# The perceived benefits and challenges of attending a Death Review meeting from an interdisciplinary perspective

Ву

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Tabl	e	of	Co	nt	en	its

# Page

Table	e of Contentsi
DECL	ARATIONv
Ackn	owledgementsvi
Abstı	actvii
Cha	oter 1 – Introduction
1.1	Introduction to the Study1
1.2	Background to the Study2
1.3	Principles and Philosophy of Palliative Care2
1.4	Death Review Meeting3
1.5	Purpose and Clinical Significance of Study5
1.6	Aims and Objectives6
1.7	Summary 6
Cha	oter 2 – Literature Review
2.1	Introduction8
2.2	The Nature of Death and Dying and Palliative Care
2.3	Interdisciplinary Teamwork in Palliative Care
2.4	The Nature of Reflective Practice
2.5.	Education and the Death Review Interdisciplinary Meeting
2.6	Summary

# Chapter 3 – Methodology

3.1	Introduction	. 22
3.2	Research Design	.22
3.2.1	Positivism	<b>2</b> 3
3.2.2	Interpretivism	. 23
3.3	Rationale for Choosing a Qualitative Approach	.24
3.4	Interpretative Phenomenological Analysis – IPA	25
3.4.1	Phenomenology	26
3.4.2	Hermeneutics	27
3.4.3	ldiography	.28
3.5	Sampling Method	.28
3.5.1	Inclusion Criteria	.29
3.5.2	Exclusion Criteria	. 29
3.6	Accessing the Research Site	. 29
3.7	Data Collection	.30
3.8	Preparation for Interviews	. 30
3.8.1	Post-interview Questionnaire	.31
3.9	Ethical Considerations	.31
2 10	Summary	27

# Chapter 4 – Data Analysis, Findings and Discussion

4.1	Introduction33
4.2	Demographics of Participants33
4.3	Analytic Framework34
4.4	Findings36
4.5	Theme 1 – Process of Meeting
4.5.1	Exchange and Detachment37
4.5.2	Acknowledging and Naming41
4.5.3	Meeting Being Mandatory and Stopping Same
4.6	Theme 2 – Self as Carer48
4.6.1	Exposed to the Reality of Death and Dying
4.6.2	Reflecting on Practice53
4.7	Theme 3 – The Craft of Caring
4.7.1	Teamwork56
4.7.2	Learning and Developing Knowledge59
4.7.3	Relationship/Skilled Companionship61
4.8	Summary of Findings65
Chap	oter 5 – Conclusion
5.1	Introduction66
5.2	Significance of Study66

5.2.1 Structure67
5.2.2 Process68
5.2.3 Outcomes68
5.3 Limitations of Study70
5.4 Implications of Study 70
5.5 Applications of Study71
5.6 Recommendations71
5.7 Overall Conclusion72
References73
Appendix 1- Participant Information Leaflet82
Appendix 2- Letter of Invitation84
Appendix 3- Letter to Gatekeeper85
Appendix 4- Interview Questions86
Appendix 5- Consent Form87
Appendix 6- Post-Interview Questionnaire89
Appendix 7- Sub-Categories in the Study

# **Declaration**

I hereby declare this this dissertation is entirely my own work and has not been
submitted as an exercise for assessment at any other University.
I agree that the library may lend or copy this dissertation upon request.
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## **Abstract:**

Background: The principles and philosophy of palliative care are grounded in person-centred and family-centred care. Clinical practice in caring for individuals who are dying, and their families, is complex. In an attempt to guide this practice, numerous theoretical approaches have been developed to assist in understanding the various considerations and challenges encountered by dying patients and their families. Health care professionals encounter many challenges themselves—particularly in relation to pain and symptom management, psychosocial and spiritual care—while also attempting to protect themselves in the midst of complex caring, grief and loss. Reflective practice, in the form of Death Reviews, provides an ideal forum for interdisciplinary team members to examine the intricacies of caring, so that the practices of end of life care can be enhanced.

**Aim:** The primary aim of this study is to gain an understanding of the lived experience of two Irish interdisciplinary Community Palliative Care teams' perceptions of attending a monthly Death Review meeting.

**Methodology:** A qualitative approach, specifically Interpretive Phenomenological Analysis was used in this study. Semi-structured interviews were utilised to extrapolate participants' experiences.

**Results:** The findings suggest that all ten participants could see the benefit of this type of reflective practice meeting. One out of the ten participants did not feel that it was beneficial personally, but could see the benefit for others on the team. Lack of participation and time constraints were perceived as challenges associated with Death Reviews.

**Conclusion:** Death reviews provide a useful forum to reflect on practice and remember and acknowledge the patients and families who have died. They also bring a sense of closure, while highlighting the importance of self-care when caring for individuals who are dying and their families. Diverse coping mechanisms with regard to responding to exposure to death and dying emerged from the findings. The importance of learning from our experiences was highlighted in this study with the ultimate aim of improving patient care.

## CHAPTER 1 INTRODUCTION

#### 1.1 Introduction to the Study

In this chapter I will introduce my research question, together with some contextualised information concerning myself, the specialist area of Palliative Care and the practice of a Death Review meeting as the issue under investigation.

Malterud (2001:483) acknowledges that:

A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions.

Having worked as a Palliative Care Nurse since 1998, I have cared for thousands of individuals and their families during their living/dying trajectory or path. My research question stems from my own learnt and lived experience of working in palliative care and journeying with these patients. Some questions which led to my research question were:

- What has helped my colleagues and me to cope and deal with this staggering number of deaths?
- How do we continue to 'be there' for our patients?

When working in the Community Palliative Care team I attended a monthly 'Death Review' meeting. I would suggest that this meeting facilitates health care professionals with both on-going support and learning through reflection from clinical practice. My research will focus on two Community Palliative Care teams working within one specialist Palliative Care service in Ireland.

The Research question for my thesis is 'What are the perceived benefits and challenges of a Death Review meeting from an interdisciplinary Community Palliative Care team perspective'?

#### 1.2 Background to the Study

Palliative care has been described as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation, 2002)

Contemporary palliative care dates back to the opening of St. Christopher's Hospice in London in 1967; it was founded by Dame Cicely Saunders, who was also the founder of the modern hospice movement. Saunders was a trained nurse who also became a social worker and finally a doctor in order to challenge the existing models of care which focused on cure, and highlight the specific plight and needs of the terminally ill/dying patient (Buckley 2008). Saunders, through her research:

set out principles of a new approach to the care of dying people which would harness together medical innovation in pain and symptom management with wider concerns for practical and social needs of patients and families, as well as a responsiveness to spiritual matters. (Clark and Seymour 1999:72)

Health care professionals from all specialisms encounter grief and loss, death and dying. Before working in Palliative Care, I had both cared for and been with patients who had died. My learnt experience as a student and nurse was to just move on to the next patient and either attempt to process both the incident and my reaction to it after work or to try to forget about it. There was no practice or meeting in place for acknowledging, discussing or evaluating the care and circumstances surrounding the death of a patient. In my opinion opportunities to learn from our experiences and change and improve practice were lost. The next section will look at the principles and philosophies of Palliative Care as outlined at the organisation where the research is taking place.

# 1.3 Principles and Philosophies of Palliative Care

 To enable terminally ill patients to live as normally as possible within the limits imposed by their illness by the control of symptoms and by providing emotional and practical support. We consider that the control of pain and other distressing symptoms is a right of all patients and that, in so far as is possible, a pain-free and peaceful death should be available to everyone.

- To involve patients in decisions about their care, reducing feelings of isolation and uselessness, and enabling them to adapt to a changing but positive role.
- To discern spiritual needs and arrange for pastoral care, if desired.
- To admit patients to the In-Patient Unit when continuing care is not possible
  in the home environment. To help the patient and family to accept the need
  for this.
- To create a life-affirming climate in which the patient maintains control over his/her life, prepares for death in his/her own way and lives his/her life in comfort with a sense of personal dignity.
- To support families caring for a dying person, both emotionally and practically and to continue this care through bereavement.

# 1.4 Death Review Meeting

A Death Review meeting is a local practice in the two Community Palliative Care teams under investigation. Enquiries with both the first nurse and social worker to work in the organisation have led me to understand that this meeting evolved over time to become what it is today. There does not appear to be any standardised meeting of this sort within the area of Palliative Care. The following provides a brief description of the meetings in both the Community Palliative Care teams where this study has been undertaken.

A Death Review is a monthly meeting that involves the interdisciplinary team gathering on the first Wednesday of every month for an hour. A candle is lit in the middle of the table and the names of all the patients who have died in the previous month are read out slowly, allowing time for reflection between each name. It is then a free forum for staff to discuss the patients who have died; their journey and

death, from a holistic perspective, including the physical, social, spiritual and emotional aspects of their care. This often involves storytelling and discussion around incidents that happened and the feelings and emotions experienced by the interdisciplinary team members associated with these events. It is an opportunity to reflect on experiences and relationships both working with and caring for patients and families.

Another significant function of this process was that it allowed staff to discuss aspects of caring for both patients and families that were challenging for them, as well as acknowledging what was done well. Through attending these monthly Death Review meetings, I not only learnt and reaffirmed the principles and philosophies of palliative care; I also experienced both the personal and professional benefits of attending this type of meeting. When I began working with the Community Palliative Care team, I was struck by the atmosphere of openness, respect and trust with which the meetings were held. I absorbed the stories and learnt through listening to the more experienced staff discussing their personal and professional challenges associated with patient and family care. This atmosphere encouraged and enabled me as a new member of the team to be open and honest in relation to my experiences with patients and families.

When I decided to pursue my Master's degree in Adult and Community Education, choosing the topic for investigation was easy for me as I had recently changed jobs and was now involved in interdisciplinary education within Palliative Care. There were a number of reasons for choosing the Death Review meeting as my research topic.

- There are complexities and challenges for those experiencing a life-limiting illness. Working with this cohort of patients, whilst a privilege, does have an effect on the health care professional involved and this can ultimately affect patient care.
- An End-of-Life care initiative conducted in three Dublin nursing homes revealed that there was no formal process or structure, such as a Death

Review, for the interdisciplinary team, when patients died (Molloy and McQuillan 2012).

 Through my experience of teaching palliative care for healthcare professionals, it became evident that no Death Review meeting took place within most organisations.

According to Hofmeyer (2003:9),

The complexity and incessant change in the corporatized health care workplace has influenced nurses' work choices, morale, quality of work life and the well-being of patients. Thus, there is an urgent moral imperative to improve the quality of work-life for nurses.

A Death Review meeting is one way to improve the quality of work life for the interdisciplinary team, which in turn affects staff morale and ultimately patient care.

The ultimate aim of Death Review meetings, in my experience, is to improve the experiences and care of dying patients and their families by enhancing the awareness and lived experience of the interdisciplinary team working with patients who die. To conclude, I am hypothesising that on the basis of my experience attending these monthly Death Review meetings, there are three lenses through which this meeting can be viewed: as a method of self-care, a practice of reflection on experience, and as an adult learning process.

# 1.5 Purpose and Clinical Significance of Study

The purpose of this study is to investigate:

- The perceptions of two interdisciplinary Community Palliative Care teams' understandings of what a Death Review meeting is from their subjective experiences.
- The benefits and challenges of attending this type of meeting.

The clinical significance of capturing this research is to ultimately enhance the care given to patients through a deeper understanding of ourselves and the work we are immersed in when caring for patients and their families at end of life. In my opinion, in order to achieve this, the interdisciplinary team must engage in reflective practice, not only to increase their knowledge base and learn from experiences but to take care of themselves in the process.

#### 1.6 Aims and Objectives

The aims of this study are to:

- Gain an understanding of the lived experience of two Irish interdisciplinary Community Palliative Care teams' perceptions of attending a monthly Death Review meeting.
- Assess and discuss the perceived challenges and benefits of attendance at such a meeting.

The objectives of this study are to:

- Ascertain the essence of the lived experience of two Irish interdisciplinary
   Community Palliative Care teams attending monthly Death Review meetings.
- Identify commonalities and diversity in perception within the interdisciplinary teams of attending this type of meeting.
- Identify the implications of the findings for all health care professionals working with grief and loss, death and dying.

# 1.7 Summary

This study explored the perceived benefits and challenges of attending a Death Review meeting from an interdisciplinary perspective, in two Specialist Community Palliative Care teams. This chapter highlighted the background, purpose and clinical significance of this research as well as outlining the aims of objectives of this study. Chapter two highlights the literature associated with the research question. Chapter three provides the reader with an overview and justification of the research design and methods used within this study, while chapter four presents the analysis, findings and discussion from the research obtained. The final chapter presents the outcomes of the study including the significance of the findings as well as limitations and recommendations for professional practice, research and education.

## CHAPTER 2 LITERATURE REVIEW

#### 2.1 Introduction

The purpose of incorporating a literature review into a thesis is to critically analyse and appraise literature that has already been published 'to establish what knowledge exists in the field' (Holloway 2008:141). This assists the researcher in determining what is currently known about the subject or concept being investigated. A literature review also allows the researcher to explore theoretical frameworks which can provide a rationale for the proposed study. Additionally, a literature review can highlight gaps in the current literature and recommend where additional research is needed. Online current literature was explored using CINAHL, Psychology & Behavioural Sciences Collection, PsycINFO, PubMed and Medline for the purpose of this study.

In this chapter, the nature of death and dying and Palliative Care will be introduced. The role of the interdisciplinary team, reflective practice and adult education and learning will also be discussed in relation to Death Review meetings. Various theoretical and conceptual frameworks have been devised over the years in an attempt to capture these complexities; these too will be discussed in this chapter.

## 2.2 The Nature of Death and Dying and Palliative Care

The nature of death and dying is complex. Humanity's fear of death is age old. Psychologists have developed theories of death and dying, grief and loss to try to rationalise emotional responses to death and dying; philosophers contemplate death in terms of being fearful of extinction and irrelevance (Kastenbaum & Aisenberg 1972). Various theoretical and conceptual frameworks have been devised over the years in an attempt to capture these complexities. I will consider some of these in an attempt to outline the multifaceted nature of death and dying.

Glaser & Strauss (1965) used a sociological approach to examine the understanding of death and dying awareness by monitoring the interactions between health care professionals and patients in a hospital setting. They utilised both ethnography and interviews to gather data. Findings suggested that awareness of the dying process occurred at four different levels. These included 'closed awareness', 'suspicion awareness', 'mutual pretence' and 'open awareness'. Each phase of awareness is unique to each individual; however Glaser and Strauss (1965) argue that constructs which permeate each phase of awareness are also unique to each individual. This ground breaking theory challenged both the attitude of and treatment provided by health care professionals to terminally ill patients (Glaser & Strauss 1965). Kübler-Ross (1969) was revolutionary in that she was the first to examine the psychological response encountered by individuals when dealing with the many losses experienced during end of life care. Analysis of the findings from interviews conducted with more than 200 terminally ill patients suggests that there are five stages associated with the dying process. These include denial, anger, bargaining, depression and acceptance. According to Copp (1998:382) this theory 'continues to be popular with health care professionals today, despite recent criticism and alternative, more contemporary theories'. While Kübler-Ross's five stage theory is considered to be plausible, it is also regarded as being overly prescriptive and, according to Pattison (1977), misinterpreted as a predictive timeline for dying individuals and loved ones to work through the various stages of grief and ultimately gain acceptance. In the reality of palliative care clinical practice, the dying process does not occur in a linear fashion. Corr (1992) asserted that Kübler-Ross's (1969) theory centred on the psychosocial issues and did not fully consider the impact of both the physical and spiritual dimensions that can contribute to conceptualising and perceiving dying and death.

Pattison (1977) supplemented the work of Glaser and Strauss (1965) by proposing the living-dying interval model for comprehending the process of dying. Pattison (1977) argued that we all have a 'trajectory' of our lives made up of concepts which change when faced with a crisis, such as an impending death. Pattison (1977)

suggested three phases of the 'living-dying interval' which included the 'acute crisis phase', the 'chronic living dying phase' and the 'terminal phase'. Pattison's living-dying interval was the first theoretical framework to incorporate in depth, the feelings, reactions and different stages that patients can experience when facing death. Kübler-Ross (1969) had of course already considered the reactions and different stages of grief and loss but did not highlight the in-depth feelings to the same extent as Pattison (1977). Experiences of dying individuals throughout those phases is multidimensional, and presents a variety of challenges to the interdisciplinary team members as they attempt to support patients throughout each phase. According to Walter (1994) listening to the unique stories of individuals is paramount in understanding patients and how they are coping with their life limiting illnesses. A criticism of this theory is that patients can often stabilise or 'plateau' and this was not taken into consideration in Pattison's work (Copp 1998).

Another theory devised by Corr (1992) suggested that the dying process involves a 'task based approach to coping with dying' that incorporates the physical, psychological, social and spiritual; this too mirrors the principles and philosophies of Palliative Care. Corr (1992: 88) espoused:

Coping encompasses more than just reacting to or defending against the events and challenges of life, coping involves an awareness of events and challenges, plus efforts to contend with them.

Some shortcomings of this task based approach included a lacking of empirical evidence and insufficient scrutiny in relation to the various tasks and sub-tasks of coping (Kasbetenbaum & Thuell 1995).

Buckmann (1993) maintained that when individuals were faced with death they would cope and react in a way that was consistent with the way they coped with challenging situations throughout their lives. Buckmann's three stage model included the initial stage, the chronic stage and the final stage. Buckmann (1993) enhanced Kübler-Ross's (1969) five stage model by highlighting that several emotions and responses had not been included in her theory, such as fear of dying,

hope, despair and humour all of which would commonly be seen in practice with patients facing impending death. Criticisms of this theory include that it is constructed around the emotions and responses of individuals and as such is too one-dimensional in the complex process of dying and death (Copp 1998).

Copp (1997) focused on the understanding and experiences of patients confronting their own death but also focused on nurses' encounters and experiences. Unstructured interviews and ethnography were used to extrapolate the dynamic nature of the nurse/patient relationship around death and dying. Copp's (1997) model was based around the notion that the body is separate to the mind. Copp's theory consisted of four different experiences that patients can go through which include: Body not ready, Person ready; Body ready, Person ready; Person not ready, Body ready; and Body not ready, Person not ready. This theory was groundbreaking in that it separated the body and mind and also incorporated the issues of pain and symptom control and quality of life for patients facing death. Through the understanding of these various theories, models and frameworks, health care professionals are facilitated to devise and deliver best practice in person and family centred holistic care.

From this overview of the theoretical approaches to death and dying, it is apparent that the nature of dying is complex. As health care professionals, we are all individual and we will all have our own coping styles and mechanisms for managing the grief and loss we encounter on a daily basis. Patients who have life-limiting illnesses undertake major social transitions and adjustments that can result in psychological, social, spiritual and physical stress, and these stressors can in turn be transferred to the staff working with these patients. Stanton et al (2007) discussed the demand for psychological adjustment in all aspects of daily living when faced with a life-limiting illness.

According to Qaseem et al (2007) health care professionals working in this area, especially frontline staff, coped with substantial psychosocial, clinical and logistical challenges as part of their everyday work. Coping skills for individuals vary and a study by Vachon (1987) espoused that stress among hospice staff occurs when

stressors in the work surroundings are increased so that staff cannot utilize their normal coping mechanisms that would generally balance their personal needs and principles against the demands of their work. Buchanan and Huczynski (2004) considered three factors that need to be taken into account when looking at workplace stress; these included:

- An individual's personality and coping mechanisms to date in his/her life
- An individual's life and work circumstances at that particular time
- Management or workplace factors which may be seen as either positive or negative.

Papadatou (2000:71), who worked in a paediatric unit, advised using six rules as guidelines for health care professionals handling grief in the workplace:

- Health professionals are expected to invest in and develop close relationships with seriously ill and dying children.
- Health professionals are expected to be affected and express their grief reactions in anticipation, at the moment of death, or after it. The intensity and expression of their grief, however, must to tempered and controlled.
- The grief of health care professionals must never be so intense as to impair the clinical judgement or lead to an emotional breakdown.
- The grief of professionals must never exceed the grief of family members.
- The grief of the professionals should never be apparent to other sick or dying children or to their parents, who should be protected at all costs.
- Team members are expected to support each other in their grief. They can share feelings and thoughts with colleagues; such sharing, however, must be limited to specific times of formal and informal gatherings and must be suppressed when tending to the care of other children.

These guidelines are very helpful for staff working with all Palliative Care patients who also acknowledge the self as carer in order to deliver best practice to patients.

Payne et al (2004) acknowledged that those caring for the dying have close and sustained contact with them, and while such relationships are valuable in person-

centered care, they require personal attunement and involvement with patients and their family members throughout the dying process. Dingwall and Allen (2001) stated that establishing and maintaining supportive relationships with patients requires a 'therapeutic use of self' which integrates the health care professionals' ability to manage the emotional exertion associated with delivering holistic care and dealing with the psycho-social issues that can arise. Establishing and maintaining these therapeutic relationships means that the health care professional potentially runs the risk of personal losses being experienced which Neimeyer (2006) advocates ought to be addressed on a continuous basis. Morse et al (1992) presented four different types of relationships that health care professionals can have with patients, namely:

- Connected response patient focused, sensitive and comforting = reflexive response
- Reflected response nurses are self-focused, distancing and guarding = reflexive response
- Professional response patient focused, therapeutic understanding, tries to
   reduce their own emotional involvement = learned response
- Detached response self focused, acts as a detached outsider and expresses
   false pity = learned response

Campbell (1984) espoused that skilled companionship forms the basis of caring, and noted the importance of boundaries. Four distinct components of companionship were illustrated: bodily presence, helping the individual moving forward, relationship between health care professional and patient, and a commitment to limited companionship (Campbell 1984). When working with palliative care patients, the importance of skilled companionship cannot be underestimated.

Countertransference doesn't announce its arrival; it sneaks in and becomes part of the therapeutic relationship. Although it is certainly preferable to catch it before it manifests, we have to expect that we will most often discover countertransference after it has arrived (Cozolino 2004:165).

This highlights the importance of self-awareness when working with this cohort of patients.

Irrespective of how dying is conceptualised, it is essential that the interdisciplinary team members possess the knowledge, skills and competencies to provide holistic person-centred and family-centred care to patients. This philosophy of care mirrors the philosophy of palliative care, particularly within the Irish context. An overview of interdisciplinary teamwork will be presented in the following section.

# 2.3 Interdisciplinary Teamwork in Palliative Care

At the core or centre of all effective Palliative Care delivery is the team working together to deliver the best care possible for patients (Meier & Beresford 2008). Teamwork, and more significantly, interdisciplinary teamwork and partnership, have been identified as a specific strength of specialist Palliative Care services (Ajemian 1993). Vachon (1995) concurred with this and also highlighted the importance of team development and support since the beginning of the hospice movement. McCallin (2006:6) proposed that:

Interdisciplinary teamwork calls for clinicians from different disciplines to interact, solve problems, and make decisions together, whilst sharing responsibility for client-centred care.

It seems reasonable to assume that health care professionals working with individuals who have life limiting illnesses will be affected by the emotional journey that patients and families experience when faced with impending death. In recent times this belief has been researched and developed, and the concepts of vicarious traumatisation (Pearlman and Saakvitne 1995), compassion fatigue (Sabo 2008), and burnout (Maslach et al 2001) has been theoretically established. According to Devilly et al (2009:373)

It makes intuitive sense that engaging in an empathic relationship characterized by the identification with and understanding of their emotional experience, similarly impacts upon the emotional experience of the therapist, both at a conscious and subconscious level.

The results of a study by Rose and Glass (2010:1405) show that

There is a pervasive interconnectedness between emotional work, emotional well-being and professional practice that is influenced by factors such as organisational and workplace issues, communication with health professionals, professional boundaries; education and professional development.

McCoyd & Walter (2007) demonstrated a lack of opportunity for interdisciplinary teams to process both personal and professional responses and reactions to a patients' death, despite the obvious importance of this. This is supported by Keene et al (2010:185) who advocated that without managing one's own grief in response to patients' deaths, health care professionals run the risk of 'physical, emotional, cognitive, behaviour or spiritual distress which could have implications for professional practice'. This will have repercussions for team functioning and support is seen as a crucial part of enabling health care professionals to deliver effective patient care (Speck 2009).

According to Worden (2006), mourning or grieving is understood to be a social phenomenon; the necessity to grieve with others is seen as significant. Parkes (1986) stated that if health care professionals working in areas of multiple deaths, like a hospice, had effective training and support, rather than weakening their humanity and care giving abilities, it would strengthen their capabilities to cope with future losses they would experience with increased confidence and sensitivity. Worden (2006:257) concurred, stating that:

Regular Staff meetings where participants are encouraged to talk about problems that arise in the care of the dying and their families, and their own feelings, can help prevent excessive stress and can facilitate the feelings associated with grief and loss.

As effective communication is one of the vital characteristics of Palliative Care delivery, it is essential to have excellent communication within the team itself (Meghani 2004). Speck (2006) maintained that interprofessional communication can be problematic if there is insufficient understanding of roles within the team and intolerance with the approach and language used. Hackman (2002) adopted a three-dimensional concept of team effectiveness which included task performance,

the quality of relationships within the team, and participant satisfaction. Goal clarity has also been acknowledged as being important; Locke & Latham (1990) described this as the measure of awareness that each participant involved in the meetings understands why a particular issue is significant or applicable to discuss in that particular meeting. Williams (1984) identified six types of meetings: command meetings, selling meetings, advisory meetings, negotiating meetings, problem solving meetings and finally support meetings.

Wainwright & Breiddal (2011:111) suggested that 'in order to care for patients and families in a holistic, person-centred, and grounded way, the team must have access to similar care'. In the next section I will discuss reflective practice, one system in place to assist health care professionals to make sense of the unique challenges of caring for Palliative Care patients.

#### 2.4 The Nature of Reflective Practice

Reflective practice has been described as a process of critically analysing and evaluating experiences (Johns 2009). The concept of reflection dates back to the Greek philosopher Socrates, but it was John Dewey, the educationalist, who promoted using questions and feedback to assist in the learning process. Dewey (1938:25) stated:

I assume that amid all uncertainties there is one permanent frame of reference: namely the organic connection between education and personal experience.

Jasper (2003) espoused that a reflective practitioner is an individual who intentionally deliberates about his or her experiences, making a link between theory and practice. Schon (1983:163), in a somewhat similar approach, stated:

In a practitioner's reflective conversation with a situation that he [or she] treats as unique and uncertain, he functions as an agent/experient. Through his transition with the situation, he shapes it and makes himself a part of it. Hence, the sense he makes of the situation must include his own contribution to it. Yet he recognises that the situation, having a life of its own distinct from his intentions, may foil his projects and reveal new meanings.

Cottrell (2008) espoused that through reflective practice; health care professionals can highlight and explore their strengths and weaknesses both personally and professionally. There are various reflective models that can be used, most of which are based on Kolb's (1984) Experiential Learning Cycle, which includes experiencing, reflection, conceptualisation and planning. Gibbs' (1988) reflective cycle is probably the most commonly used and includes describing the incident, becoming aware of your thoughts and feelings, evaluating and analysing the situation and formulating a plan of action.

The use of reflection is one way of addressing the issues surrounding grief and loss that health care professionals working with Palliative Care patients can practice. According to Schon (1983) 'reflection-in-action and reflection-on-action' provides staff with the opportunity to reflect during situations and also afterward on their own understandings, feelings and actions. This reflection forms the basis for change or adjustment if necessary, and ultimately assists in improving patient care. Schon (1987:26) elaborated and defined reflection on action as:

Thinking back on what we had done in order to discover how our knowing in action may have contributed to an unexpected outcome. We may do so after the fact in tranquillity or we may pause in the midst of action (stop and think).

Mezirow (1981) concurred with this definition and both enhanced and supplemented it when discussing the theory of transformative learning. Knowledge and learning are crucial elements of reflective practice. Understanding the nature of knowledge dates back to Aristotle, and was then further explored by Habermas and other colleagues from the Frankfurt School (Burns & Bulman, 2000). Habermas (1977) described three reasons that knowledge may arise: 'technical', which included influential work guided by empirical facts; 'practical', which related to communications, was subjective in nature and was also guided by knowledge that afforded comprehension; and 'emancipatory', which included social equality, liberty and justice guided by information gathered through the process of 'conscientisation'. The term conscientisation was coined by Freire (1972) who explained it as an epiphany of awareness towards struggles that both produce and

maintain certain social situations. Mezirow (1981) expanded this point to include the term 'emancipatory' as it guides individuals towards a fuller awareness of the basis of their situations, helping to work towards a positive solution and outcome.

A variety of authors (Sharpe & Faye, 2009, Greenwood, 1993 and Deahl, 2000) have written on the processes of reflection and debriefing, both of which are very much intertwined with the essence of a Death Review meeting. Reflection and debriefing also assist in promoting a learning organization (Senge, 1990). Senge (1990:3) portrays a learning organization as:

one where people continually expand their capacities to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are continually learning how to learn together.

Mishler (1986:75) noted, 'Telling stories is a significant way for individuals to give meaning to and express their understanding of their experience' and advocated the establishment of opportunities for this. Fay (1987) referred to the various qualities of mind which are necessary for reflection to occur, including openness, curiosity and commitment. Johns (2009:13) expanded on these to include 'energy, passion, discipline and playfulness'.

There appears to be a dearth of literature that addresses the structure, process and outcomes of Death Reviews as a form of reflective practice. In Molloy & McQuillan's (2012) report on improving the quality of life for residents living and dying in long stay settings, Death Reviews were evaluated. Their findings revealed that Death Reviews assisted staff to discuss their strengths and limitations when delivering end of life care. Death Reviews were regarded as a valuable means of providing staff support and remembering the resident. The report also stated that Death Review assisted in enhancing and developing end of life care education. One of the recommendations of the report was 'Death Reviews need to become regular practice for all deaths that occur in residential settings' (Molloy & McQuillan 2012:25). Reflective practice is considered to be the:

key ingredient for achieving: greater self-awareness, professional expertise, critical thinking, integration of theory practice links, and enhanced patient care (Knight et al 2010:428).

By taking this 'time-out' once a month to remember, acknowledge and discuss the patients who have been under the care of the interdisciplinary team, staff can reflect on the work they have done, with a view to improving and learning from the challenges faced and relationships built with the patients and families under their care. Reid (1993:305) described reflective practice as 'a process of reviewing an experience of practice in order to describe, analyse and evaluate and so inform learning from practice'. When caring for dying patients there are no second chances; it is essential that best practice is adhered to and reflecting on practice is one way in assisting this process. Tanner (2006) stated that reflection is essential for the developing of clinical reasoning and thus the enhancement of clinical knowledge. Reflective practice and education are interconnected; the next section will look at education and the Death Review meeting.

#### 2.5 Education and the Death Review Meeting

It is our belief that if we have the courage to identify and confront the totality of our responses in patient care at end of life, we can use it to inform and enrich our work. (Katz 2006:7).

Death Reviews arise from an andragogical philosophy, Mezirow (1981) described andragogy as an organised endeavour to support adult learning in a way that heightens their skills to operate as self-directed learners. Rogers (1983) who advocated a humanistic approach to education highlighted the usefulness of facilitation when teaching and the importance of the contribution of participants in the process of learning. Knowles (1990) proposed four main features of adult learning. These included that the idea of self-directed learning promotes development of self-concept, the importance of life experience in learning, the idea that students will learn what they need rather than what they have been told they need to learn and finally that adults learn through problem solving rather than through subjects. This work of Knowles (1990) is reflected in the interdisciplinary

Death Review meeting. It is not only through discussing one's own experiences and challenges with patients and families but through sharing and listening to other members of the interdisciplinary team's experiences that one can learn and adjust one's own practice.

Knowles (1990) described how adults learn - individuals bringing their own lived experience and having dialogue in relation to various dilemmas that present themselves. In Death Review meetings, this is normally presented as challenges, connections and feelings. This can be compared with the peer learning process, which according to McAllister et al (2005:120), 'may facilitate the knowledge of why something has to be learned and its relevance to real-life situations'.

Motivation is a relevant factor to be considered when discussing both learning and developing knowledge. According to Scanlon (1978) the use of a real-life case or situations gives rise to meaningfulness for an individual, which in turn intrinsically motivates them to want to learn and gain knowledge. When working with any group there needs to be an awareness of differing learning styles. Katz and Heimann (1991:239) defined this awareness as the 'preference or habitual strategy used by an individual to process information for problem solving'.

The education or learning that manifests through a meeting like a Death Review occurs on many levels, both personal and professional, and indeed is very much part of a process. Dewey (1916) emphasised the possibilities for development from a learning process which enable us to evolve and grow as human beings. Part of the essence of the Death Review meeting entails 'meaning making' of the encounters that the interdisciplinary team experiences with patients and their families.

Adult education, or having an andragogical approach, involves using individuals' experiences as a resource for learning, through problem solving, which is motivated or heightened by the presence of internal motivators like self-actualisation or individuals learning what they need to learn rather than what they ought to learn (Tennent 1986). Knowles (1984:75) illuminated the adult learning

process by postulating that adult learning is a participatory practice that involves the development of 'the skills and knowledge you will need on your growth path'. When working in an area like Palliative Care learning and psychological growth are intertwined; this mirrors the writings of Knowles (1984) who was influenced by both Rodgers (1983) and Maslow (1968). Knowles supported and encouraged the use of experience as a foundation for learning; such experiential learning techniques are central to a Death Review meeting. The concept of experiential learning was developed by Kolb (1984), who advocated exploring the cycle of learning from our experiences through the use of reflective practice on actions which would then effect future actions.

#### 2.6 Summary

Through the means of reflective practice, education was established as a core component of a Death Review meeting. An andragogical approach to learning is utilised through the interdisciplinary team reflecting on life experiences and challenges in relation to caring for patients with life-limiting illnesses. Motivation was recognized as being a key feature to learning and the use of real-life cases encouraged participation through discussion and sharing of experiences. Learning can be both personal and professional and can assist us in evolving as human beings (Dewey 1916). A Death Review meeting was proposed as a form of experiential learning.

The next chapter will look at the methodology that will be used in researching this topic.

# **Chapter 3 METHODOLOGY**

#### 3.1 Introduction

The aim of this chapter is to provide an overview of the methods and methodology related to this study. While there are a number of paradigms that may guide research, a discussion will ensue to provide a clear justification and rationale for the chosen qualitative research approach - specifically, an Interpretative Phenomenological Approach (IPA) - for this study. The theoretical foundations of IPA, which include phenomenology, hermeneutics and idiography will be introduced and discussed. The process of research design, sampling method, data collection and interviews will be explained in the context of ethical considerations and rigor for this study.

#### 3.2 Research Design

Research design has been described as the overall plan for undertaking a research study and finding answers to questions (Polit & Beck 2006). The approach taken depends on one's ideas about the world, or a paradigm, also known as a conceptual framework (Silverman 2005). The conceptual framework that guides this study is Campbell's (1984) theory of caring. Reflection in and on practice provides the foundation for this study; the practice on which reflection is taking place is that of Death Reviews. End of life care practices are multi-dimensional and complex and require health care professionals to provide intricate care, guided by evidence based practice, within the principles and philosophy of palliative care. According to Bentz and Shapiro (1998), in order to fully understand research methods, one must have an awareness of the history and traditions associated with the various frameworks and paradigms of research. This section will address both positivism and interpretivism, and aims to provide a rationale for choosing an interpretivist approach for this study.

#### **3.2.1** *Positivism:*

According to Bentz & Shapiro (1998:27)

Because positivism is a complex, composite phenomenon, because it is also a controversial and partisan set of ideas, and because it is not just a theory of knowledge but a cultural and political orientation, it is not something that can be covered by a simple dictionary definition.

Positivism has been described as 'a particular perspective of the world that is based on the natural science model and the belief in universal laws' (Holloway 2008:188). Research studies based in the positivist paradigm typically include numerical measurements, statistics and a search for cause and effect or scientifically established facts (Burns and Grove 2005). Crotty (1998:27) describes positivism as a 'mathematised world' and criticisms of this approach argue that positivism is objective rather than subjective and doesn't lend itself easily to human and social experiences (Bentz & Shapiro 1998). Though positivism is mainly associated with a quantitive approach to research (Treacy & Hyde 1999), Bentz and Shapiro (1998:28) state:

Any approach to knowledge, whether it is natural-scientific or objectivist or subjectivist, can be positivist if it does not look at the broader history and context in which knowledge is generated;

therefore both quantitative and qualitative research may be positivist in nature.

#### **3.2.2** *Interpretivism:*

Qualitative approaches to research tend to be located with the interpretivist school of thought (Treacy & Hyde 1999). Interpretivism is concerned with attaching meaning-making to a subjective reality (Polit & Beck 2006). Interpretivist roots are linked to Weber (1990), who argued that in the social sciences, *verstehen*, or understanding is needed (Crotty 1998). According to Holloway & Wheeler (2010:25) 'the methodology centres on the way in which

human beings make sense of their subjective reality and attach meaning to it'. Interpretive methodologists contend that human behaviour cannot be condensed into the laws of natural science (Poloma 1979). In an interpretivist approach, the relationship between the interviewer and the participant can potentially shape the study outcome; this challenges the idea of objectivity maintained by positivists (Guba & Lincoln 1994).

#### Research has been described as:

the systematic investigation of a specific question in order to establish new facts and draw new conclusions. It involves the discovery of new knowledge and the interpretation and revision of current knowledge. (Hickson 2008:3)

Both positivism and interpretivism are recognised as contributing to knowledge creation. For the purpose of this study, I will be exploring the 'lived experience' of two Community Palliative Care teams attending monthly Death Review meetings. This phenomenon incorporates an interpretivist paradigm which is concerned with human actions, feelings, thoughts and perceptions (Holloway & Wheeler 2010). The contextual basis on which a Death Review meeting is built or founded is reflective practice - and the practice of care delivered, is guided by both the principles and philosophy of palliative care and theoretical approaches to death and dying, grief and loss.

#### 3.3 Rationale for Choosing a Qualitative Approach

A qualitative approach, as described by Smith et al (2011:45) 'looks at how people make sense of what happens, what the meaning of that happening is'. Human nature is unpredictable and does not fit neatly into principles and laws; it is not easy to measure actions, social phenomena and relationships, but by using a qualitative research approach one can explore individuals' lived experiences. This study does not lend itself to hypothesis generation or support. It may be argued however, that because this study mirrors care tenets of the principles and philosophy of Palliative Care, that it does. Streubert and Carpenter (2000:15) describe qualitative research as 'a belief in multiple realities, a commitment to

identifying an approach to understanding that supports the phenomena studied and a commitment to the participant's viewpoint'. Qualitative research has experienced an unprecedented growth in popularity, particularly amongst health care professionals in the past ten to fifteen years (Smith et al 2011). The reason for this is thought to be that qualitative research highlights a holistic, person-centred approach to research (Holloway and Fullbrook 2001) which mirrors the principles and philosophy of Palliative Care.

My rationale for using a qualitative approach is based on reflective practice, which is centred on the concept of caring and the principles and philosophy of Palliative Care. When exploring the research question 'What are the challenges and benefits of attending a Death Review meeting?' the data needed to be rich and have depth and therefore a qualitative inquiry is the preferred approach for this study. When little is known about a topic or a researcher is seeking the emic perspective, a qualitative approach is more suitable (Hickson 2008).

There are various approaches that may be used in qualitative research included grounded theory, ethnography, hermeneutics and phenomenology. The qualitative approach I will be using in this study is interpretive Phenomenological Analysis (IPA), which will be explored and explained in the next section.

#### 3.4 Interpretative Phenomenological Analysis – IPA

IPA was first publicised by Jonathan Smith (1996) and is seen as an approach to qualitative, experimental and psychological research. IPA involves bracketing or 'to put to one side the taken for granted world in order to concentrate on our perception of that world' (Smith et al 2011:13). In order to do this Smith et al (2011) recommends that the researcher reflects, so that a cyclical approach to bracketing happens. Smith et al (2011:35) states 'We would position this view of the dynamics of preconceptions within a model of the hermeneutic circle of the research process'. In other words the 'whole' is the preconceptions that the researcher is bringing and the 'part' involves the meeting with the new participant.

IPA is interested in exploring the 'lived experience' of participants and is also concerned with how people 'make meaning' out of different types of significant life experiences (Smith et al 2011). In this study, IPA will be used to analyse the perceived challenges and benefits of attending a Death Review meeting, by asking participants to make meaning from their lived experience of attending this monthly meeting. A key feature of IPA analysis compared with other qualitative research is that it is dynamic and does not move in a linear fashion; there is movement in regard to ways of interpreting the data, it is not a fixed step by step process (Smith et al 2011). This methodology differs from other qualitative methodologies in that it identifies that the researcher has a pivotal role to play in analysing the individual experiences of the participants (Pringle et al 2011). Even though IPA originates from a psychology background, it has been used increasingly by other disciplines interested in emotional inquiries (Smith et al 2011), therefore it is very fitting for this particular research study. As the researcher of this particular study I bring with me a background in nursing and Palliative Care, and I feel that IPA is ideal for this particular study.

Using IPA allows for commonalities and/or polarities in the beliefs, perspectives and understanding of participants in relation to attending monthly Death Review meetings. According to Pringle et al (2011:21) 'the aim of IPA is to illustrate, inform and master themes by firmly anchoring findings in direct quotes from particular accounts'. This method allows for a depth of analysis that would not be possible if using a quantitative method (Ravel & Smith 2003). According to Smith et al (2011) IPA recognises and accepts participants' views and experiences, even if in a questioning manner, as opposed to critical analysis advocated by Langdridge (2007). Several key areas of the philosophy of knowledge have informed IPA, namely phenomenology, hermeneutics and idiography. These will now be discussed.

#### **3.4.1** *Phenomenology*

Phenomenology is essentially a philosophical methodology or approach to analysing lived experience. Phenomenologists are particularly interested in understanding

the human experience and what gives meaning for individuals (Smith et al 2011). Four major philosophers contributed to this methodology: Husserl, Heidegger, Merleau-Ponty and Sartre. Smith et al (2011:21) comments:

Through the work of all these writers, we have come to see that the complex understanding of 'experience' invokes a lived process, an unfurling of perspectives and meanings, which are unique to the persons embodied and situated relationship to the world.

Husserl was predominantly concerned with finding a process by which individuals could understand their own experience of a given event or occurrence, recognising a taken for granted world that we all experience uniquely and bringing this into the consciousness of the individual (Smith et al 2011). Essentially, Husserl was interested in finding the core, real meaning or essence of our lived experiences. In order to achieve this, he recommends 'bracketing out' our past experiences. Heidegger who studied under Husserl rejected the concept of 'bracketing', stating that, as human beings, we are inseparable from an already existing world (Koch 1996).

#### **3.4.2** *Hermeneutics:*

Hermeneutics is known as 'the theory of interpretation' (Smith et al 2011:21) and, according to Holloway (1997) it is the study of an approach to understanding and explaining human behaviour through the use of language, actions and literature. The three most important hermeneutic philosophers were Schleiermacher, Heidegger and Gadamer (Smith et al 2011). Both Heidegger and Gadamer 'give insightful and dynamic descriptions of the relationship between the foreunderstanding and the new phenomenon being attended to' (Smith et al 2011:29). According to Smith et al (2004:40), when using an interpretative phenomenological approach, 'the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world'. Smith (2004:40) calls this a 'double hermeneutic'. The hermeneutic circle epitomises a cyclical process whereby the preconceptions, the interpretations and the text are permitted to question each other. As a researcher who has also attended these meetings in the past, it enables me to

make meaning from the text due to my experience on a different level of understanding than an outsider coming in as the researcher.

#### **3.4.3** *Idiography*

IPA recognises the particular as being significant, in other words it endeavours to uniquely understand each participant in a personal, in-depth way. IPA regards the experiences of each of the individual participants and their meaning-making from these experiences are all significant and valid; in other words, IPA is 'idiographic' (Smith et al 2011). For research to be idiographic means that the participant's views must be represented in the findings by using in-depth quotes from the interviews.

#### 3.5 Sampling Method

For the purpose of this study, the sample refers to all staff in the two interdisciplinary Community Palliative care teams, within a specialised Palliative Care service in the Republic of Ireland, who have attended Death Review meetings. A sample of this population was selected as per the principles of appropriateness adequacy (Burns & Grove 2005). Appropriateness in this case applies to the use of participants who can best inform the research with regards to the requirements; in this research study that includes members of all disciplines who attend the Death Review meeting. Adequacy refers to having enough data to represent the participants' experiences (Morse & Field 1996). Purposive sampling will be used, as it meets the criteria of appropriateness and adequacy. This approach to sampling 'consists of detecting cases within extreme situations as for certain characteristics or cases within a wide range of situations in order to maximise variation, that is, to have all the possible situations' (Seale et al 2004). While other forms of sampling, such as random and snow ball may be used, I considered that they may not have captured those who had experienced the phenomenon under investigation.

All members of the two Community Palliative Care teams were sent information leaflets (Appendix 1) and letters of invitation (Appendix 2) through gate keepers (Appendix 3) nominated by the managers of each of the disciplines, as per ethical approval from the organisation participating in the study. Interested participants were invited to then contact the researcher directly either by phone or email to arrange a date and time that suited both parties. It was anticipated that all disciplines would be represented so participants were chosen from the first to contact the researcher from each of the disciplines.

# **3.5.1** *Inclusion criteria*

Staff included in this study must have attended a Death Review meeting and be working as a member of one of the interdisciplinary Community Palliative Care teams participating in the study.

#### **3.5.2** Exclusion criteria

Staff members who did not attend Death Review meetings and individuals who were recently affected by a personal bereavement and who did not feel able to take part in this study, were excluded.

# 3.6 Accessing the Research Site

- Ethical approval was obtained from the Research Ethics Committee of the research site and the Department of Adult and Community Education in NUI Maynooth.
- 2. All the relevant managers of the disciplines represented in the Community Palliative Care team were contacted and they nominated gatekeepers for each discipline. These consisted of administration staff and a medical lead. An information leaflet and letter of invitation was sent to all the potential participants by the gatekeeper.

#### 3.7 Data Collection

According to Polit & Beck (2006) data collection involves a process of observing, measuring or recording information. Interviews were used to collect the data; McLeod (1994:89) suggested that researchers interview in order 'to enter, in an empathetic way, the lived experience of a person or a group being studied'. Semi-structured interviews were used, as this allowed me as the researcher to have a pre-prepared list of questions to guide the interview (Polit & Beck 2006). The interviews varied in length between 30 minutes and an hour. The interviews were audio recorded and transcribed verbatim by me, which helped to increase understanding, awareness and insight into each of the individual participants' experiences.

When using IPA, the interviewer should consciously be asking participants not only about specific experiences but also their thoughts and feelings regarding same (Smith et al 2011). In order to enhance the findings, the same questions were asked in each interview (Silverman 2009), however it should be noted that as the interviews progressed and my technique improved, more questions were generated from the participants' responses.

# 3.8 Preparation for Interviews

The questions in the interviews (Appendix 4) were guided by the research question and developed from the themes that had emerged from the literature review. In order to practise interviewing and explore as to whether the questions were suitable for the study, a pilot interview was organised. This was undertaken with a former colleague with whom I felt very comfortable and who was agreeable to same. I was aware of the fact that some bias or social desirability could potentially affect the interview and observed for that during the interview. Pilot interviews are used for various reasons; including to practise using the audio recording equipment, to trial your questions and technique and to help for identify potential problems (Kvale & Brinkmann 2009). Very few changes were made from the pilot

interview in this study; I feel this is because I had focused all my questions around the research question. The remaining interviews took place either in the Community Palliative Care teams' staff room or my office, whichever suited the participant better. I attempted to create a relaxed atmosphere and had tea and biscuits waiting when they arrived. I explained in detail what would happen during the interview and advised participants that they could stop the interview at any time. I told participants that I would send them a full transcription of the interview to make sure they were happy with everything, and that if they wanted anything omitted there would be no problem. The participants then signed the consent form before starting the interview (Appendix 5). Smith et al (2011:64) states:

The most important thing at the beginning of the interview is to establish a rapport with the participant. They need to feel comfortable with you, to know what you want and to trust you. Unless you succeed in establishing this rapport, you are unlikely to obtain good data from your participant.

#### **3.8.1** Post-Interview Questionnaire

When the audio recording were finished after the first two interviews, both participants acknowledged that they found the interview thought- provoking and felt it had been helpful for them to reflect on what a Death Review meeting meant to them. As a result, I decided to send out a post-interview questionnaire to see how all the participants viewed this experience (Appendix 6).

#### 3.9 Ethical Considerations

An Bord Altranais (2000) Code of Conduct states that all participants should be provided with the appropriate information in order to make an informed consent, and that the principles of confidentiality should be upheld. I ensured that the participants' names would remain confidential and not be published or disclosed to anyone. Participants' were invited to give a pseudonym or to be identified by a number. Confidentiality was guaranteed to all participants, however, they were also informed that in the event of unethical or inappropriate practice being disclosed, this would be reported to the relevant authority. Team members were not obliged to participate in this study, and once they did, they could withdraw at any time, and

would not be penalised for this. It was also noted that as the investigator, I could withdraw any of the participant's contribution in the study at any time without his/her consent. Before commencing the research, ethical approval was granted from the ethics committee at the research site as well as the Department of Adult and Community Education in NUI Maynooth. The ethical principles of nonmaleficence, beneficence, autonomy and justice can be utilised in qualitative research through the application of informed consent, protection from harm, privacy and confidentiality, which are all valid ethical considerations that researchers have traditionally addressed (Beauchamp & Childress 2001). Rigour in research refers to the ability, integrity or the quality that is shown in a particular study (Holloway & Wheeler 2010). Lincoln & Guba (1989) outlined trustworthiness criteria which included dependability, confirmability, credibility, transferability and authenticity. As noted earlier after every interview a full transcription was sent to the participant to make sure he/she was happy with what had been said. According to Smith et al (2011:181), 'good IPA studies tell the reader something important about the particular individual participants as well as something important about the themes they shared'.

# 3.10 Summary

An overview of the methods and methodology used in this study was provided in this chapter. The paradigm of interpretivism, within which this research is grounded, was presented. Justification was given for using a qualitative approach, specifically Interpretive Phenomenological Analysis. The process of research design, sampling methods, data collection and ethical considerations were all outlined. The use and benefits of a pilot study were presented, with consideration given for the possible bias that could potentially have emerged. Data analysis, findings and discussion will be presented in the next chapter.

# CHAPTER 4 DATA ANALYSIS, FINDINGS AND DISCUSSION

#### 4.1 Introduction

The data analysis, findings and discussion of the study will be presented in this chapter. The guiding conceptual framework that I am using in this thesis is based on the process of the Death Review meeting which is used in the two participating Community Palliative Care teams. The contextual basis on which Death Review is built or founded and where the practice of care is guided is both the principles and philosophy of Palliative Care and theoretical approaches to death and dying, grief and loss.

Three main themes emerged from the data analysed in this study; eight main categories and twenty sub-categories emerged (Appendix 7) in response to the research question 'What are the perceived benefits and challenges of attending a Death Review meeting from an interdisciplinary perspective?' The rationale for presenting in this way is to facilitate understanding of the emergence of themes in this study. It should also be acknowledged that that in some cases, categories and sub-categories over-lap and interlink with each other. All excerpts are direct quotes from either the interview or the follow up questionnaire given to all the participants from this study. Whenever confidentiality or anonymity was threatened, identifying text was removed. In order to preserve the anonymity of participants pseudonyms' of their choice were used.

# 4.2 Demographics of Participants

There were 10 participants in the study (including one pilot study); one participant was male and nine were female, they ranged in age between 35 and 55 years. All professions working in the community interdisciplinary teams were represented.

There were five nurses, two chaplains, two social workers and one doctor interviewed. I have included the pilot study as part of this research.

# 4.3 Analytic Framework

The data analysis followed the framework of IPA, as documented by Smith et al (2011). This involved following the various steps of analysis, including reading and re-reading, initial noting, developing emergent themes, searching for connectedness across emergent themes, moving to the next case and looking for patterns across cases. The following were the analytic steps that were followed:

- Each interview was transcribed verbatim from the audio recorder.
- Upon completion of each interview transcription, it was read and re-read several times to gain a thorough understanding of the participant's subjective experiences in relation to his/her responses to the questions posed during the semi-structured interviews.
- Notes were then made on each transcript, highlighting the main points that were emerging.
- The next stage of the analysis focused on identifying sub-categories from each interview; and similarities were noted across all the interdisciplinary team participants' experiences.
- These sub-categories were then merged into clusters of eight categories and out of these categories three major themes emerged.
- The final three themes are a micro-representation of the shared lived experience of the participants' accounts of the perceived benefits and challenges of attending a Death Review meeting.
- The interpretive process endeavoured to remain as loyal to the individual participants' lived experiences as possible. It became apparent after extensive analysis, cross referencing of the data, and restructuring of the categories and themes into the final format as seen in Table 1 below, that the majority of participants, ninety percent, felt that a Death Review meeting was beneficial both personally and professionally.

• Validity checks were undertaken, where each theme was repeatedly examined against the consistency of its appearance within the data.

TABLE 1
Themes and Categories

Theme 1	Theme 2	Theme 3
Process of Meeting	Self as Carer	The Craft of Caring
Exchange and Detachment	<ul><li>Exposed to the Reality of Death and Dying</li></ul>	<b>↓</b> Teamwork
<ul><li>Acknowledging and Naming</li></ul>	♣ Reflecting on Practice	↓ Learning and     Developing     Knowledge
<ul><li>Meeting being mandatory and stopping same</li></ul>		♣ Relationships/Skilled Companionship

The interconnected and interdependent relationship between the participants and myself as the researcher, having also had the lived experience of being part of these meetings in the past, could be categorised as the 'hermeneutic circle'. According to Smith et al (2009:28) the hermeneutic circle regards the relationship between the part and the whole in this way; 'To understand any given part, you look to the whole; to understand the whole, you look to the parts'.

# 4.4 Findings

Through analysing the data from the semi-structured interviews, it emerged that there were three main themes or common threads linking all the participants. These themes are labelled 'Process of meeting', 'Self as Carer', and the 'Craft of Caring'. Each theme has categories, which will now be explored. In order to present a comprehensive view of the shared experiences and personal and professional impact of attending Death Review meetings for the participants, each theme will be viewed through categories in succession. Verbatim illustrations from the themes will be used to demonstrate the aspects of shared experiential meaning for all the participants. To ensure readability and brevity, an ellipsis (...) has been used to indicate omitted material. The post-interview questionnaires revealed that participants felt they learned by reflecting on the process of Death Review meetings.

# 4.5 Theme 1 Process of Meeting

The theme 'process of meeting' refers to all the features and elements that participants in the study felt were essential to the process of having an effective Death Review meeting. It is a dynamic practice, involving the amalgamation of experiences, thoughts and feelings from an interdisciplinary perspective. It is grounded on the principles of respect, trust and valuing each other's contributions to patient and family care, centred within the philosophy of Palliative Care. The categories in this theme are:

- Exchange and detachment.
- Acknowledging and naming.
- Meeting being mandatory.

These will be presented in the following section.

# **4.5.1** Exchange and Detachment

Exchange and detachment refers to the exchange of dialogues and dilemmas associated with caring for patients who died in previous month. Detaching is twofold, detaching from one's day to day work to reflect on the patients who have died, and detaching as a coping mechanism in order to self protect in the face of death and dying. In their interviews, the participants highlighted the importance of creating the right environment for a Death Review meeting.

'Generally we tend to have a little time for reflection (pause) there is one problem in that if people feel rushed emm...so we tend to create that bit of time (pause) generally a bit of reflection just for people to just stop in their actions and just reflect a little and relax and sometimes there is a little prayer or a little thought at the beginning of the meeting.' – Nicola

The correct atmosphere assisted the participants in detaching from their day to day work, to focus on remembering and exchanging stories about the patients they had cared for who had died in the previous month. The importance of stopping, relaxing and participating in some activity to focus the health care professionals on the essence of the meeting was noted.

Symbolism was used as a means to create that change of atmosphere that participants felt was required when dealing with this type of meeting; all those interviewed mentioned the lighting of the candle at the beginning of the meeting; there were slight differences in the interpretation or meaning of this for participants.

'...we light a candle to help focus us but also to remember. The candle being the sign of light and also to kind of focus and bring the patient, you know at a time of death, bring the patient to the table in a way'. - Donna

Another participant commented:

'...by lighting the candle emm (pause) it brings about a change in atmosphere, it can also be quite spiritual for people...' – Pamela

Hockey (1992:37) espouses 'because most people do need sights, sounds and smells and touches... we do need atmosphere and we do need something to hold onto afterwards'.

'We start by lighting the candle, I suppose the candle means different things to different people (pause) but there is again something sacred about it, you know it draws us into another emm area mightn't be the right word (pause) it calls us into another space but it is something that is wholesome alright and there is something about respect when we light the candle' - Rose

For another participant, the symbolism of the lighting of the candle signified an unwritten rule in relation to trust, which was seen as an essential component for a Death Review meeting to be effective. It was felt that in order for individuals to participate in this exchange, trust needed to be present. This is evident in the following:

'It should be an open rule, as they said at a recent one, when the candle is lit that means there is a little thought of trust so that once the candle is lit...whatever is said is kept within the room emm... so there has to be trust, if there is no trust then people are not free to open up and it doesn't really work'. - Nicola

Symbolism was used again at the end of the Death Review meeting when the candle is blown out; this action too had its own significance for one of the participants.

'I suppose it is extinction of life itself isn't it? So it's like an acknowledgment of it being over, it gives closure to the meeting but it's also I suppose symbolic of life in its own way.' - Siobhan

One out of the ten participants interviewed viewed the Death Review meeting as a forum for reminiscing about pleasant encounters with patients and families, rather than a medium for discussing challenges that presented themselves and learning from these.

'It's more nice things that I think are discussed or positive things, I think it would be very unusual at a death review that like anything negative would be discussed, that's my experience'. - Jane

These sentiments are interesting; however, they appear to be in contrast to a number of other participants. One participant commented:

'...If you have had a very difficult situation emm (pause) again with either patients or relatives emm (pause) sometimes it does help to talk about those situations...it is a way of unloading and being able to talk about how you felt emm... whether it was positive or negative...' - Susan

According to Gaddis (2010), it can be helpful for participants of meetings to establish and display 'ground rules'. Burnard (2001) stated that it is essential that health care professionals know the type of meeting that they are attending. The findings that emerged in this study show that the aims and objectives of the meeting were not clear for all the participants. Doyle & Straus (1976) designed a strategy for effective team meetings which focused on the purpose of the meeting whilst at the same time emphasised the group process of working together.

It became evident from the interviews that participants, just like patients, have differing styles or coping mechanisms. It is important when working within interdisciplinary teams to be aware of this in order to support and understand other members of the team.

'Emm like I suppose I could say oh (pause) in the evenings I forget about the patients when I leave here and I do something else, I entertain myself or I do some form of sports or (pause) but really there are times that you can't cut off emm... but if you were off and you're back the next day and you're worried about a certain problem, that way I think you might wake up in the middle of the night and start thinking about them, no matter how much you say I shouldn't be waking up... I shouldn't be thinking of this, you still do think. Some people might be different so I suppose in that way I find I'm not coping that well with a certain situation...' - Susan

When a health care professional gets too close to his/her patient's suffering, and countertransference occurs, 'Compassion fatigue' is said to develop; and this is not helpful to either the patient or the health care professional (Renzenbrink 2011). Freud first spoke about countertransference as an unconscious practice involving the awakening of unresolved struggles and problems of the carer; this was considered to be an obstacle to healing taking place. However this view was challenged by Maroda (2004), who regarded it as normal, appropriate and an inevitable emotional response of a clinician or carer. Jung (1983:155) commented on this in his autobiography '....The doctor is effective only when he himself is affected. 'Only the wounded physician heals'. But when the doctor wears his personality like a coat of armour, he has no effect'.

Using what is called Exquisite Empathy suggests that health care professionals can still give one hundred per cent to clinical encounters, but it is the way in which they do this that is important (Renzenbrink 2011). According to Harrison and Westwood (2009:213):

When therapists maintain clarity about interprofessional boundaries, when they are able to get very close without fusing or confusing the patients story, experiences, and perspectives with their own, this exquisite kind of empathetic attunement is nourishing for therapist and client alike...participants who engage in Exquisite Empathy describe having been invigorated rather than depleted by their intimate professional connections with traumatised clients.

One of the participants described a somewhat differing approach:

'I think I'm quite good at separating my work life and my home life and I always think I have been able to do that and I think that, like stress and work, I can honestly say has never been an issue for me and even despite having some, like you know, being in very stressful situations or dealing with very difficult cases I would very much look at it as my work and when I go home that's the end of my work...' - Jane

According to Katz and Johnson (2006:13), 'The professional, though he or she cares about the patient, may resist getting close enough to recognise, understand, and share in the patient's suffering'. The negative effect of this type of coping means

that by separating or distancing him/herself from the patient suffering, the health care professional can potentially miss opportunities for patient growth, either by having the ability to endure the challenges presented, or that the patient may accomplish or experience meaning-making from his/her circumstances. It has been suggested that in order to really make a difference or attempt to 'heal' an individual within his/her circumstances, the health care professional should support the individual to examine and explore his/her suffering (Yalom 2002).

# Summary

The findings showed that in order for a Death Review meeting to be effective, certain criteria need to be in place: the right environment, the use of the candle or other symbolism, trust, a relaxed atmosphere and clear aims and objectives for the meeting. This all assists health care professionals to detach from their normal day to day work and exchange stories and experiences of patients and families who have died in the last month.

# **4.5.2** Acknowledging and Naming

Acknowledging and naming refers to identifying or remembering the patients who have been under our care, recognising the fact that they have now died and acknowledging the challenges that participants had, personally and professionally in working with these patients.

When working with a cohort of patients who have terminal illnesses, death is an expected outcome health care professionals need to be able to process this experience?

"...everybody in the naming of people out loud, everybody is remembered ... I think at one level it allows recognition, it acknowledges the nature of the work ... It gives people the opportunity to say good-bye at a level you know, or acknowledge the work that was done with different families and different family members'. - Siobhan

The importance of remembering, naming and acknowledging both the patient/family and their journey through end of life care was highlighted in the findings. For some participants, the act of naming and acknowledging appeared to help with issues of 'closure' and being able to continue working within the daily challenges of Palliative Care.

Hockley (2001) acknowledges the significance of individuals recognising and articulating or sharing their thoughts and feelings with others in relation to their experiences of loss, and this concept transfers to health care professionals. In the naming of all patients, there is a remembering and honouring of them too.

'It's an opportunity for a team to gather together to (pause) I suppose to reflect back on our link in with the person, you know an opportunity to just (pause) first to just honour the person...their life, you know and the fact that they have died now. They are still important to us you know and it's about honouring them'. - Una

Hedtke (2002) talks about the idea of 'remembering conversations' in which the memories and connections with the individual or the family are continued and acknowledged with storytelling. According to Hedtke and Winslade (2004), to remember is more than to reminisce; it not only allows us to recall memories and stories, but also to acknowledge the reality of the loss through these conversations.

'Sometimes it's just like reflecting back on their journey through their illness or their death. Sometimes if there was something more complicated or stressful at the time or in the work with the family...sometimes it's a positive, around say, God that person was great and do you remember such and such? so there can be laughter in it as well as being quite respectful...' - Siobhan

Attig (2001:48) describes it well:

As we cherish memories, we return to freshen and deepen our understanding of those who died, attend to them again, bring them closer, embrace them in their absence, reconnect with some of the best in life, feel grateful, feel warmth of our love for them, sense that they are grateful for our remembering, and feel the warmth of their love for us.

'My experience I suppose mainly, is giving you that chance to reflect you kind of (pause) everyday we're kind of going through people emm... we meet people and go through the process and then they die and sometimes there isn't follow up from that...so it's your time to kind of gosh remember that person...remember when...it's your time to kind of go through (Pause) I suppose once the death, once you've had a chance to talk about them and remember the bits that are specific to you or had any meaning to you be it good or bad they would both be reflected on so it does give you that space'. - Sarah

Frankl (1959:116) spoke about meaning-making,

We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. For what then matters is to bear witness to uniquely human potential at its best, which is to transform a personal tragedy into a triumph, to turn one's predicament into a human achievement. When we are no longer able to change a situation – just think of an incurable disease such as an inoperable cancer – we are challenged to change ourselves.

The importance of acknowledging our own challenges and difficulties as health care professionals working with patients with life limiting illnesses was also highlighted in the findings.

'I suppose the other thing is to look at the way we journey with that person, the way we were with those people... sometimes acknowledge our disappointments... So I think that's an opportunity where we can actually express our feelings around maybe what has happened with a particular person and we can share with the other members of the team in a quiet, relaxed space you know'. - Rose

The findings show that naming and acknowledging patients under our care enables the health care professionals to process their experiences. Another benefit of acknowledging and naming patients and their families is outlined below:

'...you know also it can identify if the family had problems or emm (pause) it could bring them a bit more to the light, were they could get lost in the continuation of our work onto the next case so it can be a time to reflect on how that family were or maybe things we needed to pick up on'. - Donna

Death Reviews assist in highlighting vulnerable family members who may need follow-up bereavement support and who may otherwise have been overlooked in the continuing demands of a busy working schedule.

For job sharers, who would normally only attend the meeting every second month due to their working schedule, the naming and acknowledging during the Death Review meeting appeared to have a different significance.

'...you're on the journey so when the journey is cut off, because I have a week off, it's cut off for me but it continues for the patient and so I like to know you know how was it for them, how long more did it take for them actually and (pause) was it ok? Was the family ok? And so for me that's very important.' - Deirdre

Another job sharer had a similar experience of missing this type of meeting every second month.

'It's hugely valuable and it's something that because It's structured and you know it's going to happen once a month, it happens at the beginning of the month... you really miss it, and I job share so I'd be kind of thinking God it's not on my week on and sometimes that really strikes me because it's a time ... you hear things that you would not have otherwise heard and that could not necessarily be captured in a note in a chart ... you have a sense of how things went'. - Siobhan

#### Summary

The findings in this study show that health care professionals who are looking after palliative care patients indeed experience grief and loss as part of their work. Cooper (2006:206) suggested that, 'Time is needed to sit with emotions in order to integrate, understand, express and ultimately heal them'. It was evident from interviews that participants felt it was important to acknowledge and name the patients they had looked after; some felt it gave them a sense of closure. The importance of acknowledging the challenges associated with patients and families was highlighted, as well as drawing attention to families who may need more

support. Job sharers identified the benefits of hearing patients' experiences at end of life if they had been off work at the time.

#### **4.5.3** Meeting being mandatory and stopping same

Meeting being mandatory and stopping same refers to the fact that this is viewed as a compulsory meeting and health care professionals on both the Community Palliative Care teams are expected to attend unless they have had their own personal bereavement. The reason I asked about stopping this meeting was because this has happened in another department in the same hospice, so I was interested to hear their views. The findings show that the majority of participants (nine out of ten) felt that the meeting should be mandatory, with the remaining participant not having strong feelings either way, and acknowledging having seen the benefit of this type of meeting for other people on the team.

'I think it should be (mandatory), there should be a structured time for it, I think we can make excuses for not going very easily and I think the benefits of attending for us are better you know...I don't think we would all be at it if it wasn't mandatory for us, I think we would have gone out on our visits, we'd have gone to do the phone calls. I think it should be, I think the time should be set aside, the benefit for us and for the patients'. - Una

Knight et al (2009) explored the personal and professional impact of compulsory reflective practice groups from a UK clinical psychology training course; the results showed that whilst the majority of participants found the groups valuable, just under half reported being upset as a result of the groups. Both the style of facilitation and group size were shown to influence these feelings. This again highlights the importance of creating the right atmosphere or environment and 'ground rules' for these meetings.

Most participants stated they had never thought of or considered this particular meeting as mandatory or compulsory before being asked the question.

'Personally I think it's a good thing (mandatory meeting) emm, well I think there are pro's and con's to it cause there is bigger buy in to it if people want to be there,

if they choose to be there...I would never have thought of it as a mandatory meeting, it's just part and parcel of our work you know so that's how I would look at it...so I think the nature of the work we are engaged in, it is important, and in a way it is about at some level a sense of closure and a sense of the team coming together and acknowledging the work as a team that was done'. - Siobhan

Wakefield (2000) recommended that health care professionals should be advised to attend 'closure conferences' which consisted of all the health care professionals who were involved in caring for that particular patient getting together and having an opportunity and platform to voice their own feelings with their colleagues.

Another participant spoke about the fact that sometimes with the heavy workloads health care professionals need that time protected to just reflect rather than to keep on going and not taking stock of the work that has been done.

'It's difficult to say but I suppose it's better off if its mandatory cause we don't know our needs are our need ... and the fact that it's there makes us touch on that where otherwise we're on to the next case and we may not touch on it'. - Donna

The fact that this meeting was seen as having elements of self care was also acknowledged when I asked the question whether it was a good or bad thing that the meeting was mandatory.

'I think it's good cause to be honest we can all get overwhelmed with, well we have to do this and other stuff that's more important than a Death Review and being mandatory you know what?, you have to go to it and its part of self care and it should be to be honest' – Sarah

According to Renzenbrink (2011:118),

Self-care is about awareness and reflection of practice, conscious use of self, care for one's own spirit, resiliency, and coming to work well nourished emotionally, spiritually, and physically.

The participants were asked 'How would you feel if it was decided to stop this type of meeting?' Most participants became animated and emotional when faced with this question:

'I would be very disappointed...I would feel that it would be taking a wee bit of the, what's the right word, of the (pause) not sacredness but respectfulness away and it's spiritual so it would be very much that that would be going back to tasks and, you know, so it would be taking the emotional end of things away' (appeared to be upset). - Nicola

The importance of this meeting became apparent to the participants as a result of the interview:

'I'd be upset and I'd voice it...it's amazing even in the talking about it to you at the moment, it reaffirmed that you know, it is so important'. - Una

One participant acknowledged that it doesn't take up much time and it was important both personally and professionally:

'It happens every month and in some ways you take it for granted but it is important emm, to think about the patients and all that you look after, not just professionally but personally you need to think, (pause) so I think it should continue to be honest and it doesn't take up much time'. - Charlie

The participant who felt they didn't gain from the meeting but could see the benefit for others was the only interviewee not to get upset at the thought of the meeting being stopped.

'I would actually (pause) I would have no great issues with that at all'. – Jane

This again highlights the different coping styles/strategies that exist within an interdisciplinary team.

Participants questioned why the meeting would be stopped and this participant elaborated by saying:

'Emm, I suppose I'd have to ask why...I think I would probably be looking for it if it was removed...what will we do with all the people who have died? You know where do we put them?' – Pamela

Worden (1993:256), when speaking of professionals working with dying patients stated:

It is also important that they allow themselves to experience their sadness and other feelings after someone dies and not to feel guilty if they do not grieve the same way for each death...Regular staff meetings where participants are encouraged to talk about problems that arise in the care of the dying and their families, and their own feelings, can help prevent excessive stress and can facilitate the feelings associated with grief and loss.

# Summary

The findings highlight the importance of this type of meeting as nine out of ten felt it should be mandatory and one participant had no strong feelings either way. Most participants felt that one could always find excuses for not attending and that awareness and reflection were part of self-care. When asked about how they would feel if the meeting was stopped, nine out of ten participants said they would be disappointed or upset and the remaining participant had no issues with that at all; this highlights the differing coping strategies/styles that individuals can have within the interdisciplinary team.

### 4.6 Theme 2 - Self as Carer

The theme 'self as carer' refers to the fact that, as health care professionals, we bring ourselves and our own preconceived ideas and beliefs about life and death into the work we do; we cannot separate the 'professional self' and the 'personal self', the two are inextricably linked. According to Katz & Genevay (2002) we bring our sense of values and ethics, our sociocultural influences, our lived experiences and our memories to the work we do. Through analysing the data, it became apparent that the Death Review meeting provided the participants interviewed - or

the 'self as carer'- with the opportunity to reflect on the journey and care given to patients and thus learn from this process; it also enabled staff to support each other through this regular practice. According to Langer (1990), mindfulness about what we as 'the self' and the patient bring to the relationship is important, as this awareness enables us to do our best to help the individuals we are looking after at any given time. The categories in this theme are:

- Exposed to the reality of death and dying.
- Reflecting on practice.

These will be presented in the following section.

# **4.6.1** Exposed to the Reality of Death and Dying

Exposed to the reality of death and dying, refers to working with a cohort of patients who have life limiting illnesses. As health care professionals, we are all unique and have our own coping styles and mechanisms. Participants interviewed were asked how they coped and dealt with the fact that all the patients they looked after died.

'...everyone is different, I suppose, I would be very philosophical about the fact that you're going to die, we all have to die at some stage but that's probably a very glib answer in a way, I don't (pause)... lots of people are frightened about death and fear it and stuff and I wouldn't necessarily have that so I don't personalise it to myself, that's one thing and eh (pause) having said that there are different situations that will touch you in a way (pause) it will always bring you to raise the question about... God am I able to continue to do this? Am I doing a good job of it? You know all the questions about yourself and your ability and really I suppose you're looking at everyone (pause) the possibility of everyone having a good death and that you know if you can support them in some way...'. - Siobhan

One of the inevitable realities of working with a cohort of Palliative Care patients is that loss will be experienced on a regular basis. For the health care professional, it is important to find ways of coping with these work related losses. 'I'm very sad, I'm very sad at times, I get very close to people but then having job sharing is the balance you see, ... you know it's going to happen and it's kind of what takes over is (pause) hopefully it will be ok, so that kind of for me takes over from the actual loss end of it, because you want it to be a peaceful end and want the family to cope with it and you want them to be prepared so it's kind of like if the preparation work is done and if you feel they are going to cope well, then I cope'. — Deirdre

In order to hold an individual's suffering one must have self-awareness; Kearney (2000:92) agreed with this and stated that it had implications for carers 'To be more conscious in our caring may mean that we become more effective as healers and less likely to do damage to ourselves and others in the process. Bowlby (1980:7) expressed:

The loss of a loved person is one of the most intensely painful experiences any human being can suffer, and not only is it painful to experience, but also painful to witness, if only because we are so impotent to help.

Payne (2001) in a study of nine hospices and eighty- nine nurses, found that there were some incidences of burnout, mainly due to work stressors rather than individuals' personal lives. Dealing with death and dying was highlighted as one of the main stressors.

Some participants focused on what Palliative Care endeavoured to achieve for patients and that helped them to cope with the reality of death and dying on a daily basis.

'I think for anyone working in Palliative Care the main thing is you have to be aware, you have to accept the fact that all the patients you see are going to die and how well it goes is what matters, that's the whole thing of Palliative Care isn't it?' - Charlie

Participants being exposed to the reality of death and dying affected first hand one of the interviews, which had to be stopped as the participant, became emotional

and tearful. The reality of this type of work is that from time to time it is very upsetting and most health care professionals do get emotional.

'Yeah cause a lot of people would have passed wouldn't they? It's like you're nearly remembering them all... (pause) it's amazing (starting to cry)... yeah... but I suppose there are always individuals that will touch you, there was someone I was with yesterday and she's coming in here today (more tearful and emotional, long pause)'

Interviewer: 'Do you want me to stop the interview?' 'Yeah'. — Una

Worden (1993) advises health care professionals working with dying patients to firstly be aware of boundaries and limitations; it is not about how many patients have been reviewed but rather the quality of those interactions. Secondly, he advises that the health care professional should practice active grieving. He recommends attending the funeral if possible, however this would not work in Palliative Care as you would be attending funerals every day and would not have time for the living patients. Death Review meetings are one way of facilitating staff to deal with the reality of being exposed to death and dying.

One participant highlighted what she saw as a challenge to attending this type of meeting:

'...you could be caught off guard in the respect of you know eh (pause) you could feel emm... because you're going through your patient load and as I said earlier you move on to the next load and you may realise gosh (pause) you know eh,, this is (pause) I have dealt with so many patients, it may have been you (as the health care professional) and you just become aware at that particular time that you have either been involved in a lot of emm.. eh... deaths emm... it could provoke emm some sort of upset (pause) it would depend really (pause) I suppose emm because I mightn't particularly want to deal with that there and then you know'. - Pamela

It is important also that we look after ourselves when caring for others. Vachon (1979) compared staff stress of health care professionals working in hospice settings with those working with the critically ill in hospitals and concluded that the

most effective optimal care is given if health care professionals are cognisant of their own needs, too.

This participant summarised what a Death Review meeting meant to her as a health care professional working in the area of Palliative Care:

'...the longer I'm in this job the more you kind of (pause) actually it was funny at Christmas time I would have kind of gone wow...when we finished up for Christmas and the guy died suddenly on our team the day before Christmas Eve and you know I was driving home that evening and I actually went, do you know what? I want to just go in and light a candle. How much death have we actually gone through this year, never mind personally, professionally how much life and death and sometimes you do kind of take it for granted and you kind of just plod along and for me Death Reviews, they kind of pull it in. Every now and then to kind of go, God yeah you know how are these families doing? These people are not just numbers, they're actual people'.- Sarah

According to Katz and Johnson (2006), any health care professional regardless of experience can encounter intense and overwhelming reactions to the work. They further this by maintaining:

The context of death and dying brings these responses into an altogether unique realm of thought and practice. Countertransference responses can be complex and often enormously subtle in their manifestations. They inevitably effect every interaction, every theoretical discussion, every diagnostic workup, and every treatment plan (Katz & Johnson 2006:5).

According to Worden (1993) it is helpful for health care professionals who are working with patients who die to examine and acknowledge their own loss history in order to establish their own boundaries and limitations; self-awareness is key to delivering effective patient care to Palliative patients.

# Summary

The findings show that health care professionals exposed to the reality of death and dying have different ways of coping. Self-awareness, including looking at one's own loss history, was seen as being central to coping with this cohort of patients.

Participants stated that in Palliative Care there was an awareness that patients would die, but that it was how they would die that mattered. The Death Review acknowledged that patients were not just numbers and this was said to assist in coping with the reality of being exposed to death and dying.

#### **4.6.2** Reflecting on Practice

Reflecting on practice refers to the essence of what happens at a Death Review meeting. Reflection was mentioned, and seen as beneficial, by all ten participants interviewed in relation to the Death Review meeting. The Death Review enabled the interdisciplinary team to reflect back on practice and acknowledge how the experience was for both patients and themselves.

Reflection is learning through our everyday experiences towards realising one's vision of desirable practice as a lived reality. It is a critical and reflexive process of self-inquiry and transformation of being and becoming the practitioner you desire to be. (Johns 2009:3)

'...so it will give you a chance to reflect on what happened and then bring up and discuss and then someone starts to talk about a patient, what happened you know, their symptom control issues or how it worked out, how we managed it, you know whether it went well or not ... For the team it's good you know, you're looking at how things went well or otherwise and how we managed, so all along you are reflecting and going back to see how we can improve that'. - Charlie

Most of the literature on reflective practice concentrates on the health care professionals' ability to enhance their awareness of how they practice. Therefore reflective practice ultimately aims to enable learning and improve patient care. Johns & Freshwater (1998:185) acknowledged that '...a transformation in nursing practice will bring about a transformation in the nurse'. This could be transferred to any discipline involved within the interdisciplinary team.

'I think it's an enriching experience, I think it's (pause) you know it's a special time of transition and we should always mark it as being that and as being (pause) as learning from it because that is how we go forward (pause) by looking behind also and by seeing how our experiences have affected us and if our experience has affected us in a way that is going to influence how we are going to be in the future, well that's major'. - Deirdre

Reflecting on practice involves a discussion and exploration of the way we handled situations, and sometimes through discussion with other members of the interdisciplinary team, a change in practice can come about from Death Review meetings.

'Well personally as I said, it is the completion of the story, the feeling that you have done your best and that, you know, the feedback from the other members of the team is very important for me because if I go in and I see something and I do it, maybe it's not the way another person would do it, it's important that they say the way that they would do it, so that's important...It's good cos then you are asserting the other person's ability to do it as well, so it's about sharing experiences you know (pause) I find if you're open to sharing experiences and sharing the way you work with people'. - Deirdre

An opportunity for health care professionals to reflect and share their experiences and feelings has been shown to help foster collaborative practice and a learning organisation (Bellamy et al, 2006). This in turn has been shown to improve team building and ultimately influence the experience and quality of holistic patient care (Rhodes et al 2008).

Most participants valued the opportunity to reflect on their experiences:

'Some months it brings up more than others, others it can just be a very pleasant easy experience ... there can be sadness brought to me from the death ... at other times it would reflect to me what a good job we did but my personal experience is it's fairly positive, sometimes it's just nice but more often it brings more than that'. — Donna

Another participant commented:

'We try to create a space where you can maybe think back and emm (pause) it's sensitive you know, cos you're thinking back on people's lives and what they may have meant and the time that we met with them...I find it beneficial because it reminds me of some of the people I have worked with during the month emm (pause) and you may have worked with them for a long period of time, there may be times where you think God I did a good bit of work there or I wonder how the children are now, or I wish I could have been able to do more. So it kind of gives you a chance to kind of think about things in a way (pause) that we don't always take the time to do and sometimes it gives you that closure'. — Sarah

Reflection was also noted in the post-interview questionnaire by participants when asked what their experience of interview was.

'Very reflective and interesting. Reflection also raised in the last Death Review, as a result of interview, giving the team the opportunity to discuss the impact of such'. – Sarah

'It helped me to put words to my experience; it opened my mind to the value of Death Review'. - Rose

'It reminded me of its importance and the need to encourage colleagues within the team to value the time allowed for reflection' – Nicola

#### Summary

The findings show that all ten participants mentioned reflection when asked about the Death Review meeting, and all felt it was beneficial (nine for themselves and one for others). The importance of taking time as a team to explore practice and feelings with the ultimate aim of changing and improving patient care when needed was seen as enriching by participants.

# 4.7 Theme 3 - The Craft of Caring

The theme' the craft of caring' refers to the skill involved in caring not only for patients but for colleagues and ourselves as well. A craft has been described as 'an occupation in which skill is needed' (The Oxford Paperback Dictionary, 1994:185). The categories in this theme are:

- Teamwork.
- Learning and developing knowledge.
- Relationships or skilled companionship.

These will be presented in the following section.

#### **4.7.1** *Teamwork*

Teamwork refers to the interdisciplinary team and how they functioned as a unit. Teamwork and team functioning were viewed by most of the participants as a very important component of the Death Review meetings. Part of the craft of caring is being able to function and work effectively as a team.

'...you get the experience of the other staff, you get the experience that you haven't had maybe and ok you might have been there for a lot of it, but then it might have resolved say for the next person going in, it might have plummeted...it might have mushroomed as well for the person that came in after you. So all of that is very good to know because it's a team effort and it's part of the team to hear the story and you're part of the team and it's very much like you know, well I'm handing over to the next person and trusting that I am doing my job and they are doing theirs that's the way we work'. - Deirdre

Nine out of the ten participants stated they felt comfortable within the interdisciplinary teams, to discuss their feelings and concerns in relation to patient care and their own grieving process. The issues around a member of the team not participating in a Death Review meeting also came up as a possible challenge to attending this type of meeting:

'I think maybe one of the challenges would be if there was a member of staff in the room that didn't really take the meeting seriously (pause) and don't appear to benefit or don't appear to participate in it emm, I think that's challenging, (pause) you see then you're not inclined to give it your all, you would tend to hold back if you feel that somebody else hasn't taken part in it'. – Susan

Team dynamics ultimately affect how individuals function and operate at work (Speck 2009), but as discussed earlier, we bring our own story and experiences or – self- into any team with which we are involved. The benefits of meeting as a team to reflect and how this can bond a team during a Death Review meeting were also highlighted:

'It seems kind of informal in a way because it's relaxed, it's within the team so your able to talk openly, it's not a formal meeting, which is important when you're discussing that because you are reflecting, (pause) because for me for example, for the team it's good you know, you're looking at how things went or otherwise and how we managed, so all along you are reflecting and going back to see how we can improve that.. In a review like that it brings the team together further...it does that'.

- Charlie

The use of the team as a support system was also emphasised:

'I think it's a support meeting for us as a group you know, that if something has come up that has been very difficult and somebody might have been (pause) maybe on a weekend or whatever that really was a difficult situation, and it's an opportunity for them maybe to share a bit about it, you know it's kind of a... when it's a safe environment as well, it's a supportive environment'. - Una

The elements necessary for this type of meeting to work within a team were highlighted again:

'I don't experience it as being destructive within the team but maybe I'm fortunate working in the team I'm working in ... there is something around people trusting one

another and feeling safe and feeling they can contribute or just listen or be part of it...I think personally it adds benefit to the team that I work in'. - Siobhan

West (2004) states that for optimal team functioning, health care professionals need to respect and trust each other; they also need to have flexibility within the team and an ability to support and be there for each other when needed. These elements all appeared to be present within both teams that were interviewed, and participants noted that both trust and respect were also essential for a meeting like a Death Review to be effective. The interviews showed that participants felt empowered by being part of both these teams. Speck (2006:78) stated:

Empowerment is very much concerned with values and the belief that people matter, because they are people more than a resource or a cost for the organisation. Communication and trust are major factors in empowerment and team working is a fundamental requirement if empowerment is to be effective.

When health care professionals within a team feel empowered, there is a shift in energy within this particular group, an individual's power and position no longer determines his/her status, but rather an individual's expertise and skills outweighs his/her their job status within this type of empowered team functioning (Speck 2006).

'Well I think it brings the team together a little bit and reinforces trust to be able to speak...' – Nicola

# Summary

The findings show that participants viewed effective team functioning as an essential component for Death Review meetings. The team was seen as a support system, however certain 'ground rules' needed to be in place, including trust and respect. It was seen as a challenge if a member of the team would not participate in the meeting.

# **4.7.2** Learning and Developing Knowledge

Learning and developing knowledge refers to the learning that occurred for participants through reflecting on their experiences with patients. Throughout the interviews it became evident that learning was seen as one of the benefits for participants attending Death Review meetings. According to Beard and Hartley (1984) the principles of adult learning include that the learning needs to have purpose, that individuals must be there to learn voluntarily and be willing to actively participate in the learning. The learning that occurred in this study appeared to be both personal and professional.

According to Senge (1990:3) a learning organisation is:

One where people continually expand their capacities to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are continually learning how to learn together.

The Death Review meeting was seen by some participants as a way of clinically reviewing the care that had been given to patients and changing practice as a result.

'The main thing is that you do reflect on, you know, a clinical level, management wise, managing symptoms and sometimes changing your practice and you try to learn from basically what went right and wrong...emm and that's the clinical aspect of that'.- Charlie

As well as clinical learning, some participants mentioned that there was personal growth and learning gained through both listening and contributing at these monthly meetings.

'...I suppose the other element of it would be, learn from some of those reflections cos what we're doing is, we are reflecting on how things have been for us in the caring'. - Rose

Learning does not take place unless an individual is open to learning, this is essential to the learning process:

'I suppose I would be the type of person who would look at that kind of thing as ... a way to maybe manage things in another way... what could we have done or could we have done anything different?' - Pamela

The importance of reflecting back on our practice and questioning and acknowledging it to see how we could improve the craft of caring for our patients in the future was also discussed:

'...a learning about I suppose things maybe we could have done different, in our management you know eh (pause) symptom control and psychological, the whole package, things we may have done different or maybe learn how well we did such a thing and maybe using that again'. — Donna

According to Speck (2006), developing knowledge and learning are core components for all health care professionals working within Palliative Care and indeed are ingrained in its very philosophy. Horsburgh et al (2001) used the term 'shared learning' as opposed to the frequently used 'shared teaching'; shared teaching involves passive predetermined learning whereas shared learning involves discussion and problem solving as a group. Both Community Palliative Care teams used shared learning methods within the Death Review meetings.

There is also a learning that takes place from being able to admit that our craft of caring in a particular instance wasn't perfect, and to question and be curious about how we could have handled situations differently:

'...sometimes it's about saying oh God we never quite got on top of that or could we have done something different?' - Siobhan

The importance of having the right atmosphere to ensure growth and learning was also highlighted:

'...I would also find the freedom in the team, the dynamics are quite good at the moment so I find that the freedom to bring up things'. – Deirdre

Participants also stated on the post-interview questionnaire that there was learning through the being interviewed for this thesis:

'By answering the questions it highlighted the elements of the Death Review meeting that we sometimes missed'. – Deirdre

'Made me think more and reflect on the meetings, thus enhancing their usefulness.'

— Charlie

# Summary

The findings show the importance of creating the right atmosphere and environment for learning. A Death Review meeting contributes to creating a learning organisation by using a shared learning approach. Participants highlighted the different types of learning that take place at these meetings: clinical, professional and personal. The importance of being open to learning was emphasised in the study as well as the significance of reflection as a tool for learning. The findings showed that nine out of ten participants felt that learning took place at these meetings and had no issues in participating in them. I would advocate using a form of experiential learning, such as a Death Review meeting, as a means of highlighting the complex nature of care delivered to patients with life-limiting illness and their families.

# **4.7.3** Relationship/Skilled Companionship

The theme relationship/skilled companionship refers to the relationships that were formed between patients and health care professionals as part of the journey of caring. It also encompasses the skills of being able to function effectively for patients and their families in these sometimes challenging situations. All participants interviewed acknowledged the importance of relationships when caring for patients. Nine out of ten of the participants felt it was important to acknowledge and name the relationships formed with patients, with the interdisciplinary team, after a patient died. This was seen as another benefit of attending the Death Review meeting. Dingwall and Allen (2001:65) discuss 'holistic

emotional work' and they integrate the aspects of both 'caring for' and 'caring about' patients; relationships are central to effective patient care. For some participants the importance of acknowledging the relationship, after the patient died, was evident.

...it does help me just to recall people and I think emm, for some I might have been visiting for a good while, you know and for some you would have just got to know more, you would have got a link with families and all that so it's important...I don't like the word closure (pause) but it does something...I don't know what the word is that you could use for it... - Una

#### According to Barnard (1995:24):

The Sting of illness and death is the spectre of broken relationships and the loss of the world. Over and against this threat stand the efforts of caregivers and companions to embrace the sufferer and continuously reaffirm his or her capacity for relationship.

It was also acknowledged by participants that individuals touch and affect us in different ways, and with some patients the bonds can be stronger:

'...there are situations where something will come up that will touch me, will affect me and I think, we've all had it, and there will be situations that you get to know and we (pause) see (gets emotional) you remember someone...and I think that's ok, you know we don't take it for granted all the time either we're human'. - Una

Morse (1991) researched the different types of nurse/patient relationships and the results showed that a relationship appears to be established through subconscious negotiation between the patient and nurse until they meet a common ground that suits both parties. The evidence suggested that the type of relationship between a health care professional and a patient varied and that they depended on the extent of contact, the needs of the patient at that particular time, the nurse's dedication and finally whether the patient trusted the nurse.

The findings clearly showed that the participants differed in the types of relationships they formed with patients. This can be viewed as either a reflexive response or a learned response as a way of protecting the individual when working in an emotionally demanding area like Palliative Care. According to Meier et al (2001) when working in an area like Palliative Care, it is important for the health care professional to be consistently monitoring their own responses to the circumstances and journeys of patients and his/her families as a means of gaining better understanding of the situation.

Having the allocated time and space to acknowledge the relationship was seen by some of the participants, as a means of closure which enabled them to continue to focus in the present when caring for patients:

...on a personal level (pause) because of the nature of the work you do, you get to know the patients on some level and you're able to deal with it sometimes...it kind of gives you closure. - Charlie

When journeying with Palliative Care patients as with any relationship it's a two way process:

"... Cause in some way you're sharing a bit about yourself as well". - Siobhan

The importance of reflecting on the relationship was mentioned as a significant factor of the Death Review meeting:

'...to look at the way we journey with that person, the way we were with those people, with the person and with their family'. – Rose

The memories of the relationships and the human aspect of the craft of caring for patients are shared at the Death Review meeting:

You know we are doing the job we have gone there to do as well, but a relationship is being built you know and sometimes people will talk about emm (pause) maybe the laughs they had with the person, maybe the time that things were upset or

whatever... so there is a lot of that you know acknowledging the goodness in the person and acknowledging the human side of just the normal person'. – Rose

The loss of relationship experienced by the health care professionals was also acknowledged, and one participant described how she gained strength and positivity from this experience:

'...I'm going in as a human being...I'm bringing something as well ... relationships develop and you're with the person and what happens is most of these people will die while we're caring for them, so there is that loss and I think when somebody dies that you have been part of, there is always a little death within ourselves you know, we lose a little bit of whatever but losing that sometimes (pause) like the seed that has been lost in the soil and it kind of grows so I think we are reenergised by the people you know'. – Rose

It is through our work and indeed it is from these challenges that the most important lessons are learnt. Elizabeth Turner who was seven months pregnant when her husband Simon died on Sept 11<sup>th</sup> 2001 in the Twin Towers in New York sums it up perfectly:

The happy ending is because through a painful journey of self-discovery I have learnt that the hardest things in life can hide the most precious secrets. (Turner 2009:206).

#### Summary

The findings show that relationships are at the very core of effective patient care. The health care professionals interviewed highlighted the importance of the two-way process of relationships, both in the giving and receiving and most acknowledged the importance of naming and remembering patients after they died; for some this enabled a sense of closure to be obtained. Participants acknowledged that there were different types of relationships with different patients and family members. The lessons learnt through the loss of relationships were acknowledged as giving some health care professionals strength and renewed energy.

# 4.8 Summary of Findings

The findings of this study illustrated both the benefits and challenges for the health care professionals of attending this type of meeting. The categories and subcategories presented in the findings of this study reflect the perceptions, attitudes and experiences of the interdisciplinary team who attend the monthly Death Review meetings. All ten participants could see the benefit of this type of reflective practice meeting. One out of the ten participants did not feel that it benefited them personally, but could however see the benefit for others on the team.

# **CHAPTER 5 CONCLUSION**

# 5.1 Introduction

Katz & Johnson (2006) consider that if health care professionals have the courage and awareness to discuss, in a meeting like a Death Review, the entirety of their responses to patients during their living/dying trajectory, they can utilise it to enlighten and enrich their work. The aim of this study was to gain an understanding of the lived experience of two Irish interdisciplinary Community Palliative Care teams' perceptions of the challenges and benefits of attending a monthly Death Review meeting. A qualitative approach was used, specifically, interpretative phenomenological analysis. Semi-structured interviews were utilised to capture the participants' perceptions, and through analysis, three themes emerged: 'process of meeting', 'self as carer' and 'the craft of caring. This chapter will present a discussion of the significance of the overall findings of this research including the limitations, implications, applications, recommendations and conclusion of the study.

# 5.2 Significance of Study

The complexity of a Death Review meeting has been established and discussed in relation to patient care, team functioning, team processes and support. The importance of unpacking the layers and unravelling experiences for increased understanding has been highlighted; exploring this process has been a learning experience for me. I was clear and upfront regarding my assumptions and ontological stance in relation to Death Review meetings, which were that there were three lenses through which this meeting could be viewed: as a method of self-care, as a practice of reflection on experience and as an adult learning process.

The findings suggest much more than I originally anticipated. The experiences of the participants interviewed provide a kaleidoscope of ideas, meaning-making and thought-provoking understandings.

- The study lends support to the value of theories of grief and loss, death and dying in guiding practice, e.g. Copp's (1997) model, which highlighted the different phases that patients can experience in their living/dying trajectory.
- The ordinariness and complexity of caring was also highlighted by the theoretical approach of Campbell (1984).
- Adult learning, as an interdisciplinary activity through Death Reviews was considered to have a direct effect on patient care. Dewey (1969) also highlighted the effects of this on the health care professional in terms of personal growth.

Kastenbaum (1972) made reference to the 'rituals' within organisations that attempted and sometimes failed to manage loss; he called these the 'death system' or the way in which we live with the dead. I see a Death Review as one such ritual or system that attempts to manage loss and endeavours to create a learning organisation in the process.

The following is a summary of the significant findings from the study:

### **5.2.1** *Structure:*

Hockley (1992) advocates the use of symbolism and rituals in relation to coping with death and dying; the importance of creating the right atmosphere and environment for the Death Review meeting and the use of symbolism such as the lighting of the candle to enhance this for participants was highlighted. Gaddis (2010) emphasised the importance of having clear aims and objectives for meetings, so that all members of a team understand and are clear about the purpose of the meeting. The significance of the 'ground rules' that need to be in

place in order for individuals to feel safe to share their thoughts and feelings with colleagues was highlighted by the participants in this study.

### **5.2.2** *Process:*

Hockley (2001) discussed the importance of reflecting on care given to patients at end of life. Participants highlighted the significance of acknowledging and naming all the patients under their care who had died; this was seen for many as bringing a sense of 'closure' which enabled the health care professionals to continue giving the best care possible to all the new patients they met. Cooper (2006) highlighted the importance of 'sitting with our emotions', and participants acknowledged that being able to discuss and name their challenges within this forum was helpful, and most participants saw this as a learning process. The practice of naming all the patients helped to identify families who might require extra support. Job sharers identified the benefits of this meeting in being able to hear about the experiences of patients and their families at end of life, if they had been on their week off when a particular patient died.

## **5.2.3** *Outcomes:*

The process of reflection has been recommended for health care professionals caring for palliative care patients (Wakefield 2000). Nine out of the ten participants interviewed felt that this meeting should be mandatory when working with patients who die, stating that professionals can always find excuses not to prioritise this type of meeting. Renzenbrink (2011) recommends that health care professionals working with this cohort of patients should be mindful of self-care and endeavour to have increased self-awareness; this too was highlighted by participants. Nine out of ten of the participants stated they would be disappointed or upset if this type of meeting was stopped with one participant not having strong feelings either way. Further research may shed light on whether differing coping styles, roles and boundaries have a part to play in participants' views of this type of meeting.

The health care professionals interviewed acknowledged awareness that all the patients they were caring for would die, but that it was the manner in which they would die that mattered. The differing dying processes and trajectories were highlighted in the theories of death and dying; it is important as health care professionals working in this area to be aware of this.

Remembering patients at the monthly Death Review meetings acknowledged that those who died were human beings who progressed through various trajectories, some suffering more than others. Relationships were seen as central to patient care and very much part of the caring and supportive process (Payne et al 2004); this mirrors the principles and philosophies of Palliative Care. Worden (1993) highlighted the importance of reflecting and processing feelings and practice; reflection was mentioned by all ten participants when discussing the process of the Death Review meeting. The importance of taking that time out was stressed by participants who felt that the meeting was beneficial (nine for themselves and one for others); this again highlights the differing boundaries, roles and relationships that health care professionals can have with patients. Death Review meetings also allowed health care professionals to 'touch base' and acknowledge the care that they had given to these patients.

West (2004) specified the importance of 'ground rules' within organisations in relation to meetings and their effectiveness. Participants considered the Death Review meeting to be a bonding experience for the team but only possible when these 'ground rules' were adhered to. Participants again highlighted the importance of creating the right atmosphere for learning to take place and emphasised a shared learning approach. Most participants felt it was a support system for staff, and one of the challenges mentioned in relation to attending this meeting was if a member of the team would not participate. Nine out of ten participants felt that learning—clinical, professional and personal—took place at these meetings, which Dewey (1969) claimed helps us to evolve and grow as human beings. The significance of being open to learning was also mentioned and seen as important. The lessons learnt as a result of the loss of these relationships with patients were

acknowledged as giving some health care professionals strength and renewed energy. Relationships were seen as being at the very core of effective patient care and the importance of this two-way process—giving and receiving—was acknowledged. Campbell (1984) highlighted the differing types of relationships that health care professionals can have with patients. Participants also acknowledged that there were different types of relationships formed with patients and they got closer to some than others; Morse (1991) concurs with this in relation to his research on nurse-patient relationships.

As a result of undertaking this study, the experiences and feelings surrounding Death Review meetings has been highlighted for staff. This had never been discussed as a group before; as a result of this study one of the Community Palliative Care teams has since had a meeting in relation to the aims and objectives of a Death Review meeting. I would suggest that this alone has the potential to affect these meetings in the future.

# 5.3 Limitations of Study

Due to the time constraints of this study, the amount of in-depth analysis and further interpretations that could have been carried out was limited. For example, it was beyond the scope of this study to analyse each participant's individual grieving style. It would also have been interesting to compare the different disciplines and how they perceived the Death Review meeting. Differing philosophical approaches could have been used, such as ethnography and grounded theory which may have given different cultural perspectives of the study. This study was only carried out in one site which limits the results of the findings.

# 5.4 Implications of Study

The main implication of this study is that a Death Review meeting is a valuable practice for health care professionals looking after patients who die. It allows the team to gather and reflect on the care given to patients at the end of life and their

families, as well as assisting the health care professional to process this experience. It is important to reflect and learn from caring for our patients, not only for our future patients but also for ourselves.

# 5.5 Applications of Study

The findings will be presented in the site where the research took place and all staff from the organisation will be invited to attend. The intention is to get the findings published and submitted to conferences. The findings of this study could also be utilised in all areas where patients die.

### 5.6 Recommendations

The findings outlined hold many implications. These will be outlined in relation to practice, research and education.

### Practice:

- Wherever health care professionals are looking after patients who die they should consider having some form of a Death Review meeting.
- The importance of creating the right 'space' or atmosphere for this type of meeting needs to be considered.
- All health care professionals attending these meetings should be aware of the 'ground rules', including the aims of objectives of this meeting.

# Research:

- Further research, possibly using a variety of approaches.
- A comparative study in another site.
- Further in-depth research needs to be undertaken in relation to the differing disciplines and how they grief.

## Education:

 Health care professionals need further education in relation to effective team meetings.

- Health care professionals should have an awareness of theories of grief and loss, death and dying and relate these to their practice with patients and colleagues alike.
- All health care professionals should have basic knowledge in effective team functioning.

# 5.7 Overall Conclusion

In summary, the findings and discussion of this study have been outlined, the limitations for highlighted and recommendations made for future practice, research and education. This study has explored the perceived benefits and challenges of attending a Death Review meeting from an interdisciplinary perspective. The importance of learning from our experiences through reflection, and the necessity of self-care were highlighted in this study with the ultimate aim of improving patient care.

# According to Lugton (2002:21):

We need to understand our own emotions and to acknowledge them and to act on the advice that we often give to the bereaved, not to suppress feelings or pretend that we are always coping. Self-awareness from reflective practice is at the core of developing communication and counselling skills in palliative care.

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## **Participant Information Leaflet**

## Title of study:

'The perceived benefits and challenges of a 'Death Review' in a specialist palliative care environment – An Interdisciplinary team perspective'.

**Introduction**: In part fulfillment of a Master's in Adult and Community Education (MEd), I am undertaking a supervised research study. The primary aim of this social science research project is to ascertain the perceived benefits and challenges of a 'Death Review' in a specialist palliative care environment.

**Procedures:** I would like to draw on the experience of at least ten members of the interdisciplinary team, exploring with them, their thoughts and perceptions of being involved in a monthly 'Death Review' meeting. I would like to conduct semi structured recorded interviews of approximately 45 minutes, the findings of which shall be transcribed and analysed.

The following criteria for this study are as follows:

#### Inclusion criteria

Staff must have attended a 'Death Review' and be working in either of the Community Palliative care teams associated with the research site.

## **Exclusion criteria:**

People who have recently been affected by a personal bereavement, who do not feel able to take part in this study.

**Confidentiality**: Your identity will remain confidential and your name will not be published or disclosed to anyone. It should be noted that any inappropriate practice that is disclosed during the meeting will be reported to the relevant authority.

#### Benefits:

Reflection on the process of being involved in a 'Death Review' and learning the possible benefits of same for use in other areas of care.

To enhance clinical practice in end of life care / palliative care when caring for both patients and families.

**Voluntary Participation/Risks**: You are not obliged to participate in this study, but should you decide, you may withdraw at any time, and you will not be penalised or give up any benefits you had before entering the study.

**Stopping the Study**: There is also the possibility that the investigator may withdraw your participation in the study at any time without your consent.

Indemnity / Insurance: This study is covered by standard institutional indemnity

insurance. Nothing in this document restricts or curtails your rights.

**Payment:** There is no payment for participating in this study.

**Permission:** This study has received permission from the research site ethics committee as well as NUI Maynooth Adult Education Department.

**Further Information:** If any further information is required please do not hesitate to contact me on my email <a href="mailto:bsweeney@sfh.ie">bsweeney@sfh.ie</a> or my supervisor Mr. David McCormack at <a href="mailto:david.mccormack@nuim.ie">david.mccormack@nuim.ie</a>

Thank you for your cooperation.

Kind regards,

Barbara Sweeney.

#### Letter of Invitation

7 Ashton Court Ashtonbroc Swords Co. Dublin.

5<sup>th</sup> December 2011.

# Dear Participant

In part fulfillment of a Masters in Adult and Community Education (MEd), I am undertaking a supervised research study. The primary aim of this study is to address 'The perceived benefits and challenges of a 'Death Review' in a specialist palliative care environment – An Interdisciplinary team perspective'.

In order to achieve this I would like to draw on the experience of at least ten members of the interdisciplinary team in either of the community palliative care teams associated with the research site, who take part in the monthly death reviews. I am hoping to explore with you your thoughts and perceptions of participating in type of meeting.

I would like to conduct semi structured, audio recorded interviews of approximately 45 minutes duration. The interview will be transcribed for analysis purposes.

I wish to invite you to participate in this study. Should you agree, I would respectfully request you read the information leaflet provided to you and contact me directly so as to obtain your informed consent. I shall then contact you in due course to decide on a suitable time to conduct your interview. Again, let me assure you of strict confidentiality at all times. Thank you for your cooperation and support.

Yours Sincerely,

Barbara Sweeney

Email: bsweeney@sfh.ie

Mobile: 086 4012667

## **Letter to Gatekeeper**

7 Ashton Court Ashtonbroc Swords Co. Dublin. 3<sup>rd</sup> October 2011.

Dear Sir/Madam

In part fulfillment of a Masters in Adult and Community Education (MEd), I am undertaking a supervised research study. The primary aim of this social science research project is to ascertain the perceived benefits and challenges of a 'Death Review' in a specialist community Palliative Care team from an interdisciplinary perspective.

In order to achieve this I would like to draw on the experience of at least 10 members of the interdisciplinary team based in the community palliative care team and explore with them, their thoughts and perceptions on the benefits of being involved in a monthly 'Death Review' meeting.

I would like to conduct semi structured recorded interviews of approximately 45 minutes, the findings of which shall be transcribed and analysed using a software package.

To enable me to recruit potential participants, I would appreciate it if you would act as a gatekeeper for me in accessing staff from your discipline the Community Palliative Care team.

Should you agree, I would respectfully request you would post an information leaflet and letter of invitation to potential participants on my behalf. It is the intention that the participant will reply to me as the researcher if they wish to participate in the study and I will gain consent.

Yours sincerely,

Barbara Sweeney

# **Interview Questions**

- 1. What is your understanding of a 'Death Review' meeting?
- 2. Can you describe the process of this meeting from start to finish?
- 3. What is your experience of such meetings?
- 4. What are the challenges of attending this type of meeting for you?
- 5. What are the benefits of a death review meeting for you both personally and professionally?
- 6. How do you cope with and deal with the fact that all the patients you look after die?
- 7. A death review meeting at the moment in a mandatory meeting, do you think this is a good or bad thing?
- 8. How would you feel if it was decided to stop this type of meeting?
- 9. Is there anything else you would like to add or discuss in relation to Death reviews?

# **Consent Form**

**Project Title:** 'The perceived benefits and challenges of a 'Death Review' in a specialist palliative care environment – An Interdisciplinary team perspective'.

**Principal Investigator**: Barbara Sweeney

## Background

When exploring the current knowledge of the process of a 'Death Review' there appears to be a dearth of literature on this type of interdisciplinary meeting. The nature of death and dying has received much attention in the literature. While theories related to death and dying are valuable in attempting to conceptualise the dying process, it is questionable as to their value in guiding specific caring practices. It is acknowledged that those caring for the dying have close and sustained contact with them, and while such relationships are valuable in person centred care, it also requires personal attunement and involvement with patients and their family members throughout the dying process. This valuable relationship runs the risk of personal losses being experienced by carers, which Neimeyer (2006) advocates ought to be addressed on a continuous basis. Reflective practice provides staff with the opportunity to reflect on action, so as to form the basis of changed behaviours and also to improve caring outcomes (Johns 1999).

I would like to conduct semi structured audio recorded interviews of approximately 30-45 minutes, the findings of which shall be transcribed and analyzed using a software package. The data collected will be used for the sole purpose of this study and will not be used in future unrelated studies without your permission. The interview transcripts will remain in a locked filing cabinet where only I shall have access. Your identity will remain confidential and your name will not be published or disclosed to anyone. In the event you become upset discussing a sensitive topic, the interview can be suspended or postponed.

## 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. 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 Signatu	re
Date .	

Statement of Investigators responsibilit
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I have explained the nature and purpose of this research study, the procedures to be undertaken and any risk that may be involved. I have offered to answer any questions and fully answered such questions.

Investigator's Signature	Date
investigator s signature	Date

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process please contact the Secretary of the National University of Ireland Maynooth Ethics Committee at research.ethics@nuim.ie. Please be assured that you concerns will be dealt with in a sensitive manner. You can also read more: http://research.nuim.ie/supportservices/research-ethics

# **Post Interview Questionnaire to Participants**

7 Ashton Court Ashtonbroc Swords Co. Dublin.

20<sup>th</sup> March 2012

Dear Participant,

Thank you again for taking part in the research study for my MEd in Adult and Community Education. I have attached a copy of your transcribed interview please review the transcript so that you can check if there is anything you do not want to be included in the final dissertation. If there are any changes you would like to make please contact me. I would be grateful if you could take a moment to fill out the following form and place it in the stamped addressed envelope by 2<sup>nd</sup> April 2012.

- 1. What was your experience of the interview?
- 2. Did your participation in the interview help you to think differently about the Death Review meeting?

Each interviewee in the study will be identified either by a pseudonym or by means of an interviewee number. Please indicate which your preference is:

Pseudonym:

Interviewee Number:

If you would like a pseudonym to be used, please suggest what you would like your pseudonym to be:

Do you wish for your profession to be identified (as this is interdisciplinary research you may be more readily identifiable if your profession is specified)?

Barhara Sweeney	
Thank you,	
Yes/ No - Please circle o	ne

# **Sub-Categories in Study (20)**

- 1. Candle
- 2. Trust
- 3. Challenges and Problems
- 4. Humour
- 5. Time
- 6. Benefits of Meeting
- 7. Team
- 8. Coping with Death and Dying
- 9. Support
- 10. Stopping Meeting
- 11. Acknowledging Work
- 12. Relationship
- 13. Spiritual
- 14. Learning
- 15. Supervision
- 16. Silence
- 17. Closure
- 18. Remember
- 19. Discussion
- 20. Meeting Being Mandatory