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**A Reflexive Inquiry into Grief Support Needs for Healthcare Assistants in Residential
Care settings**

**Submitted in part fulfilment of the requirements for the Masters of Education in
Adult and Community Education**

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Declaration

This Thesis is submitted in partial fulfilment of the requirements of the Master in Adult, Community, and Further Education of the National University of Ireland Maynooth This Thesis has not been submitted for any academic assessment to any other University. I confirm that this thesis is my own work. Assistance received has been acknowledged. Permission is given to the National University of Ireland Maynooth to lend this thesis.

Signed: _____

Date: _____

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Abstract

Background: This thesis looks at the role of the Healthcare Assistant in residential care homes who care for those in palliative care/end of life. It looks at the reflexive experiences of the researcher while engaging and supporting narrative discourses with research participants about their experiences of death, loss, and grief in the vocational workplace, reflecting on supports that would benefit them working in this discipline.

Aim: A Reflexive Inquiry into Grief Support Needs for Healthcare Assistants in Residential Care settings

Methodology: This approach used a social constructivism lens with a narrative inquiry and reflexive practice, grounded in an adult education methodology. Semi structured interviews were conducted, where the interview was presented more like a conversation/discussion to create the ambiance of an adult education environment.

Results: In relation to the culture of the organisation and protocol after the death of a resident, there were positive practices and rituals identified that the staff found very comforting and which helped with the grief process. Another area identified was the importance of peer support and space, in having a physical and emotional space where staff felt free to discuss their experience in palliative care, which allowed for open dialogue and acknowledgment of feelings. Staff being supported like this helped reduce the risk of burnout. Attachment was an important part of the relationship between healthcare staff and patients but it left them vulnerable to the experience of grief within the caring role. Formal supports were discussed in the form of a death review, and while there were supports in place, many of these supports were developed due to policy. In conclusion, I felt that adult educational support could be provided so that staff can recognise grief. Even though there are supports, I felt there could be improvements put in place to better support Healthcare Assistants, especially in relation to adult and community education practices like discussion, reflection, and group work.

Table of Contents

Declaration.....	i
Acknowledgments	ii
Abstract.....	iv
Table of Contents.....	v
Structure of Thesis	vii
Introduction to the Research	1
Starting point.....	1
A few detours	1
I was Lost	1
Revisiting where it all began.....	2
The Day I Had Enough	2
Finding a Parking Space.....	4
Literature Review	7
Introduction.....	7
Healthcare background/ Palliative care.....	7
Disenfranchised Grief & Compassion Fatigue	9
Person Centred Care.....	10
Story Telling as a way of processing grief.....	12
Reflexivity as a mode of practice.....	13
Care for those who care.....	15
Transformative Learning Theory	16
Conclusion.....	18
Methodology.....	20
Introduction	20
Research Question.....	20
Ontology and Epistemology.....	20
Back to the start.....	22
How I went about my research.....	23
Contacting research participants	23
Research Participants	24
Inclusion criteria.....	24
Exclusion criteria.....	24
Location of the Interview: Creating space	24
Methods.....	25

Open question Interviews	25
Recording the Interviews	26
Storytelling	26
My First Encounter	27
Journaling	28
The start of my Journaling	29
Analysis of Methods	30
Ethical Considerations	31
Conclusion.....	32
Findings and Discussions.....	34
The culture of the environment and rituals	34
Death Review	36
Attachment in Care	37
Space for Communication.....	38
Low Morale	39
Participants’ Reflections on Interviews	40
Researchers’ Reflections on Using a Person Centred Approach with Adult and Community Education Practices	41
Analysis of Findings	42
Introduction	42
Culture of the organisation protocols and rituals	42
Formal support from the organisation and death reviews	43
Peer Support, space for communication and Low Morale	44
Attachment in Care	44
Researcher’s analysis on using a person centred care approach	46
Recommendations for grief supports in residential Care	49
Conclusion	51
My Personal Reflection.....	51
Bibliography	56
Appendices.....	62
Appendix A: Poster for workplace organisation	62
Appendix B: Statement of Ethics.....	63
Appendix C: Letter to Gate Keeper	65
Appendix D: Consent from gate keeper to facilitate research	68
Appendix E: Letter of introduction to participants	69
Appendix F: Ideas/Discussions Topics during interviews	70

Structure of Thesis

Chapter 1 will introduce the back ground to the research, my personal story which was part of the research process for me and the structure of the thesis.

Chapter 2 will introduce the literature around the research

Chapter 3 will describe the research methodology and methods by which this study was carried out.

Chapter 4 will present the findings and discussions

Chapter 5 will focus on analysing the main findings from my research study and present the recommendations

Chapter 6 will provide the conclusion, and reflections on my journey as a researcher through my own transformative learning

Introduction to the Research

Learning to find my way

Starting point

I decided after thoughtful consideration to apply for the Masters in Community and Adult Education. I was nervous, as I was aware that it would be difficult and time consuming, but I really wanted to be able to create change for Healthcare Assistants working in end of life care and encourage support or training that could enable them to be supported in their role. When I first applied for the Masters programme, I submitted a proposal, the main aim of which was to look at the benefits that bereavement training would have on residential health care staff caring for older adults in end of life care, and if the care staff would present with positives effects when trained and supported in bereavement. In addition, I hoped to be able to do this piece of research using an action research method.

A few detours

It was not long before I realised that the action research method would not be feasible due to time constraints; in addition, access to residential nursing homes seemed to be a challenge. As I progressed with my research, I began to take a different turn and began to look at the process of how I would gather my information differently. This did not happen due to my planning of a different route; it was as if the different route chose me. I began to self-reflect and look at learning from a different perspective. This was where my learning started to take place.

I was Lost

I seemed to be all over the place and had no clear direction. What was I doing? In my head, and on paper, I had my research proposal but it was all changing, and it was not going to plan. This did not sit well with me. I like plans, I like knowing what is happening and where I am heading. However, this new phase in my life was leading me in a direction that I did not revisit for a long time. I was back at my starting point, only now this starting point was over 14 years ago.

Revisiting where it all began

I was working in a residential nursing home, which I loved. I had been there over six years at this stage, and it was my first job. I started working there while on work placement from college and I had many positive experiences in this role, but some not so positive. As the years progressed, I began to have a different mind-set about my workplace, my home from home as I used to call it. Gradually, I started developing a feeling of disconnection.

The Day I Had Enough

I was tired. That is the feeling I remember. Tired of feeling like things were never going to change, tired of wearing my heart on my sleeve. Tired of the feeling that I was just a number, someone who would and could be replaced in an instant. Care was changing, the essence of caring was changing. The care for staff was diminishing. Or was this just my perception? But what I do know, is that I was changing.

I arrived at work, it was 7.40am my shift starts at 8am.

“Another Loss last night Dawn, that is three this month”.

Death in the healthcare area, especially residential care of the elderly.

Is it to be expected? Is it normalized?

“Please don’t say it was Peggy”. Deep in my heart I knew it was, I dreamt about her last night, it was such a vivid dream, it was as if she came to say goodbye.

“Awe I am sorry love, I know you were fond of her”. I was fond of Peggy as I am fond of all my clients. But Peggy will always have a little place in my heart kept just for her.

I went down to say goodbye to Peggy and pay respects to her family. I gently knocked on the door and it opened, the smell of snuff tobacco along with incense filled my nose. Along with the tight embrace of Peggy's daughter. She cried, and I wanted to cry, but I held back my tears. I comforted Mary and her sister, Ann. I spent time talking to them as they told me stories about their mother and the traditions and values she instilled on her children.

I wanted to stay, and I felt they needed me to stay but in the back of my mind were the tasks and duties of the day, the day that had already started. I knew I was already behind. The guilt that eats away at you, because you can't be enough. Time is a huge burden when it comes to caring, there is never enough of it.

I stole one last glance at Peggy and pushed a stray hair behind her ear, she looked so peaceful, and I discreetly straightened the crisp white sheet which was placed over her. I lay my hands on her cold interlaced fingers and said goodbye.

8.32am, I went into the kitchen to help give out the breakfast, “where were you Dawn? You are late for your shift”. The kitchen staff were not too pleased and no amount of explaining about my whereabouts was good enough. Time again was the issue...I was late.

Peggy was removed from the building, snuck out the back door. The family accompanied her body, no care staff were present to say goodbye except the nurse manager. We were all

too busy. Why did it have to be like that? I asked at handover what the arrangements for her funeral service were. I was met with a shrug of the shoulders. I requested that I would like to be able to attend. I felt I needed to attend. But time was an issue. It was too busy at that time of the day.

The day went by in a blur, there were people to assist and care for, jobs to be completed and beds to be made. In the back of my mind was the image of Peggy's lifeless body lying there. An anger started to bubble up inside me. Did nobody care that Peggy's death and so many others like her influenced the lives of those who cared for them. It felt like they did not in that moment. Everything went on as normal. A tiredness filled every cell in my body. I needed to go home.

Good Morning, Mrs. Smith, it is nice to meet you. I held out my hand and Peggy's frail wrinkled hand was lost in mine, she was so small in the frame that her soul embodied, and such a beautiful soul she had. She smiled and said, "call me Peggy my dear, that's what my friends and family call me". We hit it off right from the beginning. She knew she could rely on me to provide care and support, I gained her trust by being present, and listening to her stories, and allowing her to own her own emotions by understanding there will be times she might be moody, angry, upset and dismissive but I would never hold it against her, because I knew she was human and she needed to be able to express herself. So she began to trust that I would be there for her. Not only in times of emotional distress but also on the many occasions a laugh and song was shared.

We formed attachment, can any relationship truly exist without it? The longer Peggy was in my care the older and more dependent she became but so did our fondness for each other. I will always remember the words she spoke to me as I said my goodbyes at the end of my shifts. "I will see you tomorrow and remember you're one of the good ones".

Something changed in me when Peggy died, I felt tired. I did not feel like "one of the good ones". I felt false and my actions were forced to be robotic. How can I carry on like nothing has changed? How can I pretend that I was not angry at the lack of empathy towards those who cared? That was the day I decided to leave care. I needed to leave before care left me. I needed to stay true to Peggy I needed to leave so I could remain "one of the good ones". This was the day I had enough.

I decided to leave my caring role as a Healthcare Assistant. I made that decision the day my last patient died. I felt disheartened by the whole robotic process of care. I left my role with a mixture of feelings. Sadness, anger, guilt and feeling incapable. I moved on from my role as Healthcare Assistant, but there was always feelings of not being enough in my previous role. I progressed on in my career and became a healthcare tutor. In the classroom setting, many of the students commented on the lack of support during and after end of life care for their residents. When I was undertaking an undergraduate programme, I decided to research the topic on the experience of grief and loss in healthcare. It was here where I had the chance to discuss experiences which resonated with me in my previous role as a Healthcare Assistant caring for those in end of life.

Sitting across from a Healthcare Assistant as tears rolled down her face, she was talking about the experiences she had in her job as a Healthcare Assistant and the confusion she felt

at her emotions. It felt like I was staring at myself all those years ago. It was my moment of clarity. I was listening to this women talk about feelings of guilt because she felt unprofessional as she was finding the deaths of her residents getting harder and harder.

“It is hard to express emotions when the family is there, I try to be strong for them, and I deal with my own feelings when I get some time alone”

“Even though you might be upset and sad yourself, you have to keep professional, if I feel like this, I think what the family must be feeling”

“I get emotional at home when thinking of them but I have to put on a brave face at work because I have to be there for the rest of the residents”

“I felt sadness not only for me but for his family and friends, you become very fond of the people you care for and their family”

“I felt so sad, he was just like a member of my family, and it felt like I had lost a family member”

“I really should not be feeling like this at all, it is not professional is it?”

This was my light bulb moment. I was not alone in my thinking, those thoughts that haunted me were haunting others like me. What was this feeling that was being experienced by others and not only me? It was grief (Nelson, 2018).

It took me to be able to sit and talk with other healthcare staff, to be able to understand what I was feeling and why. To reflect on work place practices in healthcare allowed me to reflect on my assumptions: “We can become critically reflective of the assumptions we or others make when we learn to solve problems instrumentally or when we are involved in communicative learning” (Mezirow, 2003, p.7).

Finding a Parking Space

The space which took place during the Masters in Adult Education came to be an important aspect to my research, and also to me personally. It offered a space to reflect and learn from my own experiences. I had so much knowledge and insight into the social world around me that I had not engaged with or reflected on. I was unaware of all I knew. The Masters in Adult and Community Education created a formal space with an informal ambience, which allowed for reflection to take place. It encouraged dialogue, peer support, and guidance: “Adult and community education is much more than just a continuous development of skills; it embraces self-knowledge, covering both thoughts and feelings about who we are” (Connolly, 2007).

Group supervision was a space that opened up my own cognition in relation to the thoughts and emotions that I had previously not reflected on, and these reflections created my own awareness of why I wanted to research the area of support in end of life care for healthcare staff.

During group supervision, we were invited into the space to discuss our research, the challenges, or positive experiences we have engaged with as part of our research. On reflection, the process started by welcoming everyone into the space, the space consisting of the members of group supervision sitting in a circle, facing each other. There was no desk to create a physical barrier. This, on the first day of supervision, made me feel very exposed and unable to hide into the background. As the group supervision progressed, I began to be able to understand the importance of having no physical barriers, and it ensured that you were part of the group. It encouraged you to let your guard down so to speak. I felt it was easier to participate and engage with the dialogue taking place. The lecturers did not stand at the top of the class with a hierarchal stance, demanding attention; instead, they sat among the students, relaxed and at ease. I felt this made me feel at ease. We had a check in at the start of every supervision, and this created a space that let us identify that we are all human and experiencing similar thoughts and emotions. It let us air any upsets or happiness that we may be encountering outside of the masters programme, this helped me greatly because at times I felt consumed by the masters programme and the research. It allowed me to take a step back and realise that life is still happening, that I am still living, and this is only one aspect of my life. It also created connections with my class peers as we became a support network for each other, not only academically, but also personally. I feel it is important for adult learners to be able to have that support from each other for a more positive learning experience. As we each had the floor to speak, we could discuss our own research and what stage we were at. This helped me to verbalise aloud what was happening in my research. I could hear my thoughts and ideas come to life, where I was questioned, applauded, and constructively criticized. I felt this process allowed me to join the dots in my own head around my research. It assisted me in finding the missing links I could not see on my own. The dialogue that took place allowed for my train of thought to become more focused. As each member of the group discussed their ideas, I felt I learned something from every single supervision, whether it was academically related to my research or understanding human behaviour and individuality. I have so much support at home and from family and friends but the importance of being able to discuss the research process with other peers who are going through the same academic experience allows connection and authentic understanding

to take place. It creates a sense of belonging, which sometimes can be missing when you are an adult going back to education, simply because we are in a different space in life.

I feel it is important for me as a researcher, learner, and facilitator to allow myself to open up to this new process of reflection which I have engaged with throughout the Masters programme. It is this process of reflection and research that has allowed me to transform my own “frames of reference”, developing me as a person, learner, and facilitator.

Literature Review

Introduction

My own experience of palliative care support has brought me to this space. I wanted to be able to let healthcare staff see that I understand the losses that they feel when they lose a patient that they have been caring for. I wanted to be able to offer a support system to them by providing some sort of training programme or workshop. I have come to understand throughout this research that the support does not necessarily have to be in the form of training, but by healthcare organisations allowing and encouraging narrative discourse, where adults can discuss and reflect on their experiences in their roles in palliative care, by providing a space where conversations can take place. Although this research has changed from the starting point, the main aim has always been about supporting care staff with work related grief in some way.

I will now introduce the topic of healthcare and palliative care in Ireland to give an insight into the progression and current approach used in this discipline. I will then introduce disenfranchised grief, which healthcare staff can develop due to working with loss and death. The theme of person centred care will then be introduced to discuss the importance of using a person centred approach in relation to communicating with those experiencing loss. Person centred therapy approach falls in line with an adult education approach, which is an important part of my research. Storytelling and reflexivity are also important modes of communication and self-reflection, and are important in relation to an adult education approach and in participants' personal growth and learning. Then, the chapter concludes by discussing care ethics and transformative learning, which identifies the role of critical reflection in education, which is also central to adult education perspectives.

Healthcare background/ Palliative care

The job position of a Healthcare Assistant (HCA) is now considered a professional role, and the Healthcare Assistant is seen as a valuable member of the healthcare multi-disciplinary team.

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. Dame Cicely Saunders was a trained nurse and she also became a social worker

and finally a doctor in order to challenge the existing models of care that focused on cure, and she highlighted the specific plight and needs of the terminally ill/dying patient (Buckley, 2008). One of the many duties a HCA has is to ‘support the delivery of patient care under the direction and supervision of qualified nursing and midwifery personnel’ (DOHC, 2001). One of the key roles of a Healthcare Assistant is to support and care for patients in end of life care. Palliative Care is defined by the World Health Organisation (WHO) as the active, total care of patients whose disease is no longer responsive to curative treatment, where control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount (World Health Organisation, 1990). 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). Thus, the Healthcare Assistant’s main aim when supporting the nurse, client, and their family in palliative care is to be mindful of the principles and philosophies of palliative care. These are as follows:

1. 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;
2. 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;
3. To discern spiritual needs and arrange for pastoral care, if desired;
4. 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;
5. 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;
6. To support families caring for a dying person, both emotionally and practically and to continue this care through bereavement.

(Hospicefoundation.ie, 2016)

The Irish Hospice foundation, which was set up as a charity in 1986 to fund and develop hospice services, encouraged the area of palliative care to become a discipline in its own right. The current Irish Hospice foundation strategic plan 2016–2019 has identified the lack of training and education in the area of palliative care, noting that training “in end of life, bereavement and palliative care is not widespread. Staff in all care settings - hospitals, care homes, community settings and hospices - need support, training and development” (Hospicefoundation.ie, 2016, p.6). Healthcare Assistants who work in residential nursing homes directly with residents, experience first-hand active dying, death, and grief. However, Healthcare Assistants are often overlooked when it comes to grief and bereavement support. According to Qaseem et al. (2007), health care professionals working in this area, especially direct healthcare staff, cope with substantial psychosocial, clinical and logistical challenges as part of their everyday work. It is important to be mindful that the Healthcare Assistants can develop close relationships with residents and experience loss and grief when a resident dies. However, there is minimal recognition and formal organisational response to support staff members’ feelings of loss and grief. As older people live and die in residential settings, it is important for staff to have access to support that enhances their ability to continue providing compassionate and quality care (Rickerson et al., 2005, pp.227-223). Regular training and review of deaths can allow a space for the healthcare staff to discuss the loss of residents who died in their care. Wakefield (2000) recommends that health care professions should be advised to attend ‘closure conferences’, where those who cared, supported, and were involved in caring for that particular resident get together and have an opportunity to reflect and discuss their own feelings with their colleagues. Worden (2006, p.257) also discussed how 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.

Disenfranchised Grief & Compassion Fatigue

Disenfranchised grief is an unrecognised right to grieve (Doka, 1989), considered insignificant because the bereaved does not have a socially acceptable relationship to the person who has passed. This could be said about the healthcare staff who work with people in a health care profession. The healthcare staff are not considered to have an acceptable relationship with patients. Thus, it is considered insignificant and the healthcare staff should not be emotional concerning the loss (Kaplan, 2000). It is important for healthcare staff to

be able to recognise if they are experiencing grief, as their grief is recognised as a typical response to death. They may be able to understand their emotions and the importance of expressing their emotions, and this can be done by discussing the death or making a tribute to the patient, thereby enabling healthcare staff to properly take care of their reactions to death and to their needs in handling the grief that follows (Kaplan, 2000). Doka (2002) explains that disenfranchised grief, when applied to healthcare staff, can be divided into three different categories.

1. The first is where the relationship between the bereaved and the deceased does not exist. In the area of healthcare, the relationship is viewed as a professional relationship, with no emotional ties.
2. The second type of disenfranchised grief is where the loss is not acknowledged, even by the healthcare staff themselves, as it is expected to be part of the job, with healthcare staff moving on to the next resident without recognising that the death had an impact on them.
3. The third type of disenfranchised grief is where the griever is excluded, where they cannot take part in any grieving rituals.

Attig (2004) explains that it is the bereaved individual's right to grieve without restriction from others. He also explains that the disenfranchisement of grief "is political failure involving both abuse and serious neglect. And it is an ethical failure to not respect the bereaved both in their suffering and in their efforts to overcome it and live meaningfully again in the aftermath of loss" (Attig, 2004, pp. 200-201). These emotions and reactions, if left ignored or not supported, can lead to what is called compassion fatigue, "a stress response that is sudden and acute and has been defined as a physical, emotional and spiritual fatigue or exhaustion that takes over a person and causes a decline in his/her ability to express joy or care for others" (McMullen, 2007, pp. 491-492). Thus, it is important to be aware of our individual reactions to grief. Thus, reflexive practice can support individuals to recognise characteristics of grief, which will, in turn, support the healthcare staff to be proactive in self-care.

Person Centred Care

Person Centred therapy was developed by Carl Rogers in the 1940s and is comfortably situated among the larger humanistic and existential therapeutic movements. Person-centred therapy was seen at the time of its inception as a revolution in counselling due entirely to its

fundamental rejection of the highly analytical approaches taken by the likes of Freud and his contemporaries, and it shifted from the traditional model of the therapist as the expert. In contrast to such methods, person-centred therapy presents a far more holistic view of the client and of the therapeutic process as a whole.

Ursula O Farrell is the Author of *First Steps in Counselling*, and *Courage to Change* along with many other books that contribute to the understanding of counselling. Ursula O Farrell uses a humanist or a person centred approach based on the theories of Carl Rogers as stated in her book *First Steps in Counselling* (O Farrell, 2006, p.10). Carl Roger's work influenced the direction that counselling practice and theory took, particularly with regards to the "role of the client-therapist relationship as a means to growth and change" (Corey, 2013, p.159)

Person-centred counselling is a therapy that places the client at the heart of his or her own therapy. Carl Rogers the founder of the approach says "it is the *client* who knows what hurts, what directions to go, what problems are crucial, what experiences have been deeply buried" (Rogers, 2004, p.11). Person-centred therapists work to establish and build a relationship with their clients in which they are able develop their own self-awareness or concept of self. Through this, they help them create changes in their lives based on a better understanding of their own true feelings and behaviour, a process that will hopefully lead to the client living a more fulfilled, true, and meaningful life.

Person Centred Therapy is a holistic approach which looks at the whole client, taking into account the process involved in building relationships with the client. O Farrell's emphasis is on "establishing a relationship and encouraging the client to explore themselves" (O Farrell, 2006, p.55), then conclusively clarifying why they needed the support of the counsellor. Both the client and the counsellor need to be in psychological contact. According to Rogers, the therapist's attitudes and personal characteristics and the quality of the client-therapist relationship were primarily what determined the outcome of the therapeutic process, as cited by Corey (2013). O Farrell discussed the importance of firstly looking at the personal characteristics of the counsellor and secondly at their learned skills, stating that attributions "are characteristic qualities of each person, and skills are practised abilities, capable of being studied and learned" (O Farrell, 2006, p. 34). Throughout O Farrell's work, she discusses core conditions that are focused on person centred therapy influenced by Carl Rogers. Rogers asserted that there are three core conditions required for therapeutic change to happen. The first core condition looks at client-therapist psychological contact and he states a relationship must exist between the two and each person's perception of the other is important. Then, we have client's incongruence, which is the incongruence that exists

between the client's experience and awareness i.e. the inconsistency between how the client sees themselves (self-concept) or would like to see themselves (ideal self-concept) and their experience in reality. This assists the client with the motivation to seek therapy. The therapist's attribute of congruence or authenticity within the therapeutic relationship is hugely important, as it shows that the therapist is deeply involved and is not merely playing a part. This can facilitate the relationship by drawing on own experiences and appropriate disclosure. Another core element is the therapist's attribute of unconditional positive regard, which means the therapist accepts the client unconditionally, without judgment or disapproval/approval. O Farrell states, "it need not be voiced but it is essential that it is conveyed to the client, this can also be called non-possessive warmth" (O Farrell, 2006, p.37). This helps the client as they become more self-aware and discover where their view of their own self-worth has been influenced and become subjective. It is important that the client can have "empathic understanding", meaning that the therapist empathically understands the client's internal frame of reference. O Farrell discusses that empathy is trying to understand what the client is feeling, and it does not mean sharing the clients feelings but sensing "the clients private worth as if it were your own but without ever losing the "as if" quality" (O Farrell, 2006, p.36). This empathy helps the client to accept that the therapist has unconditional positive regard for them, that they are not being judgmental. It is also important to look at client perception, to understand what the client perceives, at least to some degree. Rogers maintained that if these three core conditions occurred over a period of time, constructive personality change would occur. Essentially, he felt that, as a person becomes more aware of their real-self, they will find their perception of their self will become more like their actual experience of themselves and he likened this to a person "getting behind the mask" (Rogers, 2004, p.108).

Story Telling as a way of processing grief

Story telling is a form of communication which allows us to connect with people, the past and other cultures, opening up the world we live in and allowing us to share it with others. Thus narrative "is one of the fundamental sense making operations of the mind, and would appear to be both peculiar and universal among human beings" (McDrury and Alterio, 2003, p.31). Telling and listening to each other's stories of lived experience is a human tendency and capacity that we engage to discover and transmit knowledge (Pfahl and Wiessner, 2007, pp.9-13). According to Reason and Hawkins (1988), storytelling can be viewed as a mode

of inquiry because it involves co-operative activity, has a qualitative focus, and encompasses a holistic perspective. When discussing topics in which personal experience are enveloped in, it is important to remember the emotional attachment which will be attached to the stories, sadness, loss, anger, disbelief, joy, excitement, and frustration. Reasons and Hawkins (1988) discuss how the key to learning through storytelling is by allowing meaning to develop through reflective dialogue. It is important for participants to be able to connect to the emotions that their stories open up, for “when we tell stories and process them, using reflective dialogue, we create the possibility for change in ourselves and in others” (McDrury and Alterio, 2003, p.38). I feel this is an important learning strategy that can be used with adults experiencing feelings of loss and grief in environments where those feelings may not be fully acknowledged, as it allows adults to be able to voice the emotions they feel through use of language and commonality of experiences. Connelly and Clandinin consider that narrative and life “go together so that the principle attraction of narrative as a method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways” (1990, p.10). I feel story telling is an important way of learning, as Connelly & Clandinin (2006) state that story can be viewed as “a portal through which a person enters the world and by which his or her experience of the world is interpreted and made” (p.477). Story telling as part of my research allows me, as a facilitator, along with my participants, to reflect on our assumptions we may have held in relation to our vocational practice. Hillier (2005) suggests that “when we reflect, we not only challenge our assumptions about why we do what we do, we can also help ourselves identify where we feel lacking and why we may be setting ourselves unnecessarily unachievable standards. How can we reflect on our approaches to our practice? What can we do? What can we uncover in the process?” (p.7). The process of storytelling through grief and loss allows for emotions to be discussed, and it gives those who are bereaved a chance to reflect and talk about a person whom they were close with. This is where I began to understand the importance of storytelling, as it is “a significant way for individuals to give meaning to and express their understanding of their experience” (Mishler, 1986). It begins with the conversations of those who I narrated stories with about loss and grief, those who shared a cup of tea and their thoughts, feelings, and emotions. It begins with me and other adults like me. We are experts in our own experience.

Reflexivity as a mode of practice

While story telling is important for me as a researcher to gain an understanding of the participants’ lived experience, it can also affect the researcher after the process of the interview, creating an emotional response for the researcher as well as the participant. Warr

(2004) considers that the emotional weight of the stories that researchers gather in the field stay with them and are carried around long after the inquiry is complete. It creates an acute awareness of the researcher's role,

the capacity to be aware of ourselves in the practice of listening to another person, the capacity to use what we are aware of in that listening, in the service of the client while at the same time being critically aware of our own frames of reference and the extent to which they are interfering with or facilitating the work we are doing with a client (McCormack, & Ryan, 2011, pp. 7-9).

The process of reflexivity encourages you to look at not just your present self (ideology) but also your previous self (ideology) and to use reflection to see if you develop a new self (ideology). Hunt (2004) states that practicing reflexivity on ourselves means an increased awareness of the rigidity of our ways of perceiving ourselves and our ways of being in the world. Mason (2002) proposes that "reflexivity in this sense means thinking critically about what you are doing and why, confronting and often challenging your own assumptions, and recognising the extent to which your thoughts, actions and decisions shape how you research and what you see" (p.5).

Etherington (2004) discusses how reflexive practice provides

An ability to notice our responses to the world around us, other people and events, and to use that knowledge to inform our actions, communications and understandings. To be reflexive we need to be aware of our personal responses and to be able to make choices about how to use them. We also need to be aware of the personal, social and cultural contexts in which we live and work and to understand how these impact on the ways we interpret our world (Etherington, 2004, p. 19).

However, thinking honestly and critically about what one is doing lies at the heart of reflexivity (Etherington, 2004). The term reflexivity is used to describe the processes involved in Mezirow's 'critical reflection', and in the light of further exploration of the nature of learning, the term encompasses the self-development and affective processes involved in transformative learning. Etherington (2004) states that researcher reflexivity in narrative research encourages the inclusion of the researcher's story, thus making transparent the values and beliefs that are held, which almost certainly influence the research process and its outcomes (p. 27). It was through my own personal reflection using reflexive practice during the research process that I began to understand the emotions and feelings I was experiencing in my early days as working as a Healthcare Assistant in the area of palliative care, experiencing grief due the losses of those I cared for. Mason (2002) argues that researchers must "be able to think themselves into the research process, using their own examples, because most of the key decisions about research are made by researchers

contextually” (p.2). Grief is an experience that is felt by those who have lost someone they care for and where an attachment has been formed. When working as a Healthcare Assistant, I found the emotional turmoil of grieving for the loss of a resident and the façade of being professional, and hiding my emotions behind a poker face, to be draining and immoral. I felt heavy in my heart, as I had to face the grief I felt at home, alone, always wondering was I professional enough to be in this role. I felt unprofessional and that I did not have the right to grieve; “sure I was only their carer”. These emotions only came to light as I listened to the participants’ stories, by reflecting on the emotions I felt while also listening to the emotions they were expressing. McCormack (2009) argues that vulnerability is an inevitable part of the learning process in adult life; that it is vital, in every sense of the word, part of change; that when it is your job to facilitate change there will inevitably be all sorts of emotions stirred up, not least in yourself; and that supporting yourself to face this distress is an essential resource in a facilitators work (p.17).

Care for those who care

This whole research is based around care, based on the care that healthcare providers provide when looking after their dying patients. This research looks at the care that healthcare providers should receive because they are working in such emotion filled environments with those in end of life care who they form attachments with. It looks at the researcher/facilitator’s role in providing a caring approach through education. Nel Noddings (1987) is known for developing the notion of *ethics of care*. She describes a caring encounter as one that involves the carer and the cared for (Noddings, 2002). A caring encounter, has three elements according to Nel Noddings:

1. A cares for B – that is A’s consciousness is characterized by attention and motivational displacement – and
2. A performs some act in accordance with (1),
3. And B recognizes that A cares for B (Noddings, 2002, p.19)

Nodding describes how a response to the care must first be acknowledge this is what she terms as receptive attention, “the attention that characterises as consciousness in caring” (Noddings, 2002, p.17). In the relationship of the Healthcare Assistant and the patient the role of care receives “receptive attention” due to the nature of the environment in the residential nursing home, the patients are there to receive care. I feel that as a researcher/facilitator during the interviews/discussions, I had a role to provide care. I felt I

wanted to let the participants know that I cared about their support needs in working in the area of end of life care. I highlighted my main aim was to support the Healthcare Assistant in some way; this was received well and they in turn accepted to be cared for, by allowing me to listen to their stories and reflections on their experiences in palliative care. Noddings sees education as being essential to the development of caring in society. She defines education as “a constellation of encounters, both planned and unplanned, that promote growth through the acquisition of knowledge, skills, understanding and appreciation” (2002, p. 283). Noddings identified that education from the care perspective has four key components: modelling, dialogue, practice and confirmation (Noddings, 2002). Modelling describes how in order to care, learners should not be just asked to care, but given reasons why caring is a good thing to do. This develops through discussion and reflection on practices in end of life care, by identifying human needs. The caring behaviour should be role modelled and reciprocated by me the facilitator by showing the participants the respect and dignity that I would want them to show their patients and also themselves in their caring role. Noddings (2002) states that in order to demonstrate positive caring we must engage individuals in discussions and dialogue about caring. I felt my main aim was for the Healthcare Assistants to understand the importance of caring for themselves in their vocational roles. She states the importance to talk directly about, and explore, our own experiences of caring encounters. She describes this as a form of self-reflection; if we can identify and analyse our own caring encounters, whether as carers or cared for, we can then in turn create a better understanding of our own relationships. This in turn contributes to the quality of care we can then offer. However, who cares for the Healthcare Assistant, in a time where healthcare is seen as big business? Thus, I feel it is important for Healthcare Assistants to understand and be empowered to provide self-care, which in turn will create a more caring environment.

Transformative Learning Theory

Mezirow has been influenced by the work of Freire (1970) and Habermas (1983) and has in turn influenced many other thinkers in adult education and critical pedagogy. Mezirow (1978, 1981, 1991), whose concept of transformative learning is implicit in the idea of critical thinking, notes that transformative learning is a theory of adult learning that utilizes “disorienting dilemmas” (Mezirow, 2000, p.50) to challenge student thinking. Students are then encouraged to develop critical self-reflection to question assumptions and facilitate new

ways of thinking and acting, challenging the therapeutic process and beliefs they have about the world. Mezirow's Transformative learning theory allows for individual interpretation of life experiences, creating transformation with resulting growth and development (Merriam, Caffarella, & Baumgartner, 2007, p. 132).

Transformative learning theory has two distinct styles of learning: Instrumental and communicative learning. Instrumental learning "focuses on learning through task-orientated problem solving and determination of cause and effects relationships. Communicative learning looks at how students communicate their thoughts and feelings and moral decisions" (Mezirow, 1990, pp.7-8). Another major component of transformative learning theory discusses meaning structures, defined as "broad sets of predispositions resulting from psycho cultural assumptions which determine the horizons of our expectations" (Keengwe, 2018, p.159). They are divided into 3 sets of codes: sociolinguistic codes, psychological codes, and epistemic codes. A meaning scheme is "the constellation of concept, belief, judgment, and feelings which shapes a particular interpretation" (Mezirow, 1991, pp. 5-6).

Meaning structures are understood and developed through reflection and Mezirow states that "reflection involves a critique of assumptions to determine whether the belief, often acquired through cultural assimilation in childhood, remains functional for us as adults" (Mezirow, 1991). Reflection allows us to review an experience and is similar to problem solving, how we "reflect on the content of the problem, the process of problem-solving, or the premise of the problem" (Mezirow, 1991). Through this reflection, we are able to understand ourselves more and then understand our learning better. Merriam, Caffarella & Baumgartner (2007, p. 147) credit Mezirow's transformative learning with using experience as a method for reflection of new information. Mezirow also proposed that there are four ways of learning, "by refining or elaborating our meaning schemes, learning new meaning schemes, transforming meaning schemes, and transforming meaning perspectives" (Mezirow, 1991).

According to Mezirow, deep learning involves the transformation of our frames of reference. This occurs when previous learning engages with present experience and we critically reflect on the process by which we assess our assumptions. The reconstruction of experiences is known as critical reflection, a cognitive process that allows us to reflect and examine our underlying beliefs and assumptions that impact the manner in which we make sense of an experience. Mezirow (1991) states that "reflective learning becomes transformative whenever assumptions or premises are found to be distorting, inauthentic, or otherwise invalid" (p. 6) and in 2000, identified 10 phases of learning that become clarified in the transformative process:

- Experiencing a disorienting dilemma
- Undergoing self-examination
- Critically assessing assumptions
- Recognizing a connection between one's discontent and the process of transformation
- Exploring options for new roles, relationships, and actions
- Planning/revising a course of action
- Acquiring knowledge and skills for implementing one's plan
- Trying new roles on a provisional basis
- Building competence and self-confidence in new roles and relationships
- Integrating the changes into one's life

A perspective transformation leads to “a more fully developed (more functional) frame of reference, one that is more (a) inclusive, (b) differentiating, (c) permeable, (d) critically reflective, and (e) integrative of experience” (Mezirow, 1996, p. 163). Transformative learning experiences are emancipatory “in that they free learners from the constraints and distortions of their worn frames of reference” (Mezirow, 1991, p. 6). As Mezirow states, “this learning occurs when there is a transformation in one of our beliefs or attitudes (meaning scheme), or a transformation of our entire perspective (habit of mind)” (Merriam, Caffarella, & Baumgartner, 2007, p. 133). However, Brookfield (2005) critiques transformative learning when he put forward an argument that the theory only allows for critical reflection on capitalism; however, Mezirow argues that the point of transformation theory in adult education is to critique all relevant ideologies and not just capitalism (Mezirow, 2006, pp. 30-31). In my opinion, I agree that capitalism is used prominently as a critique, but the point Mezirow is making is the importance of having critical awareness, and that where it is used is irrelevant; it can still be used to describe transformation in relation to education, as I can personally identify with transformative learning taking place for me as a learner and researcher, and also personally, through the Masters in Education programme.

Conclusion

In this chapter, I have outlined the history of palliative care in Ireland while reviewing the healthcare discipline, to provide an overview of the role the Healthcare Assistant plays in providing care in Ireland for those in end of life care in residential care settings. I then

discussed the literature, looking at storytelling and the importance of storytelling in the role of learning, and how the researcher can use reflexive practice to gain deeper understanding and learning from experiences. I also discussed person centred therapy and the benefits of this approach from an adult education perspective. This then progressed to discuss disenfranchised grief and compassion fatigue which can occur for those frontline staff who work with death and dying and this includes looking at care ethics. The chapter then concluded by discussing transformative learning, which identifies the role of critical reflection in education, which is central to adult education perspectives.

Methodology

Introduction

The aim of this methodology chapter is to discuss the methodical approach used to support the research project. This chapter will discuss the research paradigm and the ontological and epistemological position of the researcher. It will acknowledge the chosen methods for data collection, participant sample, and analysis of methods. It will then discuss ethical considerations related to the research.

Research Question

A reflexive inquiry into grief support needs for Healthcare Assistants in Residential Care settings

Ontology and Epistemology

Our ontology refers to how we, as individuals, view and know the world. It is the starting point of all research (Grix, 2002). Maxwell (2015) highlights the importance of this by stating that “any view is a view from some perspective, and is therefore shaped by the location (social and theoretical) and lens of the observer” (p.46). My ontological position is in line with a social constructivism view, and I believe that all experience has meaning and through the narratives that take place between my research participants and myself, learning can take place. Constructionists believe that the researcher cannot maintain a detached or objective position, and they believe that “both the researcher and the subject should actively collaborate in the meaning-making process” (Savin-Baden, & Howell Major, 2013, p. 62). I also acknowledge that I am a large part of this research process and that my experiences and world view are central in the inception, approach, and design of this research thesis. Knowledge which can be constructed when the participants and I narrate shared meaning and experiences can be “transforming for participants and researchers” (Savin-Baden, & Howell Major, 2013, p. 63). The social constructivist takes the view that knowledge is constructed when individuals engage socially in talk and activity about shared problems or tasks (Merriam & Cafarella, 1999). Denzin & Lincoln (2011) describe constructivism as constructing knowledge through our lived experiences and through our interactions with

other members of society. Denzin & Lincoln (2011) illustrate that, “as researchers, we must participate in the research process with our subjects to ensure we are producing knowledge that is reflective of their reality” (p.103).

My epistemology stems from working in the area of palliative care and having first-hand experience of death, loss, and grief, then progressing on to the area of training and education with those working in the frontline healthcare field. Here, I became acutely aware of the need for those healthcare staff to be able to reflect, discuss, and express their experiences. I feel my epistemology is grounded in dialogic (Freire, 1978; Hooks, 1994) group work (Connolly, 2008) and reflexive practices (Freire, 1978; Brookfield, 2005), which recognises the centrality of experience (Dewey, 1938), so I feel my epistemology is grounded in an adult education epistemology or way of knowing.

This became more evident to me, through my returning to education and researching the experiences of those currently working in the healthcare field, where I began to see the positive effect the space provided for reflection had on me.

Qualitative researching is exciting and important. It is a highly rewarding activity because it engages us with things that matter, in a way that matter...using methodologies that celebrate richness, depth, nuance, context, multi-dimensionality and complexity (Mason, 2002, p.1)

I feel that qualitative research is the most appropriate for my research, as I want to be able to connect with my participants and gain an understanding of their view of the world in which we live. Their ideas and emotions are an important part of this research, as are mine. That is why I undertook this research using a qualitative research approach, as this paradigm employs an “interpretive, naturalistic approach” to gain understanding about human experiences (Creswell, 1998, p. 15).

According to Mason (2002):

Qualitative research can allow the researcher to explore a wide range of dimensions of the social world, including the texture and weave of everyday life, the understanding, experiences and imaginings of our research participants, the way that social processes, institutions, discourses or relationships work, and the significance of the meanings that they generate (Mason, 2002, p.1).

This approach will be incorporated using a social constructivism lens with a narrative inquiry and reflexive practice that is grounded in an adult education methodology. Etherington (2004) states that reflexivity involves an ability to notice our responses to the world around us, other people, and events, and to use that knowledge to inform our actions, communications, and understandings. To be reflexive, we need to be aware of our personal

responses and to be able to make choices about how to use them. We also need to be aware of the personal, social, and cultural contexts in which we live and work and to understand how these impact the ways we interpret our world (Etherington, 2004, p.19). I feel it is important for me as a researcher to be open and be able to see other people's reality. Social constructionists also believe that we can only explore the realities of individuals as they experience the world, drawing on the interpretations of others, seeing that "all reality, as meaningful reality, is socially constructed" (Crotty, 1998, p.43). Constructivist philosophy also states that both meaning and reality are co-constructed by the participants' own perceptions and experiences and also by the researcher's interpretations of these perceptions and experiences (Denzin & Lincoln, 2011). Throughout this research, I kept a journal of my learning and used narratives to express the experiences and emotions which emerged from this research; "We, and our participants, live and tell many stories. We are all characters with multiple plotlines who speak from within these multiple plotlines" (Clandinin & Connelly, 2000 p. 147). Narratives enable us to understand experience because, as Dewey (1938) and Palmer (1998) attest, we are our experiences. Connelly and Clandinin consider that narrative and life "go together so that the principle attraction of narrative as a method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways" (1990, p.10). As a researcher, I feel this is the essence of humanistic interaction with participants you are researching and collecting data from; "the way you choose to collect data is illustrative of your beliefs about knowledge and human experience" (Ryan et al., 2006 p. 74). As such,

Methodology refers to a 'perspective' or broad theoretically informed approach to research, which stems from the researcher's epistemological stance or philosophical/political position. Methodology is how researchers make their epistemology and theoretical stance work for them in their research (Ryan, 2015, p. 70)

Back to the start

The methods for this research have changed from when I first sent in my proposal for my place on the Masters in Adult and Community Education Degree. I set out to complete an action research study where I would develop and deliver a training session to a group of Healthcare Assistant in a residential care facility. Due to time constraints and being unable to access residential nursing homes within a certain time period, it became a challenge and I had to change my course of plan, but it was successful in the sense that I experienced

experiential learning through the process of completing the masters programme and engaging in intimate narratives with the research participants.

How I went about my research

After reading literature on research methods, I decided to use a qualitative approach, using group interviews and discussions with open questions as the main method for collecting data. I first sent a letter of introduction to private nursing homes, as they are the gatekeepers. De Laine (2000) describes gatekeepers as individuals or institutions who have the power to provide or withhold access to a research population. I felt this was important, as I would like to be able to access the participant sample from a group of healthcare professionals currently working in the healthcare area.

After the initial contact with the gatekeeper and with positive feedback, I then forwarded a letter of introduction and a poster inviting participants to an introduction session on the research project. The next phase of the process was meeting with those who had an interest in the research proposal and introducing them to the criteria and process of research proposal.

The interviews then took place in a private space. Along with the previous methods mentioned, I also kept a journal of the process through the masters research.

Contacting research participants

I initially made contact with the participants through the HR manager of the nursing home, as she was my gatekeeper. I then forwarded a poster to be hung in the public spaces of the nursing home, like the canteen and public display wall. I had the posters laminated and used bright colours on the poster to gain attention and used large print to catch the attention of the staff. There was an image representing a care approach that I felt would engage in vocational similarities and work ethic. The poster (Appendix A) had the aim of the research and a contact number for participants to use if they would like more information. I used my name as the contact instead of printing the phrase 'contact researcher on 087xxxxxxx', as I felt it was more personal for them to see the phrase 'contact Dawn on 087xxxxxxx'. I did use my college email address just for professional ethics in relation to personal boundaries, however.

I had an introductory meeting for anyone interested in taking part in the research proposal in the nursing home. This was for thirty minutes. I introduced myself and the topic I was

researching. I explained my reason for wanting to partake in this research topic and invited people to ask questions. I gave the dates and times the interviews would take place and a contact number to use if they had any further questions.

The day of the first interview, two people showed up to partake in the research. A fortnight later the second interview took place and the same two participants arrived again.

Research Participants

The research participants who took part in the interviews/discussion were both female and chose to take part due to an interest in the topic. Both participants were in their late thirties to forties. The two participants have both worked in the same residential nursing home for over two years and both have seen multiple residents die in their care while working there.

Inclusion criteria

Participants who have cared for residents in residential care facilities in end of life care and who have experienced the death of the resident.

Exclusion criteria

Due to the nature of the research question, I had to exclude those who have not experienced the death of a resident. In addition, those who did not feel able to take part in this study are self-excluded.

Location of the Interview: Creating space

I decided that I would not conduct the interviews in the residential nursing home where I advertised for participants. I would use a neutral space that was convenient to the participants in relation to locality. I booked a room in a local centre that hired rooms/space. The room was spacious and airy. It had neutral colours. I had tea, coffee, and biscuits available for during the interviews. I also had a box of Kleenex tissues close by in case they were needed due to an emotional release. I had water available also. I opened the window to let fresh air in and I set the room up so that we were all sitting around a small table facing each other. I thought about only using chairs but I decide the table was small enough and it did not separate us as a group, but created a base as we were relatively close to each other and could

rest our upper body on the table or lean in closer to talk. I really wanted the environment to feel like we were a group of people having a chat and a coffee over a kitchen table. That is the space I wanted to create and again this attends to an adult education epistemology of creating space.

There were no noise disruptions and I felt this was important, because if we were at the nursing home, call bells would be going off, people might be walking in and out of the space, especially wandering clients, and the participants could quite possibly be called upon if they were needed due to staff shortages. I also put a sign on the door, saying 'please do not disturb'.

When the participants arrived, I met them at the door and welcomed them by allowing touch to take place, by offering my hand to shake. I wanted them to feel connection straight away. I ensured I smiled at them and welcomed them into the space. I tried to look relaxed and comfortable in the situation, hoping this would encourage them to mirror my behaviour. I really feel that creating the correct space is important for when we want to create dialogue, as it is important to set the scene. I have learned this is an important part of creating an adult education space and I will discuss this in more detail later on in my reflections.

Methods

Open question Interviews

I have chosen to conduct the research through semi-structured interviews. Chase (2005) describes the interview as “a conversation-the art of asking questions and listening. It is not a neutral tool, for at least two people create the reality of the interview situation” (p.643). I felt that seeing the interviews as research conversations was more in line with my practice and epistemology.

I felt this approach was best suited to the research process, as I wanted the participants to feel relaxed and not actually feel like they were being interviewed. I preferred a more non formal approach where discussion and narratives could take place, where there were no feelings of hierarchical dimensions between the researcher/ facilitator and the participants. Oakley (2000) advocates for a participatory model of a non-hierarchical, non-manipulative research relationship, which has the potential to over-come the separation between the researcher and the researched. I started a conversation with a purpose by welcoming the participants and introducing myself and engaged with small talk. I felt this was important as

the participants might be anxious or concerned about the process and I wanted to make them feel at ease. Even though I had no set questions to ask the participants, I did have some themes/ideas that I wanted to discuss (see Appendix E). These include experiences of death in the vocational workplace, supports and communication available to staff, and the culture of the organisation in relation to the death of a resident.

Recording the Interviews

I ensured that the participants were aware that the interviews would be recorded on the poster which was advertised looking for people to take part in the research study. In addition, when conducting the research I showed the participants the recording device and showed them where I would be placing it. I did tell the participants that if they needed me to I would stop recording at any time. I used a Dictaphone to record the interviews so the files could be transferred onto a memory stick and left in a secured safe. I advised participants that they could choose a pseudonym if they preferred, as anonymity and confidentiality must be considered when carrying out research (Sim & Wright, 2000).

I transcribed the recordings, opening up a space for recollection of the emotional experience, listening repeatedly to the emotional nuances of the interview (Bahn & Weatherill, 2013, pp.19-35) and I offered the transcripts for the participants to review to see if they were okay with everything that was discussed

Storytelling

This research started with me telling a story about a lady who I looked after in a residential nursing home, who died. However, the story was only half told, and I described in the story the scene, the day the lady died. I did not reflect on long term effects that her death and many others like her had on me. It was not until I started my research that I began to be aware of all those untold stories that were within me waiting to escape, to be understood, to be told, to be freed. These stories held my emotions and experiences. But without acknowledging them or discussing them, I was allowing myself to create my own assumptions of the experiences I had which were false and harbouring self-destructive feelings of self. I felt it was important that if I was asking the participants to share their own stories and experiences with me through narrative discourse, then I should lead by example. As part of the interview

process, I invited the participants to listen to my first experience of death in the residential care facility where I worked.

My First Encounter

Standing by the bed, I touched her cheek, it felt so cold. A shiver ran through my body, I could feel it awaken all of my senses. I was engulfed by the knowledge of death. She had no pulse, her breathing was non-existent, and her rosy glow and smile had disappeared. My heart sank. She was my first.

I was not prepared to feel how I felt, sadness for she was not only a resident but I thought of her as a friend, an honest friend, who was not afraid to tell me if I was carrying out a task incorrectly or if I was not fast enough getting to her in the morning. She was ruthless but also kind. The guilt of the thought of her dying alone in her sleep, no one to hold her hand as she took her last breath. The thoughts that haunted me for a long time after were of her wondering if anybody actually cared. I hope she felt like she mattered.

Ellie was a lovely lady who died while in a residential setting in which I worked, she died during a cold night in October. I remember it was cold because when I arrived for work that day my hands were so cold from the dark early morning walk into work. I remember the warmth of porridge heating up the bowl as I prepared the trays for breakfast. Ellie liked salt in her porridge, with a small bit of milk. I remember thinking that it was a strange concoction. But Ellie loved it. I looked forward to setting her up for breakfast. I knew her routine now. But I never got to give her that last meal.

Ellie's death was confirmed by the nurse manager, she looked at me and directed me to "Lay out the body for presentation". She turned on her heels and closed the door behind her. The room started to feel very small, my head was spinning. It felt like I stood there for an eternity rooted to the spot staring at this lovely lady who I had come to know too well. Was this really happening? What was I supposed to do? I remember the feeling of sheer panic. I never laid out a body before. As I approached her bed, it felt like my legs were laced in lead.

I bathed and cared for Ellie that morning like I did every other morning, only this time it was with a heavy heart and for the last time.

A team member arrived, she asked was I ok. She stroked my arm and said “It gets easier”.

I did not believe her.

As the morning progressed, there was other people who needed my care, some knew about Ellie’s death and others did not, the routine of the day just carried on. This shocked me, even angered me. I felt numb and very useless. Useless to Ellie and her small gathering of family and friends.

My shift ended. Ellie had been taken by the undertaker. She was gone...

It was still so cold when I left work after my 12 hour shift. But I appreciated it, the sharp cut of the wind in my face, I wanted to feel it. I needed to feel it.

Then I breathed...and shed a silent tear.

Journaling

Journaling is a method of keeping track of your thoughts, feeling, and experiences. I decided to keep a track of my learning experiences that I encountered during my research project. The idea of journaling was presented to me by a lecturer in the Department of Adult and Community Education, Dr Jerry O’Neill. He discussed the benefits of journaling as a way of noting and reflecting on the experiences during the research process, as the reflective journal “provides a vehicle for inner dialogue that connects thoughts, feelings, and actions” (Hubbs & Brand, 2005, p. 62). When I started my reflective process, I decided to get two note books, one that would reflect my personal experiences and reflections and the other to gather the research findings. This process of writing in the two journals did not really take off, as I seemed to be overlapping my personal experiences and the researcher’s experiences. Two things that I came to realise was that, the two experiences, that of my researcher self and personal self, were one, and I could not separate the two. The second thing I learned from deciding to keep two journals was that I was afraid of others accessing my thoughts, fears, and emotions. The reflective journal holds potential for serving as a mirror to reflect heart and mind, allowing access to the internal “making of meaning” (Hubbs & Brand, 2005, p.61). I felt ashamed because I did not feel good enough in my previous role as a Healthcare Assistant. McCormack (2010) talks about how journaling can be “a conducive activity to processing professional experiences, particularly experiences that are disorienting or distressing, is an important resource in professional life” (p.31). I felt I was not professional due to feeling upset due to the deaths of those I cared for, being able to note these thoughts

down and really reflecting on them encouraged me to allow myself to open up about my experiences. I was afraid of others reading this. But I have come to realise the importance of reflection, that it can act as a learning tool for me and others to benefit from, that reflective journals “can be significant adjuncts in the transformative learning process...can provide ways to illuminate automatic thinking and habits of mind” (Hubb & Brand, 2005, p. 63). It was through the process of putting pen to paper myself that I began to truly see the benefit reflective writing and journaling. Rogers (1961) discusses how the only learning which significantly “influences behaviour is self-discovered, self-appropriated learning” (Rogers, 1961, p. 276).

The start of my Journaling

Journaling, or keeping a diary as my daughter declares, is a new concept to me:

Daughter: What are you writing?

Mammy: Oh everything and anything

Daughter: Is it like a diary, it looks like a diary (she peers over my shoulder, there is nothing sacred in this house)

Mammy: It is like a diary, I am trying to write down my thoughts and feelings

Daughter: What thoughts and feelings, are you ok?

Mammy: I am love, it is for college, I am reflecting on the process of the course I am doing at the minute, I am trying to get my head around it all

Daughter: We have to do something like that in school for c.s.p.e class

PEERING OVER MY SHOULDER AGAIN

Daughter: Though mammy to be honest if I was to hand up something like that to Ms Walsh she would not be long about handing it back to me, it is very messy.

And off she trots...

To be honest she is right, it is a huge mess, how could anybody even understand what I am trying to say, it feels like there is so much information jumping out at me, I am not able to get it down on paper quick enough, and my rambling thoughts do not seem to be making sense. Or I am not making any sense on paper, it seems clearer in my head but not clear enough for me to reach a focus on one point at a time, it creates like a sub thought to another point I am trying to make somewhere else in the mind of Dawn.

I go out into the garden, I need some fresh air, or space. I am starting to feel trapped and overwhelmed.

I look at the words on the page and I pick one

I focus on it and write. I write and write and write, after I write, I read, then, reread, and then write some more.

Putting words on paper fixes a version of reality, but at the same time makes it available for reconsideration. Sometimes the process of writing may prompt subtle shifts in perspectives; then re-reading-receiving back the material – allows the thoughts and feelings to return in modified form, making it more possible to reconsider them (Best, 1998, p. 157)

This is the start of me making sense of journaling. This is how I started to journal, all the ideas scrambling around my head I just vomit them on to the page, its messy, it is not nice to look at and Ms Walsh definitely would not approve, but it is my starting point. From there I can concentrate on a reflection that emerges from my train of thought, from the writing that appears on the page. I can face those internal thoughts and capture emotions and feelings as they emerge through my experiences and research.

There is no stopping me now.

Analysis of Methods

Methodology is “the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcome” (Crotty, 1998, p. 3). When reviewing my methods for collecting my data, I have come to understand and appreciate the importance of qualitative data. It can allow the researcher to gain in-depth knowledge into the real experiences that are felt by participants, which sometimes can be overlooked or not recognised. It is from the qualitative data that true meaning and understanding can evolve for my research question. The interviews enabled me to obtain the most relevant data on the experience that healthcare staff had from working in an environment where death and loss occurs. The qualitative and narrative approaches I used during the interview process worked well for my research, as I was able to adjust the interview if I felt the need for additional probes or if I wanted to enquire more about a topic or experience raised by the participant. This allowed for a more in-depth understanding of the participants’ beliefs, attitudes, and the situation. I was face to face with the participants. I felt this allowed me to observe their behaviour and pick up on any non-verbal clues. It also

made me aware if the participants were comfortable or not by observing their body language. I also felt that doing interviews with open themes/ideas and using narrative approaches worked better for the sensitive topic of death, experiences and workplace practice, as it allowed the participants to speak for themselves; in that regard, you are empowering them and treating them with dignity and respect and as an equal, thus, their words, experiences, and feelings are important and they matter. You are allowing them to have a space to create their own narratives, express their own emotions and support and empower each other through existing knowledge. Even though there were just two participants I do feel that it allowed me to gain a greater understanding of their experiences and allowed space for narratives to be opened up, but Creswell (2009) acknowledges that qualitative research is limited because of the lower quantity of participants.

I felt that the journaling of my journey through the masters programme and while engaging with the thesis research, allowed me to become expressive in my thoughts, as I was able to capture them, then reflect on the experience. It allowed me time to reflect and engage with the thoughts that were running through my mind. It helped me create a clear focus also at times when I felt disorganised and confused. I was able to keep track in a short of linear fashion of the process of the thesis and the stages involved. I could go back to my journal and open a page and recount my thoughts after the experience. This helped me greatly when putting my thesis together on paper.

Ethical Considerations

When carrying out a qualitative research study, it is important to consider ethical considerations. Qualitative research provides a way of engaging with human participants and this requires the researcher to provide a duty of care to the participant. According to Kirby et al. (2006), ethics are paramount when carrying out research and the researcher must ensure that the participants are not harmed in any way, emotionally or physically (Kirby et al., 2006).

Participants must be treated with dignity and respect, as the participants are discussing their lived experiences. As such, the researcher followed the code of ethics as outlined by Maynooth University's research ethics policy. In this study, it is important that I include healthcare staff as part of my research who have experienced the death of a client in their vocational practice as part of my research thesis. I am working with a healthcare organisation who I used as a gatekeeper to access the participants for my research thesis. So it was

important that I formally introduced my topic and the format in which I was carrying out the research by a letter of introduction (Appendix C). I also provided them with a poster to stick up in the staff canteen (Appendix A). It was important that management reviewed and agreed with the wording of this information and that I was not conflicting with any confidently policies that were in place.

Before, during, and after research is taking place, it is important to fully respect the decisions of a participant if they decide not to participate in the research project. The participant should also be given the chance to withdraw at any time prior to publication (Gilbert, 2001). It is also important that the participants trust me, so I presented an ethical statement, which I asked my participants to sign (see Appendix B). If they felt they would like to end the interview / discussion at any time, then their decision is respected. As a researcher, I must protect the rights, dignity, and wellbeing of the participants who take part in the research. To ensure that the participants were happy to discuss themes I was interested in, I also presented each participant with an introductory letter (Appendix C), detailing the purpose of the research.

Measures will be taken to protect participant privacy (confidentiality and anonymity) by, (a) using a locked filing cabinet in a private office in Kells, Co. Meath to store all relevant information during the course of the research; (b) using a coding system to keep participant names and contact information separate from data collected during the research -this data will be destroyed upon completion of data collection; (c) altering potentially identifying information; and (d) giving all participants the opportunity to review pertinent data (i.e., final transcripts, transcript summaries, audiotapes, etc.). In lieu of the above, tapes and transcripts will be identified by a code that will be known only to the researcher. The participant should also be given the chance to withdraw at any time prior to publication (Gilbert, 2001).

Conclusion

An overview of the methods and methodology used in this study was provided in this chapter. The paradigm of a qualitative approach, which allows for “interpretive, naturalistic approach” to gain understanding about human experiences (Creswell, 1998, p. 15), which this research used, was presented. Justification was given for using a qualitative approach using a social constructivism lens with a narrative inquiry and reflexive practice. The process of research design, sampling methods, data collection, and ethical

considerations were all outlined. Findings and discussion will be presented in the next chapter.

Findings and Discussions

I began the process of listening back to the information from the discussions with the participants by listening to and transcribing all of the interviews, as recommended by Josselson (2011, p. 228). I started to identify themes which were arising using a thematic analysis, “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). At the beginning, I felt it was confusing, as there seemed to be a lot of themes emerging, but I was then able to fit each theme into an overall theme; “thematic analysis is a form of pattern recognition within the data, where emerging themes become the categories for analysis” (Fereday & Muir-Cochrane, 2006, p. 4). I have discussed below the emerging themes which I identified from my coding analysis. Braun and Clarke (2006) also state that a theme captures something important about the data in relation to the research question and is in some way representative of a pattern that is occurring in the data. To be true to my research, I ensured that, as Riessman (2005) proposes, I “re-read and re-read the transcribed interviewees several times to get a feeling for general meanings and themes” (Riessman, 2005, pp. 2-3). The themes that have emerged as part of this research include,

1. the experiences of Healthcare Assistants in relation to the culture of the environment which include rituals, death review and attachment in care,
2. the importance of communication and
3. the effects of low morale among Healthcare Assistants working in end of life care.

Also identified are the reflections that the participants felt by having a space to chat and discuss their experiences. My reflections as a researcher throughout the Masters in Education Programme was discussed in relation to the importance of using adult education principles and practices while communicating with the participants.

The culture of the environment and rituals

The data collected showed that the environment in which the participants work plays a crucial role in whether they feel supported in their role in end of life care. Every society has norms that frame grieving. These norms include expected behaviours, in addition to feelings, thinking, and spiritual rules within that society. Therefore, when a loss occurs, there are grieving rules, in how one should expect to behave, feel, and think based on our cultural

simulation. A common theme that arose in the research highlighted that the healthcare staff felt that rituals were important in supporting the grieving process and allowing healthcare staff to grieve and express the loss they feel. Rituals can be very formal, such as those seen in many religions, but they can be informally created by those needing to come to terms with the loss of a resident. It allows healthcare staff to express emotions or the loss. When the theme of rituals arose in the interviews, the participants talked about how these were important to them, as it helped them grieve.

“When the coffin is leaving all the healthcare staff and residents if able do a guard of honour as the coffin is leaving the premises, we bow our head or bless ourselves as the coffin passes, one man loved the song country roads so we had that playing as his coffin left, awe I still miss him”

“We have a tree of life, it is a big tree art piece in the front hall, when a resident dies, and we put their picture up on it”

“The nursing home started to do a mass in November for all the deceased residents, and we say prayers and poetry, all the families and residents are invite”

“When a resident dies, we put up the end of life care symbol, and a photo of them beside it in the main foyer, this is to let people know someone has died”

“There is a text message service, so when someone dies you are notified, but it is not always used. Also you need to have an app as they use a free messenger service and not all staff have the app, instead of sending out a normal text so everyone would receive the information that a resident has died. One of the carers were really upset that he missed one of the residents funerals, he did not have that app on his phone he was really close to him, he was very upset about it all”

When I asked the participants if these rituals and practices helped them in any way, they responded positively:

“Oh yes it give you time to say goodbye in some small way”

“It shows the family that we care even if we cannot openly express it”

“I feel like I am showing respect”

“It is the last thing we can do for them, we want it to be right. It gives you a small feeling of closure”

Although the participants reflected positively on the rituals in the workplace, the organisational culture around death and loss did not sit well with their own personal culture which they were accustomed to around end of life care, and this caused some distress and upset:

“I could not believe it, one of the resident died, Mary she was there a long time and the coffin had literally just left the building, when management sent down word that her room had to be cleared out straight away and belongings to be put in storage, as there was a new resident coming in. I could not believe it I was so annoyed. Like what if

the family came back to get something from her bag or a picture and we were there stripping her room. She wasn't gone 30 minute I am telling you. I felt so disrespectful. I was so angry at management for that"

"A lot of the time we do not get to their funeral, it can be hard, especially when you are close to them. A funeral kind of helps. But at least there is a representative from the home there for the family at least"

"I was so shocked, and upset when I heard that only three people were at her funeral and two of them were from our nursing home, and her coffin was a closed coffin, You do see some of the resident have no visitors, but in the back of your mind you be thinking there is someone out there somewhere belonging to them. But no she had no one only us"

Death Review

The participants discussed their experience of attending a death review, a strategy for the organisation to develop and understand the needs of the dying resident, their family and the staff:

"We have death review meetings every few months, it is where we come together to talk about the deaths that occurred in the last few months, they pick one and we discuss it. Like did we do everything right in end of life care, were the family looked after, what could we do better the next time"

"We never get to discuss really how a death made you feel, not like we are doing here. It is more just a formal practice, they only ever last 15mins, and I think the longest one ever was 30 mins. It is more a tick box sheet, Management have a sheet they ask questions and tick it then we are done"

"I made a comment once, and it made me not want to say anymore, I made the comment, how it was sad that one the residents was always on their own, and I was sad that they died alone, the manger just said well she had family, I was shut down. I only was saying I felt sad by it, I did not know she had family I never saw them"

"You do not feel comfortable talking sometimes, Sarah, the manager came in to start the meeting and before she said anything, she says come on can we get on with it, I did not get my lunch yet. We knew it would not last long"

"Not everyone gets to attend them as there are three wings, and it takes place at a certain time for 15 or 20 mins, so people are either on their break, or cannot leave the floor. Most people will not come in on their day off as it is not really worth it, as you be only there for 20 minutes at most. Some people do not even know what the death review is as they have never attended one"

"We do not talk about grief or the stages or how to identify them or if we are experiencing grief, it would be helpful to understand them more. We are told to watch out for behaviour changes in residents"

I feel from listening to the experience of the participants, that this strategy is not being utilised to it full advantage. It seems that the death review is carried out on paper and as per policy in relation to end of life care support, but it is not meeting the goal on the ground and

for the frontline staff. The importance of the death review is not recognised by the staff members due to their absenteeism, and the lack of attendance. The management structure of how the death review is carried out is also very business-like and not humanistic, which death certainly is. As such, the death review does not offer the space for staff to be able to discuss experiences in relation to end of life care due to the nature of how it is presented which could quite easily be changed. This should be mandatory for all staff provided at different times throughout the month to meet all the unit's needs. The facilitator should want to deliver the death review and be educated to understand its importance and, if utilised correctly, the benefits it could bring to the workplace; for example, staff with better morale and a more educated workforce, who are willing to engage in dialogue and gain support from each other.

Attachment in Care

Attachment in healthcare is nearly always going to form, if you are going to provide your client with holistic care, respect and dignity attachment will form. If you do not form an attachment with a client, how then can you support their holistic emotional needs? Unless attachment is formed, will they confide in the Healthcare Assistant? Can any relationship really form if there is no attachment? I feel the challenge this leaves for healthcare staff is that they are open to the continued experience of loss and grief, and this can have an overall effect on them:

“One resident died in the sitting room, she was absolutely fine, not unwell at all, she just sat down on the couch and closed her eyes and that was it, she was gone. We were walking down the hall and the carer that was with me, looked at me and said Nancy is a funny colour, I think she is gone. We went over and she was, it was such a shock, nobody was expecting it. She was absolutely fine, not bedridden or anything. We had to try get her out of the sitting room and up to her room that was hard as it's a dead body so very heavy and you're trying to be respectful and discrete, while at the mean time you're in complete shock. You know the management never even asked if we were ok after that. We are just expected to get on with it that was a very hard day. I cried a lot that night when I got home”

“I remember one lady, called Margaret, she was lovely, very quiet and did not like to leave her room, so I made an extra effort to talk to her and spend time with her. We eventually had a good banter going between us, every Monday morning when I went into her she would say to me “" Were You doing the Holy or doing the dirty" Doing the Holy was singing in the gospel choir and doing the dirty was singing in the pubs, I loved singing and she would get me to sing her a song. I still think of her often”

“I had a resident who I used to light a candle for every week at mass, and I would take the picture on my phone and bring it in to show her. She would want to ensure I had lit a new

candle every week and it wasn't the same picture, so I had to make sure she could see it was a new one in the picture. Even though she is gone now, I still have the pictures on my phone, I do not want to delete them. I do not know why, awe it is a nice memory to have"

"Paddy used to lie on the floor, in the beginning you would get a fright as you would think he was dead. After a while you got used to it, he was a bit of a joker. I know it sounds weird saying it here now, but it was just the way about him, and he was always following you around. He was always present, when he died everyone missed him, even though he needed so much attention, it was like a void in the nursing home, you would walk down the corridor passed his old room and say "wouldn't you miss Paddy"

"You always stop by the room when they are dying and pop your head in and stay for a minute between your tasks, you want to be with them and you want to be there for the family, because that is what it is like, we are a big family"

Space for Communication

The lack of physical space for healthcare staff to sit and reflect identifies the lack of understanding of the importance of narrative discourse, especially in an environment where the main support network seems to be the healthcare staff themselves. If space was afforded not only physically but emotionally to allow conversations to take place, this might benefit the organisation as a whole:

"We do not really have a formal space to talk about the death of our residents except really the death review, but we do not really do that there either"

"Sometimes in the canteen, we would start talking about the deceased residents, and it would bring back good memories or a little laugh, we would remember them with fondness, just a mention of their name, it feels good. Some of the older staff would also talk about the residents that were before my time. The staff like to remember"

"We would be walking down the hall and we would pass a room and you would make a comment like "awe you would miss Paddy, Jane, Olive" any of them. Even though the rooms have many different residents you do never forget the lovely people who lived in them before the new resident"

"We used to have a table outside that we would sit at last summer, it was a large table and all the staff would go out there at their break and we would have great banter, we could laugh and chat and talk about the losses that occurred, it was great because our canteen is too small, you see all the three units use it and there is only about 8 chairs, so there is always people waiting to sit down for their lunch so you have to just eat it and let the next person sit down, they built on another 50 rooms you see but did not increase the canteen for staff. But they took the outside table away, they said it was because of health and safety"

“To be honest we do not really get time to have any meaningful conversations, they are just fleeting moments of communication, so you do not really know how anybody is really feeling, and if all the losses are affecting them. They probably are, how could they not”

The Irish hospice foundation set up their design and dignity programmes, which are national programmes all across hospitals and residential settings, where they are changing old storage spaces into a space that will benefit the families, staff, and the dying. This is creating an environment where people feel welcomed and conversations and support can take place. A space designated to staff in this sense could be of benefit to the organisation as a whole.

Low Morale

When discussing emotions and grief and how it feels to work in healthcare, I identified that some of the healthcare staff displayed detachment to their organisation and their role. It was as if the healthcare staff extended themselves beyond the ability to emotionally care as they felt, “why should we care so much, when management do not”, due to the constant caring role that they were involved in and the feelings of lack of support. The participants discussed emotions and feeling that identified with compassion fatigue, “a stress response that is sudden and acute and has been defined as a physical, emotional and spiritual fatigue or exhaustion that takes over a person and causes a decline in his/her ability to express joy or care for others” (McMullen, 2007, pp.491-492).

“There have been many times I have thought do I really want to be here in a place like this, especially when you feel like management do not care. Like the time they made up clear up the room and the lady had literally just left in the hearse, I just felt terrible, I did not want to be there or to be doing it, it just felt so wrong. I ended up feeling so guilty, like why did they make us do that so soon. What if the family came back or anything?”

“It is a business and it is run like a business, the people in the office do not know the residents, yes they know their name is John in room 22, but that is all they know, they do not know how he likes his tea, or that he needs four pillows to be comfortable or that he was upset last week because it was his wives anniversary, so when John dies you will not be asked are you ok, or anything you are just expected to get on with it”

“Sometimes you feel like you’re just surrounded by death, all the time”

“I once reflected at the death review that I felt that the room were cleaned out too quickly, and the response I got was okay. End of story, there was no room to discuss it or even acknowledge it, just an okay and moved on. It is getting more and more like that now anyway”

“I wonder do they ever consider (management) for a second, the effects that the deaths do have on us, like I am there three years and I wonder do they ever think oh she has lost 20 residents in the last three years does it have any effect on her”

“They are up in their office, we are here on the floor, and they do not have the same attachment as we do for the residents, so they do not understand the emotions you feel”.

“There are some days you just do not want to go in, it is hard, and everybody is feeling low, the staff is always understaffed due to people being off so the workload is always heavy, nothing is done you just have to get on with it”

“Sometimes you get bogged down, you can get really busy in work so you just do the job and want to go home”

I felt some comments highlighted that “some days you come in and do your job, you just get on with it and then go home”. I felt this response, resulted from feelings of low morale, low self-esteem, and lack of feeling supported. These are emotions which can build up due to disenfranchised grief, which can lead to compassion fatigue and burnout, “a state of physical emotional and mental exhaustion caused by long term involvement in situations that are emotionally exhausting” (Pines, 1988). It is characterised by feelings of being emotionally drained (emotional exhaustion), the development of negative attitudes and feelings towards patients (depersonalisation) and a growing devaluation of self-competence and achievement (reduced personal accomplishment) (Maslach & Schaufeli, 1993; Maslach, 1993). I am not saying that this is what was happening for these participants, but there should be an awareness that this can be an end result if adequate supports and recognition are not in place.

Participants’ Reflections on Interviews

I felt that an important part of my learning took place when I identified the feeling that resonated with the participants by giving them the opportunity to voice their thoughts, and tell their stories. I felt I gave them a voice.

“It felt good to talk, I didn’t think we would have so much to say”

“I never realised how much it affected me, the losses, but they did of course, my mood and behaviour, it helps you see why you felt or behaved a certain way”

“It felt good to talk, this was like a free therapy session, and I felt great leaving here the last time”

“I was talking to my Mother during the week and I was telling her what we were doing here, and it got us chatting for a while, it felt good and it made me aware of the importance of chatting about my feelings”

“We are talking together and one of the residents left a gift of money for the staff to have a night out, but not all staff can go due to working, family arrangements etc., so we are going to propose a seating area for staff, so we can have a space to chat together seen as the outside table had to be taken away due to health and safety”.

“It is important to talk”

“I feel that by talking about the residents here, it helped me think, yes I cared for them, we had some nice times, and I can give them some proper headspace then move on, a bit like closer”

I felt that the participants really appreciated the space to talk, reflect, and remember those they cared for in end of life care. The process also allowed for thinking at a deeper level in relation to their organisational culture, both the positives and the negatives. This awareness can empower the participants to understand their own emotions or why morale may be low in their workplace. It also encouraged them to think proactively in relation to simple solutions that might arise in their workplace; for example, the idea of a new sitting area. This empowerment will increase morale and can create change in an organisation. Change can take place when one person decides to change their thinking or action, and it can have a ripple effect.

Researchers’ Reflections on using a Person Centred Approach with Adult and Community Education Practices

A theme I have seen emerge through the research is the importance of using adult education methods and person centred care approach. I feel using a holistic approach when communicating with the participants is hugely beneficial for authentic learning and dialogue to take place. The participants need to feel you are genuine, and interested in what they have to say. I felt the participants felt safe opening up to me and talking to me about their experiences. This was more new learning for me. An area of reflection that I overlooked, as a facilitator, was how did I create the conditions that enable these conversations to take place. I began to ask myself would these conversations not take place anyway if the topic were addressed. Does the facilitator have a role in creating the space for these conversations to take place? This made me reflect on my own use of facilitation skills as an adult educator/facilitator.

Analysis of Findings

Introduction

The main areas that I felt were identified throughout the research and the findings were the culture of the organisation and protocol after the death of a resident, the importance of peer support and space, forming of attachments within the caring role, and formal support in the form of a death review, and educational support. Even though there are supports in most of these areas, I felt that there could be improvements put in place to better support Healthcare Assistants in these topics which arose. I also discussed my role as a facilitator and the importance of providing person centred care approach when communicating with adults. I felt this reflection supported my own transformative learning as an adult, facilitator, and as someone who experiences loss.

Culture of the organisation protocols and rituals

The importance of rituals and protocols, which take place after a resident dies, was obvious by the comments made by the participants: *“When Michaels daughter came in to attend the mass there last November she was so surprised we had a picture of her dad up on the tree, it took her by surprise. She was so appreciative that we did not forget him”*. They discussed how this ritual in their organisation made them feel good, because it was like a mark of respect that the staff and activity co-ordinator put in place. It is like an area of remembrance. The mass/service of remembrance I mentioned previously is new to this environment and it helps with the grieving process and allows time to reflect; this was highlighted as a “lovely event” and it was nice to see “old familiar faces”. The participant mentioned how the families were really impressed by this support. When the resident’s body is departing from the residential nursing home, there is a guard of honour by the staff on duty. The participants reflected that it feels good, as it is the last thing they can do for the resident and the family and can help with closure. It is also protocol for a representative to attend the funeral of the deceased. I felt that these supports are very important for the Healthcare Assistant and the family, but I also felt that these public supports which can be seen by the family and by the public are more influenced than discreet supports which could be provided to healthcare staff and I feel I may be biased in this thinking as a researcher from past experience. In many different cultures, rituals are one way in which people search for meaning after a loss of

someone they care about. Neimeyer et al. (2002) note that rituals “serve both integrative and regulatory goals by providing structure for the emotional chaos of grief, conferring a symbolic order on events, and facilitating the construction of shared meanings among members of the family, community, or even nation” (p. 237). Thus, it is important for healthcare staff to have a sense of closure and the opportunity to grieve. It is important that grief is recognised and allowed to be expressed for the grieving process to take place; this has to be part of the cultural norm. Culture is defined as the patterns of behaviour, customs, beliefs, and knowledge of a group of people (Spradley, 1979). It is important then that organisational culture supports healthcare staff. While we understand that this is important, I felt in some of the findings presented that this can be lacking, as we have our own norms around death and loss and how to cope with them from our societal and family cultural norms. Thus, when we are not afforded these opportunities in the workplace, it can create a sense of non-closure for the grief. As such, I feel that more discreet supports could be put in place for healthcare staff where they are not performing for the public sphere.

Formal support from the organisation and death reviews

The research identified that there was formal support put in place, but many put it down to policy and not really meeting a need. As such, death reviews were in place but the participants felt it was just a tick box exercise. This perception must have come from experience. The participants discussed the limited time that was spent on the death reviews, no more than 30 minutes at a time; which was pushing it, timewise. Participants felt they could not contribute any information that might be seen negatively or they would be “shot down”. The participant discussed how they felt some staff did not even know what the death review meetings were about. The staff were not communicated to about their importance and attendance was always very low. I feel more training for management in relation to the process and facilitating of the death review is needed. This could be an invaluable opportunity to gain knowledge from the wealth of experience that Healthcare Assistants bring to an organisation and through their daily work practice. There was a messenger service, but this was not being used by all staff. A regular sign-up sheet should be updated regularly and an option available for how to be notified of a residents death. There should be the option if needed for outside support from a counselling service. Most professions that support adults through mental health, life issues, addiction etc. are supported with supervision or counselling support, but this is lacking for these Healthcare Assistants. The

biggest area I feel that improvements need to take place is in relation to acknowledgment from management of the effects that loss and grief can have on staff. There should be acknowledgment that multiple deaths may have an effect on staff, that it is not just ‘all part of the job’.

Peer Support, space for communication and Low Morale

I felt that there was an opportunity for management to utilise the support network that already is available within the organisation. I felt that the Healthcare Assistants should be afforded the opportunity to talk about grief, loss, and the experience of caring for those in end of life care. Healthcare staff should be empowered to guide and support each other through the grief process. There should be a mentoring programme or team leader support where those with less experiences in end of life care can be supported. The interviews identified that the participants had witnessed and felt episodes of low morale within their healthcare organisations. These feelings can emerge when there is feelings of not being supported in their role, which can result then in compassion fatigue. The participants told of their experiences when they tried to acknowledge feelings to management that related to their role but felt that they got shot down or were not listened to. I feel the biggest cause of low morale was the lack of acknowledgment in the losses that occur and not being afforded time to communicate and talk. One participant spoke about how you could not really be seen doing nothing, so you cannot stand there talking to staff about your feelings and about the death of patients; “You cannot even really be talking to the residents as you feel bad and they make you feel like you are slacking” and “There is nowhere to talk, it is a pity really, because we were saying we felt great after our last chat here, it really lifted us up”. I felt these comments were really important, as they identified the importance of how talking can create a positive experience. Letting people tell their stories can help with an emotional release.

Attachment in Care

The link to attachment and grief, as highlighted by Bowlby (1961), seemed to reinforce the basis for understanding bereavement. It was suggested that grief was a normal adaptive response. Bowlby felt the response was based on the environment and psychological make-up of the griever and that they were normal reactions one might expect. The ‘affectional bond’ had been broken, which result in grief. Bowlby provides an explanation for the

common human tendency to develop strong affectional bonds. He views attachment as a mutual relationship that occurs as a result of long-term interactions, starting in infancy between a child and its caregivers and he suggests that grief is an instinctive universal response to separation. Mallon (2008) observed that, in order to have loss, there must be attachment. Attachment theory proposes that we learn from and continue relationships based on our accumulated experiences of relationships (Bowlby, 1988). From listening to the narrative from the participants, it was obvious that they have developed relationships with the clients whom they cared for. This was evident by the symbolic keeping of pictures of the candles on one of the participant's phones long after the resident had died. Fondly remembering the residents and telling stories that they shared, missing the resident and being aware of the void they have left. Attachment in healthcare is nearly always going to form; if you are going to provide your client with holistic care, respect and dignity attachment will form, and if you do not form an attachment with a client, how can you support their holistic emotional needs? Thus, unless attachment is formed, you are left wondering if they will confide in the Healthcare Assistant. Can any relationship really form if there is no attachment? I feel the challenge this leaves for healthcare staff is that they be open to the continued experience of loss and grief and the overall effect it has on them.

Educational Support

I feel continuous professional development training days in end of life care and grief theory will support the Healthcare Assistant to recognise grief in themselves, their colleagues, and their residents. I also think that all new staff should have a mentor to support them as part of their orientation training. Staff that are educated in end of life care and bereavement are more aware and confident in their role, working with death, loss and grief. Although I feel this training would be relevant as a form of support, I really feel that the presentation of the training should be delivered through the practices and principles of an adult education method, where the adult education principles of dialogue, sensitivity to creating appropriate space, reflexivity, and drawing on the participants' experiences are part of the learning experience. I felt that throughout my research this was the approach I tried to instil during my interactions with the participants. I feel this approach was hugely beneficial to engaging with the participants and allowed for authentic conversations and reflections to take place, which encouraged the participants to self-reflect on experiences and question their own assumptions.

Researcher's analysis on using a person centred care approach

During one of the group supervision sessions, I was discussing my interviews I had with my two participants. I was happy with the outcome and felt that it went really well. The participants seemed happy and were willing to discuss the themes that were emerging. They were open and trusting in the information they were sharing. I was delighted and they seemed to want to stay continue talking. As mentioned earlier, an area of reflection that I overlooked, as a facilitator, was how did I create the conditions that enable these conversations to take place? I began to ask myself would these conversations not take place anyway if the topic were addressed. Does the facilitator have a role in creating the space for these conversations to take place? This made me reflect on my own use of facilitation skills.

On reflection, I have become aware of how influenced I was by the work of Carl Rogers and Ursula O Farrell and their understanding of person centred therapy. I work in an environment where one of my main aims is to encourage healthcare staff to understand the importance of a humanistic approach while providing person centred care, and I feel I have adapted this approach into my everyday life and practice unknowingly. Carl Rogers (1902-1987) was a humanistic psychologist who agreed with the main assumptions of Abraham Maslow, but added that for a person to "grow", they need an environment that provides them with genuineness (openness and self-disclosure), acceptance (being seen with unconditional positive regard), and empathy (being listened to and understood). I feel this was the approach I was trying to achieve when meeting with my participants for the interviews and although I did not set out for my research interview to be a therapy session, I still wanted to adapt the principles that are applied when using a person centred approach.

O Farrell (2006) discusses some basic requirements that are important for both the client and the facilitator. Firstly, privacy is paramount that "the client needs to feel that they are in a secure, private cocoon where self-expression can come freely and without constraint" (O'Farrell, 2006, p.54). I felt that this was the reason I chose to carry out the interviews in a space that was not the nursing home, where the participants worked. I wanted the participants to feel safe to express themselves and to know that nobody they knew would walk in and hear what they were saying. Ensuring the comfort of the participant is hugely important and this is the responsibility of the facilitator, with O Farrell highlighting that the environment should be neutral but also comforting with adequate lighting, adding "the counsellor should physically put themselves in the seat of the client to see the environment from their perspective" (O'Farrell, 2006, p.57). This is why I arranged the seating as I did in a circle, with each person facing the other, as I wanted the participants to feel connected but not too

close, though close enough to share inner thoughts. Sometimes when we share inner thoughts, our voice can become lower, so I wanted us to be close enough so this would not hinder the conversation. I wanted a room that was spacious and airy and not too distracting and I ensured the window was open to allow fresh air in, and there was refreshments available. I felt if their basic needs were met, they would be more open to me and the interview. Time constraints are important and being punctual is key and for this reason I was there waiting and ready for the interviews before they arrived, as the participants need to know I was attentive to them. I informed them that the interview would be up to two hours long at the induction meeting, with a clock visible in the participants' view, allowing them to be aware of the time and also giving them time to "pack up mentally" before the interview ended (O Farrell, 2006). O Farrell (2006) states that note taking should generally not be done during the session, as it takes the attention away from the participant and may lead the participant to not truly express themselves. In addition, the participant might become conscious of what is being written and become distracted. All of this was the reason I decided to use a Dictaphone, with permission gained from the participants. Record keeping is important and I felt this aspect could be done after the interview was over by listening to the recording and using my journal as a form of reflection.

The first introductions for participants can be overwhelming and, as O Farrell (2006) stated, the instinctive likes and dislikes we may often formulate when meeting someone new may be heightened for the participants, as they may be feeling a mixture of emotions. Thus, it is important to have empathy for the participants and not feel the need to illustrate competence, as this may come off in a negative way to them. I felt a humbled response to their support was appropriate, as it was a genuine response. When greeting the client, O Farrell (2006) discussed the importance of effective communication skills, that it is important to move towards the participant, and have open body language, and to greet the participants in a friendly approach; this will ease the initial introductions into light chit-chat. I feel by doing this you are showing awareness of the participants' emotions and already forming a relationship and it is important for the participant to feel this unconditional positive regard. They need to understand that the facilitator has deep and genuine care toward them. I felt I demonstrated this after I introduced myself by making the participants feel appreciated by being thankful that they showed up but they could also leave if they needed to. The participants at the start stated: "sure I do not know if we will be any use to you but sure we said we would come and talk to you anyway" and "we do not have much to say". O'Farrell (2006) states we must let the participant see that this is their time to spend how they wish

and that there are no set guidelines. I felt I tried to emphasise this by not having a set of structured questions but having themes that I might introduce depending on how the interview progressed. When a participant is introduced to an interview for the first time, it is important to remember that this is not a “normal” situation for them and the process will not be familiar as it will be for me as a researcher. O’Farrell (2006) suggests that “contracting” is an important part of the process, as it is giving some structure and guidance to the participants, and I felt by providing an ethical statement and discussing the research and who would have access to the research, this allowed them to be able to make the decision if they still wanted to go ahead with the interview. This, in turn, gives the client empowerment. O’Farrell (2006) discusses the importance of moving forward and allowing the participant to express themselves through talking about whatever is on their mind. It is important that there is attentive listening but also allowing the participant to see that the facilitator is responding and aware of what is being said; O Farrell notes that using nonverbal and minimal verbal responses will encourage this. I felt I found this challenging at time, as I wanted to explore narratives that arose during the conversations. When listening back at the Dictaphone, there were times I can hear that by asking a question I lead the conversation in another direction; at the time, I did not notice it, but it made me wonder if I continued to let them talk on that topic where it would have lead, and so for the second interview I was very mindful of that. When responding to the participants for the second interview, I tried not to use direct questions or closed question, as this can cause self-expression of the participant to cease, as they may feel the facilitator is judging them or it will encourage the participants to talk about the situation instead of the emotions that the situation caused. During the interview, I made sure to reflect back and show empathy for the participant and the narratives they were sharing, and I hoped this showed I was genuine and that I understood they are experiencing emotions that could be affecting their work life and personal life. During the interviews, the participants would be discussing work based practices and the effects it was having. At times, they were finding it hard to express themselves and due to having lived their experiences I really wanted to answer for them, but I knew it was important that I not put words into their mouth and that they reached the point they wanted to make themselves, when they were ready. I found this challenging and in the first interview there were times where I joined in and also expressed my thoughts and feelings but did not overtake their thoughts or influence them. I felt by sharing a bit allowed them to see that I was authentic and genuine in understanding their experience. Throughout the interview, I did need to clarify information, but this was done in an indirect way, which allowed the participants to answer as they saw fit: “How did you feel having to pack away the residents belonging” or

“perhaps you would like to tell me more about the support you received”. This is an open question and gives the participants the freedom to move the interview in whatever direction they want, allowing the participant to have ownership over the space and conversation. A communication approach I used was silence, and it was important to not feel the need to fill it, as silence allows the participant to reflect on what they are saying and in some cases they may be hearing their thoughts out loud for the first time and this can be overwhelming. It could also mean that they are finding what they are expressing difficult, and so the facilitator can acknowledge this: “I get the sense this is not easy for you talking about your residents death”. The facilitator and the participant have to explore these feelings further and as cited by O Farrell, it is not merely enough to stay on the surface of words, connection of feelings need to take place and the participant needs to become self-aware, to focus on their feelings and claim ownership of their feelings. From doing so, change can occur, which is similar to Mezirow’s transformation theory, as discussed earlier. I feel that the process used by myself during the interview was an unconscious awareness of understanding the need for space to be available for the healthcare staff to discuss their experience of end of life care in their vocational area, due to my lived experience. It was my own conversations that allowed me to become self-aware of the emotions I was harbouring, and I wanted to welcome others to have that opportunity. By doing this, I hoped that I empowered the participants to understand that they could express themselves with their colleagues and that it was ok to talk about the feelings they experience in their workplace. I wanted open dialogue and I did wish for conversations around death, loss, and grief not to be silenced.

Recommendations for grief supports in residential Care

- Encourage staff to reminisce about residents after they have died. Management should let the Healthcare Assistant know that the end-of-life care they provided to the resident is valued and meaningful;
- Allow space for discussion to take place, where staff feel they will be listened to and afforded the time to reflect;
- Implement organisational procedures to support staff dealing with grief and loss; for example, holding peer-led post-death debriefings after every death, frequent memorial services, and always acknowledging staff’s feelings of loss when a resident dies.

- Implement effective organisational communication systems to share knowledge of a resident's death in a timely way with all staff. Continued use of the end of life care symbol at the entrance of the residential nursing home, issuing an email to all staff, text message, in-house Mass cards or death notice put up in staff canteen.
- Support staff with the time and resources to reach out to residents and staff after the death of a resident to acknowledge their grief and loss. This, not only supports others, but also promotes a sense of completion for staff, which can aid the grieving process.
- Implement organisational strategies and rituals to acknowledge all residents who die in the residential nursing home. This will include those already in place and staff could be asked what rituals they would like to see implemented.
- Implement continuous professional development training programmes in palliative care education for staff, including strategies for managing their grief and loss. Make information visible and accessible to staff for both their own use and to offer as support for bereaved families; for example, pamphlets about grief and where to access counselling resources.
- Management should recognize the benefits of informal peer support in residential care facilitates and the value of experienced staff in mentoring inexperienced staff, especially where staff have no previous experience of death and dying. When providing a mentoring role, the mentor should be made feel appreciated for their role.

Conclusion

My Personal Reflection

Throughout this research piece, the main aim was to reflect on what support might be beneficial for Healthcare Assistants who work in residential care services who experience the loss and death of clients they cared for. Throughout this research, I began to reflect on my own experiences which were similar to those I was interviewing. It was through reflexive practice while chatting and listening to others that I became aware of my own thoughts, experiences, and assumptions. It took for me to be able to sit and talk with other healthcare staff, to be able to understand what I was feeling and why, to recognise I was experiencing grief (Nelson, 2018). To reflect on work place practices in healthcare allowed me to reflect on my assumptions, that we “can become critically reflective of the assumptions we or others make when we learn to solve problems instrumentally or when we are involved in communicative learning” (Mezirow, 2003, p.7). Mezirow (2003) discusses how “self-reflection can lead to significant personal transformations” (p. 7). I felt at this point in my life I finally began to understand I was grieving for losses that I felt I could not grieve for professionally. I had been experiencing disenfranchised grief and compassion fatigue. I was not feeling supported in my role which resulted in my own lack of self-esteem and leaving a job I loved. This was huge for me, as it made me accept that it is ok to feel sad, upset, and grieve when someone you are caring for professionally dies. To this end, Mezirow (1991) states that “reflective learning becomes transformative whenever assumptions or premises are found to be distorting, inauthentic, or otherwise invalid” (p. 6). The cultural assimilation of my previous workplace organisation identified that it is unprofessional to express emotions of grief. Disenfranchised grief is an unrecognised right to grieve (Doka, 1989). This can be felt by healthcare staff when they feel they need to maintain professional boundaries in their place of work, where it was certainly felt by me. With this in mind, the healthcare staff may feel they do not have the right to grieve openly for the patients they cared for and supported holistically by meeting their physical, social, emotional, and psychological needs. We may be called on to support others in their loss, with no acknowledgment that the death is a loss for us as well. A frame of reference is a “structure of assumptions or taken for granted beliefs we have about reality” (Mezirow, 1991). In my role as a Healthcare Assistant, my “frame of reference” did not allow me to feel like I had the right to grieve for the loss of my patients, however. In my role as a Healthcare Assistant, I felt it was important to be professional; to be professional, I should not experience grief.

However, through the narratives I was having with others who had similar experiences, I began to interpret my experience differently, as we give “meaning to experiences in large part by participating in dialogue with others” (Mezirow, 1991, p.58). Merriam et al. (2007) highlights that “that transformation is the process by which we transform our taken-for-granted frame of reference to make them more inclusive, discriminating, open, emotionally capable of change, and reflective so that they may generate beliefs and opinions that will prove more true or justified to guide actions” (p. 133) and Mezirow adds that reflective learning involves assessment or reassessment of assumptions (1991, p. 6), that: “Transformative learning experiences are emancipatory in that they free learners from the constraints and distortions of their worn frames of reference”. Through my narratives and discourses with other healthcare staff, this provoked a reaction in me. I wanted to be able to support others who were experiencing grief in their vocational role. As Mezirow (1995) stated, “A transformative learning experience requires that the learner makes an informed and reflective decision to act” (pp. 30-70).

I wanted to be able to support staff through some form of training programme, but what I have come to identify is that if there is space created not only physically but emotionally where adults can come together and reflect on their own experiences and learn from them and from each other, then authentic understanding, care, compassion, and learning can take place. Mezirow (1991) states “our need to understand our experiences is perhaps our most distinctively human attribute. We have to understand them to know how to act effectively” (p. 10). I wanted to understand the theory of transformative learning and how as an adult it allowed me to experience transformation in my own thoughts, beliefs, and assumptions. The Transformative Learning theory best explains why adults learn, as “it offers a theory of learning that is uniquely adult, abstract and idealized, grounded in the nature of human communication” (Taylor, 2007, p. 173). My transformative learning enabled me to want to create change, where learning may be understood as “the process of using prior interpretation to construe a new or a revised interpretation of the meaning of one’s experience in order to guide future actions” (Mezirow, 1991, p.11). The change may simply be understanding the importance of conversation, or listening and supporting each other through experiences around death loss and grief. As previously discussed, according to Mezirow deep learning involves the transformation of our frames of reference. This occurs when previous learning engages with present experience and thus we critically reflect on the process by which we assess our assumptions. I felt Mezirow’s theory was relevant to myself and my research, in relation to the importance of healthcare staff being able to discuss their thoughts, emotions,

and experiences through narrative discourse. This allowed the healthcare staff to be able to discuss their emotions, as it involves “active participation”, which takes into account the experiences the healthcare staff had with their patients in end of life care and how their experiences of grief and loss represented their “frames of references”.

The discourse in which the participants and I got to discuss our experiences, or as Mezirow describes as our “disorienting dilemmas”, enables transformative learning, as it incorporates sharing experiences with others; which Mezirow (2000) saw as a necessary component of transformative learning. It is important for critical reflection and collaborative discourse, which question the basis for assumption and so it is important as a facilitator that I create a space which allows discourse to occur in an environment that the participants feel freedom to speak and have respect for each other’s viewpoints, trust, and solidarity. Transformative learning has become a dominant teaching paradigm discussed within the field of adult education and has become a standard of practice in a variety of disciplines and educational settings, including higher education, professional education, organizational development, and community education (Taylor, 2009). According to Mezirow, the goal of adult education and transformative learning is “to help adult learners become more critically reflective, participate more fully and freely in rational discourse and action, and advance developmentally by moving toward meaning perspectives that are more inclusive, discriminating, permeable, and integrative of experience” (1991, pp. 224–225). Through reflection and discourse, the healthcare staff will then be able to acknowledge feelings or emotions linked to work practice – *for example, grief and loss* – and be able to identify them. One of the pivotal elements of adult learning is the ability to reflect and it is defined as “the process of critically assessing the content, process, or premise of our efforts to interpret and give meaning to an experience” (Mezirow, 1991, p. 104). Therefore, the essential element to Mezirow’s theory is critical-reflection. Through self-reflection, one begins to address issues in life, problem-solve, and reason. Dialogue (with self and others) enables the learner to engage in more rational discourse and plans of action. The central characteristic of this transformative experience is when individuals reflect critically on their long held assumptions and beliefs and consciously construct new ways of understanding their worlds (Mezirow, 1995 pp. 39-70). In general, cultural and previously learned assumptions are evaluated for meaning and newer ways of thinking and acting are thus changed. This will enable the participants and myself to become conscious owners of our own emotions.

This thesis looked at the role of the Healthcare Assistant in residential care homes caring for those who are in palliative care/end of life. It looked at the reflexive experiences of the researcher while engaging and supporting narrative discourses with the research participants about their experiences of death, loss, and grief in the vocational workplace. We reflected on supports that would benefit them in this discipline. The approach utilized in this thesis incorporated a social constructivism lens with a narrative inquiry and reflexive practice, grounded in an adult education methodology. The methods used were semi-structured interviews where the interview was presented more like a conversation/discussion, with a purpose of creating the ambiance of an adult education environment. The main areas that were identified throughout the research and the findings were the culture of the organisation and protocol after the death of a resident. There were also positive practices and rituals identified which the staff found very comforting and helped with the grief process. Another area which was identified was the importance of peer support and space, and having a physical and emotional space where staff felt freely to discuss their experience in palliative care will allow for open dialogue and acknowledgment of feelings. Staff being supported like this can reduce the risk of burnout. From working in an environment where you are providing personal care, compassion and friendship, attachment is an important part of the relationship. However, it can equally leave the healthcare staff vulnerable to the experience of grief within the caring role. Formal supports were discussed in the form of a death review, but many of these supports were developed due to policy and were felt to be a tick box exercise by the participants. I felt that adult educational support could be provided so that staff could recognise grief. Even though there are supports, I felt there could be improvements put in place to better support Healthcare Assistants, especially in relation to adult and community education practices like discussion, reflection, and group work.

I felt as a researcher and adult educator that I now understand the importance of using adult education methods in the workplace and when communicating with adults, especially if they have experiences where they felt they have not been heard in the past. This research piece at times was challenging for me, as I had to reflect on my own “assumptions” and “frames of references”. I had to reflect on experiences that I felt I had moved on from, but which realistically were still present, swimming below the surface of the front that I put on. I have continued to journal, and I feel this is something that I am not going to stop now. It offers a place of reflection for me to park my thoughts, and I can come back to them when I am ready to face them, or when I want to question my assumptions, ideologies, and experiences.

The main aim of this research, as mentioned, was to provide some sort of grief support. At the beginning of this journey, I did not know how that support was going to be presented. I had these big ideas, that I wanted to create big changes, but on reflection I did not create big changes for a large quantity of people. However, I did create a positive change for myself and the two participants who took part in my research, and I am happy with that. I created an environment where we could chat, laugh, reflect, and acknowledge our feelings. I am proud of that. I hope that the participants themselves will acknowledge the importance of conversation and a simple chat while they are in their workplace. Hopefully, they will open dialogue with their colleagues and patients around feeling and emotions that are felt in end of life care. I am happy to say I do not feel angry with myself anymore for not feeling good enough in my role as a Healthcare Assistant.

“I sat with anger long enough, until she told me her real name was grief”

Author Unknown

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Appendices

Appendix A: Poster for workplace organisation



**Maynooth
University**
National University
of Ireland Maynooth

VOLUNTEERS WANTED

To Participate in a Research Study

My name is Dawn Nelson, I am currently undertaking a Master's Degree in Community & Adult Education in Maynooth University. As part of this degree programme I am required to carry out a supervised research study. The overall aim of this research study is to identify if staff can benefit grief supports, which will enable staff to learn about, and articulate their experiences of grief. Volunteers will be required to attend three recorded group discussions each lasting approximately two hours. We will explore thoughts, perceptions and experiences of loss in your vocational area. If you are interested in taking part please contact me by the 9th of February.

Requirements:

- (1) Volunteers must be over 18 years of age.
- (2) Must be available to attend all meetings.
- (3) Experience of caring for someone through end of life care.



IF YOU ARE INTERESTED CONTACT DAWN

DAWN.NELSON.2015@MUMAIL.IE

0873463380

Appendix B: Statement of Ethics



This research project is being carried out as part of a thesis for a Masters in Adult Education at National University of Ireland Maynooth. The purpose of the research question is to carry out a qualitative inquiry. The aim is to identify if staff who work in end of life care can benefit from creating sustainable staff development support space which will enable staff to learn about, and articulate experiences of grief. The methods employed for gathering information for this research project will be a series of group meetings. It is noted at this point that the information gathered will be of a sensitive nature and during the discussion process sensitive information often comes to the fore.

Therefore due consideration is given to the respondents and any information disclosed during the group meeting will be treated as such and remain confidential. No person's name will be used and any recordings and transcripts will be destroyed after this research project has been assessed.

Respondents may if they wish to do so alter any contributions that they have made to this project either by adding to or retracting any statements that they have made during the group meeting process.

Respondents are free not to contribute to any particular question or questions should they choose not.

Respondents may also withdraw completely from this project at any time and any statements made during the interview process or otherwise will be destroyed and not be used for the purpose of this or any other project.

Permission From respondents

I _____ Hereby give permission to the researcher to include my contributions during the group meetings for the purpose only of this research project.

I am participating voluntarily.

I choose to take part in group discussions, I give permission for my contribution to be digitally recorded.

I understand I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand I can withdraw permission to use the data prior to the completion of the thesis, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts of my contribution to the group meetings may be quoted in the thesis and any subsequent publications if I give permission below:

Signed.....

Date.....

Researcher: Dawn Nelson

Appendix C: Letter to Gate Keeper

Clonleason Cottage

Clonleason

Fordstown

Navan

Co. Meath

15th January 2019

Ms Elaine Smith

Hr Manager

Palm House Nursing Home

Boycetown

Kilcock

Co. Kildare

Dear Elaine

I am currently undertaking a Master's degree programme in Maynooth University. As part of this programme I have to conduct a research study. I have detailed below information about the research topic I am undertaking. I hope you can assist me by allowing the opportunity to carry out this research in Palm House Nursing Home. I would be very grateful.

RESEARCH TOPIC: A Reflexive Inquiry into Grief Support Needs for Healthcare Assistants in Residential Care settings

I would like to invite you to assist me in conducting a research study. Before you decide you need to understand why the research is being done, and what it would involve for you, and for the participants. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to facilitate this research.

I would need your assistance by allowing me to invite members of your care team to voluntarily take part in an research process. This would entail me providing you with a poster advertising the invitation to take part in the research. I would ask you to display this poster in an area that staff could view it. I would need at least four members of your care team who have experienced the death of a resident in their care to take part. I would need to have three meetings with the participants.

The first meeting would be an invitations for any members of the care team who would like information about taking part in the research study. This meeting will take up to 30minutes.

The second meeting would last up to three hours with those who have decided to take part in the research study.

The third meeting would last up to three hours.

If possible the meetings would take place in your nursing home or alternatively another venue can be arranged. The meeting will take place on:

Meeting One (Invitation to take part in the research) - February

Meeting Two – Late February

Meeting Three – March

All information gathered will be kept confidential, the participants and nursing home will not be identifiable in the data collected. The only people who will have access to the data collected is my academic supervisor Dr Jerry O’Neill.

The results of this thesis will be published and may be used for teaching use, conferences and publications. The participants and nursing home involved in the study will not be identifiable in the dissemination of the final research product.

Kind Regards

Dawn Nelson

Dawn Nelson

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

Researcher:	Dawn Nelson dawn.nelson.2015@mumail.ie
Supervisor:	Jerry O'Neill Department of Adult and Community Education Maynooth University Jerry.oneill@mu.ie
Purpose:	Action research inquiry that aims to create sustainable staff development support space for staff to learn about and articulate experiences of grief.

Appendix D: Consent from gate keeper to facilitate research

I..... voluntarily agree to help facilitate this research study.

- I understand that even if I agree to help now, I can withdraw at any time without any consequences of any kind.
- I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
- I understand that I will assist by allowing the researcher to invite staff to participate in the research study
- I understand that all data collected in this study is confidential and anonymous.
- I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

Signature of gate keeper _____ Date _____

Signature of researcher _____ Date _____

I believe the participant is giving informed consent to participate in this study

Signature of researcher

Date

Appendix E: Letter of introduction to participants

Clonleason Cottage

Clonleason

Fordstown

Navan

Co. Meath

13th February 2019

Dear Participants

Thank you for taking the time, to consider participating in this project. This research project is being carried out as part of a thesis for a Masters in Adult Education at National University of Ireland Maynooth. The purpose of the research question is to carry out a qualitative inquiry. The aim is to identify if staff who work in end of life care can benefit from creating sustainable staff development support space which will enable staff to learn about, and articulate experiences of grief. The methods employed for gathering information for this research project will be a series of group meetings. It is noted at this point that the information gathered will be of a sensitive nature and during the discussion process sensitive information often comes to the fore.

Therefore due consideration is given and any information disclosed during the group meeting will be treated as such and remain confidential. No person's name will be used and any recordings and transcripts will be destroyed after this research project has been assessed. Respondents may if they wish to do so alter any contributions that they have made to this project either by adding to or retracting any statements that they have made during the group meeting process.

Respondents are free not to contribute to any particular question or questions should they choose not. Respondents may also withdraw completely from this project at any time and any statements made during the interview process or otherwise will be destroyed and not be used for the purpose of this or any other project.

Regards

Dawn Nelson

Appendix F: Ideas/Discussions Topics during interviews

Areas of interest to me for purpose of research during interview

1. Stories of end of life care
2. How participants feel supported
3. Culture of the organisation

(These are the areas which I initially wanted to discuss, but during the group discussion I let it go where the participants wanted it to go. I wanted them to be self-expressive, from this approach other themes also arose during discussion/conversation)

4. Communication
5. Space
6. Rituals
7. Low Morale
8. Researchers approach- Person centred care