RESEARCH PROPOSAL

An Exploration of Paediatric Nurses’ Lived Experiences of Children’s Shift of Care from Cure to Palliation in Ireland.

Research proposal submitted to University of Dublin Trinity College, in partial fulfilment of the requirements for the Bachelor in Science (Nursing) (B. Sc. (Cur.))

Wednesday, 10\textsuperscript{th} March 2010.
I hereby declare that this research proposal is entirely my own work and has not been submitted as an exercise for assessment at this or any other University.

Print Name:________________________
Signed:___________________________
Date:_____________________________
Acknowledgements
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Abstract

**Research Question:** What are paediatric nurses’ lived experiences of children’s shift of care from cure to palliation in Ireland?

**Background:** The death of a child is regarded as one of the greatest tragedies to occur. The aim of palliative care for children is to add life to the child’s time, not to add time to the child’s life. Nurses face many difficult challenges when caring for dying children. It is apparent from the literature review conducted that children’s transition into palliative care causes considerable stress and uncertainty for the nurses caring for them. Curative care and palliative care are often viewed as mutually exclusive. Ideally, cure-directed care and palliative care should co-exist, from the time of diagnosis, alternating in dominance according to the child and families needs. While paediatric palliative care has received increased attention in the past decade, there is a dearth of research examining nurses’ experiences in providing this vital care, particularly in Ireland.

**Aim of Study:** The aim of this study is to explore paediatric nurses’ experiences of children’s shift of care from curative treatment to palliative treatment in Ireland.

**Methods:** The research method for this proposed study is qualitative phenomenology. Ethical approval and access will be obtained from the relevant institutions prior to commencement of the research. Semi-structured, tape-recorded interviews will be used for data collection. The researcher plans to interview twelve paediatric nurses from three urban paediatric hospitals in Ireland. The sample will be sought through posters displayed in staff rooms and on staff notice boards.

**Data Analysis:** It is intended that the tape-recordings will be transcribed verbatim as soon as possible after data collection. Colaizzi’s seven-stage process (1978) will be adapted and used for data analysis. A computer-assisted qualitative data analysis package called Ethnograph will be utilised to help organise and code data.

**Findings:** It is hoped that the findings of the proposed study will provide an insight into paediatric nurses’ experiences of children’s shift of care from cure to palliation in Ireland. It is also expected that this research will highlight the difficulties nurses experience in the transition of such care and elucidate if nurses, in Ireland, view palliative care as mutually exclusive. The researcher proposes to use member checking as a means of validating findings.
Providing Paediatric Palliative Care: The Challenges Nurses’ Face.

And when life’s sweet fable ends,
Soul and body part like friends;
No quarrels, murmurs, no delay;
A kiss, a sigh, and so away. Crashaw (1652) as cited in Collins (1961 p105).

Chapter 1

1.1 Research area of interest

The death of a child has long been acknowledged as one of the greatest tragedies to occur because it happens out of the natural order of life. Palliative care as defined by the World Health Organisation (WHO) (1998) is the active, total, continuing care of a patient whose disease is no longer responsive to curative treatment. It has become evident in recent years that palliative care needs for children differ from those of adults (Himelstein 2006, Department of Health and Children [DoHC] 2001, Goldman 1998; WHO 1998). Palliative care for children and adolescents should be both child and family orientated, with focus on enhancement of quality of life for the child and support for the family through management of distressing symptoms and other problems, whether physical, psychological, social or spiritual. Respite and bereavement care is essential for the family and should be provided for as long as is needed (WHO 1998). The purpose of palliative care is to add life to the child’s time, not add time to the child’s life (Romesberg 2004).

A life-limiting condition may be defined as ‘any illness in a child where there is no reasonable hope of a cure and from which the child or young adult will die’ (DoHC 2005 p10). Children with life-limiting conditions requiring palliative care have been classified into four broad groups (See appendix 1).

From the years 1996 to 2001 the average annual death rate of all children under 18 in the Republic of Ireland was 563 (a rate of 5.4/10,000) of which 370 (a rate of 3.6/10,000) children died from life-limiting conditions (Central Statistics Office n.d).

Healthcare professionals face many difficult challenges when caring for dying children (Davies et al 2008, De Graves & Aranda 2005, Rushton 2005, Papadatou et al 2001, Papadatou 1997). It is nurses, of all the healthcare professionals, who work more closely and frequently with dying children and their families (Rushton 2005, Jennings 2005, Costello & Trinder-Brook 2000, Papadatou 1997). Although paediatric palliative care has received increased attention in recent years, unfortunately there is limited literature

The very nature of palliative care mandates addressing the needs of nurses caring for dying children. Having experienced personal grief as a current student nurse and seeing firsthand the effects providing palliative care for children has on nurses, the researcher developed an interest in this topic.

1.2 Literature Review

Parahoo (2006) defines a literature review as a piece of literature that informs the various phases of a project and puts into context what is already known on the subject. The researcher searched online databases Cinahl, ScienceDirect, Sage and Proquest. A manual search of Trinity College Dublin Library and the Irish Hospice Library was also conducted. The following search terms were used: paediatric palliative care, nurses, experiences, life-limiting conditions, transition of care, grief and difficulties. Articles found dated from 1997 to 2009. Eleven research articles were reviewed from these searches, of which two were quantitative and one used mixed qualitative and quantitative approaches. Twelve further articles were reviewed related to the topic. One Irish qualitative article was found.

The following themes became evident from the literature: Shift of care from cure to palliation; ending of close relationships with child and family and the need for more support. The literature will be reviewed under the first two themes.

Shift of care from cure to palliation.

The death of a child is considered to be a medical failure (Romesberg 2004, Papadatou 1997). When a child is diagnosed with a life-limiting condition, the focus of treatment is primarily on a cure. An unrealistic drive to cure can create a barrier to the benefits of
Palliative care (McCulloch et al 2008). The acceptance of the transition from curative to palliative care is often coupled with the idea of ‘giving up’ (Price & McNeilly 2009, Marsella 2009). It can be difficult to initiate palliative care particularly when health professionals want to maintain a sense of hope for the family and themselves (DeGraves & Aranda 2005). The transition between cure and palliation is also less clear in children, making it more troublesome to identify the right time to involve the palliative care team (McCulloch et al 2008, Hynson et al 2003, Hynson & Sawyer 2001, Goldman 1998). The transition often presents as a crisis late in the disease trajectory.

DeGraves & Aranda’s (2005) qualitative study exploring the challenges of caring for a child with cancer no longer responding to curative treatments, highlights the difficulties associated with the shift of care from cure to palliation. Convenience samples of five nurses, six doctors and three social workers were used to examine how they viewed their role during the shift from cure to palliation. In-depth interviews and group discussions were used for data collection. Content and thematic analysis was carried out to identify important themes from the transcripts. Three main themes emerged from the analysis: hope, uncertainty and interface between cure and palliation.

Hope was seen by the participants as the fundamental factor that helps families cope with childhood cancer. Many families never give up hope for a cure until the last minute which makes the initiation of palliative care problematic for health professionals. The participants felt that removing hope from the families can leave them feeling abandoned at their greatest time of need. The participants commented frequently on how uncertainty impacted on their practice. Uncertainty was greatest when a child’s condition relapsed, as the treatment following relapse was predominately curative. The knowledge that some children survive against the odds impacts on the decision to cease treatment, also causing uncertainty. Likewise, this was found in Davies et al (2008), Steele et al (2008) and Contro et al 2004 studies. For the participants, lack of clarity surrounding prognosis and continued hope made it difficult to know when to stop active treatments and initiate palliation. Their reflections elucidate how the boundaries between curative and palliative care in childhood cancer are vague. By making cure and palliation mutually exclusive, the palliative needs of the children are sacrificed for the hope of a cure.

DeGraves and Aranda (2005) suggest the need for models of paediatric palliation that are integrated throughout the disease continuum, with focus increasing as the child approaches death. Cure-directed care and palliative care should co-exist alternating in dominance
depending on the child’s and families needs (Knapp et al 2009, Liben et al 2008, Goldman 1998). The difficulties, according to this study, faced by health professionals in providing paediatric palliative care can be lessened by adapting such models of care. This study had a number of limitations. Firstly, it was based on the experiences of health professionals from a single paediatric oncology unit, making international application difficult. Secondly, the sample size was rather small and a pilot study was not conducted, decreasing its credibility. Also nurses’ opinions were dominant over doctors and social workers. However, the findings of this article are significant and advocate for further research to build on its results.

The above identified themes are comparable to Yam et al’s (2001) study of the experiences of neonatal intensive care nurses caring for dying infants in Hong Kong. Using convenience sampling, ten nurses were selected and interviewed. Eight categories emerged from the content analysis of the interviews. Like DeGraves & Aranda’s research, the participants of this study also experienced uncertainty and difficulty in accommodating the transition from curative care to palliative care. They did not know how to cope with the dilemma of providing both curative and palliative care. The participants were torn between two competing dichotomies. They were obliged to preserve life and at the same time, they had a moral and ethical duty to minimise any unnecessary pain and suffering. Limitations of this study include the small sample size and single setting; nonetheless, its findings are relevant and it makes valuable recommendations for nursing practice and future research.

Unlike the above studies, Davies et al (2008) conducted a quantitative study using self-report questionnaires to explore the barriers to palliative care experienced by paediatric health professionals caring for seriously ill children. The study focused on the responses of 117 nurses and 81 doctors. Approximately half of the respondents reported 4 of the 26 barriers listed in the questionnaire as almost always or frequently occurring. Two of these barriers were uncertain prognosis (54.6%) and family not ready to accept incurable condition (51.1%). More than 30% of the sample reported family preferences for more life-sustaining treatment as frequently or always occurring. This study recognises that uncertainty in prognosis encourages parents’ hope and pursuit for a cure. This can cause moral distress for health professionals who view curative therapies as increasing a child’s suffering, similar to the findings in DeGraves & Aranda’s (2005) and Yam et al’s (2001) studies. This pursuit for a cure may confine palliative care efforts to late in the disease course. An uncertain prognosis should be an indication to initiate, rather than to delay,
palliative care (Davies et al 2008, DeGraves & Aranda 2005). Correspondingly to DeGraves & Aranda’s study, this study acknowledges that palliative and curative care should be integrated into a coherent whole.

Clarke and Quin (2007) also found that the nurses in their qualitative study used expressions such as ‘unpredictability’ and ‘guess-work’ (p1223) to describe trying to recognize the need for a palliative care transition. Further evidence to support the suggestions provided by these studies is Rushtons (2005) framework for integrated paediatric palliative care. Using two case studies of children, Rushton (2005) illustrates different approaches to palliative care: one that aggressively uses curative treatments to maximize chances of survival and another that focuses on the child's overall quality of life integrating mind, body and spirit. This study provides strategies for integrating palliative care into paediatric practice similar to the other studies. It is apparent from the literature described that nurses experience many challenges in the transition from curative care to palliative care. Integrating palliative care with curative treatments from the beginning of the disease trajectory, instead of viewing the two as mutually exclusive, may ease the troubles nurses face.

**Ending of close relationships.**

It is not unusual for nurses to form a close relationship with a child and family, especially if they have cared for the child for a protracted period of time (Rallison & Moules 2004, Costello & Trinder-Brook 2000). Rashotte et al (1997) found that when a child dies, nurses experience various levels of grief depending on the intensity, quality and closeness of the relationship they had with the child. Rashotte et al (1997) conducted a qualitative phenomenological study to investigate paediatric intensive care nurses’ grief experiences. Non-probability purposive sampling was used to select 6 paediatric intensive care nurses and interviewed them using a semi-structured format. The data was analyzed for recurring ideas using Colaizzi’s method and revealed 8 themes; one regarding their grief responses, two that described the influencing contextual factors, and five that displayed the coping strategies used to control their grief. One of the contextual factors that influenced their grief responses after the death of a child was the nature of the nurse-family unit relationship. The participants explained how feelings of grief were more intense and of longer duration when an emotional attachment had been made with the child. Furthermore, participants acknowledged that sometimes it was the attachment developed with the family that caused even greater grief when the child
died. They get to know the parents well during the child’s illness and when the child dies the relationship comes to an end. While this article makes some excellent recommendations for practice and directions for further research, no limitations are quoted making its trustworthiness questionable.

In Costello & Trinder-Brook’s (2000) study of nurses’ experiences of caring for dying children in hospital, they also found that many nurses became attached to the child and family when the child was in hospital for a long time. This study used questionnaires, focus group and individual interviews to investigate 44 nurses’ experiences. The participants shared the sense of loss felt by the parents when the child died. The perceived negative aspects of caring for the dying child that emerged from the interviews and questionnaires were summarised as: the nurses experienced an emotional attachment to the child; their involvement with the family; the nature and timing of medical interventions; poor staffing levels and sudden death. The positive aspects of caring for the dying child were recognised as: being able to give support to grieving parents; feeling able to give the child attention; controlling symptoms and providing follow-up care for the family after death.

These findings compare with Clarke and Quin’s (2007) study of professional carers’ experiences of providing a paediatric palliative care service in Ireland. Three themes emerged from the 15 focus group interviews. These were: the emotional cost of providing such care, clarity of definition plus complexity of engagement, and seeking to deliver a palliative care service. The researchers used purposeful selection of different health professionals providing hospital and/or community-based care in the voluntary and statutory areas. They interviewed participants using open-ended questions. The participants described caring for children with life-limiting conditions as a struggle. This study reveals that the participants, similar to those in the above studies, identified the ending of relationships as a source of grief. The participants explained that the family of a child who dies after a protracted illness suffers a loss on two levels: the loss of their child and also the loss of the relationship and caring regimen that grew up around their child. The study found that organisation of memorial services played a role in enabling the ending of close relationships between the health professionals and families. This need to establish a sense of closure regarding the nurse-family relationship after the child’s death was also noted by Rashotte et al (1997).
This study has no limitations quoted in it thus its trustworthiness is uncertain; however, it still provides a unique insight into the participants understanding of the struggles that they and families face as they strive toward providing paediatric palliative care in Ireland. In the study by Rushton et al (2006) of interdisciplinary interventions to improve paediatric palliative care and reduce health professional’s suffering it found that when participants were asked “what was the most difficult aspect of caring for the child?”, the most common response was that the death brought an end to the long term relationship with the child, correlating with the literature. These four study’s findings are comparable and validate the conclusion in Papatatou et al’s (2001) comparative study of nurses’ experiences of caring for dying children in Greece and Hong Kong; this conclusion being that the loss of close relationships with a child and their family irrefutably affects nurses.

Conclusion
The initiation of palliative care for children with life-limiting conditions can be troublesome, with the focus of treatment being primarily on cure. It is evident from the literature that the dilemma of when to commence palliative care causes stress and uncertainty for nurses (Clark and Quin 2007, Yam et al 2001). The difficulties health professionals’ experience may be eased by integrating palliative care with curative approaches from the time of diagnosis, as suggested by Rushton (2005) and DeGraves and Aranda (2005).

As shown in the literature, often the most difficult part of the death of a child is the ending of the relationship nurses’ formed with the child, and/or the family. Organizing a memorial service or attending the funeral proved to play a role in enabling the closure of the close relationships.

The transition into paediatric palliative care is an integral, yet largely unexplored, journey of living with a life-limiting condition (Steele et al 2008). There is a paucity of research focusing on the transition into such care. Further research could include focusing in greater detail on nurses’ experiences of the shift of care from cure to palliation. It is evident more extensive Irish research should also be carried out on this subject. In addition, there is a need for more thorough research exploring models of care and frameworks that integrate palliative care from the time of diagnosis.
1.3 Research question

Consequently, in light of the above studies, the research question for this proposal is: What are paediatric nurses lived experiences of children’s shift of care from cure to palliation in Ireland?

1.4 Aim and objectives

The aim of this research proposal is to explore paediatric nurses’ experiences of children’s shift of care from curative treatment to palliative treatment in Ireland.

The objectives of this study are:
- to provide an insight into nurses experiences of the shift of care from cure to palliation.
- to pinpoint the difficulties they face in the transition of care.
- to examine if they view palliative care as the opposite of cure-focused care i.e. see it as a clear shift in goals or the two as mutually exclusive.

Chapter 2

2.1 Proposed Research Design

A research design is a plan that illustrates how, where and when data are to be collected and analysed (Gerrish & Lacey 2009). Not only does the plan explain the steps to be taken but represents the thinking and beliefs of the researcher and the logic of the question (Parahoo 2006). The ideal research design is one that will accurately answer whatever question is being asked (Lobiondo-Wood & Haber 2010). For the purpose of researching the proposed phenomenon in question, a qualitative descriptive research approach will be utilized. The methodology of qualitative descriptive research centres on the way human beings make sense of their subjective reality and attach meaning to it (Sandelowski 2010, Holloway & Wheeler 2006). By using the qualitative descriptive approach of phenomenology (founded by Husserl) the researcher will describe nurses’ lived experience of the shift of care from cure to palliation in Ireland. Holloway & Wheeler (2006) define phenomenology as a philosophy which explores the meaning of a person’s lived experience through their own description of it. Phenomenology re-examines a taken-for-granted lived experience and, through examining the qualities of the lived experience, allows us to identify its essence or ultimate structures of consciousness (Balls 2009).
Phenomenology will allow the researcher to gain in-depth understanding of the experiences, feelings and beliefs of paediatric nurses’ who care for children transitioning into palliative care. This, the researcher believes, makes it an appropriate method for the proposed question.

2.2 Population and Sample
A population is the total number of units (or individuals) from which data can potentially be collected (Parahoo 2006).

The population to be researched in this study will be paediatric nurses from three urban paediatric hospitals in Ireland. By forming an inclusion criterion, the researcher can ensure the target population for this study can be accessed and participants are suitable to meet the proposed study aims (Burns & Grove 2005). Participants in this proposed study must fit the following inclusion criteria:

- Registered paediatric nurses with An Bord Altranais.
- Experience with children who have transitioned into palliation while under their care.
- At least two years experience in paediatric nursing.
- Participants who are prepared to be involved in the research and to give their consent.
- Participants who are willing to articulate their feelings and experiences.

The criterion for having experience with children who have transitioned into palliative care, while under the nurse’s care, was chosen in order to be able to achieve study aims. The participants must have at least two years experience in paediatric nursing so that they have sufficient time to gain experience and because newly qualified staff may have added stresses that could influence the study. It is expected that participants who meet the above criteria will enhance the likelihood of collecting rich consistent data on the proposed research question (Gerrish & Lacey 2009).

Sampling involves selecting people from the population to represent the entire population (Polit et al 2001). Purposive sampling will be utilised in this proposed study so that the best available people to provide rich data on the research question can be selected (Polit & Beck 2008). Morse (1991) as cited in Coyne (1997) describes purposive sampling as selecting participants with a broad general knowledge on the topic or those who have undergone the experience. The sample will be accessed by displaying posters in staff rooms and on staff notice boards inviting nurses who fit the above criteria to participate. A
letter will be sent to the Director of Nursing asking for permission to display the posters and access participants (appendix 2).

Each poster will have the researcher’s phone number attached to it, so that anyone interested in the research can tear it off and ring the researcher to inform her of their interest (see appendix 3 for poster example). Once the researcher is contacted by a participant, the researcher can send out a letter of invite (appendix 4) and consent form (appendix 5) to the participant to take part.

Sample sizes in qualitative research are usually small, thus the sample size in the proposed study will be 12. This is a manageable number of participants and data saturation should be reached. It is argued that too large a sample could lead to loss of the unique and idiographic (Holloway & Wheeler 2006). If a large number of nurses respond to the posters, 12 names will be randomly selected from a hat to take part. If there is a poor response to the posters the researcher will use a gatekeeper to access participants. A gatekeeper is a person who occupies a role that enables the researcher access to research participants or to a setting (Gerrish & Lacey 2009). Permission to use a gatekeeper will be sought from the Director of Nursing.

Four weeks will be assigned to the collection period to give nurses time to respond.

### 2.3 Data Collection

In qualitative research, data collection involves gathering narrative data from the participants through interactive processes such as observations or interviews (Burns & Grove 2005). The researcher serves as an instrument through which data is collected (Sorrell & Redmond 1995). The researcher in this proposed study will use interviews for data collection. The purpose of the interview as identified by Holloway & Wheeler (2006) is to discover participants’ experiences, feelings, perceptions, and thoughts. An in-depth interview is able to focus on the complexity of the experience and can provide a clear focus for exploration (Gerrish & Lacey 2009). For the proposed study, a semi-structured interview format with open-ended questions will be utilised (appendix 6). This will allow the researcher to ask predetermined questions and give the opportunity to the participant to explain their answers by using probes (Nieswiadomy 2010). Semi-structured interviews retain the flexibility necessary to follow topics raised by the participants that had not been anticipated by the researcher (Gerrish & Lacey 2009). Rigour is enhanced in using semi-structured interviews because, with the use of probes, participants can be helped to understand the questions and the researcher can also ask for clarifications if necessary.
The researcher will use minimal control and structure during the interviews to allow topics and perspectives emerge, and to gain a holistic understanding of the experience (Lobiondo-Wood & Haber 2010). The semi-structured interviews will have 7 guiding questions based on the objectives of the study and will be derived from themes that emerged in the literature (Polit et al 2001).

Interviews will be held in the hospital where the nurses work. They will take place in a quiet room away from the main flow of activity. A ‘do not disturb’ sign will be put on the door of the interview room and any telephones or other distractions will be turned off (Easton et al 2000). Each interview will take approximately 50 minutes and will be held outside of working hours, so as not to disturb patient care and the running of the wards in which the nurses work. The researcher intends to portray an attitude of trust, acceptance and safety and to build rapport with each participant to help make them feel comfortable. This is intended to aid the participants in giving a truthful account of the lived experiences in question (Jasper 1994).

Because of the researcher’s interest in the topic, bracketing will be used to prevent bias and to stop the researcher’s assumptions and beliefs from influencing the research process (Balls 2009, Koch 1995). Bracketing is the attempt by the researcher to deliberately examine his/her own judgement, experiences and beliefs about the phenomenon and temporarily suspend these, in order to avoid them from influencing the findings of the study (Cutcliffe & McKenna 1999, Rose et al 1995, Jasper 1994). This process will enhance the trustworthiness of the research. In order to preserve the participants’ words as accurately as possible, tape-recording will be used with permission from the participants (Parahoo 2006). To avoid the pitfall of equipment failure, the researcher will check all equipment before each interview to ensure they are functioning correctly. Spare tapes, batteries and a tape recorder will be on hand in case they are needed. The researcher will also keep a diary so that once the interview is completed, any non-verbal aspects such as body-language and expressions can be documented (Burns & Grove 2005). The diary will also help in preventing biases because the researcher will continuously document personal values, beliefs and perceptions (Sorrell & Redmond 1995, Jasper 1994).

Speaking about dying children and the experiences related to the subject may be a painful reminder of various situations for the nurses. The experience of the interview may be distressing and upsetting for some participants; however, it may also be a therapeutic and validating experience for others (Cutcliffe & Ramcharan 2002). The name and number of
the hospital counsellor will be provided to participants if they feel the need to avail of counselling following the interviews.

2.4 Trustworthiness and Rigour

In qualitative research, the robustness of the study refers to how trustworthy and rigorous the study is (Burns & Grove 2005). Rigour is the means by which the research shows integrity and competence (Holloway & Wheeler 2006). Trustworthiness means the methodological soundness and adequacy of the research (Holloway & Wheeler 2006). Lincoln & Guba (1985) developed a set of principles to examine how trustworthy a qualitative study is. These principles are: dependability, credibility, transferability and confirmability. The researcher will use these principles to ensure the trustworthiness and rigour of the research in question.

**Dependability**: A study is dependable if the findings are consistent and accurate. An audit trail is necessary in order to achieve a dependable study. An audit trail will allow the reader of the proposed study to follow the decision path of the researcher and will demonstrate how the researcher reached her conclusions (Long & Johnson 2000, Sandelowski 1986).

**Credibility**: A study is credible when it presents such truthful descriptions of the lived experiences, that the participants of the study would recognise their own experience and words within the findings (Sandelowski 1986). The researcher intends on using member checking to establish credibility. Member checking involves returning the findings of the study to the participants and asking them whether they feel that the interpretation is a true and realistic representation of their experience (Lincoln & Guba 1985). This process will help avoid misunderstanding and misinterpretation of the participant’s words and experience (Holloway & Wheeler 2006, Cutcliffe & McKenna 1999, Jasper 1994).

**Transferability**: Lincoln & Guba (1985) use the term transferability instead of generalisability. It refers to being able to apply or transfer the findings of the research to other settings. Transferability is considered inappropriate in phenomenological research because the aim is not to produce a theory or general application (Jasper 1994). However if the researcher gives adequate detail about the study setting, sampling, collection and analysis, the research may be repeated in other settings (Balls 2009). It is anticipated that the themes found in the proposed study can be used in the future to guide wider-scaled studies from an informed starting point (Jasper 1994).
Confirmability: Confirmability refers to how objective the data is (Holloway & Wheeler 2006). It is judged by the way in which the findings of the study achieve their aims and are not just a result of the researcher’s preconceptions and beliefs (Sandelowski 1986). The researcher will use an audit trail, as described in Dependability, to ensure confirmability (Koch 1994). This will allow the reader of the proposed study to trace the data to their sources and follow the path of the researchers’ decisions (Holloway & Wheeler 2006). The researcher will also use bracketing (as described in data collection) to ensure trustworthiness.

2.5 Data Analysis

Qualitative data analysis is a complex and creative process, which is interactive, inductive, reflexive, and ongoing (Gerrish & Lacey 2009). Qualitative data analysis takes place during data collection and thereafter (Parahoo 2006). The purpose of data analysis in phenomenological research is to preserve the uniqueness of each lived experience of the phenomenon in question, while allowing an understanding of the meaning of the phenomenon itself (Banonis 1989). There are various techniques for analysing qualitative data. However, most techniques involve transcribing the material, coding the material into themes, clustering these into categories and then putting them in order, to help describe the findings more easily (Holloway & Wheeler 2006, Parahoo 2006, Jasper 1994,). The researcher intends to transcribe the interviews herself, thereby living with the data and familiarising and immersing herself within it (Balls 2009). The interviews will be transcribed verbatim as soon as possible after the interview, while it is still fresh in the researcher’s mind, to enhance rigour (Polit & Beck 2008). Transcriptions will include any hesitations, emotional tones and expressions to avoid any misrepresentations (Sandelowski 1994). The transcriptions will be thoroughly read and re-read to ensure accuracy, gain an overall impression of the data and to identify any recurring information and variations (Balls 2009, Holloway & Wheeler 2006). Once no new information is coming from the data, data saturation is achieved (Polit & Beck 2008).

The researcher intends to use Colaizzi’s (1978) phenomenological seven-stage process (cited in Holloway & Wheeler 2006) (appendix 7) as a means of analysing data. Ethnograph is a computer package that the researcher intends on using to aid data analysis. Computer assisted qualitative data analysis packages can be useful in the retrieval, organisation, management and storage of data (Holloway & Wheeler 2006, Robson 2002).
However, computer programmes should not be seen as the quicker option. It takes time to learn how to use them (Robson 2002, Morison 1998). It is anticipated that it will take approximately a month for the researcher to learn how to use Ethnograph (see appendix 9 for timetable). The computerised data will be backed up on a u.s.b storage device and updated regularly in case anything gets accidentally deleted. The u.s.b and computer package will be password protected which only the researcher will have access to. Each tape will be labelled with the participant’s pseudonym immediately after each interview to provide anonymity. All tape recordings, transcriptions and computerised data will be stored in a locked cabinet for 5 years and destroyed thereafter in accordance with the Data Protection Acts (Government of Ireland 2003).

2.6 Pilot Study
A pilot study is a preliminary, small scale study carried out before the main research process (Gerrish & Lacey 2009). A pilot study can give advance warning about where the research process could fail and help identify practical problems that have not been anticipated by the researcher (Teijlingen & Hundley 2002). A pilot study of 2 participants from the sample will be conducted. The researcher will conduct the pilot study using the same data collection and analysis methods that is proposed for the main research study. This will assist in identifying limitations of the interview format and data analysis and will help to eliminate them. Carrying out a pilot study will also give the novice researcher some much needed practice in interviewing to enhance confidence and technique. The participants in the pilot study will not be part of the main research study sample.

2.7 Ethical considerations
There are ethical implications in all stages of the research process (Polit & Beck 2008). At all times, the participant’s rights, well-being and safety should take precedence over research objectives (Nieswiadomy 2010). The researcher intends on using four ethical principles to ensure the proposed research is ethically acceptable. These principles are respect for autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress 2009). Underlying these principles are the four rights of human research; the right to full disclosure, the right not to be harmed, the right of self determination and the right of
privacy, anonymity and confidentiality (Parahoo 2006). Ethical approval will be sought prior to commencement of the proposed study from the Trinity College Faculty of Health Sciences Ethics Committee (appendix 8). Permission to access the potential participants will be sought from the Director of Nursing in each hospital (appendix 2).

**Respect for Autonomy:** This principle falls under the right to full disclosure and means that the participants in the study must be allowed to make independent and informed choices without coercion (Lobiondo-Wood & Haber 2010). This can be achieved through informed consent. Informed consent is a process of ensuring that the participants are fully aware of what the study involves, understand the potential risks and benefits and freely agree to take part (Noble-Adams 1999). Information on the proposed study will be given to participants in writing on the letter of invite (appendix 4). The researchers contact details will be provided should they have any additional questions. Once the participants are fully informed on the study, they can voluntarily consent to partake or decline participating (appendix 5 for consent form). The consent form will highlight any benefits or potential risks of the study, will describe how anonymity will be kept and will emphasize that the participant can withdraw from the research at any stage without penalties (Milton 2000). The consent form will be signed and dated by both researcher and participants.

**Beneficence:** Any research study should benefit the participants and society in general (Parahoo 2006). The benefits of the research must always outweigh the risks for the participants (Beauchamp & Childress 2009). The benefits of the proposed study include contributing to the knowledge on the topic and the interviews may also be a therapeutic experience for participants.

**Non-Maleficence:** The research should not cause any harm to the participants (Holloway & Wheeler 2006). Due to the sensitive nature of the topic, the researcher of the proposed study must make every effort to avoid psychological harm to the participants. If a participant appears upset or distressed at any stage in the interview, the interview will be stopped and the hospital counsellor will be contacted if needed.

**Justice:** This principle refers to the participant’s right to privacy and to be treated as an equal. The research must be fair and just (Beauchamp & Childress 2009). The researcher will ensure the participant’s needs’ come before the objectives of the study and that their anonymity and confidentiality is kept at all stages of the research process.
Chapter 3

3.1 Proposed Outcomes

It is envisioned that this research will provide an insight into paediatric nurses’ experiences of children’s shift of care from cure to palliation in Ireland. It is hoped this research will highlight the difficulties nurses experience in the transition of such care and bring to light whether nurses’ see curative care and palliative care as mutually exclusive. Additionally, it is expected it will build on the existing literature on this topic and inspire further studies to be conducted to increase the knowledge base.

The main limitation of this proposed study is the researcher’s inexperience in carrying out research. This inexperience may cause problems with sampling, data collection and analysis. However the researcher intends to seek supervision and support from a more experienced researcher in an attempt to overcome this limitation. It is hoped the conducting of a pilot study will give the researcher some practice before the main study is carried out and will identify any practical problems, thus further reducing this limitation. Another limitation of this proposed study is the broad research question and objectives. Nevertheless due to the lack of research done on the topic in question, especially in Ireland, a broad study is justified. It is hoped this proposed study would enthuse further in-depth and focused research to be conducted. Further studies could include focusing on a specific group of children transitioning into palliative care e.g. age group or health status. Additionally, more detailed research is needed examining frameworks that integrate palliative care with curative care from the time of diagnosis.

3.2 Dissemination of the Findings

The researcher plans to write up the findings of this study in a research report and present them in a narrative style using the participants’ own words. Any changes made to the participants’ actual words will be highlighted in italics (Caelli 2001). The researcher will provide all participants of the study with a copy of the final report. The researcher aims to prepare the proposed study for publication in journals such as The Journal of Advanced Nursing, The Paediatric Nursing Journal and The International Journal of Palliative Nursing. The researcher also intends to present the findings of this study to paediatric nurses and other health professionals working in paediatric palliative care.
3.3 Timescale

It is expected the proposed research will take 20 months to complete. See appendix 9 for a table presenting the estimated duration of each phase of the research process.
Appendix 1
The Four Groups of Children with Life-Limiting Conditions Requiring Palliative Care.

**Group 1**: diseases for which curative treatment may be feasible but may fail e.g. cancer.

**Group 2**: diseases in which early death is anticipated but treatments may prolong good quality of life e.g. cystic fibrosis.

**Group 3**: progressive diseases for which treatment is exclusively palliative and may last for many years e.g. batten disease.

**Group 4**: conditions with severe neurological disability that are not considered progressive but which may cause susceptibility to complications likely to cause premature death e.g. cerebral palsy, spinal cord injuries.

Appendix 2
Letter of access to the Director of Nursing

Researcher’s Name
Researcher’s Address
Researcher’s Number
Date.

Director of Nursing’s Name
Address

Re: Research Study: Paediatrics nurses’ lived experiences of children’s shift of care from cure to palliation.

Dear XXX,

I am a fourth year general and paediatric nursing student currently undertaking a Bachelor of Science in Nursing at Trinity College, Dublin. As part fulfilment of the course, I am proposing a research study. The study I have chosen aims to explore paediatric nurses’ lived experiences of children’s shift of care from cure to palliation in Ireland. It is expected the findings will provide an insight into paediatric nurses’ experiences of children’s shift of care from curative treatment to palliative treatment and highlight the difficulties nurses experience in the transition of such care. Additionally, it is hoped this research will bring to light whether nurses’ view curative care and palliative care as mutually exclusive.

I am writing to you to ask your permission to invite approximately four nurses from X hospital to participate in the research study.

Each participant will be asked to partake in a semi-structured, tape-recorded interview with the researcher. Interviews for this study will take place out of the nurses’ working hours, so as not to affect patient care in any way. Interviews will last approximately 50 minutes and will be held at a date and time that suits the participants.

I would greatly appreciate your permission to display posters in staff rooms and on staff notice boards, inviting paediatric nurses to participate in the study. Should I not get an adequate response to the posters, I may have to ask the clinical nurse managers or nurse practice development for a list of staff nurses whom I could write to asking for their voluntary participation in the study. I have enclosed a copy of the research proposal and participant consent form, for your information purposes. I have also enclosed a sample of the poster I intend to use. Please do not hesitate to contact me on the above address or alternatively you can ring me on 08XXXXXXXX should you have any concerns or enquiries.

I look forward to hearing from you at your earliest convenience.

Yours Sincerely,
Researcher’s Name.
B.Sc. (Cur) Student.
Are you a registered paediatric nurse with experience of children who have transitioned into palliation while under your care?

Would you be interested in participating in research examining nurses’ experiences of children’s shift of care from cure to palliation?

Do you have at least two years experience working in paediatrics?

If so, please take a phone number below and contact XX (researcher’s name) to find out more.

Participation in this research is entirely voluntary.

Confidentiality and anonymity will be maintained at all times.

I look forward to hearing from you!
Participant’s Name
Participant’s Address.

Dear Participant,

Firstly I would like to thank you for responding to the posters I displayed in the hospital. I am a fourth year general and paediatric nursing student, currently undertaking a Bachelor of Science in Nursing at Trinity College, Dublin. As part fulfilment of my course, I am proposing a research study. The study I have chosen aims to explore paediatric nurses’ lived experiences of children’s shift of care from cure to palliation in Ireland. I would much appreciate your participation in this research study.

Ethical approval for this research was obtained from the Ethics Committee in Trinity College and from the Director of Nursing in XX Hospital.

The research process involves meeting with the researcher, at a date and time that suits you, to conduct a tape-recorded interview. The interview will be held in the hospital where you work, for convenience, and will be conducted outside of your working hours, to avoid disrupting patient care. The interview will take approximately 50 minutes. To maintain confidentiality and anonymity, a pseudonym replacing your name will be used in the research. Also all tapes used will be transcribed verbatim, stored in a locked cabinet and later destroyed. Only the researcher will have access to the tapes and transcripts. Following transcription of the tapes and analysis of the findings, the researcher will contact you to ensure correct interpretation and representation of your experiences. A copy of the research study will be given to you when it is completed and written up into a report.

A potential risk of participating in this research study is that the interview process may remind you of various situations that could cause you to become upset or distressed. Should this happen, the interview will be stopped immediately and the hospital counselling service will be available to you should you need it.

Participation in this study is entirely voluntary. If you would like to be a part of this research study please sign the consent form enclosed and return it to me in the pre-stamped envelope. Should I not hear from you again, I will assume that you do not want to participate in the study and I will not contact you again.

Thank you for taking the time to read this letter. Should you have any further questions or concerns, please do not hesitate to contact me at the above address or alternatively you can ring me on 08XXXXXXXX.

Yours Sincerely,
Researchers’ Name.
Appendix 5
Informed Consent Form

I fully understand the requirements needed to partake in this proposed research study.

I agree to participate in a semi-structured, tape-recorded interview with the researcher at a date and time that is suitable for me. I am aware that any information I disclose with the researcher will be kept strictly confidential and my anonymity will be maintained throughout, with the use of a pseudonym.

I understand and accept that the researcher will contact me to ensure that the findings are a correct interpretation and representation of my experiences. I have been informed that a copy of the research report will be given to me following completion of the study.

I am aware that the interview process might remind me of situations that may potentially cause me to become upset or distressed. I have been informed that if this happens, the interview will be immediately stopped and a hospital counselling service will be available to me, should I require it.

I accept that my participation in the proposed study is entirely voluntary, and understand that I can withdraw from the study at any time without penalty.

I understand that if I have any concerns or enquiries, I can contact the researcher at any time by telephone, email or in writing.

I hereby give my consent to participate in this proposed research study.

Participant’s Name (Block capitals) __________________________
Participant’s Signature __________________________ Date:

Researcher’s Name (Block capitals) __________________________
Researcher’s Signature __________________________ Date:
Appendix 6
Interview schedule
The purpose of this interview schedule is to retain a certain amount of flexibility, so that the researcher can follow issues raised by participants that had not been anticipated (Gerrish & Lacey 2009). The use of probes will enable the researcher to seek clarification and obtain more complete answers from participants (LoBiondo-Wood & Haber 2010). Refreshments will be provided to each participant during the interview. The interview will start with ‘warm-up’ questions (question 1 and 2) to help the participants relax and ease into the interview process (Parahoo 2006).

1) Can you tell me how many years you have been a registered paediatric nurse?

2) How many children, roughly, would you care for in a year requiring a transition into palliative care?

3) Think about children you have cared for whose needs changed from curative treatment to palliative treatment while under your care. Can you tell me about your experiences of caring for these children?
   OR
   Tell me about your experiences of caring for children where cure-focused treatment was no longer an appropriate option (DeGraves & Aranda 2005).

4) Can you recall any particularly positive experiences you had caring for a child who was transitioning into palliative care? (Yam et al 2001, Costello & Trinder-Brook 2000).

5) Can you recall any negative experiences you had caring for a child who was transitioning into palliative care? (Yam et al 2001, Costello & Trinder-Brook 2000).

6) What is the most difficult aspect of caring for a child who is making the transition into palliative care? (Rashotte et al 1997).

7) Do you view curative care and palliative care as opposites or as a clear shift in goals? Why? (Identified as a gap in the literature by DeGraves & Aranda 2005).

8) Do you see any advantages of integrating curative care with palliative care?

9) Do you see any disadvantages of integrating curative care with palliative care?

Probing questions
-Can you expand on this please?
-Can you tell me how you felt?
-Why did you feel like that?
-Can you elaborate on this please?

Time will be given to each participant at the end of the interview session to ask questions and voice any concerns they may have. The interview process may remind the participants of distressing situations they had to deal with in relation to the research question. The name and number of a hospital counsellor will be provided to each participant following the interview, should they feel the need to avail of a counselling service.
Appendix 7
Data Analysis
The researcher intends to adapt Colaizzi’s seven-stage process (1978) for data analysis as cited in Holloway & Wheeler (2006 p181).

1) The researcher will transcribe verbatim each interview and read all of the participant’s descriptions, in order to acquire a feeling for them, and to gain an understanding of their experiences.

2) The researcher will return to each description and extract from them phrases or sentences which directly relate to the investigated phenomenon; this is known as extracting significant statements.

3) The researcher will then try to spell out the meaning for each significant statement; these are known as formulated meanings.

4) Next, the researcher will repeat the above for each description and organise the collective formulated meanings into clusters of themes.
   a) The researcher will then refer these clusters of themes back to the original protocols in order to validate them.
   b) At this point, discrepancies may be noted among and/or between the various clusters; some themes may contradict others, or may appear to be totally unrelated to others. (The researcher is advised by Colaizzi to refuse the temptation to ignore data or themes which do not fit).

5) The results of everything thus far will be integrated into an exhaustive description of the investigated topic.

6) An effort will be made to formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible. This is often termed as an essential structure of the phenomenon.

7) The final validating step will be achieved by returning to each participant and asking them about the findings. This will ensure no misrepresentation or misunderstanding.
Faculty Ethics Committee,
Trinity College,
Dublin 2.

Re: Research Study: Paediatrics nurses’ lived experiences of children’s shift of care from cure to palliation.

Dear Sir/Madam,

I am a fourth year general and paediatric nursing student currently undertaking a Bachelor of Science in Nursing at Trinity College, Dublin. As part fulfilment of the course, I am proposing a research study. The study I have chosen aims to explore paediatric nurses’ lived experiences of children’s shift of care from cure to palliation in Ireland. It is expected the findings will provide an insight into paediatric nurses’ experiences of children’s shift of care from curative treatment to palliative treatment and highlight the difficulties nurses experience in the transition of such care. Additionally, it is hoped this research will bring to light whether nurses’ view curative care and palliative care as mutually exclusive.

I intend on interviewing twelve paediatric nurses from three urban hospitals about their experiences of caring for children who are transitioning into palliative care. Interviews will be held at the hospital where they work, and will be conducted outside their working hours so not to jeopardise patient care.

Your ethical approval to conduct this study would be much appreciated. I have enclosed the completed ethics booklet for your consideration. Any recommendations that may help this study adhere to the ethical guidelines would be gratefully welcomed.

I appreciate your time and consideration on this proposed research study.

Yours Sincerely,
Researcher’s Signature.
B.Sc. (Cur.) Student
**Appendix 9**

**Time Scale**

|                     | Jan | Feb | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Jul | Aug | Sep |
|---------------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| Literature Review * |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Find Research       |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Question & Design   |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Ethical Approval    |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Access and Sampling |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Pilot Study         |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Learn Computer      |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Programme           |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Data Collection     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Data Analysis       |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Findings            |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Dissemination       |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |
| Findings            |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |

*The researcher acknowledges that new research may be available on the area of interest during the proposed research process. The researcher intends to continue to search for new research material and use it accordingly until the time for dissemination of findings.*
## Appendix 10
### Budget

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Reference List


Bibliography


