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Bachelor in Science (Nursing) B.Sc. (Cur.)

NU4S01- Research Proposal

A qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

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

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.

Name:

Signed:

Date:

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Abstract

Background: The proposed study aims to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process. Historically it was assumed that people with intellectual disabilities did not have the cognitive ability to grieve, however it is now accepted that an understanding of the concept of death is not a precondition to grieving. Death and dying are an unavoidable aspect of the human experience; people can face multiple losses within their lifetime, yet the aftermath of bereavement seems to be largely neglected for the person with ID. A review of the literature surrounding the bereavement needs of people with intellectual disabilities illustrated that this topic is gaining momentum. Nevertheless, the paucity of studies involving people with profound intellectual disabilities accentuates that the bereavement needs of this group of people has been largely neglected in research.

Methods: The researcher proposes a qualitative descriptive design for the study. The sample will comprise of nine care staff using a non-probability purposive sampling technique. Data collection will entail the researcher conducting one to one semi-structured interviews which include open-ended questions with the participants. Data analysis will be guided by Colaizzi's (1978) framework. Ethical approval for the study will be sought from Trinity College and from the hospital research committee.

Conclusion: It is hoped that this study will enhance current knowledge of the bereavement needs of people with a profound intellectual disability and serve as a catalyst for further research on the topic.

Keywords: bereavement, grief, care staff, profound intellectual disability

Chapter One

Introduction and Identifying Issue of Interest

Bereavement and loss have a significant impact on the lives of people with intellectual disabilities (ID) (Brickell & Munir 2008). Stressful life events such as bereavement can have a detrimental effect on the psychological well-being of people with ID (Hulbert-Willimas & Hastings 2008), nonetheless Arthur (2003) asserts the emotional lives of people with ID have been primarily neglected in research.

The researcher has particular interest in this topic as having been in a working situation where a person with a profound ID had been bereaved the researcher realised she was unaware of how to best meet the needs of this individual or of individuals in this situation in future practice. The lack of knowledge as regards the bereavement experiences and support for people with ID was recognised which highlighted the importance of continuity of care between all stakeholders in supporting the bereaved person. Clements (2004) highlights that there is a dearth of literature surrounding the bereavement process for people with ID. In this chapter the researcher will present the aim of the proposed study and a review of the literature on bereavement and people with intellectual disabilities. The research question with the aim and objectives of the proposed study will follow the literature review.

Aim

The aim of the proposed study is to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

Literature Review

A literature review provides a background of current knowledge on a topic and highlights the necessity for new studies (Polit & Beck 2010). The aim of this literature review is to identify and examine research previously undertaken surrounding bereavement and people with intellectual disabilities. To obtain the research articles used in this review, electronic searches were carried out using online databases such as CINHAL, PsycArticles and Wiley Interscience in conjunction with manual searches for articles from relevant journals. The

articles used in this review are peer reviewed and date back over a ten-year span from 1999-2009.

Twenty-six articles were found to be of relevance to the topic area. Of these articles, sixteen were of a qualitative nature, six used a quantative research design and three employed a mixed method approach, Dodd *et al.* (2005), Dowling *et al.* (2006) and Reynolds *et al* (2008). The main themes which emerged from the review were involvement in rituals, disenfranchised grief and supporting people with ID through the bereavement process. The researcher will now through a thematic approach develop these themes.

Rituals:

Dodd *et al.* (2005) conducted a mixed-method study to examine staff and organisational attitudes and practices in relation to bereavement and people with ID in the Republic of Ireland. The study contained quantitative multiple choice questionnaires and likert-scale questions which were combined with qualitative open-ended questions. The sample consisted of sixty care staff from within one health board area and seventeen organisations which were geographically dispersed throughout the country. The results of the study showed high levels of participation in grief rituals by bereaved individuals with ID and staff had positive attitudes regarding inclusion in rituals. However, staff did not discuss the possibility of challenging behaviour or mental health problems as a consequence of bereavement. The researchers assert that staff education and training along with the development of individualised support for people with ID is crucial.

Comparable results were produced in a study by McGarry & Taggart (2007); all eleven participants in this qualitative study were included in some part of the funeral process such as an opportunity to view the deceased, presence at the church service, funeral cortege and at the graveside. However, an English study carried out by Raji *et al.* (2003) suggests it is not uncommon for a person with ID to be denied the chance to partake in the funeral of a family member. The high levels of participation in rituals in Irish studies could be linked to the influence of religious organisations in service provision in the past in Ireland (Dodd *et al.* 2005).

An American study by Clements *et al.* (2004) in which three case studies are presented also supports this claim. They propose that it is not uncommon for the person with ID not to be informed about the death of a loved one until considerable time has passed resulting

in them being excluded from the funeral process. Dodd *et al.* (2008) advises conducting a bereavement ritual history on an individual basis to take into consideration the person's previous involvement in mourning rituals while striving to develop the comprehension of such rituals is crucial to minimise distress. The way people are informed or not informed can have profound effect on how they cope with their grief in the months and years to come (Read 2000).

Grief:

Doka's (1989) work on disenfranchised grief is cited in some of the literature obtained by the researcher surrounding grief therefore the researcher has included it although it is past the ten year limit for this review. Disenfranchised grief is described as grief that cannot be freely acknowledged, publicly mourned or socially facilitated (Doka, 1989 as cited in Todd 2004; Read 2005; Read & Elliott, 2007). Doka highlights that disenfranchisement occurs when the bereaved person is not deemed capable of grieving. Therefore as people with ID are a marginalised group who are not legitimised by society they are at an increased risk of disenfranchised grief (Read & Elliott 2007).

Historically it was hypothesised that as a consequence of their limited cognitive ability, people with ID did not grieve (Read 2005). Knowledge of the concept is not precondition to experiencing the emotions associated with grieving; people with ID will grieve for the loss of the deceased with or without an understanding of the concept of death (Dodd *et al*. 2005). Read & Elliot (2007) highlight that for healthy grieving to occur it is essential that professional carers find ways of enfranchising people with ID.

Dodd *et al.* (2008) conducted a study of complicated grief symptoms in people with ID, applying a quantitative research design seventy six participants were involved. They identified this to be the first study of this nature, half of the group had encountered parental bereavement within the previous two years; the remaining thirty eight people were the comparison group and involved individuals of the same age group who had not been bereaved within this time frame. The sample was recruited from two voluntary agencies in Dublin providing day and residential services. The aim of the study was to examine precise symptoms associated with complicated grief; a bereavement history and involvement in rituals were also studied for possible association the development of symptoms.

Complicated grief is defined by Dodd *et al.* (2008) as the occurrence of particular grief related symptoms after a certain period of time has elapsed. It is generally accepted that within one to two years of bereavement the significant symptoms of grief should have passed. These symptoms include, longing for the deceased, loneliness, disbelief, anger feeling insecure and detachment from others. The results of this study revealed one third of the bereaved group experienced ten or more clinical symptoms. A significant strength of this study is the use of a comparison group which enabled strong conclusions to be drawn from the data; nevertheless all information gathered was based on carer observations. In view of the sample involving only higher ability adults with ID, it cannot develop our knowledge regarding the bereavement experiences of adults with a severe or profound ID (Dodd *et al.* 2008).

The term traumatic grief is described by Prigerson *et al.* (1999) as involving two core components, separation distress and traumatic distress. Dodd *et al.* (2005) suggest further research is crucial to accurately describe symptoms of traumatic grief for people with ID. This request is supported by Brickell & Munir (2008) in a review of grief and it's complications in people with ID, they agree that such a description will enhance knowledge of how this group of individuals experience bereavement. The study proposed that people with ID have an elevated risk of traumatic grief due to the possibility of secondary loss, difficulty in communicating about the loss and their cognitive ability to make sense of the loss.

Meeusen-van de Kerkhof *et al.* (2006) study of the perceptions of death and management of grief in people with ID examined the way people with different levels of ID cope with death and mourning. The researchers provide a framework for how people at each level of ID, profound to mild experience and perceive death and their perceptions of grief and bereavement with advisable means of counselling provided also. The researchers recognise that each individual has different experiences which shape development therefore the stages provided by them should not be considered absolute. Further research into this relatively unexplored area is recommended.

An additional stressor is the multiple losses, which people with ID experience. Four of the participants in McGarry & Taggart's (2007) study were moved out of their family home into a residential service after the death of a loved one. The loss of familiar environment and social networks may contribute to further distress for the person. This is echoed by

MacHale & Carey (2002) and Stoddart *et al.* (2002) they propose that extensive losses for instance the death of a parent, loss of their home, possessions and familiar routines can complicate the bereavement process for people with ID. Blackman (2008) proposes that linked with complicated grief is the level and type of support offered to the bereaved person.

Support:

Carers need to recognise that people with ID are capable of grieving and can react to death in a very profound way (Reed 2000). McGarry & Taggart (2007) conducted a study using a qualitative approach with a retrospective design. A retrospective design involves researchers looking for information from the past to study a current phenomenon (Parahoo 2006). The researchers conducted semi-structured one to one interviews with eleven people with ID who were living in community services in the west of Ireland. The aim of the study was to explore the support clients received from front-line staff around the time of bereavement and to explore the bereaved person's perceptions of the support offered.

Some of the study's findings included how staff encouraged the person to remember the deceased through the use of personal keepsakes and photographs. Positive and negative effects were reported by participants from these, some felt it enabled them to reminisce on happy times while three participants reported it to be a painful depressing experience. One participant reported feeling staff were supportive at the time of bereavement but she felt they did not identify with her as the grieving process transpired. McGarry & Taggart (2007) emphasise that staff education and training on various aspects of supporting the bereaved person is necessary in conjunction with collaboration between all stakeholders and the bereaved person will enable an integrated approach to care.

In a clinical review Read (2000) discusses ways for carers to assist people with ID cope with bereavement and suggests some appropriate professional responses. All carers should conduct an assessment to determine what the individuals needs are at the time. Effective communication, which is simple to understand clear and consistent is essential. Talking to the person illustrates an acknowledgement of their loss and invites them to grieve thus enabling the carer to explore the person's prior experiences and current understanding of death. Summers & Witts (2003) support this claim; they suggest the finality of death needs to be explained to the bereaved person.

Bereavement counselling can be a beneficial method of encouraging people with ID identify and manage their grief (Read 2005, Read & Elliott 2007). Participants in Read (2001), Summers & Witts (2003) and Dowling *et al*. (2006) reported that bereavement counselling had a positive effect on their lives. Carers also observed positive results such as a decrease in anxiety and irritability combined with increased communication regarding their feelings. Friendships and new interests developed signifying a vast improvement in the individual's quality of life. Nevertheless McGarry & Taggart (2007) emphasise that the lack of continuity between counselling sessions and residential settings can cause unnecessary stress for the person. Counsellors also need training to enable them to develop a therapeutic relationship with individuals with ID (Dowling *et al*. 2006). Read (2000) highlights that the professional carer spends the majority of the time with the individual therefore they are a central part of the overall bereavement support. Dodd *et al.* (2005) advises that there can be a reliance on counselling rather than establishing more beneficial life style changes.

Bonell-Pascual *et al.* (1999) recommend that when caring for individuals with challenging behaviour the long-term effects of bereavement should not be overlooked. MacHale & Carey (2002) assert people with ID are at risk of diagnostic overshadowing as carers may inadvertently associate behavioural expressions of grief as challenging behaviour or psychiatric disturbances. They examined the effects of bereavement on challenging behaviour and mental health. The sample consisted of twenty adults with ID who had been bereaved within the pervious two years and a control group of twenty adults who had not experienced significant life events in the pervious two years. A substantial increase in challenging behaviour among those that had been bereaved was found. Irritability, crying lethargy, hyperactivity and temper tantrums were the most commonly observed behaviours. Blackman (2005) asserts that carers of people with ID often fail to recognise signs of grief in those they are supporting. Failing to provide information and support only serves to intensify the vulnerability of this population (Mappin & Hanlon 2005).

MacHale *et al.* (2009) in a quantative study explored caregiver perceptions of service users understanding of death, levels of support required and staff confidence in proving support following bereavement. Forty-two staff rated people with ID whom they worked with regularly. The findings suggest carers tended to overrate knowledge levels and highlight that staff lacked confidence in providing post bereavement support. A limitation of the study involves potential bias with the participant selection as they were nominated by the

staff and the majority had a mild ID. However, the study emphasises the significance of research focusing on staff appraisal of service user abilities and the need for further research.

Only one service out of the seventeen involved in Dodd *et al.* (2005) study had an official bereavement policy. The researchers recommend that services need to formalise their procedures on bereavement care to ensure quality of service which shows consideration for bereaved clients. Blackman (2008) is in the process of developing an assessment tool to assist professionals in identifying specific bereavement needs for an individual with ID. The purpose of developing such a tool is to enable carers to appreciate the impact of the loss on the individual at the time it occurs. The feasibility study has highlighted areas that need to be adapted and the researcher is currently refining the BNAT.

Conclusion

In the past it was believed that people with ID did not have the cognitive ability to grieve, they were a marginalised group who were not legitimised by society. The researcher discussed the themes of involvement in rituals, grief and supporting people with ID through bereavement as these appeared frequently within the studies obtained for this literature review. It was noted that many studies recommended further research in the area and to involve people with a profound intellectual disability. Numerous studies, (Read 2000, Bennett 2003, Read 2005, Dodd *et al.* 2008, MacHale *et al.* 2009) address the significant role care staff have in the lives of people with an ID. Furthermore studies by Murray *et al.* (2000) and Dodd *et al.* (2005) highlight that care staff have a great deal of knowledge surrounding the grieving process and of post bereavement support for people with ID. As a result of dearth of studies pertaining to people with a profound ID combined with the significance of the role of the care staff, the researcher proposes to conduct a qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

Research Question

The research question assists the researcher to focus on the questions which need to be answered and is therefore fundamental to the research process (Parahoo 2006). The research question posed here is: What are the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process?

Aim of the Study

The aim of this study is to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

Objectives of the Study

- To explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.
- To explore the supports offered by care staff to the person with a profound intellectual disability that has been bereaved.
- To establish if care staff feel adequately trained to facilitate the bereaved person.
- To explore the resources available to care staff in supporting people with a profound intellectual disability that have been bereaved.

Summary

Within chapter one the researcher presented a literature review on bereavement and people with intellectual disabilities. The themes of ritual involvement, grief and support were discussed. The researcher presented the research question, aim and objectives of the proposed study, A Qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

Chapter two: Methodology

Introduction

This chapter presents the proposed research method and design of a qualitative research study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

Research Design

A research design is a plan that explains the how, when and where data are to be collected and analysed, the researcher must choose the most appropriate design to meet the aims and objectives of the study (Parahoo 2006). A research design can involve a quantitative design or qualitative design. Qualitative research is a broad term used to describe research that is focused primarily on human experience through exploring attitudes, beliefs, values and experiences (Whitehead 2007). Qualitative research is more in-depth and holistic than quantitative, generating rich material on which to base the findings of a piece of research (Polit & Beck 2010).

Sandelowski (2000) asserts that qualitative descriptive studies present a comprehensive summary of an event in everyday terms of those events. The researcher has chosen a descriptive qualitative design for this study as it proposes to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process. Whilst conducting the literature review on the topic the researcher noted the majority of the articles obtained employed a qualitative approach to the research.

Population/ Sample

Polit & Beck (2010) illustrate that a sample is a portion of the population chosen to represent the entire population. The purpose of sampling is to attain data from a smaller particular sample which in turn increases efficiency by allowing generalisations to be made about the population without having to examine every member. Sampling technique will affect the validity of the research therefore it should be undertaken with maximum rigour (Procter & Allan 2007).

For the purpose of this study the researcher has chosen to use non-probability purposive sampling for the following reasons, Procter & Allan (2007) highlight that in qualitative research non-probability sampling is used to study the population of interest and to

ascertain that the research samples rich sources of data. While purposive sampling is predominantly used in qualitative research as it involves the researcher intentionally selecting who to include in the study on the basis that those selected can present the requisite data (Parahoo 2006).

According to Parahoo (2006) in the preparation of a study deciding on the number and characteristics of participants is one of the most fundamental decisions. In qualitative studies, samples are typically small and based on information needs (Polit & Beck 2010). Whitehead & Annells (2007) suggest a common range in qualitative research is usually between eight and fifteen participants but this can vary. The small sample size is suitable because of the potentially detailed data that can be generated from each participant.

The population of interest in this study is care staff in intellectual disability services that have supported people with a profound intellectual disability through the bereavement process. The researcher has chosen a sample size of nine and proposes to accept the first nine people who meet the inclusion and exclusion criteria. The establishment of inclusion and exclusion criteria will increase the precision of the study and strength of evidence (Haber 2006).

Inclusion criteria: This refers to specific characteristics or criteria that participants must possess to be included in the study. For the proposed study the characteristics that the care staff will be required to meet include:

- Care staff who are working full time in a residential setting for people with a profound intellectual disability and involved in direct client care.
- All participating care staff must have at least 3 years experience caring for people with a profound intellectual disability and are currently working with this client group.

Exclusion criteria: Participant characteristics or attributes that are not suitable for inclusion (Polit & Beck 2010)

- Staff who are not involved in direct client care and care staff that have no experience caring for people with a profound intellectual disability.
- Participants who have less than 3 years of experience caring for people with profound intellectual disability.

Gaining entrée usually involves negotiations with gatekeepers (Polit & Beck 2010), gatekeepers are individuals or groups who control access to participants and data (Hunn 2007). The co-operation of 'gatekeepers' in the selected site is a prerequisite. A Dublin based residential service catering for people with intellectual disabilities will be the site for this proposed study. Once the researcher has gained ethical approval from the Hospital Ethics Committee (Appendix 2) the Director of Nursing will be contacted (Appendix 4).

Participants will be recruited by sending a letter of explanation (Appendix 5) to relevant units which cater for people with a profound intellectual disability. This letter of explanation/invite concerning the study will then also be provided for all who decide to partake in the proposed study, along with a letter of consent (Appendix 6). A requirement of the Bachelor of Science programme is approval from Trinity College, therefore, a letter seeking approval (Appendix 3) will be sent to the Faculty of Health Sciences.

Data Collection Procedures

Polit & Beck (2010) highlight the goal of data collection is to generate data that is of exceptional quality. Qualitative research relies on methods that permit researchers into the personal lives of the participants. To facilitate this process flexible and varied strategies are required (Parahoo, 2006). These data collection methods include interviews, observations, focus groups and action research.

Interviews are a common method of data collection in nursing research, the individual questions must be clear to the respondent, free of suggestion and use correct grammar (Whittemore & Grey, 2006). Semi-structured interviews allow the researcher to have a framework in which necessary open-ended questions are posed to encourage the participants to talk freely about their experiences (Polit & Beck 2010). Face to face interviews are beneficial when the researcher is interested in obtaining more personal information from the respondent. Open-ended questions are frequently used in qualitative research studies when the researcher wants the participants to respond in their own words, thus enabling richer and more complex data to be collected (Whittemore & Grey, 2006).

As a result of this the researcher has chosen semi-structured interviews with open-ended questions which will take place on a one to one basis as the data collection method. Davies (2007) asserts that the researcher must be able to engage with the interviewees in a setting that is relaxed and familiar to them, free from distractions and conducive to a conversation

to allow the participant to talk freely about possibly emotional and confidential matters. Permission for the use of a suitable room within the organisation to conduct the interviews in will be sought from the Director of Nursing (Appendix 4).

Davies (2007) suggests interviews which are audio tape recorded are common in qualitative research to enable the researcher to pay full attention to the participant and note non-verbal behaviour. The audio recording facilitates a detailed account of the participant's responses and a verbatim transcript for analysis (Meadows 2003). This will also prevent the researcher from being biased by means of poor notes or memory of the interview. Therefore the researcher will audio record all interviews in the proposed study. The duration of the interview will vary on an individual basis; Cormack (2000) suggests time restrictions may hinder the free flowing nature of the interview. It is hoped that the interviews will last approximately forty minutes or until there is data saturation.

Interview Guide

The interview guide will contain a list of open-ended questions which have been derived from the aims and objectives of the study. These open-ended questions must be balanced, unbiased, sensitive and clear (Whitehead & Annells 2007) (See Appendix 7).

Pilot Study

A pilot study can be described as a small scale version or trail run, done in preparation for a major study. A pilot study can be used to improve a project, assess its feasibility, improve its clarity, eradicate problems and refine methodology (Polit & Beck 2010).

The researcher proposes to conduct a pilot study with one staff member who fits the inclusion criteria, this person will then be omitted from the proposed study. Any findings will also be excluded also. The pilot study will be carried out in the same location as the proposed study using the same interview guide. This will enable the researcher to test that the audio-recording equipment is working and picking up both voices, the interview guide is applicable and asses the suitability of the environment (Davies 2007). This will enable the researcher to determine the approximate length of the interview. The participants will also be invited to give their opinion on the interview, the setting and the interview guide. It is intended that the pilot study will facilitate the researcher to identify problems which can then be amended before the proposed study commences.

Data Analysis Procedures

Data analysis is conducted to reduce, record, organise and give meaning to data. Qualitative researchers must maintain a balance between the need to be concise and to preserving the richness of their data (Polit & Beck 2010). According to Parahoo (2006) a significant characteristic of qualitative data analysis is that data collection and analysis are conducted simultaneously and after data collection is completed. One of the more common frameworks used in nursing research to analyse data from qualitative studies is that of Colaizzi (1978). The basic outcome of this method is the description of the meaning of an experience often through the identification of useful themes. Themes are a way of describing large quantities of data in a condensed manner (Streubert Speziale 2006). The researcher has chosen to use Colaizzi's (1978) framework for data analysis (Appendix 8).

The principles of the Data Protection Acts of 1988 & 2003 (amendment) will be adhered to in this research proposal. Pseudonyms will be given to each participant to reduce the risk of personal data being lost. All data will be stored in a locked safe which can only be accessed by this researcher. This storage will remain in place for the requisite time of one to five years as this is in keeping with the recommendations of the Data Protection Acts. After this time all electronic data will be overwritten and all manual data will be shredded, in accordance with the Data Protection Acts.

Streubert and Carpenter (2003) assert that all tapes should be duplicated in case of damage. All tapes will be transcribed verbatim which will then be entered into a computer through a word processing program. There are various computer programs which are available to support qualitative data analysis. For the purpose of this proposal the researcher proposes to use NVivo 7, to assist with the data analysis. Davies (2007) suggests NVivo is an extremely powerful database, it enables researchers to handle large data sets, perform complex searches and organise material. Once themes have been identified by the researcher the software is able to search for reoccurrences. Description of the phenomenon under study will be made and as guided by Colaizzi's (1978) method all participants will be asked to confirm findings.

Robustness of Study

Rigour refers to the extent which the researcher strives for excellence and how they adhere to detail and accuracy. Parahoo (2006) highlights that although rigour can be difficult to determine in qualitative research, researchers want their findings to reflect truthfully the phenomenon they are studying and to contribute to knowledge that is beneficial to others. The researcher proposes to use a framework by Lincoln and Guba (1985) as cited in Parahoo (2006, p.410) and Polit & Beck (2010, p.492) to increase the trustworthiness of this study. This framework encompasses the following four criteria for developing trustworthiness of a qualitative study, credibility, dependability, confirmability and transferability.

Credibility refers to confidence in the truth of the data and interpretations of them. According to Polit & Beck (2010) it is considered by Lincoln and Guba to be fundamental goal of qualitative research furthermore member checking is deemed an important technique for establishing credibility in qualitative research. Member checking can be undertaken both throughout the data collection and after data analysis has occurred in a follow-up conversation. The researcher proposes to use member checking to gain credibility in the proposed study through contacting the participants by telephone to verify the findings and clarify their descriptions.

Dependability is concerned with the ability of the data to remain stable over time, would the study findings be replicated if undertaken with similar participants in a similar context. Credibility cannot be attained in the absence of dependability. The researcher proposes to use an audit trail to enhance the dependability of the study. This involves tracking and recording all decisions which have influenced study so an outside individual can examine the data (Dempsey & Dempsey 2000). The researcher will keep a record of all decisions regarding the proposed study with all other information in a locked press (Appendix 10).

Confirmability refers to the data representing the information participants provided. There should be no biases or subjectivity in the study; the findings must represent the participants voice (Polit & Beck 2010). The researcher will uphold this principle by clarifying all information with the participants. Transferability involves the extent to which the findings of a qualitative study can be useful to similar groups or situations (Parahoo 2006). It is hoped that the proposed study will enhance knowledge and subsequently result in

developments in practice for people with a profound intellectual disability that are bereaved.

Ethical Considerations

Ethical issues in research relates to the protection of human participants to ensure the absence or lessen the possibility of harm, anxiety, discomfort or trauma (Coup & Schneider 2007). Parahoo (2006) asserts there are ethical implications at each stage of the research process from the choice of topic to selection of design and publication of the findings. It is ultimately the responsibility of the researcher to protect their participants and conduct all research in an ethical manner (Dempsey & Dempsey 2000). The researcher is cognisant that each research approach and every study has its own ethical implications (Parahoo 2006) therefore the researcher proposes to implement and abide by the following ethical principles:

Autonomy: Participants should be given clear unambiguous information regarding the research, comprehend the information and the option to consent or decline participation voluntarily (Polit & Beck 2010). Informed consent will be sought from every participant, at initial contact the researcher will explain the study verbally, then providing them with a copy of the consent form (Appendix 6). Hunn (2007) advises the consent form should be clear, concise and easy to read with no jargon. These forms will be stored in a locked press which only the researcher has access to. The researcher will also explain to participants they have the right to withdraw from the study at any time.

Beneficence: Polit & Beck (2010) assert a fundamental ethical principle in research is beneficence, where the onus is on researchers to minimise harm and maximise benefits for the participants themselves, other individuals or society as a whole. The sole aim of this study is to be of benefit. The researcher hopes that this study will be of benefit to the nursing profession and subsequently improve the lives of people with a profound intellectual disability.

Non-maleficience: Research should not cause any harm to participants either physical or psychological (Parahoo 2006). The researcher is aware that the topic bereavement may be difficult for the participant, she will listen attentively to the participant, questions will be phrased in a caring manner and probing questions will only be used when it is deemed

necessary. The researcher will also provide an opportunity for the participant to voice any concerns or queries they have regarding the proposed study.

Fidelity: This involves the building of trust between the researcher and the participants (Parahoo 2006). The researcher should always put the safety and well-being of the participant above the completion of the study. The researcher will uphold this principle by ensuring the participant is aware they can withdraw from the study at any given time and no information will be used within the study.

Confidentiality: Confidentiality is essential; the researcher will safeguard participant's identities and responses from public disclosure (Dempsey & Dempsey 2000). Assurances will be offered by the researcher that confidentiality will be respected at all times and that in no way will the participants be identified or identifiable. Pseudonyms will be used throughout the study. Participants will be assigned an identification number which will be used throughout the study and no identifying information will be entered onto computer files. Encryption technology will be used to protect electronic data in keeping with the Policy on Good Research Practice (Trinity College 2009).

Conclusion

This chapter has provided the rationale for the researcher's choice of data collection and data analysis methods to conduct the proposed study which is a qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process. It outlined the steps the researcher will undertake to perform the proposed study, a pilot study will be conducted and the ethical principles guiding the study were outlined also.

Chapter Three

Introduction

The proposed outcomes of the study and dissemination of the findings as directed by the hospital research committee will be described in this chapter. A timescale and budget for the proposed study are provided.

Proposed Outcomes of the Study

The purpose of this study is to explore the experiences of care staff that have supported people with a profound intellectual disability who have been bereaved. Using the inclusion and exclusion criteria the sample should produce the requisite participants. Through the use of the interview guide and probing questions, rich descriptions of the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process are expected. The aim and objectives of the proposed study should subsequently be answered by these descriptions. It is hoped that this study will in some way address the void in the current literature regarding bereavement and people with profound intellectual disabilities and serve as a catalyst for further studies on the topic.

Dissemination

Dissemination of findings involves the distribution of findings in a range of formats such as conference presentations, seminars and published papers (Parahoo 2006). In order to enhance evidence based nursing practice the researcher aims to share the results of the proposed study by dissemination of the research findings. It is proposed to forward the findings of this study to the participants and the hospital ethics committee. A copy of the study will be donated to the hospital library. It is also proposed to present the findings at a relevant national conference and to relevant journals.

Time Scale

The researcher proposes a period of eighteen months to carry out the proposed study. The researcher believes that this time frame should provide adequate time for the study.

	2010							2011										
	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov
Literature Review	*	*																
Ethical Considerations			*	*														
Pilot Study					*	*												
Refining Data Collection Methods							*	*										
Data Collection									*	*	*	*	*					
Data Analysis									*	*	*	*	*					
Transcription and Analysis														*	*	*		
Preparation of final report																	*	*

Proposed Budget

Bond & Gerish (2007) suggest preparing a budget involves translating the plan of work and timescale into monetary terms. See table below for estimated costs.

Item	**Budgeted Amount**
Stationary	€80.00
Postage and S.A.E	€20.00
Photocopying	€40.00
Digital Voice Recorder	€50.00
Digital Voice Tapes	€40.00
Computer Software (NVivo 7)	€415.00
Telephone Costs	€150.00
Travel Expenses	€100.00
Allowance for unforeseen circumstances	€200.00
Total:	**€1,095.00**

Conclusion

The researcher proposes to conduct a qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process. On reviewing the literature surrounding bereavement and people with intellectual disabilities the researcher became aware of a void within current research on the bereavement needs of people with a profound intellectual disability. The proposed method of data collection by conducting semi-structured interviews was discussed. Data analysis will be guided by Colaizzi's (1978) framework and the use of a computer package to assist with data analysis was described. Lincoln and Guba (1985) criteria will be applied to enhance the robustness of the study. The researcher addressed ethical principals and will uphold these throughout the study process.

The methodological issues within the proposed study involves the chosen methodology and sample size. Given the small sample size the issue of generalisability arises. However Parahoo (2006) highlights if the study is carried out well it can be of significant value beyond the sample studied. The researcher proposes to use member checking to verify the data collected thus enhancing the robustness of the study. Further research is advised to increase knowledge of the bereavement needs of people with a profound intellectual disability.

Appendices

Appendix 1. Letter to research committee

Researchers Address,
Xxxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxxx.

The Hospital,
Xxxxxxxxxxxxxxxxx.
Xxxxxxxxxxxxxxxxx.
Dublin.
dd.mm.yyyy.

Re: Reserach Study: **A Qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.**

Dear members,

My name is ....., I am currently undertaking a Bachelor in Science (Nursing) B.Sc. (Cur.) in Intellectual Disability Nursing at Trinity College Dublin. As part of the course I am required to carry out a research proposal. My proposed study is a qualitative study which aims to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

I hope that the results of my study will enhance nursing knowledge and contribute to evidence based practice in relation to supporting people with intellectual disabilities through the bereavement process.

I have read the requirements of the Hospital Research Committee. I understand that upon completion of my proposed study, I am obliged to:

- Acknowledge and document the support given to this researcher by the hospital.
- Acknowledge and document joint ownership of the research project i.e. the Hospital and this researcher.

- Present a copy of my study to the organisation.
- Give a presentation of my study and its findings at a research seminar.
- Obtain permission from the research committee in the event of publication.

If you have any queries or would like to contact me regarding the proposed study please contact me on 087 XXXXXXX. I look forward to hearing from you.

Yours sincerely,

_____

Appendix 2: Letter to Hospital Ethics committee

Researchers Address,
Xxxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxxx.

Ethics Committee,
Xxxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxxx.
Dublin.
dd.mm.yyyy.

Re: Research Study: **A Qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.**

Dear Chairperson,

My name is ....., I am currently undertaking a Bachelor in Science (Nursing) B.Sc. (Cur.) in Intellectual Disability Nursing at Trinity College Dublin. As part of the course I am required to carry out a research proposal. My proposed study aims to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

I hope that the results of my study will enhance nursing knowledge and contribute to evidence based practice in relation to supporting people with profound intellectual disabilities through the bereavement process.

I am seeking approval to carry out the proposed study. The ethical principles of autonomy, beneficence, non-maleficinece, fidelity and confidentiality have been described relevant to the proposed study. A letter of invite/explanation has been provided for participants and along with a consent form. Participants will be advised that they have the right to withdraw from the study at any time and their data will not be included in the study. To enhance anonymity and confidentiality pseudonyms and identification numbers will be utilised for each participant.

If you would like to contact me regarding the proposed study please contact me at the above address or alternatively on 087 XXXXXXX.

Yours sincerely,

_____

Appendix 3: Letter to Trinity College Faculty of Health Science

Researchers Address,
Xxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxx.

The Research Committee,
Xxxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxxx.
Dublin,
dd.mm.yyyy.

Re: Research Study: **A Qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.**

Dear members,

My name is ....., I am currently a fourth year student under taking the Bachelor in Science (Nursing) B.Sc. (Cur.) in Intellectual Disability Nursing in Trinity College Dublin. As part of my course I am required to carry out a research proposal. My proposed study aims to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

I am writing to you to seek permission to undertake the proposed study. Enclosed you will find a copy of my research proposal together with letters of explanation and a consent form, a copy of request for study approval to the Hospital Research Committee, Ethics Committee and Director of Nursing.

If you would like to contact me regarding the proposed study please contact me at the above address or alternatively on 087 XXXXXXX.

Yours sincerely,

_____

Appendix 4: Letter to Director of Nursing

Researchers Address,
Xxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxx.

Director of Nursing,
Xxxxxxxxxxxxxxxxx,
Xxxxxxxxxxxxxxxxx.
Dublin.
dd.mm.yyyy.

Re: Research Study: **A Qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.**

Dear Director,

My name is ....., I am currently undertaking a Bachelor in Science (Nursing) B.Sc. (Cur.) in Intellectual Disability Nursing at Trinity College. I am required to carry out a research proposal as part of the course. My proposed study aims to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

I am requesting permission to conduct the study at the hospital and with your consent recruit participants. I propose to conduct one to one semi-structured interviews with nine participants. Participant's names and the name of the hospital will be held confidentially and will not be disclosed to anyone other than the researcher. All participants will be given a letter of explanation and asked to sign a consent form. Participants will be advised that they have the right to withdraw from the study at any time and their data will not be included in the study. Issues of ethics, confidentiality and anonymity have been addressed within the proposed study.

I would be grateful if I could conduct the interviews in a conference or meeting room within the hospital where the participants will feel comfortable and confidentiality can be maintained.

It is this researcher's opinion that exploring the experiences of care staff that have supported people with a profound intellectual disability will enhance nursing knowledge and understanding in this area, which will in turn contribute to evidence based practice.

I will be guided by my research supervisor from Trinity College throughout the study. If you would like to discuss this further, please contact on 087 XXXXXXX or alternatively at the above address.

Yours sincerely,

_____

Appendix 5: Letter of explanation/invite to participants

My name is ……. I am a 4th year student currently undertaking a Bachelor in Science (Nursing) B.Sc. (Cur.) in Intellectual Disability Nursing at Trinity Collage, Dublin. I am required to carry out a research proposal as part of the course. My proposed study aims to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

I am inviting you to participate in this study. I hope that the findings of the proposed study will enhance nursing knowledge and facilitate an improved quality of life for people with profound intellectual disability.

If you would like to participate in the proposed study you will be required to give consent. I will contact you to arrange a suitable time for an interview within the hospital in one of the conference/meeting rooms. The interview will be audio taped. All information will be confidential and no identifiable data will be included in the study. All data from the interview will be managed, stored and disposed of as per the Data Protection Acts of 1998 & 2003 and Trinity College Data Compliance Guidelines. Also, your right to withdraw from the study at any stage is guaranteed.

If you would like to participate in the study, please sign the attached consent form and return it to me in the stamped addressed envelope. If I do not hear from you I will assume that you do not want to participate and I will not contact you again.

If you have any questions before making a decision, please feel free to contact me at 087 XXXXXXX.

Yours sincerely,

_____

Appendix 6: Trinity College Consent Form

PROJECT TITLE: A Qualitative study to explore the experiences of care staff that have supported people with a profound intellectual disability through the bereavement process.

PRINCIPAL INVESTIGATORS: Xxxxxxxxxxxxxxx

BACKGROUND: I propose to conduct one to one semi-structured interviews with nine care staff, these interviews will be audio taped and all data will be stored, managed and disposed of as per Data Protection Acts of 1998 & 2003 and Trinity College Data Compliance Guidelines. I am aware that findings may be published but no identifiable data will be included. The data provided will not be used for any other study.

DECLARATION: I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME: ……

CONTACT DETAILS: ……

PARTICIPANT'S SIGNATURE: ……

DATE: ……

STATEMENT OF INVESTIGATOR'S RESPONSIBILITY: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE: ……

DATE: ……

Appendix 7: Interview guide

This list of topics and questions will guide the researcher. It does not have to be adhered to systematically or completely. The participant's response will guide the questions also.

Probing questions:

1. What are your experiences of caring for people with profound intellectual disability who have been bereaved?
2. What supports do you offer to the bereaved person?
3. Have you any suggestions to develop the support you provide?
4. What types of resources are available to assist you in supporting people with a profound intellectual disability who have been bereaved?

Prompts:

1. How did you do this.....
2. Can you tell me a bit more about this.....
3. Anything else you would like to add.....

Appendix 8: Colaizzi's (1978) Framework

1. Read all protocols to acquire a feeling for them.
2. Review each protocol and extract significant statements.
3. Spell out the meaning of each significant statement i.e. formulate meanings.
4. Organize the formulated meanings into cluster of themes. Refer these clusters back to the original protocols to validate them. Note discrepancies among or between the various clusters, avoiding the temptation of ignoring data or themes that do not fit.
5. Integrate results into an exhaustive description of the phenomenon under study.
6. Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible.
7. Ask participants about the findings thus far as a final validating step.

Appendix 9: The Ethics checklist Adapted from Hanson (2006)

Topic: Phenomenon of interest

Guiding Questions:

1. Is the research study relevant, important and most appropriately investigated through a qualitative design?
2. Are there any aspects of the research or phenomenon of interest that appear to be misleading to participants?
3. Is the researcher primarily being conducted for personal gain on the part of the researcher or is there evidence that the research will somehow contribute to the greater good? What are the benefits to the participants or society as a whole?

Topic: Review of the literature

Guiding Questions:

1. Has all the available literature been reviewed?
2. Are all citations accurate in terms of referencing and quoting?
3. Is the basis for inclusion of the articles referred to explicit?

Topic: Research design

Guiding Questions:

1. How did the researcher protect the physical and psychological well-being of the participants?
2. Is consent freely given?
3. How were participants recruited and protected?
4. Did an Institutional Review Board approve the research?

Topic: Sampling

Guiding Questions:

1. How was the confidentiality of participants protected?
2. Is there any evidence of coercion or deception?

Topic: Data collection

Guiding Questions.

1. If more than one researcher collected data, were they adequately prepared?
2. Is there evidence of falsified or fabricated data?
3. Is there intentional use of data collection methods to obtain biased data?
4. Was data collection covert? If so, does the researcher explain why?
5. Have the participants been misled with regard to the nature of the research?

Topic: Data analysis

Guiding Questions

1. Was data analysis conducted by more than one person?
2. Is there evidence of data manipulation to achieve intended findings?
3. Is there evidence of missing data that may have been lost or destroyed?

Topic: Conclusions and recommendations

Guiding Questions

1. Is there evidence of intentional false or misleading conclusions and recommendations?
2. Is confidentiality broken given the presentation of the findings?

Appendix 10: Storage of information

An identity number will be produced for each participant so the data can be anonymised and will be distinguished via this identity number. The only exception is one document which contains participant's personal information.

Data will be managed in the following way:

1. The researcher will store the document bearing personal information in a locked cabinet with access strictly restricted to personnel working on the study.
2. All computerised data/information will be stored in a locked cabinet with restricted access and password.
3. The researcher responsible for the project will be the person with access to the data/information generated by the study.
4. All computerised data/information collected should be anonymised by using identity number for the participants.
5. The data/information will be stored for the duration of the study i.e. until the work is fully reported and disseminated. It will then be kept in a locked cabinet for five years.

Reference List:

Arthur A.R. (2003) The emotional lives of people with learning disability. *British Journal of Learning Disabilities* **31**, 25-30.

Bennett, D. (2003) Death and people with learning disabilities: empowering carers. *British Journal of Learning Disabilities* **31**, 118-122.

Blackman N. (2005) Supporting bereaved people with intellectual disabilities. *European Journal of Palliative Care* **12**(6), 247-248.

Blackman N. (2008) The development of an assessment tool for the bereavement needs of people with learning disabilities. *British Journal of Learning Disabilities* **36**, 165-170.

Bond S. & Gerrish K. (2007) Peparing a research proposal. In *The Research Process in Nursing*, 5th edn. (Gerrish K. & Lacey A., eds), Blackwell Publishing, Oxford, pp. 123-137.

Bonell-Pascual E., Huline-Dickens S., Hollins S., Esterhuyzen A., Sedgwick P., Abdelnoor & Hubert J. (1999) Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry* **175,** 348-350.

Brickwell C. & Munir K. (2008) Grief and its complications in individuals with intellectual disability. *Harvard Review Psychiatry* **16**(1), 1-12.

Clements P.T, Focht-New G & Faulkner M.J. (2004) Grief in the shadows: exploring loss and bereavement in people with developmental disabilities. *Issues in Mental Health Nursing* **25**, 799-808.

Cohen M.Z. (2006) Introduction to qualitative research. In Nursing Research: Methods and Critical Apprasial for Evidence Based Practice, 6th edn. (LoBiondo-Wood G. & Haber J., eds), Mosby Elseiver, St. Louis, pp.131-147.

Cormack, D. (2000) *The Research Process in Nursing*, 4th edn. Blackwell Science Limited, Oxford.

Coup A. & Schneider Z. (2007) Ethical and legal issues in research. In *Nursing & Midwifery Research: Methods and Appraisal for Evidence-Based Practice*, 3rd edn. (Schneider Z., Whitehead D., Elliott D., LoBiondo-Wood G. & Haber J., eds), Mosby Elsevier, Sydney, pp.80-101.

Data Protection Commissioner, Data Protection Acts 1988 and 2003 - *A Guide for Data Controllers*. Retrieved from http://www.dataprotection.ie/ViewDoc.asp?fn=/documents/guidance/Guide_Data_Contollers.htm&CatID=90&m=y on 25 January 2010.

Davies M.B. (2007) *Doing a Successful Research Project: Using Qualitative or Quantitative Methods*. Palgrave MacMillian, Houndsmill.

Dempsey P.A. & Dempsey A.D. (2000) *Using Nursing Research: Process, Critical Evaluation and Utilization,* 5th edn. Lippincott, Philadelphia.

Dodd P., Dowling S. & Hollins S. (2005) A review of the emotional responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research* **49**(7), 537-543.

Dodd P., Guerin S., McEvoy J., Buckley S., Tyrrell J. & Hillery J. (2008) A study of complicated grief symptoms in people with intellectual disabilities. *Journal of Intellectual Disability Research* **52**(5), 415-425.

Dodd P., McEvoy J., Guerin S., McGovern E., Smith E. & Hillery J. (2005) Attitudes to bereavement and intellectual disabilities in an Irish context. *Journal of Applied Research in Intellectual Disabilities* **18**, 237-243.

Dowling S., Hubert J., White S. & Hollins S. (2006) Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research* **50**(4), 277-287.

Haber J. (2006) Sampling. In Nursing Research: Methods and Critical Apprasial for Evidence Based Practice, 6th edn. (LoBiondo-Wood G. & Haber J., eds), Mosby Elseiver, St. Louis, pp.260-288.

Hulbert-Williams L. & Hastings R.P. (2008) Life events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review. *Journal of Intellectual Disability Research* **52**(11), 883-895.

Hunn A. (2007) Gaining access to the research site. In *The Research Process in Nursing,* 5th edn. (Gerrish K. & Lacey A., eds), Blackwell Publishing, Oxford, pp.138-154

MacHale R. & Carey S. (2002) An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities* **30**, 113-117.

MacHale R., McEvoy J. & Tierney E. (2009) Caregiver perceptions of the understanding of death and need for bereavement support in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **22**, 574-581.

Mappin R. & Hanlon D. (2005) Description and evaluation of a bereavement group for people with learning disabilities. *British Journal of Learning Disabilities* **33,** 106-112.

McGarry G., & Taggart L. (2007) An exploration of the support received by people with intellectual disabilities who have been bereaved. *Journal of Research in Nursing* **12**(2), 129-144.

Meadows K.A (2003) So you want to do research? 1: an overview of the research process. *British Journal of Community Nursing* **8**(8), 369-375.

Meeusen-van de Kerkhof R., van Bommell H., van de Wouw W. & Maaskant M. (2006) Perceptions of death and management of grief in people with intellectual disability. *Journal of Policy and Practice in Intellectual Disibilities* **3**(2), 95-104.

Murray G.C., McKenzie K. & Quigley A. (2000) An examination of the knowledge and understanding of health and social care staff about the grieving process in individuals with a learning disability. *Journal of Learning Disabilities* **4**(1), 77-90.

Parahoo K. (2006) *Nursing Research: Principles, Process and Issues,* 2nd edn. Palgrave MacMillian, Houndsmill.

Polit D.F. & Beck C.T. (2010) *Essenitals of Nursing Research: Appraising Evidence for Nursing Practice,* 7th edn. Wolters Kluwer Health | Lippincott Williams & Wilkins, Philadelphia.

Prigerson H.G., Shear M.K., Jacobs S.C., Reynolds III C.F., Maciejewski P.K., Davidson J.R.T., Rosenheck R., Pilkonis P.A., Wortman C.B., Williams J.B.W., Widiger T.A., Frank E., Kupfer D.J. & Zisook S. (1999) Consenus criteria for traumatic grief. *British Journal of Psychiatry* **174**, 67-73.

Procter S. & Allan T. (2007) Sampling. In *The Research Process in Nursing,* 5th edn. (Gerrish K. & Lacey A., eds), Blackwell Publishing, Oxford, pp. 173-188.

Raji O., Hollins S. & Drinnan A. (2003) How far are people with learning disabilities involved in funeral rites? *British Journal of Learning Disabilities* **31**, 42-45.

Read S. & Elliott D. (2007) Exploring a continuum of support for bereaved people with intellectual disabilities. *Journal of Intellectual Disabilities* **11**(2), 167-181.

Read S. (2000) Bereavement and people with learning disabilities. *Nursing & Residential Care* **2**(5), 230-234.

Read S. (2001) A year in the life of a bereavement counselling and support service for people with learning disabilities. *Journal of Learning Disabilities* **5** (1), 19-33.

Read S. (2005) Loss bereavement and learning disabilities: providing a continuum of support. *Learning Disability Practice* **8**(1), 31-37.

Reynolds S., Guerin S., McEvoy J. & Dodd P. (2008) Evaluation of a bereavement training program for staff in an intellectual disabilities service. *Journal of Policy and Practice in Intellectual Disabilities* **5**(1), 1-5.

Sandelowski M. (2000) Focus on Research Methods Whatever happened to qualitative description? *Research in Nursing & Health* **23,** 334-340.

Stoddart K., Burke L. & Temple V. (2002) Outcome evaluation of bereavement groups with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **15**, 28-35.

Streubert H.J. & Carpenter D.R. (2003) *Qualitative Research in Nursing Advancing the Humanistic*, 3rd edn. Wolters Kluwer Health | Lippincott Williams & Wilkins, Philadelphia.

Streubert Speziale H.J (2006) Evaluating qualitative research. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice,* 6th edn. (LoBiondo-Wood G.& Haber J., eds), Mosby Elsevier, St.Louis, pp.176-200.

Summers S.J. & Witts P. (2003) Psychological interventions for people with learning disabilities who have experienced bereavement: a case study illustration. *British Journal of Learning Disabilities* **31**, 37-41.

Todd S. (2004) Death counts: The challange of death and dying in learning disability services. *Learning Disabilty in Practice* **7**(10), 12-15.

Trinity College Dublin (2009) *Policy on Good Research Practice 1.0*. Retrieved from http://medicine.tcd.ie/research/newsletter/doc/Good-Research-Practice-Doc-2009-College-circulation.pdf on 25 January 2010.

Whitehead D. & Annells M. (2007) Sampling data and data collection in qualitative research. In *Nursing & Midwifery Research: Methods and Appraisal for Evidence-Based Practice,* 3rd edn. (Schneider Z., Whitehead D., Elliott D., LoBiondo-Wood G. & Haber J., eds), Mosby Elsevier, Sydney, pp. 122-137.

Whitehead D. (2007) Common qualitative methods. In *Nursing & Midwifery Research: Methods and Appraisal for Evidence-Based Practice,* 3rd edn. (Schneider Z., Whitehead D., Elliott D., LoBiondo-Wood G. & Haber J., eds), Mosby Elsevier, Sydney, pp. 106-121.

Whittemore R. & Grey M. (2006) Data-collection methods. In *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice,* 6th edn. (LoBiondo-Wood G.& Haber J., eds), Mosby Elsevier, St.Louis, pp. 317-334.