosphere and make the participant feel more comfortable. Also, because it will take place towards the latter end of the interviews the relaxed atmosphere will be conducive to aiding the Chief Investigator to engage in a debriefing with the participant where she will explore whether the participant is happy with what they have shared.

Details of the activities participants will be invited to complete are as follows:

Interview 1
My family tree (appendix 6): The principle purpose of using this visual aid is to enable children and young people to express their ideas and feelings about who belongs in their family and how different people and relationships within the family have changed with the onset of someone’s illness. The participants can choose to either draw faces of family members into the spaces or write their names. The structure of the tree is not intended to reflect relational dynamics as with the aforementioned ecomaps; insight into the participant’s perspective of familial relationships will be elicited by the Chief Investigator whilst the tree is being completed, using a series of broad questions (see appendix 6). Furthermore, as is stated above, this task will be a useful way to introduce participant’s to the research process when the relationship between researcher and researched is in its first stages. It gives the participant the initial control to sketch the contours of their family before more detailed accounts of family life are elicited.

If my family were a tin of baked beans... (appendix 7): This activity is designed to indicate what the concept of being in a family or having a family means to the participants. How the children and young people choose to ‘label’ their family will be discussed in the interview and in the context of their feelings, ideas and stories about everyday family life.

Ingredients list (appendix 8): As a continuation of the analogy of a tin of beans designed with the intention to help children and young people to consider the idea that being/ having a family is made up of, and achieved by things that are done in everyday family life, participants will be invited to write down the ‘ingredients’ of their daily family life. What is entered here will represent what it is that happens in a mundane, everyday sense that constitutes the experience of living in the participant’s family.
Interview 2

Vignette for children age 9-12 (appendix 9): This activity will use a fictitious character that is of a similar age to the participant and the same gender, and who also has a person in their close family living with a life-threatening illness. Using a vignette to explore this issue allows the participant to express their ideas and feelings without having to talk in a personal way about themselves, which may feel, especially in the potentially sensitive context of the proposed research, a little exposing (Wade, 2006). The Chief Investigator has decided to use it at the start of the second interview to gauge how comfortable the participant is with talking around these issues before moving onto the broad questions which ask directly about the participant’s life (appendix 5). It is possible since the last session that something could have developed either in the relation to the illness or generally in the participant’s life which may make them more sensitive or reluctant to talk specifically about themselves.

Scenario – producing a leaflet for young people aged 13-16 (appendix 10): This activity will be completed as above for the vignette.

If a child or young person does not wish to partake in some or any of the activities the Chief Investigator will invite them to talk about their experiences and initiate the ‘chat and craft’ element of the interview earlier.

For all the interviews (with adults and children) the Chief Investigator will seek permission from participants to tape-record the interviews. All interview material will be transcribed verbatim by the Chief Investigator in her home study at the earliest convenience after the session has taken place so that data can be analysed as it is collected. This will take place before a subsequent interview is conducted to ensure the Chef Investigator is familiar with the material. It will be stored securely on a password
protected computer, with all identifiable details removed. Fieldnotes pertaining to the domestic setting (if interview conducted in family home) and the interview process generally will be made. Fieldnotes will act as a substitute for interview transcripts if participants would rather not have the meetings recorded.

**Debrief**

At the end of the interviews, the Chief Investigator will debrief participants about the research project, i.e. what the data they have provided will be used for and what will happen next. The Chief Investigator will spend time ensuring that the participant feels okay about their participation, and if required she will provide further support (see section 8.5 pg. 61 or appendices 2 and 4, for debrief details). Further support will consist of the Chief Investigator sign-posting the participant towards an organisation or an individual (e.g. member of nursing team at the day unit), and ensuring that they have the correct details to contact these sources and access support. The Chief Investigator is currently compiling a resources pack which she will be able to draw upon if she needs to help a participant to access support.

**Telephone contact**

Between the first and second, and the second and third face-to-face interviews the Chief Investigator will make telephone contact with some of the participants, who have agreed to keep this contact. This will happen no more than on a couple of occasions and the purpose of maintaining contact is to help the research achieve its aim of understanding the day-to-day experience of everyday family life over the illness process. Participants will be invited to update the Chief Investigator on anything they would like to share about how family life has been since the last interview; there will be no schedule or predetermined questions. Being able to speak to participants between interviews will allow the Chief Investigator to build up a fuller picture of what are immediate concerns and what is current in the lives
of the families she is working with. It will also help to forge a closer relationship and build trust and rapport, whilst allowing the Chief Investigator to gain a sense of how a family is getting on and perhaps enabling her to be alerted to a change in a family’s circumstances. She can then operate more sensitively and offer them the option to stop being involved in the research, if she learns that since the last interview a family has been having an especially stressful or difficult time. The Chief Investigator is also mindful that particularly in sensitive research such as that which is being proposed here, it is important to make the research feel inclusive for those who take part and not to leave participants feeling that their experiences have been ‘used’ (Grinyer, 2002). Therefore keeping contact with participants over the process and making them aware of how the project is getting along is important. Furthermore, it was decided that using this method to collect additional data about the everyday lives of participants would be less demanding and time consuming for participants than adopting a diary method which has been used elsewhere in healthcare research to try and gain a sense of people’s day-to-day experiences (Jacelon and Imperio, 2005).

Although it will be explained to participants that the Chief Investigator will be using this contact as another way to collect data about their everyday lives, it will not be referred to as a ‘telephone interview’ and the term ‘telephone contact’ will be used. Primarily this is because the phone calls, as is outlined above, will be made for purposes other than the collection of data, and the term contact seems to more appropriately convey the multiplicity of reasons for including this in the research design.

**Researcher diary and fieldnotes**

The Chief Investigator will keep a diary of her experiences during the interviewing process to facilitate reflexive practice and to help manage the emotional aspects of conducting sensitive research (Rowling, 1999). The Chief Investigator will also make field notes which will relate to the how participants
respond to the interview process and if interviewed in the home, any information about the domestic setting so this data can be compared with how families on the ward use hospice space as a setting for the continuation of family life.

**Participant observation**

**Context**

Seymour (2007) describes ethnography as an approach to research that involves,

> an evolving and flexible design; the presentation of a mediated reality; seeing the researcher as an instrument of data collection; and focusing closely on research participants’ view and the contexts within which these are expressed (2007:216).

She suggests that participant observation is a ‘hallmark’ of ethnographic work, and the outline she provides above reflects the approach to be taken in the proposed research. Importantly for the proposed study which focuses on the day-to-day aspects of everyday family life, an observational approach will allow the researcher to focus on and explore, ‘the routine ways in which people make sense of the world in everyday life’ (Hammersley and Atkinson, 1983:2). In observational studies the researcher enters a particular setting such as a hospice, so they can learn about an issue or a way of being in the world. To achieve this they need to observe those ‘in the know’ and to draw on the knowledge of people - in this case patients and their families- in that setting/situation (Hammersley and Atkinson, 1983:2). In many ways participant observation is an approach to research which positions participants alongside researchers as co-constructors of social knowledge because meaning and an understanding of a situation is produced intersubjectively between the researcher the and researched, in the research encounter (Usher, 1996). Also, because the researcher is actively immersed in the setting and interacting with people there through talk as well as observation, informal, opportunistic conversations play an important role within the data collection (Hammersley and Atkinson, 1983). It is through this interactive process of observation and conversation that the researcher is enabled to acquire knowledge of the issue they are exploring. Furthermore, it has been suggested by Savage (2000) that adopting a participatory approach
Doing participant observation on the ward

To run concurrently with the interview phases of the project there will be a period of participant observation taking place of the inpatient unit at the hospice. Using participant observation will allow the Chief Investigator to explore how family life is continued and recreated by families in this setting. The observation will take place over a period of 7 months, beginning in September 07 and ending in March 08. The Chief Investigator will spend between 2-3 days a week (average of 10-15 hours a week) on the ward over this time period. To get a broader picture of how families conduct themselves in the ward environment, the days and times spent on the ward will vary, but where possible staff will be informed at the end of each week when the Chief Investigator plans to be on the ward the following week. The acting matron at the hospice has granted permission for the observation to take place, pending ethical and research governance approval.

So that the Chief Investigator can be involved more fully in ward life and interact with the patients and their families, a participatory role as a ward volunteer will be adopted. The Chief Investigator has already had all the necessary training which the hospice provides to equip someone to be a volunteer on the inpatient unit (see attached CV). The volunteer co-ordinator at the hospice supports the proposed
research and is happy for the Chief Investigator to perform the duties of a volunteer and have a more active role in ward life. However all patients and their relatives will be made aware that the primarily role of the Chief Investigator is one of researcher and this is explained in the participant information sheets (see below for details of recruitment process).

Aiming to cause minimal disruption to the hospice environment the Chief Investigator will endeavour to foster positive relationships from the outset and will therefore send a personally addressed letter in early September to each member of staff on the ward informing them about the research (appendix 11). In this letter the Chief Investigator has assured staff members that she will not be observing work relationships or how care is provided to patients and their families, in the hope that this will avoid staff feeling that they are going to be ‘spied’ upon (Walsh, 1998) and demonstrate an intention to work in an inclusive way and to be transparent throughout the research process.

The focus of the observational work will be to collect data about how family life is conducted on the ward. This might include the Chief Investigator seeking to observe the following:

- Family routines
- Significant moments
- Changes in the family/dynamics/actions.

And the observation will also be guided by similar questions to the ones which follow:

- What do family members do/talk about when they visit?
- How do they arrange themselves around their relative’s bed?
- What items do they bring to the ward? Do any of these symbolise family life or are they involved its facilitation/recreation?
- Are there any changes to observe when different family members enter the space and then leave?

- Who in the family does what?
- How do families understand their ‘place’ within the hospice space and routines? – What spaces, furniture etc. do they use?

It is anticipated that children and young people will be present on the ward whilst the observation is ongoing, although from the Chief Investigator’s previous experience of the ward it is considered that their visits are not likely to be as frequent as those made by adult visitors. In accordance with child-centred work within the sociology of childhood, for the purposes of this research the Chief Investigator considers children and young people as active participants in the construction of their social worlds and understands that they are social actors in their own right who contribute to family life (James and James, 2004; James and Prout, 1997). Therefore it is for theoretical and analytical reasons that they are included like any other family member in the remit of the project, but it is also important for ethical reasons that they to be given the opportunity to participate and the option to decide (Alderson, 1995).

**Recording the data and making fieldnotes**

Practically it is difficult for researchers who have an active role in their observation setting to make extensive field notes whilst they are in the field, and it might also be undesirable to do so because this can disrupt the normal conditions of the setting or it might feel inappropriate (Lawton, 2000; 2001). The Chief Investigator intends to carry a dictaphone device to enable her to record memos to herself throughout the day about significant ideas and details and she will, if the opportunity arises, make brief written notes during breaks. Code names will be assigned to individuals and families so that identities are protected immediately and nothing is voice-recorded or written down which might lead to identification. After each day of observation the Chief Investigator will return to her study to write up detailed fieldwork notes. These will be typed onto the Chief Investigator’s home computer which is
password protected, with all identifiable details removed. The Chief Investigator will also keep a fieldwork diary to record more personal feelings about the research process (Rowling, 1999).

**Justification**

As is the case with all research in a palliative care context, researchers face a particular set of ethical challenges and have to negotiate and justify the value of their work against a backdrop of ‘perceived cultural sensitivities associated with palliative care’ (Seymour et al., 2005:170; see also Sheldon and Sargeant, 2007 and Lawton, 2001). The Chief Investigator recognises that this project will involve working with families and patients who may be experiencing a difficult and emotional time in their lives, and that as a result of this any potential participants are to be considered as belonging to a ‘vulnerable group’ (Liamputtong, 2007). She is aware that some people have asked whether it can ever be morally justifiable to conduct any sought of research with people in such an emotionally challenging context (de Raeve, 1994) - and yet she is also mindful that excluding those who are dying and members of their families from having the choice to participate in research could lead to their further marginalisation within a society which has struggled to talk openly about personal death (Walter, 1994; 1999).

Furthermore, very recently leading researchers in the area of palliative care who specialise in the use of qualitative research methods have pointed to the value and importance of developing the field and extending the application of qualitative methodologies to understand the complex issues those receiving palliative care are experiencing (Payne, 2007; Seymour, 2007). Specifically with regard to observational methods, Seymour states, ‘ethnographers provide an in-depth understanding of sensitive issues that are difficult to address using other research approaches’ and she advocates a more extensive use of this particular method which allows the researcher to become ‘involved in the daily lives of a
particular group of patients or caregivers’ (2007:211). She goes on to cite important ethnographic studies (studies which draw primarily on data gathered through participant observation as a method) that have taken place within hospices, including work conducted during the late 1980’s by Professor Jenny Hockey (Hockey, 1990).

However, it remains the case that despite the great advances that have been made in the arena of palliative care research in recent years, it is still a relatively under-developed research area with only a small pool of investigators (Addington- Hall, 2007). Addington- Hall argues that:

*We currently lack the evidence we need to enable all patients with life-threatening illnesses to live as fully as possible for as long as possible, and to enable us to support their families appropriately both before and in bereavement* (2007:2).

And so, in light of this and drawing on the consensus which now exists amongst experienced researchers in the area of palliative care that it ‘is not a special case and that the usual methods for protecting research participants ... therefore apply’ (Addington - Hall, 2007:5-6), the Chief Investigator offers the following reasons to justify why participant observation is an important part of the research design for this project and why it is a necessary method of data collection to achieve the research aims. The specific ethical implications of using this method are considered fully in a later section.

1- Using an observational method will provide insight into the latter phases of the dying process. Over the 5 years that the Chief Investigator has been involved with a hospice in a voluntary capacity, service provision has changed its emphasis and there is now many more hospice bed spaces being made available for patients who are in the very terminal stages of their illness and for those that are requiring urgent symptom control. Admissions for respite care for those who are in the earlier stages of the illness journey are now virtually non-existent. Therefore many of the families visiting the inpatient unit and spending time there will be ‘doing’ family life at the end stages of a relative’s life.
A hospice ward is one of the very few places where the Chief Investigator can gain access to this experience as it is happening, rather than having to rely on retrospective accounts that are sought after death has occurred. The fact that this project has a temporal focus and is concerned with exploring how everyday family life is experienced across the illness process, being able to generate data which reflects what family life is like during the last stages of a family members’ life is practically – in terms of informing service provision - and theoretically, important.

2- The Chief Investigator would like to argue that an ethical strength of observational based methods is that they are less intrusive or invasive than other methods such as recruiting and interviewing people at a time when their relative is very poorly. Furthermore, this method does not demand much in terms of time or prolonged commitment from participants (Darlington and Scott, 2002; Lawton, 2001).

3- Being involved in life on the ward and observing families interacting in this setting will help to inform the interview guides and highlight issues to explore with the families during the interview phases of the research. Because the two methods for collecting data will be running concurrently, this combined approach offers the opportunity to engage with one of the key principles of a grounded theory approach (Glaser and Strauss, 1967b). Data and ideas generated through the observation can be filtered back into the research process and explored further in interviews to generate new concepts and themes and to ‘test’ if these are significant for participants.

4- Being a participant observer will allow the Chief Investigator to have insight into spatial and embodied aspects of how family life is carried on at this time, because interactions between family members within the hospice space can be directly observed. Thus, observation is important to
enable the research to explore how spaces and aspects of material culture (objects) affect the way family bonds and intimacy are created and maintained at this time.

5- Theoretical justification for doing observation is that it will allow the application of important developments in sociology of the family to the arena of palliative care, where original and novel insight can be created. The Chief Investigator is particularly interested in using an approach which views ‘the’ family as less of a reified, given ‘thing’ and more as an embodied and fluid set of ‘practices’ (Morgan, 1996). Or in other words, how ‘family’ gets created by the things members do together and the interactions that go on between them day-to-day. Therefore to understand how family life gets ‘done’ and is embodied, the study needs to use a method which allows the Chief Investigator to see family life in action.

6- Finally, participant observation is a method which is being used with increasing frequency in medical and health care settings (Savage, 2000). There are many examples of where it has worked successfully and produced important and timely contributions, and challenges to the field of palliative care and our understanding of death and dying (Lawton, 2000; Seymour, 1999; Hockey, 1990. Also see Bluebond-Langner, 1978 for work with dying children; see Glaser and Strauss, 1967a for significant work on awareness contexts in care of the dying and see Sudnow, 1967 for development of the important theoretical concept of social death and the marginalisation of the dying).

5.3 Data analysis

The aim of this study is to explore people’s accounts of their everyday family life and how they are experiencing this over the illness process. The study will capture accounts from the perspective of the
person who is ill – the patient – and members of their family; including where possible the experiences of children and young people. As qualitative techniques have been chosen to capture these accounts and stories, the Chief Investigator’s aim will be to ‘use an analytic approach that is consistent with the underlying principles of qualitative research’ (Becker and Bryman, 2004: 5.13 p.307). Thus the data will be analysed within a framework which seeks to make sense of the data in a way which accords with the phenomenological approach to the data collection (Seymour and Clark, 1998). The stages of data analysis are discussed below. All data analysis will be carried out by the Chief Investigator in her home study or at the University of Sheffield.

**Interview data**

The proposed research is ‘concerned with inferring meaning from data’ and it will seek to ‘draw inferences about what people think, feel and do’, and therefore it is an ‘experiential’ approach to understanding family life during life-threatening illness (Seymour, 2007:151). As Seymour (2007) points out, experiential approaches lend themselves to narrative and phenomenological data analysis methods. Therefore a narrative analysis approach, which is also informed by a phenomenological focus on making sense of the everyday world (Seymour and Clark, 1998), is applicable to the objectives of the research. Significantly, the history of narrative inquiry reveals a long-standing interest in gaining insiders’ views and stories about events and conditions in their everyday lives (Chase, 2005). Primarily what a narrative approach aims to achieve is to ‘lay bare individual and/or group experience of social context and relationships...’ (Roberts, 2004), which is especially relevant for a study proposing to explore individual and collective, familial experiences. The questions on the interview topic guides and participatory activities have been designed to elicit narratives and encourage participants to tell a story about their familial relationships and everyday family life at the time of the interviews. Importantly, there is a link between narrative and time, which fits with the temporal focus of the research upon
exploring family life at different points across the illness process (Roberts, 2004). Furthermore, as Roberts (2004) points out:

*The importance of narrative analysis of lives for social policy research lies in a focus on individual and shared accounts of daily experiences...and responses to significant life changes (2004:321).*

Although the proposed research is not explicitly concerned with social policy, it is intended that the data generated will help make a contribution to enhancing service provision for families experiencing life-threatening illness, and that taking a narrative analysis approach will ensure that the results of the analysis are applicable for this purpose.

A thematic approach to analysing the narratives will be taken, and this essentially entails familiarisation with the data. This will involve reading and re-reading transcripts and other research material to identify themes and sub-themes, and then continually reviewing these in the context of the dataset as a whole, i.e. including data generated from the observational phases of the research. The Chief Investigator may use the qualitative data analysis software package Nvivo to manage and assist with the analysis. Interview transcripts can be imported into the software which has functions that will enable analytic comments to be linked with, and mapped onto, sections of the interview material and any fieldnotes which are made. It is also possible within Nvivo to keep a reflexive diary and the Chief Investigator may also use this to record personal thoughts and feelings about the research process and how she understands these to be shaping the data which is collected and the interpretations being developed. The Chief Investigator has received training at the University of Sheffield in how to utilise the Nvivo package and recognises the importance of keeping accurate records. Remembering to ensure that all transcripts, fieldnotes and diary entries are dated and carefully organised (electronic or hand-written) will be necessary to enable the Chief Investigator to gain a deeper, more reflexive understanding of how the analysis as a process has developed, as well as the theoretical ideas and themes which will start to emerge.
Visual data

The interviews will incorporate activities with the purpose of facilitating discussion. However, the outcomes which are produced will in some instances constitute data in their own right. The analysis of these is discussed below.

**Adult activities:**

*Activity 1 (interview 1): ‘My family story’ timelines (appendix 1)*

Data derived from the three timelines – past, present and future –will be analysed to indicate significant events and themes in the respondent’s family story to provide insight into how they understand and what they think about their family, and about being a part of it. This analysis will provide a context for subsequent analysis of narratives to be placed within and to be related to.

*Activity 2 (interview 1): People in my family ecomap (appendix 3)*

Data derived from this task will be analysed to ascertain details about which family members the participant identifies as significant in their own family life, and will indicate aspects of relational dynamics. Again, this analysis will provide a useful context for the analysis of other interview material to be related to.

**Children aged 9-12, and Young People 13-16 activities:**

*Activity 1 (interview 1): My family tree (appendix 6)*

The principle purpose of using this visual prop is to enable children and young people to express their ideas and feelings about who belongs in their family and how different people and relationships within the family have changed with the onset of someone’s illness. Analysis will relate to the narratives facilitated by this task. In the majority of cases it is anticipated that it will not be a visual data source in
itself, as the family tree is not intended to have any relational significance like a traditional kinship diagram and is simply a representational device for participants to talk about who is in their family and what they do.

**Activity 2 (interview 1): If my family were a tin of baked beans... (appendix 7)**

This data will be analysed to indicate what the concept of being in a family or having a family means to the participants. How the children and young people choose to label their family will be discussed in the interview and the content analysed to provide some context for the narratives participants share about family life.

**Activity 3 (interview 1): Ingredients list (appendix 8)**

The ingredients participants enter here are intended to represent what they do in their day-to-day family life and what it is that happens in a mundane, everyday sense that constitutes the experience of that family. This data will be discussed further and inform the ‘broad questions’ element of the interviews (appendix 5). What the participants contribute here will be collated into themes.

**For children aged 9-12 - Activity 4 (interview 2): Vignette (appendix 9)**

The vignette will be discussed in the interview to explore children’s experiences of what family life is like and how it might be different when someone has a life-threatening illness. The children’s stories and ideas will be analysed and emerging themes identified.

**For young people aged 13-16 – Activity 4 (interview 2): Scenario – producing a leaflet (appendix 10)**

As for activity 4 for children aged 9-12 above.

**Participant observation data**
Silverman (2001:65) suggests that, ‘in making fieldnotes, one is not simply recording data but also analysing them’. In other words the participant observer will make two types of notes – descriptive and analytic. As noted previously, the Chief Investigator’s participatory role on the ward will enhance her ability to engage with this process, and to go beyond just describing what she sees, and to start the process of developing analytical ideas early on. Analysis will based upon the ‘interpretation of the meanings and functions of human actions’ (Seymour, 2007:212), in accordance with the principles pertaining to experiential research approaches and the intention to produce ‘descriptive and analytical accounts[s] of stories and experience’ (Payne, 2007:154). As above, a thematic approach shall be taken that will include familiarisation with the data, re-reading fieldnotes to identify themes and sub-themes, and then reviewing these themes as further observational data is collected and in the context of the dataset as a whole, i.e. including data generated from the interview phases of the research. In terms of structuring the field work data the Chief Investigator may use the aforementioned computer software to store the descriptive data and also take advantage of its functions to enable analytic comments to be linked with, and built onto descriptions of what she has recorded about family life on the ward.

5.4 Research setting

Interviews

The Chief Investigator has suggested to potential interview participants in the information sheets, that they can be interviewed either in their own homes, at the University or the hospice. In the adult material the Chief Investigator has emphasised that she would like to visit participants in their own homes, explaining that the domestic space is often considered a significant setting for family life (Gubruim and Holstein, 1987) and that therefore visiting the participant in this space would be of particular interest to her. It would also mean that the participant, particularly if they are a patient, do not have to worry about getting themselves to a venue and arranging transport. Furthermore the setting in which an interview
takes place is very important and the familiarity of the home may make the experience feel more comfortable and lend a sense of control to the participant; although privacy and therefore aspects of maintaining confidentiality may be an issue. If a participant would like to do the interview at their home, the Chief Investigator will suggest to them that they arrange a time when they are most likely to have privacy. She will enquire if the home has a space which will be conducive to maintaining confidentiality, and if not, offer the alternative venues so participants can make a more informed choice. The Chief Investigator can book a private room either at the University or the hospice, if the participant would prefer.

**Participant observation**

As previously stated, the observation element of the research will take place on the inpatient unit at the hospice from September 2007 until March 2008. The unit has provision for up to 8 patients aged 18 years and over, and the criteria for admission to the ward are a need for symptom control, terminal care or urgent respite care. There are four private rooms, a further four bedded unit and an open-plan communal area which hosts a seating area for visitors and the nurses station. The ward is a relatively small space and often even in the private rooms the doors are left open or at least ajar. Bearing this in mind the Chief Investigator will seek to remind participants that confidentiality may be compromised in the ward environment and she will conduct herself in a manner which will afford patients and their families some privacy when it is sensed that this it was they would prefer at that time.

**5.5 Study participants and recruitment**

**In-depth Interviews**

The hospice provides day care service for approximately 80 patients at any one time. The referral criteria for the service stipulates, that attendees must live in the area, be over the age of 18, facing life-
threatening illness and have palliative care needs. If a person is eligible they usually attend the unit for 1
day, on the same day each week for as long as their need of the service remains appropriate. The day
unit is open weekdays and provides an opportunity for caregivers to have some rest time whilst patients
can, amongst other things, have a meal, socialise, do craft work, play games and get advice on issues
such as medication or any symptom problems related to their disease. The study proposes to invite
patients who attend the day unit to take part in the interview phases of the research. It is anticipated that
no more than 5 patients in total will be recruited; however more may be approached if the initial patients
identified by the recruitment team at the hospice do not wish to take part. The patients will act as
gatekeepers with regard to the recruitment of members of their family to take part in the research. The
recruitment process has been designed this way to ensure that if a patient is not happy with the idea of
their family being involved with the project, then they get the initial control over whether the
information pack (see below) gets passed onto them or not, and a situation where the patient feels
pressured or uncomfortable is avoided. The Chief Investigator cannot stipulate exactly how many
family members will be interviewed, although an overall maximum participant figure to include patients
and their family members should not exceed 16. To make the process more manageable it is proposed
that interviews will take place in 2 phases, as follows:

**PHASE 1:** September 2007- February 2008 (aim to recruit and interview approximately 6-8
participants).

**PHASE 2:** March 2008- July 2008 (aim to recruit and interview approximately 6-8 participants).

(Please note dates are provisional pending ethical approval).

Having fewer participants to work with at any one time, rather than a larger number running over the
entire 10 month period, will enable the Chief Investigator to have more time to be flexible and therefore
to respond sensitively to participants practical and emotional needs. With each phase lasting for roughly
5 months, it is proposed that the Chief Investigator will interview each participant 3 times for approximately 1.5 hours on each occasion over this period. If the maximum numbers of participants are recruited and each is able to be interviewed for the desired 3 times, this would equate to a total of 48 interviews over the 10 month period. As previously stated, it is impossible at this stage to anticipate in advance how many family members will opt to take part, and also whether those participants who do initially participate will be able to sustain that involvement for the full 5 months and the 3 interviews. For these reasons the recruitment process needs to have flexibility to ensure that enough data can be generated to comprehensively explore the research questions, without generating an unrealistic amount to be analysed for a PhD study. It is therefore proposed that changes may be made once recruitment has begun. For instance, depending upon the participant numbers for phase 1, the Chief Investigator will instruct the day care recruitment team to recruit accordingly at phase 2 to keep the overall number of participants and contributions at a manageable level and in line with the resources available for undertaking the study.

The Chief Investigator has already arranged with the acting matron at the hospice for the recruitment to take place pending ethical approval. She has also confirmed with the day unit Sister and two members of the occupational therapy team who all work closely with day care patients and their families, that they are happy to support the study and to approach patients from the unit on the Chief Investigator’s behalf. A meeting has been provisionally arranged for the Chief Investigator to meet with the team in mid August to discuss recruitment details, prior to recruitment beginning in mid September (pending ethical and research governance approval). The recruitment process and timings are detailed in a recruitment guide that the Chief Investigator has prepared for members of the day care recruitment team. They will receive a copy of this at the aforementioned meeting.
The recruitment process

Initially the day unit team will meet to identify which patients they are going to approach (see below for inclusion criteria). It is anticipated that the aim will be to recruit 2-3 patients to take part in phase 1 of the interviewing. A member of the day unit team will approach the patients in person to explain the study. The Chief Investigator will not be involved in approaching patients to minimise the pressure they might feel to agree to participate. She will not be aware of the identity of any patients who were approached and who declined to take part. If the patient agrees, an information pack will be issued consisting of a letter of introduction for the patient (appendix 12), and one for family members (appendix 13), copies of a participant information sheet, which are the same for both patients and family members (appendix 14), reply slips (appendix 15), guidance pertaining to the inclusion of children and young people (appendix 16) and leaflet containing contact details for the local NHS advice service. A decision regarding participation will not be required immediately and potential participants will be informed in person and in writing that they can contact the local NHS advice service for independent advice regarding participation. If at this point a patient asks about the inclusion of a child or young person that they have in their family, an information pack consisting of a letter for parents (appendix 17), participant information sheets for children (appendices 18 and 19) and parents (appendix 20) respectively, a reply slip to be completed by both (appendix 21) and a local NHS advice service leaflet can be issued. Otherwise, as the guidance letter (appendix 16) within the original information pack stipulates, a family can request a children and young person’s information pack at a later date from the day care recruitment team. If the patient decides that they do not want to participate, but would like to give their family members the option, they will be informed that this is okay and the information pack can be passed on accordingly to those members. The Chief Investigator has stipulated in the information sheets that to keep the family-focus of the research, only family members can be included in the project. Patients will be instructed that they and their family members should return the enclosed reply slips to
the hospice within 2 weeks if they wish to participate. Upon receiving positive responses, the Chief Investigator will contact the participants to arrange the interview and whether anyone has a preference to be interviewed with another member of their family. The date, time and location will be confirmed by post. When the third and final interview is completed, the participant’s involvement in the research as an active participant ends. The recruitment process for phase 2 of the interviewing will also follow the above procedure.

Participants will be given opportunity to access further information regarding the research. The participant information sheets inform potential participants that they can contact the Chief Investigator for further clarification and her contact details are provided. A mobile number is included so the Chief Investigator can be contacted in evenings and at the weekends. This handset is for use relating to the project only, and therefore is not the Chief Investigators personal mobile phone number. Potential participants can also consult the local NHS advice service for independent advice regarding participation.

Sample and inclusion criteria

Up to 5 of the potential participants will be patients currently attending the hospice day unit and it is anticipated that they will range in age from 18 years upwards, with an equal gender split being sought. Only patients who the day unit recruitment team deem are physically and emotionally well enough to engage in participation will be approached. Further potential participants will be related to these patients whether through blood or marriage, i.e. belonging to the same family. These potential participants will have regular contact with the patient and thereby have some shared sense of family life. It is anticipated that a very small number of these family members may be children over the age of 9, or young people aged between 13 and 16 years.
Although the anticipated maximum number of participants might appear small at only 16, qualitative, interview based projects only require a small number (often less than 20) to ‘facilitate the researcher’s close association with the respondents, and enhance the validity of fine-grained, in-depth inquiry in naturalistic settings’ (Crouch and McKenzie, 2006:483). Generalisation is not a primary concern in studies of this nature, because as Grinyer (2002) points out:

> Like other qualitative research methods, narratives do not generate representative samples, numerical data and statistically generalizable findings. Rather, the purpose is to give rise to experientially based understanding of how lives are lived... (2002:20).

Therefore it is proposed that this approximation of 16 participants - each to be interviewed on 3 separate occasions - will be sufficient to generate enough data to explore the research questions posed, whilst enabling detailed data analysis to take place. Since there are a number of patients attending the day unit at any one time, it is anticipated that the small number of participants required for this study will be attainable.

Only English speaking people will be approached, as it is not feasible to use an interpreter. Although, in accordance with the NHS's position regarding equality and anti-discriminatory practice, a patient or family member who has a learning disability will not automatically be excluded from the study. In the case of such a patient, the day care recruitment team would make an assessment regarding whether they should be approached. Whilst in the case of a family member, the Chief Investigator would seek advice from a consultee (person responsible for the care and protection of the person with a learning disability).

**Participant observation**

*The recruitment process*
It is proposed that patients who are staying on the ward whilst the participant observation is on-going will be identified as potential participants and approached by the Chief Investigator to ask if they would like to consider participation in the study. Patients will therefore be identified and recruited by the Chief Investigator. Family members who attend the ward to visit a patient whilst a period of observation is on-going will also be identified as potential participants. They will be informed about the research on their arrival at the ward when they will be provided with an age-appropriate participant information sheet (appendices 22, 23, 24) and a covering letter (appendices 25 and 26) by the volunteer receptionist at the main entrance. The volunteers who staff the reception will be provided with training delivered by the Chief Investigator to ensure that they understand the importance of informing all visitors that the research is taking place on that day. The Chief Investigator will be available to support the receptionists with this task at all times. If on occasion, a relative manages to reach the unit not having received an information sheet, the ward is small enough for the Chief Investigator to be personally introducing herself, and the study, as and when she encounters new arrivals. She can then approach the issue of participation with the potential participant and an information sheet can be administered at this point and prior to any observational work having taken place. Where relatives are already present on the ward when the Chief Investigator arrives, she will identify new potential participants when she first reports to the ward staff for an update on any new admissions and important information she might need to know for the day. The Chief Investigator will approach these visitors in person to explain the study and provide information sheets. In the information sheet it informs participants that they can contact the local NHS advice service to gain independent advice regarding their participation and that the Chief Investigator and ward staff can provide leaflets containing contact details.

**Sample and inclusion criteria**
The study sample will be comprised of family members visiting patients on the hospice ward during periods when the Chief Investigator is present undertaking participant observation. To ensure that a broader and more representative picture of family visiting practices is observed the Chief Investigator will vary the times of day she conducts the observation which will also ensure that family members who, for instance can only visit after work, can be included in the sample. It is anticipated that children and young people of all ages may be included in the sample (see section 8.1 for details for consent procedures). While once again, as with the interviews, patients or family members with a learning disability will not automatically be excluded from talking part and advice will be sought from a consultee (family member). However non-English speaking people will be excluded because without an interpreter or translated information sheets it would be impossible to ascertain that the people had given their informed consent to be included. As far as possible to maintain the family focus of the research, non-family members who visit a patient on the ward will not be included in the observational work. It is impossible to state how large the sample size will be. To give some indication of possible recruitment opportunities - the observation will be conducted over a period of 7 months with the Chief Investigator present on average 2-3 days a week (approximately 10-15 hours a week) during this time. The ward has provisions to care for up to 8 patients at any one time, and patients generally do not stay for longer the 3 weeks at a time.
5.6 Intervention

Patients and their families will be involved throughout the course of this study. The stages and nature of their involvement are outlined below in Figures 1 and 2.

**Figure 1: Typical participant intervention for in-depth interviews**

<table>
<thead>
<tr>
<th>Participant information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice day care recruitment team approach patients and ask if they would like to receive an information pack to consider their own, and family member’s participation in the research. The research is explained verbally and in person to patients.</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Participant recruitment 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients distribute information sheets to family members and each decides on their involvement. They return reply slips to the hospice to indicate a decision to participate or request further information.</td>
</tr>
</tbody>
</table>

↓

<table>
<thead>
<tr>
<th>Further information (if requested)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants may seek further information or clarification before confirming participation.</td>
</tr>
</tbody>
</table>

Children and young people information (if requested)
Hospice day care team issue children and young people information pack if requested by a patient or family member.

Fieldwork arrangements
Upon receipt of positive responses to involvement, the Chief Investigator contacts participants by telephone to arrange a time and location for the first interview to take place.

(Continues over page)

Interview 1
Chief Investigator confirms that participant is happy to continue, following the pointers on the consent guide. The Chief Investigator and the participant sign 2 copies of the consent form (one for Chief Investigator’s records and one for the participant to keep). First interview is completed and second interview is provisionally arranged.

Telephone contact (if agreed)
With agreement from the participant the Chief Investigator will contact participant sometime before the second interview to see how everyday family life is at this time. Chief Investigator will also ascertain that the participant is happy to continue with participation.

Interview 2
Interview 2 takes place 6-8 weeks after the first interview. Chief Investigator confirms that participant is satisfied to continue involvement and reiterates key consent issues. Second interview is completed and third interview is arranged.

Telephone Contact (if agreed)
As above.
**Interview 3**

Interview 3 takes place 6-8 weeks after the second interview. Chief Investigator confirms that participant is satisfied to continue involvement and reiterates key consent issues. Third and final interview is conducted. Participant’s involvement in the research ends.

**Dissemination of findings**

Chief Investigator to send a summary report to participants at the end of the study.

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**Figure 2: Typical participant intervention for family members - participant observation**

**Participant information**

On their arrival at the inpatient ward the participants are issued with an age-appropriate information sheet and covering letter to inform them about the observation taking place at that time on the ward.

**Participant recruitment 1**

Participants read their information material and make a decision regarding their participation.

**Further information (if requested)**

Participants may seek further information or clarification.

**Participant recruitment 2**

The Chief Investigator introduces herself to participants and ascertains that they are satisfied with her presence on the ward and are willing to participate. She also clarifies consent with regard to children and young people if appropriate. If participants are willing to be involved, the Chief Investigator will include them as participants in the observation.
The Chief Investigator excludes any participants who opt out of taking part in the research.

**Participant observation**
The Chief Investigator interacts with and observes participants throughout the length of their stay during the designated observation period. The final time the participant encounters the Chief Investigator in the ward setting, indicates the end of their involvement in the research.

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**Figure 3: Typical participant intervention for patients - participant observation**

**Participant information**
The Chief Investigator verbally explains the research to patients and seeks their informed consent. If desired, an information sheet is issued. Initial feelings around participation are sought.

**Participant recruitment 1**
The Chief Investigator leaves the patient to further consider participation and to read their information sheet if one was requested.

**Further information (if requested)**
Patients may seek further information or clarification.

**Participant recruitment 2**
The Chief Investigator clarifies if the patient wishes to participate. If patients are willing to be involved, the Chief Investigator will include them as participants in the observation.

**Participant recruitment – (if opting out)**
The Chief Investigator excludes any patients who opt out of taking part in the research.
Participant observation

The Chief Investigator interacts with and observes patients during the length of their stay during the designated observation period. The final time the patient encounters the Chief Investigator in the ward setting indicates the end of their involvement in the research.

6. Project plan

The table below outlines the major project stages over a 2-year period spanning from September 2007 until September 2009. However, the project would only be running within the hospice setting for approximately 11 months.

The provisional work schedule is as follows:

<table>
<thead>
<tr>
<th>Date</th>
<th>Project stages</th>
</tr>
</thead>
<tbody>
<tr>
<td>September 2007</td>
<td>Notify hospice day care staff to begin phase 1 recruitment of families.</td>
</tr>
<tr>
<td>September 2007- March 2008</td>
<td>Participant observation on hospice ward (2-3 days a week), with concurrent data analysis of fieldnotes.</td>
</tr>
<tr>
<td>September 2007- February 2008</td>
<td>In-depth interviews with patients and members of their family, recruited from day care (phase 1). Concurrent data transcription and analysis.</td>
</tr>
<tr>
<td>February 2008</td>
<td>Notify hospice day care staff to begin phase 2 recruitment of families.</td>
</tr>
<tr>
<td>March 2008- July 2008</td>
<td>In-depth interviews with patients and members of their family, recruited from day care (phase 2).</td>
</tr>
</tbody>
</table>
### Proposed structure of the PhD thesis

- **Chapter 1: Introduction**
- **Chapter 2: Literature review**
- **Chapter 3: Methodology**
- **Chapter 4: Findings**
- **Chapter 5: Discussion**
- **Chapter 6: Conclusions and Recommendations**
- Bibliography
- Appendices

### 7. Project management and expertise

The Chief Investigator, a PhD student based in the Department of Sociological Studies at the University of Sheffield will carry out the ongoing tasks of the research. These are to include liaising with participants and staff at the hospice, arranging the fieldwork, negotiating informed consent with participants, conducting the fieldwork and carrying out data analysis. She has previous experience of conducting research with vulnerable participants and children, as well as applicable experience gained in voluntary and paid posts which have involved working with, and supporting vulnerable people; some in
a palliative care context (see attached CV). The Chief Investigator has also actively made connections with experienced researchers in her field whom she will be able to contact for guidance on specific issues that are encountered during the course of the research. She is member of the Bereavement Research Forum (BRF) and also of the ‘Sheffield Death and Dying Group’. This group benefits from having a multidisciplinary membership base which includes the valuable grass-roots knowledge of a number of practitioners working within the field who can, if required, provide a further source of advice and support for the Chief Investigator.

The supervisory team consists of Professor *** and Professor ***. A particular strength of the supervisory team is that throughout their distinguished careers they have collaborated as co-applicants for research grants, as co-authors, co-editors and as part of research teams. They are both based in the Department of Sociological Studies at the University of Sheffield where they coordinate and teach a series of modules together, as well as individually.

Professor *** is a leading academic in the field of death, dying and bereavement and has expertise in the application of qualitative research methodologies in this area. She has published extensively on a range of issues in death studies and also in the area of identity, health and illness. She has recently completed a qualitative study which explored the making of heterosexual relationships within families and is currently involved in another project about masculinities in transition, which also has a focus on family life and the home.

Professor **** helped to pioneer theoretical and methodological approaches to research with children which are now central to the field of childhood studies. Her experience of conducting research with children is innovative and extensive. She has an international reputation for developing the massively
influential perspective of the child as a social actor. She also conducts research and publishes in the field of health and illness.

8. Ethical issues

8.1 Consent

*Interviews*

As previously stated, early on in the recruitment process the Chief Investigator will not be involved in approaching patients to minimise the pressure participants may feel to agree to participate. The decision has also been taken not to disclose at the initial point of recruitment, the Chief Investigator’s personal relationship with the day care Sister (friends). This is because it also might influence a participant’s response to the initial approach made by a member of the day care team. If their initial decision to consider participation was made out of a sense of obligation to the day care Sister, there will be implications for how freely given any future consent might be. The Chief Investigator will explain the personal relationship she has with the day care Sister to any participants who express an interest in participating by returning their reply slips. She will do this during the telephone call she will make to arrange the first interview, which would then give the participant time to reconsider their decision to participate before the interview date arrives. The Chief Investigator will strive to facilitate an open relationship with participants and she considers that not disclosing this would undermine the honesty and transparency with which researchers, aiming to reduce the disparity of power between them and their participants should operate (Oakley, 1981).

Formal consent will be obtained at the first interview. After spending some time discussing the research with participants and ensuring important points listed on a ‘consent guide’ (see appendices 2 and 4), the Chief Investigator and the participant will sign copies of consent forms (appendix 27). Both parties will
keep a copy of the form. At subsequent interviews, although formal consent will not be sought the issues addressed in the aforementioned ‘consent guide’ will be revisited again with participants. Thus informed consent will be regarded as a matter of process and ongoing relevance throughout the duration of the research (Hallowell et al., 2005; Homan, 1992).

Where participation might involve children or young people, then informed consent will be gained from parents and participants respectively. If a patient recruited from day care decides that they would like to invite a child or young person in their family to participate they will make contact with the day unit staff to request a children and young people’s information pack. Providing literature to both parents and their children will ensure that both can give informed consent. The formal aspect of this will take place at the start of the first interview when the Chief Investigator, the parents and the child or young person will sign copies of consent forms (appendices 28 and 29). All parties will keep a copy of the consent form. Prior to this, the Chief Investigator will spend time explaining to the child or young person and their parent about the research and what informed consent means. Once again the Chief Investigator will use a ‘consent guide’ documenting important issues to reiterate and expand upon to ensure any consent given is fully informed (appendix 30). As with the adult participants, these issues will be revisited again when the Chief Investigator checks that participants are still willing to be involved at the subsequent interview.

In the course of doing all the above it will have been made apparent to participants, both in writing and in person, that participation in the research is voluntary and that they are free to withdraw at any time without the care they, or their relative receive from the hospice being affected. They will also have been informed in writing and in person that the research is not being conducted by, or for, the hospice so that once again participants do not feel a sense of obligation to take part.
Participant observation

As already stated, the inpatient ward is a relatively small area and there is only one route through which visitors can access it. On arrival at the hospice visitors are admitted via a door-release mechanism which is controlled by volunteers who staff the main reception desk on weekdays from 9am until 8pm. After this time and on a weekend, access is controlled by staff on the ward. Once inside the building visitors are asked by the receptionist to sign in before they are granted access to the ward which is a twenty second walk away. On entering the ward though a single set of double doors it opens up into the communal area which hosts the nurse’s station and a comfy seating area. It is virtually impossible for anyone to enter the ward without being noticed and officially signed in. Taking this into consideration it is an attainable and realistic task to ensure that all visitors arriving whilst a period of observation is being conducted will be informed of the Chief Investigator’s presence. Initially this will happen with the provision of age-appropriate participant information sheets and covering letters to all visiting relatives who arrive during a period of observation (appendices 21, 22, 23 and 25 and 26). The most frequent way in which these will be received is, as relatives first arrive and report to the reception desk to sign in. The volunteers who staff the reception will be provided with training delivered by the Chief Investigator to ensure that they understand the importance of ensuring all visitors receive the appropriate information on their arrival. The Chief Investigator will be available to support the receptionists with this task at all times. If on occasion, a relative manages to reach the unit not having received an information sheet, the ward is small enough for the Chief Investigator to be personally introducing herself and the study, as and when she encounters new arrivals. An information sheet can then be provided at this point, and prior to any observational work having taken place. Where relatives are already present on the ward when the Chief Investigator arrives, she will identify new potential participants when she reports to the ward staff
for an update on any new admissions and important information she might need to know for the day. The Chief Investigator will approach these visitors in person to explain the study, provide information sheets and ascertain early indications regarding consent. The information sheets stipulate that if someone would prefer not to be observed or approached during their time on the ward, then they need to opt out of the study by doing one of the following:

- Informing the Chief Investigator directly
- Informing a member of the ward staff
- In the case of children and young people, it has been suggested that they can do either of the above or ask another family member to take this action on their behalf.

If the Chief Investigator is made aware that a family member is unhappy about being observed, in the first instance they will be assured that no recordings will be made relating to them. However in some circumstances it may be appropriate to exclude an entire family, where it would be difficult to conduct observation when only a couple of people have consented and other non-consenting members are present. In the event that the Chief Investigator feels an individual (patient or relative) or a particular family appear either annoyed or deeply worried by the presence of a researcher, then the observation element of the project will be suspended. The Chief Investigator will leave the ward and not return again until the patient’s stay has ended. Terminating the observation for a period will not be detrimental to the study and it is deemed by the Chief Investigator as the most sensitive course of action to take in such circumstances. In doing this the Chief Investigator will be acting in accordance with principle (1a) of the ASA’s ethical guidelines, that state a researcher’s ‘paramount obligation is to their research participants and that when there is conflict, the interests and rights of those studied should come first’ (1999:2).
Essentially the opt-out approach proposed here is the only practical way of ascertaining consent in this environment. It is impossible to anticipate in advance who will be admitted to the ward throughout the study, and it would also be impossible to make contact with all relatives who are likely to visit the ward beforehand, to discuss their potential participation. However, as has been indicated above, the Chief Investigator will actively seek to discuss participation with the majority, if not all visitors a short time after they or she has arrived on the ward and that they have had the chance to read the information material. The Chief Investigator will also wear a badge which identifies her as a researcher from the University and there is a photo included on the participant information sheets to aid identification.

If a child or young person has not opted out of the study, the Chief Investigator will make every effort to ensure that an adult accompanying them on the ward (where possible a parent/ guardian) is happy with the child or young person’s decision to participate. In an instance where the child is younger than 8 years and has not been able to access the information booklet in meaningful way, the Chief Investigator will approach the adult accompanying them and discuss their feelings around the child being included in the observations. The Chief Investigator will also speak to the child about what research is and about the project, in a way which seems appropriate to their level of comprehension.

The approach for securing informed consent from patients staying on the ward will be slightly different, and involve an opt-in model. Initially the Chief Investigator will have a conversation with each patient, explaining with the help of a ‘consent guide’ (see appendix 31) what the research is about and inviting them to participate. Lawton (2000) advises that researchers adopting a voluntary role whilst conducting observation on a hospice ward, need to be mindful that patients may misidentify them and forget their research role when they see them performing similar tasks to those undertaken by volunteers. Having the initial time to spend with patients talking about the research will enable the Chief Investigator to
ensure that her role as researcher is explained clearly; the issue can then be periodically revisited in subsequent interactions. It was decided that the Chief Investigator would talk to patients using the ‘consent guide’ as a prompt in the first instance, as some patients might feel quite weak and therefore prefer not to use their limited energy reading a document. The Chief Investigator also feels that introducing the research to the patients personally has a more human touch which might be welcomed by patients who are potentially quite vulnerable and may feel disempowered due to their condition and the dependency on the hospice (Liamputtong, 2007). While the patients are staying at the hospice they are encouraged to view it as a ‘homely’ place, and the Chief Investigator feels that because of this, a more personal approach would be the most appropriate and it would also allow patients, who due to their condition may not be able to get around the ward so freely, to ask questions immediately instead of waiting for the Chief Investigator to come to them. To accompany this verbal consent process there is also a written information sheet for patients, which will be offered to patients to keep as a further and future, point of reference (see appendix 32). If a patient does not want to take part in the research, the Chief Investigator will not observe any visiting family members either; the entire family will be excluded from the research so as to minimise any distress to patients.

The decision has been taken that formal, written consent agreements will not be used in the observational element of the research. Due to the nature of the setting and the number of individuals who might become participants in the research, it would be impractical for the Chief Investigator to ask everyone to sign a consent form. Furthermore in the case of visiting family members it would be a somewhat ‘empty’ task in the sense that the Chief Investigator would be physically unable to sit with each participant and guide them through the form, to ensure they understand the conditions they are agreeing to. Due to the observation timetable it is likely that many individuals will only encounter the Chief Investigator on a couple of occasions and therefore their involvement with the research will not
tend to be sustained, extensive or especially intrusive. For these reasons, and the fact that ethnographic projects aim to disturb the environment they are studying as little as possible, avoiding undue intrusion into people’s lives (ASA, 1999: 3), written consent will not be obtained from patients or families members involved in the participant observation. However inpatient staff will be able to check that patients are happy to be involved with the research as they provide care to them during their stay. And therefore, although they might not be present when informed consent is sought, staff can bear some witness to the fact that patients have consented.

8.2 Location and safety

Interviews

As stated previously, it is proposed that interviews will take place in participants’ homes; although there is also the option for them to take place in a more public place - either at the hospice or at the University of Sheffield. The latter two locations would mean that the Chief Investigator is not entering unfamiliar territory and that therefore personal safety would be less of a concern. However before visiting participants in their homes, measures will need to be in place to ensure the Chief Investigator remains safe. If it is necessary for an interview to be scheduled for the evening, then the Chief Investigator, who will use her own vehicle for the visits, will park in a well lit area. A personal safety alarm will be carried at all times. Before every visit the Chief Investigator will provide a member of her family or a member of staff at the hospice with details of the location she intends to visit and a time she expects to complete the interview. She will then contact the designated individual by an agreed time, to inform them that she is safe and the session has ended. A mobile phone will remain switched on throughout the sessions, and check up calls will be prearranged. Should the Chief Investigator fail to contact the designated individual within the time scale arranged that person will attempt to contact the Chief Investigator by mobile phone. If the Chief Investigator fails to answer the call, appropriate action will
be taken and if necessary the police will be notified. The Chief Investigator has received personal safety training for the work she has undertaken in a women’s refuge and consequently has a heightened awareness of personal safety issues.

To ensure participants feel assured about their personal safety the Chief Investigator will give them the option of deciding the location they are most comfortable being interviewed in. She also has a recent (May 07) Criminal Records Bureau (CRB) check, which participants can request to see and will always carry identification to the first meeting.

**Participant observation**

Due to the Chief Investigator adopting an active, participatory role on the inpatient ward there are various hazards and issues pertaining to contamination to consider. Where necessary basic precautions such as wearing gloves and frequent hand-washing will be employed to help minimise the risk of infection, to either the Chief Investigator or patients. Advice will be sought from the nursing team at the onset of the observation and then as and when it is required over the course of the fieldwork. This will ensure that appropriate measures are taken to keep the Chief Investigator up to date with health and safety practices. The Chief Investigator will not involve herself in any tasks which would not be expected of a volunteer; for instance lifting patients.

**8.3 Support for Chief Investigator**

Due to her previous involvement with palliative care and bereavement services, the Chief Investigator considers she is prepared for the emotional difficulties she will experience undertaking research with participants who are at times likely to be very distressed and experiencing a great deal of emotional and
physical pain. She also recognises that there is the possibility that conducting this research might bring to the fore previous grief experiences, causing personal upset and a sense of fatigue (Rowling, 1999). There is a growing awareness and general consensus that the emotional wellbeing of researchers ought to be a considered a priority and that mechanisms to formalise ‘self-care strategies’ should be put in place (Rager, 2005). Indeed there are more and more researchers writing about this issue and their emotional experiences (Hallowell et al., 2005; Johnson and Macleod Clarke, 2003; Cannon, 1989).

Following advice in the literature, the Chief Investigator intends to access her experienced supervisor for emotional as well as academic support (Sheldon and Sargeant, 2007; Rager, 2005). She also feels that she will be able to share her feelings with members of the hospice team who are experienced in coping with the emotional demands of working within palliative care. As a further measure to help discharge stress a research journal will be kept (Rowling, 1999) and previous experience the Chief Investigator has of managing her emotions whilst supporting- in a voluntary and paid capacity- vulnerable people facing difficult challenges, will be drawn upon (see attached CV).

### 8.4 Confidentiality

Information collected over the course of the research will be kept strictly confidential, and what one family member shares with the Chief Investigator will not be disclosed to another, or to members of the hospice team. The storage of data and research-related material will comply with the stipulations of the Data Protection Act 1998. All data will be anonymised and nothing which could identify participants will be stored on a computer. All research material containing personal data, such as signed consent forms will be held securely at the University of Sheffield. A secure lockable storage space has been made available in the department of Sociological Studies. All computers used – one in home study and the other at the University- will be password protected. *Although all personal, and identifiable data and information related to the project will be destroyed within 3 years of the project’s completion date (i.e.
submission of PhD thesis), the Chief Investigator would like to retain anonymised copies of the interview transcripts and fieldnotes for future re-analysis, publications and research work. It is also a requirement of her ESRC funding that the interview transcripts are prepared (fully anonymised) for potential depositing with an online data archive - the Economic and Social Data Service (ESDS). The service has a specialist branch called Qualidata, which preserves qualitative data for effective use in research, teaching and learning and therefore any data accepted by the service (not all is suitable, but obligation to offer it is in operation) may be subject to future consideration and analysis by other researchers, academics, teachers and professionals. A separate consent form will be used to gain approval from participants for their interview transcript to be retained in anonymous form by the Chief Investigator and the ESDS (appendix 33*).

Participants will be asked to choose their own pseudonym which will be used in all material – written and electronic – which is gathered during the research process, e.g. fieldnotes and interview transcripts. It will also be used to refer to participants is all future publication material and conference presentations. However, as is sometimes the case in research where participants tell deeply personal stories, conversely, rather than feeling they do not want others to realise what they have said, the story and the telling of it represents a significant part of a person’s sense of self and they have no desire for it to be represented as though it was someone else’s (see Grinyer, 2002). In the event that a participant specifically requests not to have their data anonymised and for the Chief Investigator to use their actual name, the Chief Investigator will spend time over the research process revisiting the issue with the participant and exploring some of the negative consequences which might be experienced. Furthermore

*Note that this was decided after initial ethical approval for this project. Retrospective consent was gained from interview participants and ethical approval to ask for permission to retain the transcripts had to be sought from the ethics committee via a Substantial Amendment.
to make it clear to participants how their stories will be represented, the Chief Investigator will produce an example of an academic paper or chapter which makes extensive use of verbatim participant quotes, so the participants can get an idea of how their material will be used. Therefore when they consent to take part in the project the Chief Investigator is also assured that they are happy for her to use their intellectual property in future research-related publications (Data Protection Act 1998).

While confidentiality must be guaranteed to research participants, there is also a responsibility to protect and support participants and other members of society. As Cowburn (2005) discusses a researcher needs to be clear with his or herself about where they draw a boundary between confidentiality and protection, and they need to have communicated this comprehensively to their participants, so they are aware of the circumstances under which confidentiality will be breached, and for what reasons. Accordingly the Chief Investigator will inform participants that if something is mentioned during an interview or an exchange on the ward, which prompts concern and relates to the safety of them or an identifiable other, then appropriate action will be taken.

The chief investigator will also inform the participants that sometimes maintaining confidentiality when researching in a familial context can be compromised (Daly, 1992), and that, although it is unlikely, there is the small possibility that a detail in publication may enable one family member to recognise the contribution of another.

8.5 Distress and providing support

It is anticipated that there is a potential for upsetting issues to arise during an interview, given the nature of what the project is about and the difficult challenges some participants might be facing at this time. The following strategies will be employed if such an event does arise and a participant displays signs of distress or, particularly in the case of patients, they become unwell:
There are consent and opting out procedures which will be ongoing and will reinforce that participation is voluntary and can be stopped at any time if involvement becomes overly upsetting.

If a participant has another person available at the time to provide support and they want the Chief Investigator to leave, she will end the session. Later that day the Chief Investigator will make a phone call to check how the participant is. During the call the Chief Investigator will suggest to the participant that she will ring back in a few days to discuss whether the participant wishes to continue their involvement with project. The Chief Investigator will check at this point and again during the future phone call, if the participant would like contact details of appropriate support agencies. The Chief Investigator will draw on information she has gathered for a resources pack and consult contacts at the hospice if required.

If the participant is happy for Chief Investigator to do so, she will stay with the participant until they are feeling better and either leave or restart session depending on participant’s wishes.

If the Chief Investigator feels there is need for immediate concern regarding either the physical or mental health of a participant, she will inform the participant of her intention to take appropriate action, e.g. call GP, or contact the hospice to inform an appropriate person of the situation and to get advice.

Everything discussed above will also apply for children and young people, and their parents/guardians will be informed of any incident of distress occurring during an interview to ensure there are immediate support provisions in place for the child or young person.
8.6 Benefits

The Chief Investigator is aware of the problematic nature of suggesting that research experiences can have a ‘therapeutic’ value for participants, and yet there is a number of examples in the literature that underline how participation in qualitative research focusing upon illnesses (Peel et al., 2006), bereavement (Hyson et al., 2006) and life-threatening or terminal conditions (Grinyer, 2004; Barnett, 2001) was considered as a positive experience by participants. Most often when participations report a positive, helpful experience the methodological approach has involved the use of unstructured, in-depth interviews, where participants are provided with ‘considerable control over the interview process’ (Corbin and Morse, 2003:335). Morse and Corbin (2004:335) argue that involvement in interview based research can be beneficial for participants and that any resulting distress which may be caused is no ‘greater than in everyday life’. This view is supported by the Mental Capacity Act 2005 Code of Practice where section 11.15 states that:

*It might be that participation in the research itself will be of benefit to the person in particular circumstances. For example, if the research involves interviews and the person has the opportunity to express their views, this could be considered of real benefit to a particular individual.*

The Chief Investigator has stressed in the information literature that experiencing the research process in this beneficial way is not necessarily something which happens for all, or the majority of research participants, and she has underlined that aside from this possibility, there are no other direct benefits for the participants. However it is intended that the research will contribute to the development of services for families experiencing life-threatening illness.

8.7 Risks

The University of Sheffield ethics policy for research involving human participants states that:
Researchers have a responsibility to protect participants from any harm arising from research. As a general rule, people participating in research should not be exposed to risks that are greater than or additional to those they encounter in their normal lifestyles (2005:8).

Although participants who are involved with the proposed research should be considered as particularly vulnerable, and that it is important to acknowledge with them how talking about their experiences for research purposes may make them feel upset, it remains the case that participants are having to encounter these difficult circumstances on a daily basis. So, whilst the Chief Investigator has identified for participants in their information sheets a potential emotional risk, she feels it cannot be assumed that this ‘risk’ universally applies, or that the potential to feel distressed in the research context is significantly greater than it would be in more everyday encounters. Experienced researchers in the field of palliative and health care argue that the research community cannot allow assumptions surrounding ‘vulnerability’ to exclude people from certain groups, for instance the terminally ill, from exercising their right to make choices about being involved in research (Liamputtong, 2007; Seymour et al., 2005). And in particular when, that research is seeking to understand more about the experience of living as someone who falls into one of these particular groups.

With specific reference to patients staying in the hospice ward (both those with, and those without the capacity to provide consent), the Chief Investigator refers to section 11.19 of the Mental Capacity Act (MCA) 2005 Code of Practice pertaining to research, which states:

*Actions will not usually be classed as unduly invasive if they do not go beyond the experience of daily life, a routine medical examination or a psychological examination.*

According to the above MCA guidelines the severity of invasiveness likely to be experienced by patients who are the subjects of observation is not considered undue in comparison to what will be experienced in the ward environment generally. Whilst residing on the ward, and particularly in the open-plan bedded area, patients can be observed by a number of people, including those visiting other patients,
hospice volunteers and relatives of prospective patients who might request to look around the ward. Therefore the increased risk posed to privacy for the participants by taking part in the observation is important to acknowledge and it will be a key priority for the Chief Investigator when the fieldwork begins, however it should also be considered in line with the impeded privacy patients may already be experiencing in the ward environment.

Apart from what has been discussed here, there are no other known risks associated with taking part in the proposed research.

8.8 Incentives

To avoid participants feeling pressured or coerced into taking part and because it somewhat undermines the ethical standards pertaining to freewill in the consent process, monetary or other larger incentives will not be offered (British Sociological Association (BSA), 2002). To convey her appreciation of the time and effort participants have invested in the research the Chief Investigator will send personal, hand-written thank you cards to all the participants involved in the interview phases of the research. She will also suggest that participants request a copy of any visual work they produce in the interviews. Any children and young people who make crafts during the sessions will be offered those to keep, along with any resources used, e.g. pens, craft materials. The Chief Investigator will also bring a pack of biscuits or similar small food token to be shared during the interviews. Any travel expenses incurred by participants will be reimbursed.

Due to the more fleeting nature of contact the Chief Investigator anticipates she will have with patients and their families who visit the hospice impatient unit, it will be difficult to present a gesture of thanks, such as a card to these participants. However, should a closer relationship develop with a particular
family or patient and the Chief Investigator deems that it is appropriate, a thank you card or notelet will be given.

8.9 Complaints and concerns

Participants will be informed that they may contact the Chief Investigator in the first instance, or the project’s primary supervisor, if any complaints or concerns arise during the course of the research. They will also be instructed in the information sheets that they can contact the local NHS advice service, and leaflets about the service will be made available to participants.

9. Dissemination

It is anticipated that dissemination activities will entail:

- Communication of research findings with participants involved with the interviews.
- Communication of research findings with participants involved with the observation element of the study via a report to be placed in the seminar room at the hospice.
- Communication of research findings with staff at the hospice. This will be in the form of a written report and possibility via seminar presentations.
- Conference presentations.
- Submission of papers to peer-reviewed journals such as Mortality, Qualitative Health Research, Sociology of Health and Illness.
- Interview transcripts (anonymised) deposited with ESDS.

10. Taking the work forward
It is anticipated that the novel data produced from this research will help direct future related research. It will also support applications for funding from external funding bodies. Furthermore as the interview data may be made available via ESDS Qualidata it has the potential to inform future ideas and research in this area. The Chief Investigator may also use anonymised transcripts and fieldnotes in further analysis, publications and research.

11. Intellectual property

The policy frameworks for the management of intellectual property within the NHS and the University of Sheffield will be adopted.

12. Costing and funding arrangements

Expenses incurred from this study will be minimal. They will relate to travel expenses for the Chief Investigator and office expenses. It is projected that these will not exceed £1500 and this will be covered by an award made to the Chief investigator from the Economic and Social Research Council (ESRC). Any additional costs, such as those relating to publications, conference attendances or specialist recording equipment will be met by a Research Training Grant paid to the department of Sociological Studies from the ESRC. The Chief Investigator can access this for the 3 years that her project is funded.

13. References


