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Portfolio for Professional Doctorate in Counselling Psychology (DPsych)

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Table of Contents

2

List of Tables and Figures

<u>Acknowledgements</u>

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Preface

This thesis represents both an ending and a beginning. It is the culmination of my three-year journey as a trainee counselling psychologist and it also represents the beginning of my journey towards becoming a chartered counselling psychologist. This preface establishes the three required components for the doctoral thesis portfolio, all linked by the theme of the body in bereavement.

The first part consists of a client study, which explores awareness in non-verbal communication and taking risks. The second section is a piece of doctoral research that explores how the body is experienced by bereaved people in the context of being physically present or absent at the moment of death. The final part is a publishable paper taken from the doctoral research findings, which focus specifically on bereaved individuals and their relationship to the body in the context of physical absence at the moment of death.

The portfolio has been presented in this manner as it follows a temporal progression from being inspired by my client work to pursue the research topic further. The findings from the research can then be disseminated into a wider community of both counselling psychologists and other healthcare professionals to continue the practice-based knowledge foundation.

Part 1: Professional practice

This first section is a client study that reflects my clinical abilities as a counselling psychologist. The aim of the paper is to demonstrate my capability of being able to integrate theory into practice through interactions with the client and myself (as therapist).

The client study is based upon 46 sessions with a bereaved client that spanned 16 months. The client, a woman in her early forties, came for bereavement counselling as her partner of 15 years had died suddenly of a brain haemorrhage. Despite not having much experience in using the Gestalt approach, I felt that with the support of my Gestalt-trained supervisor, this was the most appropriate theoretical approach to use with this client, as it focuses on the here-and-now. The therapeutic journey took an unexpected turn almost halfway through our therapy sessions as she too, suffered from an undiagnosed brain haemorrhage but survived. The body, in this instance, played a vital part in how the client made sense of her bereavement and also her own mortality. As Gestalt therapy focuses largely on the here-

and-now through the body, I was much more focused on the client's non-verbal communication and had an awareness of both of our bodies. This piece of work reflects my development in viewing the client in a more holistic way (that encompasses both the mind and the body in therapy sessions), which consequently reflects my development as a practitioner.

Part 2: The research

The second component of this portfolio consists of my original doctoral research, which was inspired by working with bereaved clients in an inner city hospice. Throughout my work there I noticed that clients consistently brought up the moment of death as an experience that, with a multitude of emotions, was rarely spoken about. It highlighted for me that this was not accounted for in the bereavement theories I had studied. My overarching goal of the research was to have the stories of these participants heard, as so frequently in bereavement counselling I have listened to clients express the barriers they have come up against when trying to talk about the death of their loved one to friends and relatives.

The research aims to explore bereaved people's embodied experiences at the moment of death within the context of them being present or absent. Semi-structured interview data were gathered and, following that, the qualitative method of interpretative phenomenological analysis was undertaken to identify themes.

The themes express and explore the convergences and divergences amongst the participant group.

The findings from the research are discussed in the light of existing research within the field of death, dying and bereavement. My research leaves room for implications to practicing counselling psychologists as well as a wider context.

Part 3: Publishable paper

Stemming from the research, the publishable paper aims to focus on a specific aspect of the relationship to their body that participants described due to their absence at the moment of death. As an overwhelming proportion of self-selected participants were physically absent at the moment of death, the importance of the body (both that of the participants and the dying person) was stressed throughout the research interviews and therefore I felt that it deserved its own focus. As psychotherapies have mainly focused on the 'talking' aspect, the

body has largely been neglected within counselling research, especially in bereavement. The publishable paper also aims to present the research findings in a way that will make a contribution to counselling psychologists by informing professional practice.

<u>Thematic connection</u>

This portfolio did not begin with a clear focus on the relationship of the body in bereavement, however it was something that developed throughout my journey of training as a counselling psychologist as well as a researcher. Being more attuned to the client's body, as well as my own, opened up a whole new dimension of therapeutic work that often meant connecting to the client in a deeper therapeutic relationship. As someone who was never aware of how much the body was involved in counselling, I found this journey at times scary and challenging, yet extremely rewarding. What brought all of the practice and theory together was actually the simple realisation that, in bereavement, it is the loss of the relationship between one human body and another. Death became a universal exchange and language between my clients and me - it was a common experience that we would both eventually share. There was no hiding from death; it brought about an awareness of the fundamentals of life. In the therapy sessions, it was one human body interacting with another.

With recent developments in technology, scientists have attempted to prolong the eventuality of death by researching cures for diseases and postponing life through machines. As counselling psychologists are often found working in medical environments, they can sometimes become engulfed within the medicalisation of death, whilst attempting to value the humanistic fundamentals in counselling psychology. This was a struggle I encountered whilst working throughout a variety of mental healthcare settings. The intention of presenting these three components is to illuminate and create awareness for other counselling psychologists about how important it is to listen to the client's body and also our own body, which can often get lost when working within a medical environment. It is going back to basics, as awareness of our body is something that is common to us all as human beings.

Part 1: Professional Practice

Awareness with non-verbal communication and taking risks

A client study using the Gestalt approach

Part A: Introduction and the start of therapy

Rationale for the choice of the case

At the end of my second year of training leading into the final, I set myself some goals that I wanted to have at least attempted. The first was to become more aware of my non-verbal communication in the therapeutic process as well as that of my client. The second was to take more risks personally and with clients. Within this client study, I would like to demonstrate the particular challenges I faced in leaving my intellectual comfort zone to work in a model that is poor on theory. Through these difficulties, the process of change and the power of our co-existing relationship emerged both for the client, as well as myself.

Background information about the client

Sarah[1] was a white, middle class British woman in her early forties. She worked as a team manager for a medical trial department at a hospital. Her family comprised her two brothers and both of her parents – all of whom lived a short distance away from where she resided. Sarah had been in a 15-year relationship with James when he died extremely suddenly of a brain haemorrhage on his way to work. He was pronounced dead at the scene and Sarah learnt of his death through a call from the hospital.

The context for the work

As a trainee counselling psychologist, I worked for an adult hospice bereavement service that provided therapy for local residents aged 18-50 as well as to any resident whose bereavement happened under the care of the hospice. The sessions were usually 50 minutes long and the length of therapy was negotiated between the client and therapist. Sarah approached the bereavement service by telephoning for an initial referral. She had a call from a qualified team member to initialise a full referral which included details of the bereavement, previous mental health history, risk factors and what type of counselling she was looking for (i.e. individual or group). Sarah was then allocated to me because our schedules were compatible and so I began seeing her.

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[1] All names and identifying information have been changed in order to protect the confidentiality of the client.

Initial impressions

I remember reading the referral before actually meeting Sarah and I felt nervous as I had never worked with someone whose partner had died suddenly at such a young age. I already began having feelings of being moved. Perhaps this was also what I expected the client to be like – emotional, distraught, and powerless because I was imagining how I would feel in her situation.

When I picked up Sarah from the waiting area, I was immediately drawn to her red/orange hair, yet at the same time her plain and dark clothes. This was when she became alive to me. This was the beginning of my awareness of the non-verbal aspects of therapy.

Convening the first session

I began the first session by introducing myself and explaining how the service worked. Gravell (2010) emphasised that no matter which theoretical approach the therapist is coming from, containment of the therapy sessions provides boundaries and a sense of stability upon which trust can be built. Despite the fact that it would be open-ended therapy, we would be able to periodically review the sessions to see if Sarah's needs were being met. This was to provide a safe space for Sarah to allow for open exploration and at the same time to monitor the therapy and our relationship in general.

From the beginning of the session, Sarah was extremely tearful as she began to explain why she had initiated contact with the bereavement service. James, who had died five weeks prior to her commencing therapy, was the reason why she was currently in a state of struggle and feeling overwhelmed with different emotions. She described, in significant detail, the events that had occurred on the day that James died. One of the main aspects that Sarah was finding difficult was the fact that she felt 'stuck' emotionally and existentially. She had planned out a future with James which no longer existed. To me, 'stuckness', felt heavy in the room, like a car that is revving in the snow wanting to move but cannot. It was apparent that she was not at ease sitting with her emotions; I noticed that whenever I attempted to comment on them she would change the subject or talk about her feelings as opposed to letting those feelings enter the room. In a direct quote she said "talking about feelings is not helpful". After she said that I felt a sense of disappointment. I was not sure how I would be able to help her if she was unwilling to bring feelings into the room. I had previously worked with clients who struggled with emotions and I had a sinking

feeling that Sarah might be the same and that I would have to start from the beginning in order to get her to own her emotions. I sensed my own agenda creeping in at this point – my client *should* emote. This was something I parked at the side and would keep an eye on throughout our sessions.

One of the major aspects that Sarah brought into the room was the part of her that was seeking answers to questions where there were no particular answers. Sarah was asking me how she should be thinking, feeling, and acting; what she could do to measure progress; and how she could get things back to the way they were before. I informed Sarah that in therapy I would not be able to provide answers or solutions to her questions and that it would be a joint relationship in which we could discover and explore her difficulties.
After that first session, I was left feeling powerless as I was unable to provide her with what she was asking for. This parallel process demonstrated the connection that I had made with Sarah. Despite this, my anxiety was that she would disengage and would not return to the next session.

In terms of the therapeutic approach to take, I was left with a dilemma. One possibility was to take an existential route with the client because when she spoke of the dreams of her future with her partner, which had been taken away in an instant, it brought to my mind some core existential issues around life, death, and freedom[2] . At the same time, I felt that the key issue that Sarah brought was her loss of self and an overpowering sense of reaching out to others to solve her difficulties for her. The demonstration of Sarah wanting to disregard her emotions also felt to me like there was an element to her that was being denied or left out. In other words, there was no 'wholeness' in the way she presented. With these two key components in mind, I made the decision to work with Sarah in a Gestalt approach. With its underlying influence and blend of a few psychoanalytic terms (Perls, 1947) as well as some key philosophical underpinnings from existentialism (Sartre, 1943), I felt that Gestalt therapy would enable Sarah to come to an awareness of her current state and situation.

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[2] For an in depth account of some key existential issues I invite the reader to consult Yalom (1980).

Summary of theoretical orientation

Gestalt therapy, as stated by some more modern authors, is not merely a therapy but a philosophy of being (Levin and Levine, 2012). A starting point for understanding Gestalt therapy is to go back to Fritz Perls' (1947) first published book in which he introduced his basic ideas about therapy as well as about the nature of man. Perls believed that it is the way facts, information, behaviour, and phenomena are organised rather than the individual parts of them that denotes meaning. In other words, there are certain things that will grab your attention and stick out for you depending on your perception. For example, if we take a stir fry dish, it is made up of different vegetables, spices, herbs, etc. If someone does not particularly like garlic then that element within the dish will stand out for them. In Gestalt therapy we are not so much interested in why the person does not like the stir fry, but rather in how they sense and feel it. How do they experience the stir fry? The garlic in the stir fry is an example of a key concept that Perls refers to as 'figures and grounds relationships'. Figures refer to what is at the centre of our awareness – it stands out from the background. Healthy individuals adapt their figures and grounds depending on their here and now[3] needs. When issues from the past are still residing, the person cannot live in the present and therefore their current needs are not being met.[4] This is why Gestalt therapy is primarily focused on the here and now experience.

One of the basic concepts of Gestalt therapy is that of 'contact'. Lewin's (1952) field theory proposed that it is the combination of internal personal drives and external social forces that produce a 'whole' relationship. The nature of contact is the meeting place between an individual and their setting (O'Leary, 1996). This boundary, in a healthy person, is fluid and the person is constantly adjusting. However, in an unhealthy person, the boundary becomes stuck due to repetitive behaviours. Instead of the person listening to what their needs are, they are using up energy avoiding contact or maintaining unhealthy behaviours (Polster and Polster, 1974). It is important to note that, as a therapist, I am part of the client's field and vice versa. The combination of both people produces a co-creation of existence.

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[3] Levin & Levine (2012) define the 'here' as the "embodied sensory experience" and the 'now' as "temporal propinquity" (p.3)
[4] Perls, Hefferline and Goodman (1951) define this as 'unfinished business' where feelings and experiences that are incomplete persist in the individual.

Harman's (1974) summary on Gestalt therapy introduced the idea that the main goal in therapy is to work with an individual so that they can be aware of themselves as they exist in the present moment. In Gillie's (2010)[5] most recent adaptation of the experience cycle[6], she illustrated the natural process where clients progress from a state of sensation to awareness, then to mobilisation and action, to resolution, and finally beginning and ending the continuum with withdrawal. Harman (1974) stated that the ways we can achieve this overarching goal of maintaining a healthy cycle is through awareness, maturation, integration, authenticity, responsibility, self-regulation, and change in behaviour. All of these features are interlinked, meaning that if change occurs in one of these aspects it is likely that change will then follow in other areas. The process that I believe is most relevant to Sarah is that of maturation which is why I shall focus solely on this.[7] The reader should be aware that this is my mobilising interest (as seen on Gillie's, 2010, continuum) because Sarah's answer-seeking is what stood out for me. I am naming my interest and awareness in her.

The concept of maturation within Gestalt therapy is where the client moves from environmental support to that of being able to self-support (Perls, 1969a). It is the same principle as when we develop from a child, relying on our parents, to a self-sufficient adult. Since we are social beings and constantly interact with our environment, it is obviously unrealistic that we will become completely self-sufficient individuals. However, I believe Perls was trying to state that people take on responsibilities and only ask for help when needed. Although the final end product of maturation can be freeing, it also means that along the way certain feelings of comfort and safety need to be let go. Take, for example, a child learning to ride a bicycle. Although the final goal is to learn to ride independently, the child might start off with stabilisers or training wheels. The prospect of taking the training wheels off can be daunting and it is not something that is likely to happen overnight.

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[5] There are several authors who have attempted to portray this cycle (Parlett and Hemming, 1996; Zinker, 1977; and Hall, 1977). The reason for choosing Gillie's (2010) adaptation is that although she followed the contemporary Cleveland school of Gestalt (Wheeler, 1998) she substituted their term of 'contact' with 'resolution' which I, personally, prefer. Resolution is the word that resonates most with me in working with this client.

[6] See Appendix 1 – Figure 1. The continuum of experience (Gillie, 2010).

[7] Definitions, examples, and a greater understanding of the terms awareness, integration, authenticity, responsibility, self-regulation, and change in behaviour can be found within Korb, Gorrell and Van De Riet (1989); Perls, Hefferline and Goodman (1951); and Harman (1974).

Eventually, when the time is right and with a little guidance, the stabilisers can be removed and the child is riding on their own.

As a therapist, the way to work with this in the room would be to set up graded experiments (Perls, 1973) where the client will embody their experiences as opposed to completing a task.

So how exactly does maturation occur in therapy? Korb et al. (1989) set forward steps in maturation. They stressed that these are not intended to be used in a linear way, but more as a rough framework in understanding a complicated process.

The first step is for the client to focus on their present behaviour. This relates to the experience rather than the intellectual explanation (O'Leary, 1996). In Sarah's case, she came to therapy because she was aware that she was finding it difficult to cope with the death of her partner. She felt extreme sadness as well as many feelings which she could not articulate. She also brought to the session a confusion around what she should or should not be doing in relation to what other people had said to her. This then leads onto step two of focusing on old business. It can be said that present behaviour is generally a repetition of previous behaviours which we have learnt in order to survive. Sarah became 'stuck' (Krause, 1977) where her inner experience did not match the perceived expectations of others. Gestalten[8] from her past are therefore left unattended. When exploring more about the disconnection between the inner and outer experience, we can look at the core self-concept (step three). This means exploring the client's early childhood experiences and discovering what the client thinks of themselves and their environment. Bringing the client back into the present can allow them to then look at step four – focusing on the life decision-making process. Relating back to responsibility, the client is able to choose and decide on creating their lives. Once the change has occurred of re-gaining responsibility, the final phase is to focus on the new behaviour. It is bringing the client into living as opposed to merely existing. Statements such as "I'm useless" become "I can do some things on my own and need help for other things".

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[8] The definition of 'gestalts' according to Parlett & Hemming (1996) is the temporary process of an individual's experience which forms, completes, and then dissolves.

Negotiating a contract and therapeutic aims

Despite being a novice to the Gestalt approach I gained some theoretical background knowledge and combined this with the support of my Gestalt trained supervisor. I felt that, given Sarah's context, Gestalt therapy was the most appropriate way to work. The work would focus on exploring Sarah's continual adjustment to her life after James' death and I would gain an experiential learning of the approach and a different understanding of the client. Had I not decided to work within the Gestalt approach, I would have lost a completely unexplored dimension of the client and would have stayed within my comfort zone. The following section will give the reader an understanding of the progression of the therapy sessions and processes that Sarah and I experienced.

Part B: Development of the therapy

Beginning of therapy

Sarah started off by attending regular weekly sessions for a total of 11 months. For the first few sessions, we explored Sarah's coping strategies and whether she had any previous experiences of death and loss. Those 11 months felt flat; I was finding it difficult to know where to go and what to do. It felt like Sarah was trying not to let me in during those sessions, yet at the same time I did not take the risk and challenge her on this because I was unsure of the strength of our relationship. Clarkson (1989) talked about typical issues in the early engagement phases of the therapeutic process. She brought to my attention the polarity of trust and distrust. I knew that in Sarah's case she was a private person and did not share many details with others. I wondered whether she trusted me and what motivation she had to trust me. Did she think that the environment I was setting up for her would be nourishing or caring? The questions around trust also brought up the notion of accepting help (from me as therapist) but at the same time being independent within the relationship. Again, this is something that would move along a continuum as our sessions continued.

During those 11 months some major events occurred in Sarah's life which included planning the scattering of James' ashes, her birthday, her brother's wedding, and a memorial service in James' honour. From the beginning, I knew that Sarah had difficulties expressing not only her emotions but also taking a minute to stop and become aware of her current state. In the

early days of our work together Sarah was very much focused on her intellectual side and it felt slightly rigid. The challenge with this is that I, too, am someone who relies heavily upon my intellectual side. I noticed that after a while, Sarah and I sometimes got caught up in intellectual debates and it became a struggle between us. This was the point where I was aware of my agenda (of wanting to challenge Sarah on an intellectual basis). My supervisor, who could see my frustration, suggested that I simply point out the obvious to Sarah. Telling Sarah how I experienced our relationship, i.e. she defended herself when I made a comment, would set an example of sharing my present moment with her. By displaying to Sarah what she was doing she then had the choice as to what she could do next. When the situation arose again in a subsequent session, I brought her behaviour to her attention and she justified it and followed it by giving me an intellectual reason as to why she did it. Although I thought at the time this intervention did not work well for Sarah because of her immediate defensiveness, she brought it up with me a few sessions later by saying that she had noticed herself doing it a lot more and that this was something she wanted to change. The mere fact that Sarah had now stated that she wanted to 'try' to change was self sabotage. She had thus demonstrated an example of the paradoxical theory of change (Beisser, 1970) which posits that "the more we work at becoming who or what we are not, the more we remain the same" (Gorey, 2012 p.214).

I was aware that perhaps at this point I, too, had become a 'powerful other' voice for Sarah. I wondered if she had interpreted my observation as a criticism and therefore felt that she needed to change. Both Sartre (1943) and Perls (1969a) pointed out the importance of how someone relates to another and how people can be influenced by others. We have our external environment (others) saying how we should or should not be and our internal environment (emotional and physiological) telling us otherwise. An experiment I could have done with Sarah in acceptance work comes from the original idea of Houston (1993). She suggested working with the client to try saying "yes" at the beginning of every statement. For example, "Yes, I become defensive when I respond to comments". By doing this, Sarah would see her behaviour in a more affirmative light. We could then explore what was brought up for her whilst she was saying the statement.

After looking back on this encounter with Sarah I wondered whether this was what Yontef (1993) was talking about when he discussed resistance from the client. He believed that when a therapist 'leads' a client then they will instinctively resist and stay the same. Did

Sarah perceive my comment as an intrusion? This also ties in with the concept of 'introjection' [9] (Polster and Polster, 1974) which is seen as an obstacle to contact. A possible intervention at this point could have been to acknowledge Sarah's behaviour but then re-inforce the fact that I was not interested in what was 'good' or 'bad' behaviour. It would be about acknowledging that she had this side to her and exploring the polarities that occur. By doing this it would inadvertently convey to Sarah that she was allowed to have these thoughts, feelings, and behaviours because they are part of who she is. I was left wondering why there was no space in our relationship for Sarah to say that she did not think I accepted every part of her.

Middle of therapy

A major event that occurred during our sessions, which happened just under a year of us seeing each other, was when Sarah was hospitalised for having a previously undiagnosed brain haemorrhage. My initial reaction to this news was that of shock as well as worry for Sarah's physical and emotional well-being. I felt a very real and live connection to her as there was the possibility of death. After spending three weeks in hospital Sarah came back to therapy. This was a major indication for me to look out for Sarah's non-verbal communication as her body was already providing clues that something was wrong. When I asked her what brought her back to therapy she said that this was the first time she was able to actually process what had occurred. She wanted to see how she would feel whilst talking to me about the event. What stuck out for me the most was Sarah's repetition of how much she missed James. We talked about how James provided her with the emotional, practical and psychological support that she needed. We also discussed other ways she could re-gain the different kinds of support that James used to offer, for example reaching out to friends and family. Sarah was incredibly upset by the fact that she previously did not have to think about the different kinds of support she needed as James was always there to provide her with them. When she was with James, she never had to be aware of who she could turn to if she needed help with something because he was always there. She expressed her resentment at the fact that she was now so much more conscious of herself

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[9] 'Introjection' refers to when a person takes on the expectations, feelings and behaviours of others because they feel safer doing this than being independent and self sufficient.

in friendships, relationships and daily life without him there. Now the question became what she would decide to do with this awareness.

Korb et al. (1989) discussed the consequences of having unfinished business. If, for example, Sarah did not resolve feelings that she had towards James (e.g. hurt, disappointment, anger, sadness etc.) then her experience would remain incomplete. If Sarah held onto these unresolved issues then she was using energy that she could be otherwise using to take in new experiences. If she did not attain closure then it could express itself in physiological ways. Reich (1949) and Rolf (1977) have both demonstrated how this energy can manifest itself in bodily complaints.

In the few sessions following Sarah's return to therapy, the themes that emerged were mainly centred around re-gaining control (over self and body), power and empowerment. During these sessions I explored the impact that the haemorrhage had had on her, but also looked at symptom awareness. We focused on different body parts and what was going on for her in the physical environment. It was clear that Sarah felt uncomfortable talking about this because she would often change the subject or her speech would become abrupt, as if she were trying to cut me off.

As I looked back on the interventions that I made, I was aware through group and individual supervision that I missed many different aspects of Sarah's experience. As Imes, Clance, Gailis, and Atkeson (2002) and Kepner (1987) reminded me: in Gestalt therapy we look at the mind and body in conjunction; we take the holistic approach meaning that the psychological and the somatic aspects are linked. In their work with chronically ill patients, Imes et al. (2002) suggested an alternative intervention which involved creating a dialogue between the different body parts. By getting Sarah to speak to her anatomical brain versus her mind, new material could have surfaced concerning the different parts and aspects of Sarah otherwise left unmentioned.

I found Sarah's haemorrhage extremely difficult to cope with in our therapy sessions. There appeared to be a parallel process occurring where we were both experiencing unexplained physiological symptoms. I became concerned about ethics because it was proving to be hard for me to separate my health anxiety from hers. After taking it to both individual and group supervision there was an agreement that I, as a person and therapist, needed to take the personal risk and be more authentic. It meant revealing to the client some useful aspects of myself and my experience, rather than feeling like I could not share anything at all. By using

that energy to conceal all aspects of what I was going through, I was leaving myself unaware of what was going on in my relationship with Sarah – a classic example of unfinished business in Gestalt therapy! Despite sharing some of my feelings of sadness and worry about her, I was still left with a sense of incompletion. I felt as if I had not re-assured Sarah that I was okay and that she did not have to either look after me or constrict how she wanted to be with me in further sessions[10].

After Sarah's brain haemorrhage, there was a significant change in our therapy sessions. To begin with, she asked if she could change from weekly sessions to a fortnightly routine. She felt that although there were still many different areas she would like to work on, the specific issues relating to James were less important. I want to acknowledge the self-responsibility that Sarah took in bringing up changing our sessions because I believe that she was attempting to trust what felt right for her. Although I could have explored this shift in much greater detail, I felt that by doing so we would have gotten back to the 'why' questions which might possibly lead us back to intellectualising the situation.

Once we started the fortnightly sessions, I noticed that Sarah began to bring a lot of work issues to the space. She would talk about conversations she had had at work, the stresses of her job and how it had taken over her life. I commented at the end of one of these sessions that I had noticed she had been talking a lot about work. It was not until the following session, when Sarah was extremely tearful throughout, that she acknowledged that she had been avoiding talking about James because it was too painful. I was able to see a more open side to Sarah that day compared to previous sessions.

The subsequent sessions demonstrated a complete shift in Sarah's way of being. She not only started to take ownership for her feelings but as a result, was also able to self-regulate (Harman, 1974). In earlier sessions a recurring unresolved issue was around other people's expectations of how she should cope and of how she should be. Throughout the sessions, I often tried experiments that uncovered a conflict within her, something that Greenberg & Rice(1997) believed that through discovery as opposed to interpretation can help uncover emotions. Sarah was conflicted by her current friendships. On the one hand, she felt an

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[10] See Appendix 2 - Reflective diary entry.

obligation to be friends with certain people because she had known them since her school days. On the other hand, she was left with feelings of anger and disappointment after meeting up with them because she felt they did not meet her needs. She brought this conflict to the therapy sessions and we experimented by allowing her to speak freely about her friends and how they made her feel. We also tried looking at it from one particular friend's point of view and what she might say to Sarah. This allowed us to see how Sarah was projecting her own responsibilities onto others. Perls (1973) described projection as a neurotic mechanism that distorts the boundaries between ourselves and our environment. In the end, Sarah decided to let go of the obligatory friends because she found that they caused her more distress than comfort. By Sarah no longer responding to the 'shoulds', she was being true to herself and responding to her present needs.

Part C: Conclusion and review of therapy

After attending 44 sessions over the course of 16 months, Sarah announced that she was in the process of concluding some things before the end of the calendar year and felt that counselling was one of those things. We agreed that we would have two further sessions to work through a therapeutic ending. These final sessions were aimed at looking at the current ways in which Sarah functioned and how she could continue to take this forward.

I will admit that I struggled for a while in supervision around the issue of bringing up endings. I suppose I had jumped to the conclusion that previously when Sarah had said she wanted to change her sessions to fortnightly, it was an indication that she wanted to finish therapy. After checking out my confusion around fortnightly sessions with Sarah, I brought it to discuss in supervision and perhaps there was a part of me that felt that she was ready to finish at that point. Clarkson (1989) discussed engagement levels with clients throughout the course of therapy. I noticed that, after Sarah mentioned she wanted to change to fortnightly sessions, my engagement levels dropped. I felt slightly distant from her in sessions and less engaged with our relationship. Perhaps this had something to do with my own issue around rejection and might be something I could look at further in personal therapy as well as supervision. With Sarah, I was encouraged to keep seeing her and to allow her to decide when she would like to stop her therapy sessions. Sure enough, when the time was right, she brought up the issue of ending. I felt that I had been expecting an

ending for months before she brought it up in a session and so it was a relief for me that she had taken the initiative and wanted to end on her terms.

A key session I would like to mention was the second to last session where she was discussing her Christmas plans. This time last year she had decided that she was going to try to be assertive by telling her family that she did not want to spend it with them. What happened in the end was her unwillingly going to stay with them for an extended amount of time over the holidays. She found it difficult to speak out against other people and to put her needs first. This year, however, was different. From the outset Sarah stated her position on Christmas to her family and was confident in telling people what she wanted to happen. Again, I believed this demonstrated the different ways that Sarah had matured and integrated her needs into her environment. There was also a level of self-acceptance that Sarah had reached which brought about a fundamental change (Yontef, 2007).

I believe that, especially with bereavements, it is extremely important to work through endings with clients. It is a large part of the reason why a client will come for counselling – to work through the difficulties around a loss. Zilberstein (2008) believed that in adult therapy the idea of terminating therapy is reached when the client has gained an independent functioning. She believed that the feelings evoked from the permanence of the loss are what need to be worked through. She was also keen to point out that there are some positive aspects that a client can gain upon termination such as satisfaction, achievement and self respect. I believe this was true of Sarah's case. When our final session came, I was full of mixed emotions that ranged from satisfaction (from seeing the client grow) to sadness (about losing our fortnightly routine and hearing how she had been changing). I did not know what to expect and how she would react to our ending.

Throughout the course of therapy, Sarah had been keen to monitor her development through practicalities, one of which was gardening. She enjoyed the process of gardening, an activity which involved hard manual labour but also an element of sitting and waiting until shoots, leaves, and flowers had grown. In our very last session she wanted to show me photographs of how her garden had developed and her sense of pride at being able to do these tasks on her own. I, too, felt proud for her. Upon reflection, I could have done a graded experiment with Sarah using her metaphor of gardens in looking towards the future.

For example, I could have used the changing seasons and highlighted that all plants go through different cycles depending on the seasons and they find a way to cope. I am wondering how she would cope in the 'winter' seasons and what she would look forward to as the next 'spring' approached. By sticking with her metaphor, it could appear less threatening and it would allow her that slight distance in talking about herself.

A couple of weeks after our therapy finished I received a card from Sarah simply thanking me for the support I had given her, describing how she had changed, as well as wishing me well for the future. I was very moved by her words.

Discussion

In my work with Sarah I believe that there were many rewarding aspects-as well as some opportunities for my own growth - areas that I have learnt from, things I would do differently in future sessions.

With Sarah, I felt that our relationship was trusting and respectful. I knew that the expression of emotions was a sensitive issue for her and I was careful to respect her boundaries, As a result she trusted me enough to hold some of those emotions in the room with her. Although I challenged her in this way, I did not challenge her to the point of pushing her away. We developed some humour throughout the course of therapy and there was a genuine sense of caring for each other. For example, if I had been off sick she would enquire how I was and vice versa. In following more modern therapists practicing the approach (as opposed to Perls' traditional Gestalt), I believe that it is a two-way relationship and that my experiencing, as a therapist, can be a valuable contribution (Dolliver, 1981; Shepherd, 1970).

Overall, I found working from a Gestalt perspective extremely tough. Theory in Gestalt therapy can be found few and far between because there is a belief that by using theory it becomes prescriptive. The aim in Gestalt is to be open and so, by using theory, it can restrict our views on the here and now. This is why Perls was a keen follower of experiential work and relied less on theory. Tying into this, I can often depend too heavily upon psychological theory, which is why my goal of taking more risks by letting go of this reliance was relevant in this case. It should be noted that this theory-poor element is what many authors have

written about when discussing the limitations of working in the Gestalt approach (e.g. Wagner- Moore, 2004).

Supervision played a vital role in ensuring I was being supported in my use of Gestalt theory. The relationship I had with my supervisor allowed me to explore the processes that occurred between Sarah and I. It helped me develop as a practitioner and ensured that our well-being (both Sarah's and mine) was maintained. As previously mentioned, when I was feeling 'stuck' with Sarah, I shared this difficulty with my supervisor. During these sessions, I was able to gain an awareness of how I experienced Sarah in my sessions with her and together my supervisor and I looked at the different ways I could be supported in facilitating Sarah's process. I found Kaplan, Kaplan and Serok's (1985) suggestion of listening to how my supervisor was experiencing our supervision sessions a useful way to further understand my therapeutic relationship with Sarah. As my supervisor also expressed his here-and-now experience in supervision, we were able to discuss for example, whether my frustration was related to my relationship with Sarah or rather to my personal issues.

The intellectual versus sensory experience has been something that I personally have struggled with, where I have a tendency to rely on my intellectual explanations rather than calling upon some of my physiological aspects in sessions. Even when the thought of consciously trying to be aware of non-verbal communication arises, I feel extremely anxious to the point where I can feel my stomach churning. It feels overwhelming to be looking for non-verbal communication, verbal communication, changes in tone, language, etc.; these are the exact same feelings that I remember getting at the beginning of my training - sensing that I needed to be aware of things and make an effort otherwise I might miss something important or vital about the client. At the same time, the fact that I cannot hide behind words feels incredibly exposing and that even if my language says one thing, my body might be communicating something completely different. I have experienced this in supervision where my supervisor has commented on some non-verbal cues that I was not even aware I was doing. As useful and insightful as it was, there was also an element of feeling vulnerable and exposed, which is why I hesitated using these kinds of experiments with Sarah. I did not want her to feel unsafe, uncontained, exposed and vulnerable. I still cannot sort through whether they are my issues of insecurities of being a therapist or if it

27

was an element of Sarah's self that she was projecting onto me. Either way, something that I would like to continue to work on in therapy sessions is noticing non-verbal cues, actually being able to comment on them to the client and then using them as graded experiments.

Conclusion

In conclusion, I believe that both consciously and unconsciously I have achieved parts of my goals of becoming more aware of non-verbal communication (both mine and the client's) as well as taking more risks. I feel that in a sense, I took a risk by attempting to lose my dependency on the intellectual side of therapy sessions and I started to trust more in my instincts and have become more open to different kinds of experiences. I feel a real sense of maturation both from the client and from myself. I genuinely believe that these goals are key concepts within the Gestalt approach which is why I chose to attempt this way of working. My hope for the future is that I will continue to work in this fashion so that focusing on the here-and-now becomes second nature. I feel I have to direct my focus and energy on noticing the client's movements, my bodily feelings, our interactions, speech, tone, volume and so on. I believe that by doing this I will become a more well-rounded therapist and person who can see life in a different light.

Part D: References and appendices

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Appendices

Appendix 1: Figure 1 – The continuum of experience (Gillie, 2010)
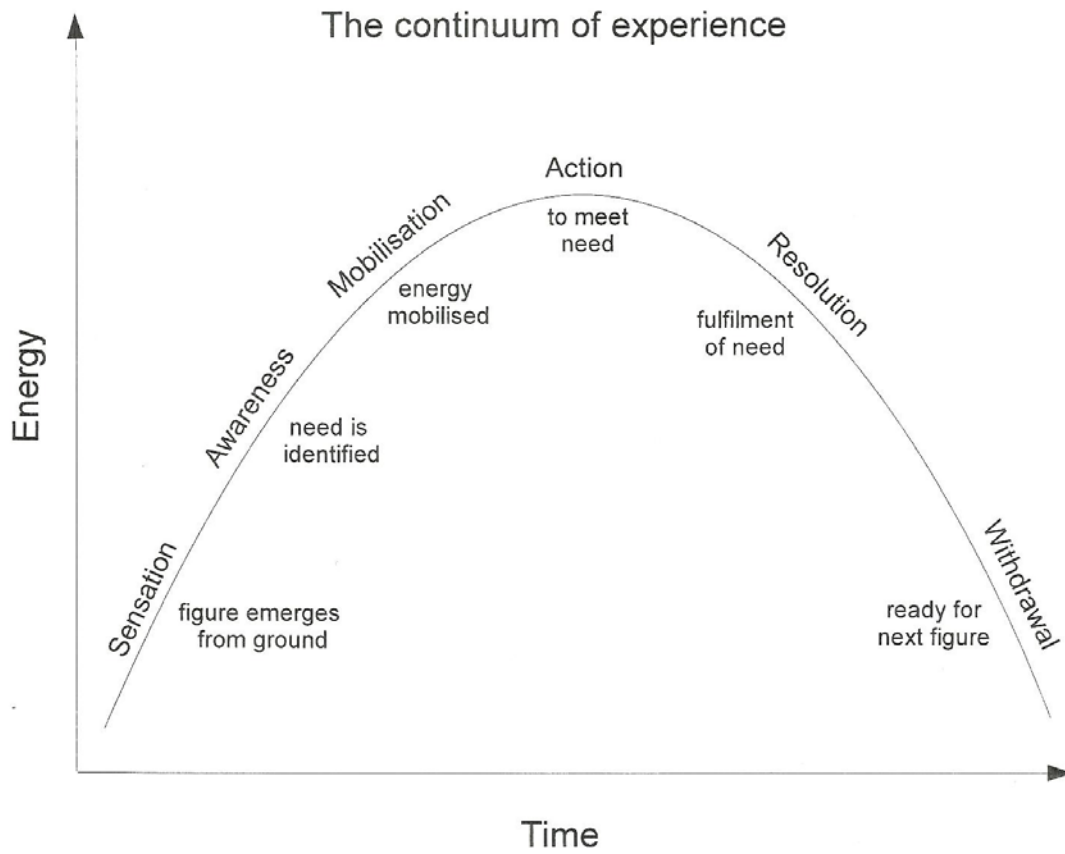
Appendix 2: Reflective diary entry

<u>**Dear...**</u>

Today was the return of my client since I heard she had been in hospital. Something very unsettling has resided in me and I have not been able to fully put my finger on what the feeling is and why it is still there. The closest is that it is sadness. Perhaps this is linked to my personal issues, or perhaps it is linked to her. I cannot distinguish. The build up to today felt very intense. Before the session I had managed to tell myself that staying at a practical and surface level was comfortable enough for me and see what happens after that. I knew that I could take a lot of the lead from the client, which reassured me and I went in there with confidence in myself and my skills.

The start of the session went well. She took the lead by letting me know where she was as she probably thought I was wondering. She kept very factual and explained all the medical procedures she underwent. It got difficult for me when she was beginning to show her process of the event and how it had affected her. There was discussion of injustice, unfairness, frustration and what a horrible year she has had. She was able to be tearful and I allowed myself to go there as well. She did not comment on it and I was not able to either because I felt that drawing attention to it would make it uncontrollable.

I am left feeling drained (emotionally) but also angry with myself. We had spent the session talking about how she feels the need to protect herself and others by not divulging too much information about herself because she cannot handle other people's worries and anxieties. It got to the end of the session and we were talking about what brought her here today since she has been instructed to rest for 4 weeks. She wanted to hear her process out loud and begin to see it from a stable point of view. We talked about how much information I had known before today and there was a lack of holding back on my behalf. I explained I had only just found out what exactly had happened and I specifically mentioned the link I had made between the event and the death of her partner. I am angry at myself because she had just told me how she cannot handle someone else's worries and yet I had told her how worried I was. It was the end of the session and I was not able to tell her that I am ok and that I am not someone else she has to worry about. I am left worrying how this will

affect our relationship. Is she now going to retreat? Why did I feel the need to tell her this information? The very things I knew would result in tears and instability?

Part 2: Doctoral Research

Bereaved individual's embodied experiences at the moment of death within the context of them being physically present or absent

Abstract

Despite there being a vast amount of research within the field of bereavement, as well as death and dying, there are still some experiences which are yet to be explored within the literature. One of the aspects seen within the bereaved and medical communities is that of patients and relatives achieving a 'good death'. The 'good death' has transpired as being physically present at the moment of someone's death. Although there have been a handful of studies which have looked at presence at the moment of death, the current study explored the embodied experiences of bereaved people who were physically present or absent at the moment of death. Nine participants took part in semi-structured interviews, which explored how they made sense of the phenomenon. Interpretative phenomenological analysis (IPA) was used to analyse the transcripts and what emerged were three inter-connective super-ordinate themes of: 'connecting to the body and emotions', 'putting the moment of death into the wider context' and 'endings and beginnings'. Participants spoke of their relationship with their bodies, their emotions and the dying person's body. As the experiences were context bound, participants mentioned the challenges of choice at the moment of death and the connectivity to their wider family and societal networks. Finally, physical presence or absence at the moment of death not only brought about the significance of saying goodbye but also life changes in response to the event. These findings go against the longstanding medicalied view of death to offer a different way of looking at bereavement as well as death and dying. In doing so, they offer application to practice for counselling psychologists, but also those working with the dying as an attempt to incorporate the body into providing holistic care to people.

Introduction

Being physically present at the moment of a loved one's death has been embedded into both western and eastern cultures as something of great importance to the dying, the bereaved and to healthcare professionals. The purpose of this chapter is to review the specific literature around the moment of death within the field of death and dying and bereavement to set the aims for the current doctoral research topic.

The first section of the chapter begins with the foundational elements of exploring death. They include the medicalised perspective of there being a separation of mind and body as well as the phenomenological holistic view. The literature will then focus on the development of bereavement theories from Freud's severing attachment bonds to more modern conceptualisations of bereavement, such as continuing bonds. Having explored the relationship between bereavement theories and the way they affect the conceptualisation of bereavement, the significance of contextualising findings and the role that culture plays in understanding participant experiences will be explored.

The second part of the chapter moves onto the concepts of 'good deaths' and 'bad deaths', exploring what those terms mean within different contexts and the underlying assumptions and expectations around needing to ensure that the dying have a 'good death'.
As one of the main criteria cited by the dying, bereaved individuals and healthcare professionals in achieving a 'good death' was having someone physically present at the moment of death, the final section of the literature review examines the findings from studies that have specifically focused on the moment of death. Themes such as continuing bonds, saying goodbye, fulfilling roles and awareness of the dying trajectory were all seen to be important to people that were physically present when their loved ones died.

The existing literature in bereavement and more specifically the moment of death, has focused on the experiences of people that were physically present when their loved one died. To date, there have been no studies that have looked at individual experiences of physical absence at the moment of death. The research aim of looking at people's experiences of embodiment at the moment of death in physical presence or absence begins

to challenge the underlying assumptions around 'good' and 'bad' deaths. The final section of the chapter brings my personal reflexivity into the research and looks at how my assumptions and previous understandings have shaped the creation, development and outcome of the research.

Making sense of death

The death of person, mind and body

The death of a human being is a complex phenomenon, which incorporates the death of the person, mind and body. In trying to understand the complexities of the body, there have been two main schools of thought: the positivist and the phenomenological.

The positivist view on death believes in the 'dualism' of mind and body, which originated from Descarte's philosophy that has since dominated the western medical world (Haddow, 2005). The medical world operates from the point of view that the body becomes a site for diseases and needs to be fixed. The view of a distinct split between the non-tangible self and the tangible body became known as the Cartesian dualism. The implication for viewing the person as having a separate mind and body is that following the death of a human being, the body remains but is devoid of all relationships and significance (Drayton, 2013).

Contrary to Cartesian dualism, within the phenomenological philosophical movement, Merleau-Ponty focused on the lack of ability to separate the experience of self and body (Morris, 2013). In his book, *Phenomenology of perception,* Merleau-Ponty (1945) discussed several important points about our relationship to our bodies. According to Merleau-Ponty, the body is not something objective but rather we *are* our bodies. As he stated "nothing determines me from outside, not because nothing acts upon me but, on the contrary, because I am from the start outside myself and open to the world" (pp. 529–530). Morris (2013) went on to state "the body mediates meaning, is mediated by meaning and is thus our opening to the meaningful being" (Morris, 2013, p. 114). In other words, the body is something that is entwined with a sense of self as well as meanings. As humans, we are lived bodies[11]. If we think about the body as being a reminder that we are going to die, then

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[11] Taken from Merleau-Ponty, the 'lived body' refers to "the subject's own body" (Ayouch, 2008, p. 339)

according to Merleau-Ponty, a change in the body will therefore result in a change of our way of being in the world and vice versa.

Gudmundsdottir (2009) supported Merleau-Ponty's point when she explored bereaved individuals and how their bodies reacted to grief. In her study, Gudmundsdottir interviewed 15 relatives of a child who had died suddenly, about their experiences of the grieving body. She specifically focused on the changes of awareness that occurred to the participants' lived bodies and it was noted that their sense of body felt different and somehow changed as a result of the experience. The change manifested itself in pain, as if carrying a heavy load, something missing and an indescribable difference. The death of the child therefore, was a change to the person's physical environment, which also meant that their bodies reacted according to this change.

Gudmundsdottir recognised that the participants' accounts consisted greatly of psycho-somatisation, which is currently the predominant discourse within the medical field. This way of thinking can be traced back to Freud's original work on *Mourning and Melancholia* (1957/1915) where grief was a psychological phenomenon. Certain emotions were extremely difficult to express and so hysteria was a form of indirect body symptom (Feltham, 2008). The body symptoms were therefore somatisations[12] of an emotional cause. Despite somatisation being described by participants, Gudmundsdottir (2009) realised there was a stark contrast between the medical Cartesian view of separation of mind-body compared to the lived experiences of people whose bodies held meaning and created meaning in relation to their bereavement.

Gudmundsdottir's phenomenological study highlighted the different perspectives that exist in relation to understanding the person, the mind and the body. As the author stressed, the accounts were demonstrative of not just the participants, but also the environments in which they lived. The language described participants' bodily reactions as a manifestation of the emotional pain they were suffering. This study brought the awareness that coming from Merleau-Ponty's view of embodiment was a helpful way to interpret the participants'

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[12] Somatisation is defined as "the process by which psychological distress is expressed as physical symptoms that have no organic base" (So, 2008, p. 167).

stories as there was no straightforward split between mind and body. As the study focused more on the phenomenological experiences, the predominant discourse in positivism of labelling, diagnosing and pathologising the grief was not helpful for participants, whereas gaining a greater understanding of how they adapted emotionally and physically to the sudden death of a child was of greater importance to them.

As Merleau-Ponty discussed, our sense of the world is linked with our sense of the body. Seeing a person's body deteriorate towards death will not only result in a change in how that person interacts with us, but also in how we (and our bodies) interact with them. Lawton (2000) discussed this point further when referring to hospice patients. From qualitative interviews and observations with terminally ill people's relatives, she looked at the change that occurred when the dying person went from being a 'body-subject' to a 'body-object' [13] (Lawton, 2000 p. 82). Her participants described how when their relatives' bodies started to deteriorate and they became more dependent, the participants became responsible for the bodily tasks that their dying relatives could not perform themselves. For example, if the dying person could not speak, then the participant would speak on their behalf. This, in turn, changed the experience of sense of self for both the dying person (as they could not directly express their wishes) as well as the participant (as they now had to take on the perceived wishes of the dying person). It was almost as if the two people were living through each other, where the body and mind of the non-dying person was used as a vehicle to express the needs of the dying person.

What these interviews and observations further reveal to the reader is that the lived body can drastically change the meaning of who we are in relation to our bodies. The relatives were attuned, empathising and came to assumptions about the needs of the terminally ill patients through their deteriorating bodies.

Death and culture

If death is a universal experience, why is it that people interpret the experience of death in different ways? The underlying factor for both the positivist and phenomenological

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[13] 'Body-subject' refers to an individual being seen as a body that has self identity. 'Body-object' refers to the loss of self and the person being seen as a sum of body parts that are either functioning or not functioning.

viewpoints is the context in which both experiences are viewed from. As death is interpreted in different ways depending on social background, by looking at different cultures a wider understanding of experiences can be gained. In her theoretical paper, Zeiler (2009) attempted to understand death as a concept by exploring it from the perspectives of Christianity, Judaism, western society, Japanese culture and the Malay people. By looking at these different beliefs, Zeiler believed she could demonstrate the importance of pluralism in gaining different perspectives around how people make sense of death.

Zeiler began by looking at death as the separation of the soul from the body within the Christian faith. As this was difficult to witness, it became the "irreversible cessation of breathing and/or irreversible cessation of cardiac activity" (Zeiler, 2009; p. 451). Although the view in Judaism agrees with Christian belief that death is the separation of the body and soul, the difference between the two faiths lies in when this takes place. The Jewish faith believes that someone is dead when they stop breathing. In the western medical environment there is an ongoing debate amongst healthcare professionals between the whole-brain death (biological) versus the higher-brain (consciousness) death. Japanese society believes that death encompasses the body and soul but their definition of body and soul is different to that within western society. In Japan they believe that the soul is distributed throughout the body whereas in the west it is largely seen as something that exists in relation to the mind. In contrast to all of the above concepts, Malay people believe that death occurs when all of the blood within the person leaves their body.

All of these different viewpoints reveal that death as a concept means something completely different depending on the context that it is situated within. Zeiler (2009) stressed in her conclusion that there are differences both within and between societies around understanding death.

Bereavement theories

Research in the latter half of the 20th century and early 21st century has begun to look at the influence of culture on bereaved people's experiences. Much like the research into death and the struggle between Cartesian dualism and the phenomenological perspective, bereavement theories exemplify the struggles and also highlight the importance that culture plays.

The early developments of therapeutically working with bereaved individuals began with Freud's (1917) idea that grief was something that needed to be 'worked through' or resolved. Freud's initial work with grief had the aim of severing the ties with the deceased because it was thought that keeping an attachment takes the person away from reality (Bonanno and Kaltman, 1999). Severing the attachment bonds between the bereaved and the dead person became a goal for individuals and therapists alike. Freud also placed grief on a continuum of 'normal' to 'pathological' where the latter resulted in the bereaved individual misdirecting emotions of the deceased inwards and some of the consequences resulted in psychological symptoms, such as depression and anxiety.

In Freud's words, the aim of grief work was related to the "attachment to the non-existent object" (1917/1957, p. 166). Bearing in mind that Freud was initially a psychiatrist immersed in the medical and psychological field, his work follows the medical tradition of positivist thinking. Freud saw the deceased as an 'object'; once they were dead there was no person left therefore there was no need to continue an attachment with the object that remained.

Freud's views have dominated the bereavement field over the past century. As Freud was a psychiatrist he was able to heavily influence the western medical environment. Therefore the western medical world followed suit in placing a strong emphasis on being able to assess the positive or negative changes in psychological states that bereaved individuals experienced (Paletti, 2008). The disagreement that many authors (such as Stroebe and Schut, 1999 and Paletti, 2008) in the field have had with seeing bereavement as a psychological state that can be recovered from, is that it has a medical connotation. One of the usages of the term 'recovery' implies restoration to a previous state of functioning. Authors such as Cadell and Sullivan (2006), however, have shown that following a bereavement, participants showed positive changes in life goals and existential meaning. The authors used a mixed method design of combining questionnaires and in-depth interviews to explore post-traumatic growth[14] among caregivers of people with HIV/AIDS. They found themes that included discovering new possibilities in life, positive outcomes in relating to others, gaining personal strength, an increased appreciation in life and spiritual change. These findings would suggest that the participants surpassed a level of 'recovery'

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[14] Post-traumatic growth can be viewed as "a person is, in some sense, left in a better psychological state as a result of struggling with the adversity." (Gerrish, Dyck & Marsh, 2009).

from their state of pre-bereavement to a better state post-bereavement (Gerrish, Dyke and Marsh, 2009).

In a small examination using his previously conducted studies, Rosenblatt (2008) discovered that when looking at individual's experiences in bereavement, the term recovery did not appropriately describe their experiences. Rosenblatt (2008) noticed that although the participants in the studies that he reviewed did confirm that they felt they were in a different state post-bereavement compared to pre-bereavement, there was not an element of recovery but rather an integration and re-defining of the self. Rosenblatt (2008) and Balk (2004) began to discuss the origins of the word 'recovery' and they noticed that the term was embedded within the Euro-American culture that was seen as desirable. As the western mentality, in general, is based upon individualism, Rosenblatt (2008) commented that people have adapted their way of thinking to reflect the societal norms of emphasising the individual. For example, grief work has focused around helping the individual re-establish and redefine a sense of self that is sometimes lost after someone has died. Rosenblatt (2008) recognised that basing grief work around universal psychological states did not encompass the bereavement experiences that people expressed, therefore professionals within the field needed to look into individual differences.

It was not until the emergence of Stroebe and Schut's (1999) Dual Process Model (DPM) [15] and Klass, Silverman and Nickman's (1996) continuing bonds theory that stepped away from the medicalisation of grief and moved towards researching the individual's experience of bereavement. One of the most widely used theories on bereavement in current times is that of continuing bonds first proposed by Klass et al. (1996). They believed that, in order to look at the bonds we continue to form with the deceased, we must first go back to Bowlby's (1969) attachment theory which proposes that without understanding an attachment, we cannot look at the loss involved.

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[15] The DPM encompasses the oscillation that occurs in everyday life between the bereaved individual focusing on loss-orientated and restoration-orientated processing. When an individual is focused on the loss-orientated processing, this refers to the specific, often painful, grief work that searches for the lost person (Stroebe & Schut, 2008). The restoration-orientation processing focuses more on the consequences of bereavement that require the individual to attend to life changes, look at new roles/relationships and distract them from the primary grief work.

Bowlby (1969) believed that as humans, we have a natural inclination to form attachment bonds with our primary caregivers. He believed that grief was therefore a natural reaction to a break in that bond. Contrary to Freud's grief work, Klass et al. (1996) took the attachment theory and suggested that the nature of grieving was to continue the bond with the dead person and adapt the relationship around the death. For example, a bereaved individual who keeps the jacket of their dead parent is continuing the bond by grasping onto a physical object as a representation of the relationship. Where Freud would have classified the bereaved individual holding onto the jacket as a 'pathological' symptom, the continuing bonds theory states that this is 'normal'.

Contextualising bereavement

The significance of the emergence of new attitudes towards bereavement was that cultural manifestations of grief began to surface. Authors such as Bonanno and Kaltman (1999), Becker et al. (2007), Hardy-Bougere (2008), Paletti (2008) and many other researchers have all shown that bereavement cannot be viewed in isolation and therefore it is important to understand the context in which the loss occurred. The context does not only include looking at the cultural background of the bereaved but also, more specifically, looking at the age of the deceased, the type of loss (e.g. unexpected or illness deaths) and gender (Bonanno and Kaltman, 1999). For example, Hardy-Bougere (2008) explored in her article the importance that culture played in how someone interpreted their experience. By understanding the cultural interpretation of the death through the eyes of the bereaved we can begin to uncover some of the explicit and implicit expectations that lie within that culture. Paletti (2008) extended the claim further by stating that responses to bereavements varied depending on culture.

To put this theoretical knowledge into clinical examples, several authors have studied the experiences of bereaved people from different and opposing cultures in an effort to understand to what extent culture plays a role in people's experiences. Researchers such as Lalande and Bonanno (2006), Pressman and Bonanno (2007) and Valentine (2013) have focused upon the divergences in continuing bonds across cultures. For example, in Freud's original papers on *Mourning and Melancholia*, the idea of continuing a bond with the deceased was considered a problem. On the other hand, in Asian cultures, such as Japan

and China, the ancestors play an important part in the bereaved family rituals after death and continuing relationships with the dead are therefore not seen as pathological.

Lalande and Bonanno (2006) recruited participants from both the United States of America (USA) and the People's Republic of China (P.R.C) to complete quantitative measures looking at levels of continuing bonds with the deceased and their effect on participants' adjustment to the bereavement. The authors recruited participants who were either parental or conjugally bereaved under the age of 66. Both sets of participants answered three questionnaires (continuing bonds, distress and grief processing) at four months post-bereavement and again at 18 months post-bereavement. The authors felt that choosing participants from both the USA and P.R.C was appropriate as these two groups of people had varying cultural views. For example, the USA tends to have an individualistic emphasis on the self and achieving personal goals. In contrast, the P.R.C (as well as many other Asian countries) places more emphasis on the communal and familial bonds in both life and death. The results revealed that participants from the P.R.C demonstrated higher continuing bonds at the initial round of questionnaires compared to those from the USA. In the second round of questionnaires this difference was not statistically significant. The authors attributed this to culture. They felt that the Chinese culture incorporates more communal rituals in the first few months of bereavement, which in turn increases a communality and social support.

Although the results from Lalande and Bonanno's (2006) study appear straight-forward in terms of the influence of culture on bereavement, there are some considerations and limitations with the study that need to be considered. Firstly, looking at the quantitative self-report measures that were used for both sets of participants, there were often translations from English to Chinese and from Chinese to English. This is important to note because things could be lost in translation. Furthermore, as two of the three scales were originally developed in the west, the questionnaires might not adequately capture the essence behind the Chinese culture that is aimed at being explored. The third scale that was used was developed collaboratively between the American and Chinese investigators therefore it throws into question the quality and validity of the scale. Additionally, the authors mentioned that the participants were paid to take part in the study. An individualistic monetary gain may have affected the reliability of the self-report measures because participants may not necessarily have cared about the questions but rather were

more concerned with receiving the payment after each questionnaire session. Bonanno and Kaltman (1999) mentioned the importance of age on the interpretation of a bereavement experience, however, in Lalande and Bonanno's (2006) study they only recruited participants who were under the age of 66 without providing a rationale. This in itself brings to light a cultural assumption that the experiences of those over the age of 66 are not as valuable or credible as those who are younger.

To explore more in-depth accounts of bereaved people's experiences, Valentine (2013) examined the narratives of nine British mourners and three Japanese mourners. The author explained that her rationale for choosing participants from such culturally diverse populations was because they both acknowledged the importance of continuing bonds with the dead, however, the way that the bonds were manifested depended on their cultural background. One of the main points that stood out from Valentine's (2013) study was how the participants in both cultures negotiated their way through the social norms. For example, with some of the British mourners they described attempting to hold both a rational understanding of sensing the presence of the dead versus a more spiritual or religious belief. Perhaps this was their way of attempting to grieve on an individual level but also putting their grief within the wider social context and wanting to justify their experience to be culturally acceptable.

Within the Japanese culture in general, there is greater emphasis placed upon the social grieving, which includes a longer period of mourning for family members (Irish, 2000). The accounts from the Japanese participants that Valentine (2013) interviewed interwove the cultural traditions that Japanese people should adhere. For example, seeing the dead person's face at the moment of death is regarded as important because if the dead person's face is 'peaceful' the implication is that the family has succeeded in fulfilling their duties to the dead, which in turn will bring the family protection. It is important to note that the participants in Valentine's study were mourning the loss of a loved one through suicide which is a death that is frowned upon within society. The suicide deaths that the participants experienced were difficult because they were attempting to negotiate their personal grieving for the loved ones whilst being fully aware of the social undertones and implications of this 'bad death'.

Valentine (2013) concluded from her exploratory study that the grieving process of British and Japanese mourners was affected by the culture in which they lived. The tension for the participants arose when they struggled to make sense of their individual experience when those experiences did not adhere to the cultural norms.

The importance of creating an understanding around grief that either goes with or against the cultural norms is something that is echoed through Neimeyer, Klass and Dennis's (2014) theoretical paper. They believed that "the meanings people find through the situated interpretative and communicative activity that is grieving must either be congruent with the meanings that undergird the larger context or represent an active form of resistance against them" (p. 485). The congruence and resistance referred to here are apparent in Valentine's (2013) study; participants expressed that they followed some cultural norms but were also aware that their experience of the nature of death went against the larger cultural context. Neimeyer et al. (2014) went one step further by stating that they believed society instructs bereavement through certain practices, feelings, thoughts and actions. For instance, the psychology and psychotherapy world has seen numerous revisions of how bereavement is viewed. From Freud's (1917) severing the attachment bonds to Kübler-Ross's (1969) stage model[16] to Worden's (1991) task model[17] and Stroebe and Schut's (1999) DPM. These different models have brought about new ways that the western culture has viewed grief and consequently dictated ways in which acceptable and non-acceptable coping of grief were viewed. With these heavy influences on behavioural codes of conduct in bereavement, Neimeyer et al. (2014) stressed that greater attention needs to be paid to understanding individual experiences within a societal and cultural framework as the ways in which bereavement is being conceptualised are constantly changing.

Bringing continuing bonds into a contemporary context, counselling psychologist Elaine Kasket (2012) shared her work on death in the digital age. By using the social media site

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[16] The stage model proposed by Kübler-Ross (1969) identified five potential emotional reactions to grief that a bereaved person could experience. These stages included: denial, anger, bargaining, depression and acceptance.

[17] The task model of bereavement is for the bereaved to accomplish tasks in order to have a complete bereavement. These four tasks include: accept the loss of reality, work through the pain of grief, adjust to an environment where the deceased is missing and emotionally relocate the deceased and continue with daily life (Worden, 1991).

Facebook she analysed, using qualitative document analysis, 943 wall posts within five in-memory-of groups. She additionally analysed three administrators of the in-memory-of groups. One of the themes that emerged was that of experiencing continuing bonds within a digital context where the wall posts and interviews showed a continued investment in keeping the bond with the deceased. Posts included updating the deceased on recent activities, having one-way conversations with them and letting the deceased know they were still being included mentally despite not being alive physically. With the participants in this study, there was less of a focus on saying goodbye to the dead person as the person was constantly being co-constructed by friends, relatives and co-workers. The participants were learning more about the deceased after their death, which could suggest that the participants were constantly re-negotiating their relationship with that person. For example, finding out information about the dead person might make them see the deceased in a different light. Kasket (2012) highlighted how social networking sites can break the boundaries of physical and social distance previously felt between the bereaved and the deceased. For example, participants still felt very connected to the deceased when they were alive in spite of living far away.

Kasket's (2012) study has demonstrated that a change in the social and cultural context changes the way people grieve. Although the underlying theory of continuing bonds (Klass et al., 1996) remained, the way in which it was experienced was different to what it was a few decades ago. The increased use of technology means that bereaved individuals are being accustomed to a changed way of grieving that negotiates the relationship they had with the deceased in the material and virtual worlds.

Counselling psychology and bereavement

Although the changing theories of bereavement have influenced the way counselling practitioners have conceptualised grief, there has been a distinct lack of research explicitly for counselling psychologists. The paucity of research into how counselling psychologists interact with bereavement could possibly be a result of the epistemological struggle that counselling psychology faces between the 'scientist-practitioner' and 'reflective-practitioner' (Woolfe, Dryden and Stawrbridge, 2003) models. As counselling psychologists can often find themselves working within medical and scientific environments, they are

surrounded by the medical model which views a phenomenon as being observable and testable (scientist-practitioner). On the other hand, counselling psychologists value the importance of client's meaning-making, subjectivity and feelings (reflective-practitioner). Counselling psychologists therefore identify with the on-going debates within bereavement research where there is a constant negotiation between the medicalised positivist views and the phenomenological experiential views.

Counselling psychologists are however, beginning to recognise the importance of exploring participant experiences that are outside the medical and positivist views. For example, Feltham (2008) drew attention to the fact that there is great ambivalence within the world of counselling psychology toward its relationship with the body. Further supporting Feltham's (2008) observation, counselling psychologist Carol Shillito-Clarke (2008) recognised the lack of research and practice within the field around being mindful of the client and therapist's embodiment[18]. She highlighted for the reader that the leading therapeutic approach within the American and British mental healthcare system is currently CBT, which places a greater emphasis on the mental processes, as opposed to the physical, despite the introduction of mindfulness into the approach. She went on to stress the importance of bringing the embodiment element back into therapeutic practice as although it might not be the reason why a client comes for counselling, their bodies would, in some way, become involved in the therapeutic work too. She stated that viewing and working with the client as a whole (including their body) would increase the client's awareness but also continue the reflexive practice of counselling psychologists, which fully encompasses 'listening' to clients on a verbal and non-verbal level.

The works of Merleau-Ponty (1945), Lawton (2000) and Gudmundsdottir (2009) have all highlighted the interconnectivity of the body in bereavement. Despite their findings, counselling psychology appears to be caught in the middle of different epistemological contexts within the profession as well as in understanding and working with bereavement.

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[18] Shillito-Clark (2008) referred to the works of Merleau-Ponty (1962) and Groth (2001) when defining embodiment as "the 'lived body' or the 'body I have' which includes the dynamic experience and subjective nature of existence: the 'body I am'." (p.82)

'Good death' and 'bad death'

Despite numerous research papers recognising different understandings of what death means in different contexts, the idea of a 'good death' preoccupies different societies. In Japan, a study by Akechi et al. (2012) showed, through self-administered questionnaires to the general elderly Japanese population, that trusting the medical staff in decision-making and being listened to were the two most important components of a 'good death'. In America, Vig, Davenport and Pearlman (2002) used qualitative interviews with geriatric outpatients and showed that themes such as not feeling pain, dying in their sleep and not suffering equated to a 'good death' for these participants. The understanding of what a 'good death' is has been researched from the perspectives of the dying person, the relatives and those directly involved in providing healthcare (such as doctors and nurses). The common feature from these studies is that there is no agreed understanding as to what consists of a 'good death'. So far, the purpose of the studies that have looked at achieving a 'good death', has been to ensure that those providing direct medical care to the dying can create policies around easing physical suffering of patients (Scarre, 2012).

The following section will describe and discuss the early interpretations of what a 'good death' should look like from a religious perspective. The literature will then explore the concept of a 'good death' in modern contexts and how there is a struggle amongst healthcare professionals and individuals to understand what a 'good death' and a 'bad death' looks like.

The 'good death'

The earliest written trace of what was considered a 'good death' is the *Ars Moriendi*, otherwise known as 'the art of dying', a text written in the Middle Ages by members of the Christian faith. It listed a prescriptive method in order to achieve a 'good death'. Consequently, the *Ars Moriendi* were also texts that became a prescriptive way to live life in order to prepare for death (Rodriguez, 2004). The texts were to be read by both the person that was dying as well as those in their company.

Continuing along the religious lines, the popular *Arminian Magazine* established by John Wesley in the 1700s was used to communicate to the Methodist community and to teach them what deathbed scenes should look like and how to achieve a 'holy death' (Bell, 2005 p.

213). The magazine emphasised the final days and hours of the dying person, which was a transition period from the current physical cessation to a new level of existence where people went to another place (i.e. heaven or hell). One of the main tasks that a dying person was required to fulfil on their deathbed was to demonstrate their strength of faith by preaching to their family and friends the Methodist religion. The dying person would convince the people around their deathbed of the teachings of Jesus Christ and in doing so, would begin the process of preparing those left behind for their own death (Bell, 2005).

In both the *Ars Moriendi* and the *Arminian Magazine*, the moment of death proved to be a social occasion, which involved a collaborative approach between the dying and those who would remain. A 'good death' equated to a 'holy death'.

Although the idea of a 'good death' has been around for centuries, the more modern conceptualisation can be found within the recent developments in hospice and palliative care. Clark and Seymour (1999) demonstrated the principles and requirements that were intended for medical healthcare professionals to provide a 'good death' for patients, which involved having control, individuality, respect and awareness of family issues. The current NICE guidelines (2011) in the United Kingdom have also set up the high quality standards of end-of-life care, which recognise the individuality of patients, their relatives, communication between all involved and care, both pre- and post- bereavement. Despite a large emphasis on the importance of the individuality of patients, there are established general guidelines. All of these guidelines and procedures do not capture how a 'good death' is experienced from a patient or relative's perspective, but rather state the aims and goals from the legal and medicalised points of view.

Kehl (2006), who came from a palliative care nursing background, recognised that the concept of a 'good death' has changed over time. She therefore explored what a 'good death' consisted of by performing a concept analysis of existing research from within different medical disciplines. Although she found discrepancies within the research, she recognised certain attributes that were important in the majority of cases. These included: being in control, being comfortable, a sense of closure, affirmation/value of the dying person recognised, trust in care providers, recognition of impending death, beliefs and values honoured, burdens minimised, relationships optimised, appropriateness of death,

leaving a legacy and family care. The studies were looked at from the perspectives of patients, relatives, nurses and physicians. Shneidman (2007), coming from a clinical psychology perspective, also came up with ten criteria for a 'good death', which were similar to Kehl's (2006) findings but named slightly differently.

The attribute that was cited the most within the literature was that of the dying person being in control, more specifically having control over the timing, location and presence or absence of others. It is worth noting that being in control can only be relevant in cases where patients had conscious awareness that they were dying. In the literature surrounding the medical healthcare professional's view, it was also felt that people being present at the death of someone was necessary in order for it to be considered a 'good death'.

Kehl (2006) found in her literature analysis that in order to look at a 'good death', one needed to look at a 'bad death'. The common characteristics included: not being in accord with patient's wishes, the death being prolonged, patients being dependent, death being traumatic, the patient suffering, feeling unprepared, patient care being disorganised, the patient knowing death was imminent, the family feeling burdened, the patient dying alone and the patient being young.

There is a concern around creating criteria for a 'good death', as Shneidman's (2007) paper highlights, as there were no studies around which he appeared to have based these criteria. His paper did not state theoretical background, individual cases, or any evidence that these ten criteria could be considered useful. Also, the language he used could be considered insensitive. An example of this was his criteria, which he called "civilized" (p. 246). He described this as "To have some of your loved ones physically present. That the dying scene be enlivened by fresh flowers, beautiful pictures, and cherished music" (p. 246). Shneidman began with the underlying assumption that death was a bad thing and that it needed to be "enlivened" (p. 246). He also did not take into consideration that not only in each culture and religion are there different practices around death, but that within each family there are also certain beliefs, rituals and ceremonies that can be performed. It could be argued that his view of a "civilized" 'good death' came from a western and Christian background, where such things as flowers, pictures and music are a more common tradition around

death. The concern around taking the criteria that he proposed at face value, without questioning them, is that there appeared to be a lack of humaneness.

Masson (2002) suggested that the criteria for good and bad deaths would become idealised as a 'perfect death' and that in reality, this is a questionable goal to try and achieve. This challenges the usefulness of needing to label death in a binary 'good' and 'bad' way. Perhaps it underlines the question: who is the death good or bad for? If a patient, for example, died alone, then according to the criteria, this would be classified a 'bad death'. It does not take into consideration the fact that perhaps this patient wanted to die alone. The consequences of the term 'bad death' could have an effect on the relatives that perhaps 'allowed' this person to die alone and could consequently bring up feelings of guilt or shame. Hart, Sainsbury and Short (1998) also drew attention to the often-romanticised view of achieving a 'good death'. After reviewing the existing sociological literature, they emphasised the difficulties that healthcare professionals, patients and family members encountered in order to achieve a 'good death'. If patients were to follow the 'dying trajectory'[19] (Glaser and Strauss, 1965), then professionals and family members would see this as following the path to a 'good death'. However, if the patient's death was sudden or unexpected then this was considered a 'bad death'.

The 'bad death'

The focus of healthcare professionals has been on providing the dying with a 'good death'. However, by looking at what it is considered a 'bad death' we can begin to understand the relevance of a 'good death'.

Yalom (1980), along with Freeman and Berger's (2009) study, illustrated that participants considered dying alone as a 'bad death' despite the recognition that eventually everyone must die alone. Freeman and Berger administered questionnaires to military veterans regarding their end-of-life and the results showed that an overwhelming majority of people were afraid of dying alone. Following on from this, Seale (2004), who wanted to paint a more in-depth picture around the public's social construction of dying alone, set about using

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[19] Glaser & Strauss's (1965; 1968) 'dying trajectories' is seen as the individual's path of dying and the recognition that different patterns of dying exist.

the media as a medium for analysis. By analysing the content of newspaper articles, he found that the media generally portrayed dying alone as something caused by violence, human malpractice or negligence. The location of death also played an important part in setting the scene for a 'bad death', as those who died away from home were seen to be socially isolated. Deaths in medical institutions were also considered bad as it was seen as scandalous that no one (not even a member of staff) was present at the moment of death. Furthermore, the analysis revealed that the character of those who died alone was often described as "reclusive eccentric" (Seale, 2004 p. 970). The other major focus of these media articles was on those who could and should have prevented the dying person from dying alone. There appeared to be blame, shame and responsibility placed upon those who failed to prevent the person dying alone.

What needs to be taken into consideration about Seale's (2004) study is the fact that only the media was used as guidance for the portrayal of dying alone and the meanings that people constructed. The media has the power to construe different portrayals of a situation by evoking different emotions in its readers. Overall, the general consensus seen through the media was that dying alone was considered a 'bad death'.

Qualitative studies in 'good death' as seen by the dying and their relatives
In an attempt to find out how individuals experience a 'good death', one could start by looking at the qualitative research within the field. Studies that look at the lived world of participants have been used to gain a greater in-depth understanding of 'good death' experiences.

Masson (2002) explored perceptions of a 'good death' from the points of view of both patients and relatives of deceased patients in order to obtain more insights within the context. He used a combination of both face-to-face interviews as well as obtaining written accounts of participants describing a 'good death' and a 'not-good death'. His findings were, overall, consistent with previous studies (e.g. Payne, Langley-Evans and Hillier, 1996 and Bradbury, 1999). The main findings included a recognition that what the patient considered a 'good death' was not always considered good by their relatives and that a 'good death' was relevant to the way the person's life had been lived (e.g. someone who had many

children in life was thus surrounded by many people at death). Flexibility was also considered important (e.g. the location of death and not letting pain interfere with the continuation of life). Masson (2002) noticed from the findings that the patients' accounts were more succinct and had a more limited content in comparison to the relatives' experiences. He suggested that this could be related to the patients having a more focused understanding of what they wanted as a 'good death' because theirs was more imminent.

The main conclusion that Masson (2002) arrived at in his paper was the concept of a 'good enough' death, which refers to the more fluid and negotiating experience described by the participants as opposed to the more static formulation of achieving a 'good death'. Issues such as communication were highlighted amongst all people involved (e.g. patient, carer, doctor). If the patient was unable to communicate then who and how is it decided what a 'good enough' death consists of?

Although it was insightful to hear individual experiences from participants regarding the concept of a 'good death', Masson's (2002) study left the reader questioning the 'not-good death'. Despite asking participants to describe 'not-good deaths', there was no evidence of the experiences regarding this subject in his analysis. The focus of the study was on the 'good death'. Therefore, the reader was left wondering why he asked the participants about a 'not-good death' as there was no follow through. By looking at both the 'good' and 'not-good' deaths this could have led to a greater understanding of both.

Asking patients similar, open-ended questions, Pierson, Randall Curtis and Patrick (2002) conducted a grounded theory study on the domains of 'good deaths' and 'bad deaths' with patients who had advanced AIDS. They interviewed 35 patients by asking them "How would you describe a good death?" and "How would you describe a bad death?". From their analysis the domain that emerged the most was that of having people present. Twenty-two participants identified it as favourable, one as unfavourable and nine stated their indifference. Having a loved one present whilst the patient was dying did not only include family members but also carers, friends and pets. Some of the other domains mentioned were symptom control, death scene, acceptance of death and spirituality. From their results, the researchers felt that the experiences of the participants could be used by all involved to discuss and address the issue of dying. What they emphasised was that, although there were key domains that the participants mentioned, there was a large

variation in the way that the domain was perceived, depending on the individual and the importance it held for them. For example, location of death came up as a key domain for participants, yet within that, there were individual preferences in terms of hospice, hospital, home, etc. This implies that generalisation of the terms 'good death' and 'bad death' cannot be realised due to the fact that despite overall themes, these themes are interpreted in different ways depending on the individual.

What Pierson et al.'s (2002) study left the reader with was a more in-depth personal account of what patients with advanced AIDS considered a 'good' and 'bad' death. It highlighted people's expectations and hopes despite being surrounded by a medical environment. At the end of their paper, Pierson et al. (2002) believed that their results could be used to help create guidelines and educational programmes around providing end-of-life care. To add to the usefulness of the findings, participants' experiences could also help others in facilitating discussions around death. Learning from individual experiences would open the discussion for more people and benefit broader communities. The anticipated benefit would be that it would enable those working with dying patients and relatives to recognise the individual differences and take them into account, as opposed to creating unachievable goals (e.g. a 'good death') and assumptions that all people want to die in a specific way.

There were a few limitations to Pierson et al.'s (2002) study, which the authors were aware of and that were discussed. However, there were other areas where the reader was left wondering. Firstly, although 15 domains were identified through the interviews, the authors only focused on 12, as those were mentioned by at least two participants. I was left curious about the content of the other three domains and have put their exclusion down to the choice of grounded theory methodology. Had, for example, Interpretative Phenomenological Analysis (IPA; Smith, Flowers and Larkin, 2009) been used, then the other domains could have been explored and analysed. Another limitation was that the researchers were all physicians who focused solely on the domains where they could have a direct influence (e.g. pain control). The holistic care, which would include the psychological needs, was not addressed despite it being part of the patient experience. The authors emphasised the importance of client-doctor communication but left out the patient-doctor-multidisciplinary team communication that is also vital in the patient's care.

The current literature on 'good deaths' and 'bad deaths' has attempted to provide more clarity around criteria for achieving such deaths without taking into consideration the individuality of death. The implications for creating such achievements is that physicians and nursing staff have been less focused on the patient's and relatives' needs and more on the organisational requirements placed upon them (Costello, 2006).

Qualitative studies have begun the process of exploring what a 'good' and 'bad' death means from the perspective of the dying person and their relatives, although there are still many aspects that require further exploration. One such aspect is that of being physically present at the moment of death, as this was one of the aspects of dying that was most frequently cited in the 'good death' literature, yet has received little therapeutic investigation.

Physical presence at the moment of death

Dating back to the *Ars Moriendi*, the idea of having someone physically present at death has been of significance both from the perspective of the person dying as well as the people witnessing the death. Relating this concept to the modern literature, one of the key features that emerged from research exploring good deaths (Kehl, 2006; Shneidman, 2007; Masson (2002) and Pierson et al., 2002) was the aspect of someone being physically present at the moment of death. Having someone physically present at death is considered a 'good death', whereas dying alone is considered a 'bad death' (Kehl, 2006). More specifically, what is the significance of having someone physically present at death that makes it an important part of the dying experience? Studies that have focused on the moment of death have highlighted four main experiences related to the importance of being physically present. These include the bereaved individuals' continuing bonds with the deceased, being able to say a farewell, fulfilling roles and the moment of death within the dying trajectory. The following section will discuss, in further detail, the four main experiences highlighted in previous qualitative studies that have looked at bereaved people's experiences at the moment of death.

Saying goodbye to continue the bond

The act of saying goodbye and having a death farewell provides "interpersonal exchanges of affection, reassurance, acceptance, reaffirmation and support" (Davis, 2003 p. 201). Several

studies have shown that farewells come in many forms, through dialogue, song, gestures, gifts and words (Davis, 2003; Kellehear and Lewin, 1989; Kastenbaum, 1997; Kates, 2001; and Nosow, 1998). What these studies have shown is that the act of having a death farewell creates a shared meaning between the dying and the living, which could continue after the person has died. This continuation of a bond between the dead and the living, links into Klass et al.'s (1996) continuing bonds theory.

Saying goodbye at the moment of death could also be viewed as a way to continue the bond in an embodied relational way with the deceased. Ribbens McCarthy and Prokhovnik's (2014) sociological paper demonstrated through autobiographical accounts and empirical research "that the embodied relationship with the other does not die with the person, but can be inscribed in the body of the living" (p. 22). They disregard the dualism between mind and body to stress that a biological death is not the death of the relationship between the bereaved and the deceased. The authors question the definition of death, as even if someone is physically present at the moment of death and has said goodbye, the relationship between the deceased and bereaved is still very much alive. The death is then purely biological and the existence of the relationship is maintained through the embodied relationality.

Saying goodbye physically

Another significant aspect of being physically present at the moment of death is the ability to connect physically with the person dying and to say goodbye using non-verbal communication. In a personal account of the death of her father, Weintraub (2007) began by telling the reader that coming to a sense of closure was something important to her and that this was facilitated by her trying to be present at the moment of death. She introduced the element of touch as being a vital experience in being with the dying person in her description: "I held his hand and stroked his face and chest" (p. 357). She felt that touch enabled her father to know that the family was giving him permission to die and helped them communicate that they were all going to be fine once he died. She also went on to describe touch as a way of each person knowing that they were saying their good-byes. Despite her and her family 'waiting' at his bedside for their father die, it so happened that they had left the room to reminisce about him when he actually died. Weintraub (2007)

described being particularly upset by the fact that he had died alone and that they had left him to die alone.

In this paper, it would appear that Weintraub (2007) was trying to describe to the reader that the importance around saying goodbye to her father was to reassure him that things were going to carry on after his death. Although she said goodbye to her father verbally, she also mentioned the importance of connecting her body to his body as another level of saying goodbye. This physical connection is what is missing from, for example, Kasket's (2012) study on death in the digital age. The different forms of saying goodbye (verbal, physical and digital), all hold and encompass a different aspect of the phenomenon of saying goodbye to the deceased.

Fulfilling roles

The other main theme from the existing literature around physical presence at the moment of death was the experience of fulfilling roles. In their qualitative study Williams, Bailey, Woodby, Wittich and Burgio (2013) explored next-of-kin experiences at the moment of death, from a nursing perspective within the context of a military veteran's medical centre. They interviewed 78 relatives who had been recently bereaved and one of the items included asking participants about the dying patient's last days and, more specifically, about the actual moment of death. One of the themes that stood out from their analysis was the role that the relatives played whilst the person was dying and at the moment of death. One such role was that of the caregiver, which often spanned several years for some participants and was something that continued throughout the dying process. Some next-of-kin expressed that being physically present at the death of the veteran, was their last opportunity to continue to nurture them and to provide advocacy on their behalf. This study highlighted the struggle that participants expressed in wanting to gain control within an environment where, as they were not medically trained, their role as caregiver was demoted in relation to the physicians' and nurses' medical experience. It also showed the importance of family rituals being maintained within a hospital-type environment.

Following on from this, Donnelly, Michael and Donnelly (2006) and Donnelly and Battley (2010) aimed to explore the experiences of carers and relatives at the moment of death within the context of death at home and death in a hospital. Donnelly and Battley, in their

(2010) study, interviewed 24 relatives of patients who died in a tertiary hospital. Themes that emerged from their analysis painted a picture of participants waiting for the death of their loved one. Descriptions of vigils and waiting by the patient's bedside were common and there was a particular focus on the physical details (breathing, body parts and medical processes) as this was part of their hospital experience.

Similarly the Donnelly et al. (2006) study, which interviewed carers about the moment of death where their relative had died at home, found the importance of the relationship between the carer and cared for. As the study explored the moment of death within a home setting, the participants shared their experiences of fulfilling the role of carer until the moment of death and beyond. Participants also described their function within the family at the moment of death through experiences of having to be responsible for continuing family, cultural and societal traditions.

What was apparent in the Donnelly et al. (2006) and Donnelly and Battley (2010) studies was the medicalised focus placed around the moment of death. As the authors were medical doctors themselves, the emphasis was on providing physical comfort for the dying patient and their relatives. The psychological needs of both the patient and the bereaved were not mentioned, which does not reflect the holistic care approach that is proposed by the NICE guidelines (2011) in working with imminently dying patients and their relatives. There were some limitations that could be seen from the study. In terms of the methodological procedure of the study, the authors felt that interviewing participants closer to the death was to ensure that they recalled information accurately. The authors therefore put forward the assumption that grief is something that can be recalled accurately or inaccurately and that leaving the interview to months or years after the death could produce inaccurate recollections. As seen earlier in the Lalande and Bonanno (2006) study, where only participants under the age of 66 were interviewed, an assumption was made in all of these studies regarding the reliability and validity of participant experiences. The methodological choices in bereavement studies, therefore, continue to illustrate the complicated relationship between the positivist and phenomenological traditions. Despite the recognition of people's individual experiences holding great value in the contribution towards understanding bereavement, the methodological design of qualitative studies still

holds assumptions around participant ages (i.e. only people of a certain age will contribute 'useful' experiences in studies) and time of recollection (i.e. bereavement research can only seek to look at experiences that are within a certain timeframe post-death).

A moment within the 'dying trajectory'

The previous studies that have focused upon the importance of physical presence at the moment of death have placed more emphasis on the 'doing' (i.e. continuing a bond, saying goodbye and fulfilling roles). Valentine (2007) found that her participants also experienced the moment of death within a wider dying trajectory context. Coming from a sociological perspective, Valentine (2007) explored the moment of death by using a grounded theory analysis of themes that emerged from a conversational response, which asked participants to look at their overall experience of bereavement. The participants were 25 individuals whose bereavements occurred within six years of being interviewed. The deaths ranged from sudden to illness-related. The type of relationship to the participant (e.g. father, partner, mother, etc.) also differed. Valentine's findings indicated that the participants situated themselves, and described the process of making sense of the moment of death, within a 'dying trajectory' (Strauss, 1971) as opposed to a single stand-alone moment. The participants who were not physically present at the moment of death illustrated the way in which they thought a deathbed scene should have occurred, had they been present. Participants had uncertainty until the moment the person died. This provided relief and certainty. Finally, participants expressed the importance of the physical as well as emotional connection they felt to the dying person at the moment of death. Non-verbal connections occurred through hand-holding and gazing stares.

Valentine's study placed the moment of death within a different context to the previous Christian view that relatives of the dying were there to support the dying person into the next life (Rodriguez, 2004). She illuminated the significance of a relative's presence at the moment of death as an event that was part of a wider picture.

Although the study mainly focused on participants being physically present at the moment of death, Valentine (2007) also briefly mentioned two examples of those who were not present. What could be explored further are the experiences of those who were not present, as this is an area of research that has not been looked at previously. By looking at

the phenomenon of physical absence, one can gain a greater understanding of the significance that participants place upon the moment of death.

<u>Conclusion</u>

The critical literature review began by looking at the positivist view that humans can be separated into mind and body, which is the current dominant discourse in the western medical world. In contrast, the more recent trend of research from the phenomenological point of view has emerged, which see humans in a holistic way, not separated into mind and body. The tension between the positivist and phenomenological views has manifested itself in the way death and bereavement is perceived across different cultures as well as throughout bereavement theories. Although there has been a move towards recognising individual experiences of bereavement, the concepts of 'good' and 'bad' deaths are still a dominant discourse within western society. The importance of someone being physically present at the moment of death has been experienced by the dying, bereaved and healthcare professionals as a 'good death'. Various qualitative research studies have identified the ability to continue a bond with the deceased, saying goodbye physically, fulfilling roles and a moment within the 'dying trajectory' as being significant in people being physically present at the moment of death.

The current literature fails to question and challenge the underlying assumptions around the importance of physical presence at the moment of death. Despite the recognition by some researchers of the need to see people in a more holistic way, one that includes the person and body, research has not looked at embodiment and the relationship of the body in bereavement at the moment of death. To date there have been no studies that have focused on the individual experiences of people that have been physically absent at the moment of death. The research aim for this doctoral thesis was therefore to look at bereaved individuals' experiences of embodiment regardless of whether they were physically present or absent at the moment of death.

<u>Research aims</u>

The aim of this research was to take an in-depth look at the embodied experiences of bereaved people whether they were physically present or absent at the time of death. By attempting to explore physical presence and absence, the intention for the research was to

challenge underlying cultural assumptions associated with the need to be physically present at the moment of death. There was a particular emphasis on people's understanding of the significance of embodiment and of being there or not being there at a death, as current bereavement research does not fully embrace the holistic nature of viewing a person and body in death.

The research question was "what are bereaved people's experiences of embodiment at the moment of death within the context of either being physically present or absent?"

Personal reflexivity[20]

By situating myself within my own assumptions and beliefs at the beginning of the research, I attempted to understand how my lived experiences and previous understandings affected the way I viewed my relationship to the research (Finlay, 2002). How I chose this topic of research, as well as my personal connection to it, means I can put forward my individuality and its effects on the research (Gough, 2003). This is in order to improve its quality (Maso, 2003) and to be 'open to' the research participants describing their lived world experiences (Finlay, 2008).

The concepts of death and dying have always intrigued me, as death is the one certainty in life that we will all experience yet at the same time it is the one thing that we can never fully understand. Having worked previously with euthanasia patients as well as those suffering from life-threatening illnesses, one of my clinical placements on the doctoral course was at a bereavement service within a hospice setting. It was through working with a client that the idea for my thesis came about. My client described over and over again the difficulties she was living with, by not having been physically present at the moment of her partner's death.

When I thought back to my own personal experiences of people dying, I realised I had not been physically present when my relatives had died and yet I had had a different experience to my client. I was left wondering why the fact that she was not there when her partner had died had such a significant impact on her and I wondered about other people's experiences with regards to being there or not when someone died. Having done a preliminary literature search, I realised that the current theories of bereavement did not take into consideration

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[20] The sections on personal reflexivity are written in the first person so as to address the reader directly.

the individual experiences of physical presence at the moment of death and I was also left questioning how to work with this phenomenon with my clients. I knew that this topic would sustain my motivation to carry on researching it for years, whilst at the same time offer development within the field of bereavement. I wanted to be able to apply my findings to counselling psychologists, as well as to the wider community context.

My previous research experience has been largely quantitative, where the findings were arrived at objectively through questionnaires and statistics. Whilst I have experience of focusing on an individual's experiences through counselling sessions, this could be a benefit and a hindrance during the course of the research. As a benefit, it allowed me to form an interviewer-participant relationship, which enabled the participants to tell their stories. As a hindrance, I found it difficult to maintain a researching point of view as opposed to seeing the participant as a therapy client. Particularly during the interview stage, I was very conscious of seeing myself as a trainee counselling psychologist researcher. I began to question my identity as a counselling psychologist and then my identity as a researcher. Going back to the epistemological struggle within the field of counselling psychology, I experienced firsthand the challenge of trying to value the subjective participant's experiences whilst simultaneously attempting to produce a piece of scientific research.

As a half British and half Japanese woman in her twenties living in London, I recognised that I had grown up with two completely different cultures embedded within me. Within the Christian faith, it is believed that those who have confessed their sins and turn to Jesus Christ before death will be forgiven and will join Jesus in heaven (Blanche and Parkes, 1996). Japanese Buddhists place great emphasis on their ancestors and reincarnation. They believe that once someone dies, they become ancestors who continue bonds with the living (Klass and Goss, 1999). Despite growing up with these differing perspectives on death, I chose not to be religious and do not hold any of these beliefs. Therefore, it made me even more aware of and sensitive to the fact that other people can have strong beliefs about the moment of death and what happens after someone dies.

Death and dying was not a subject that was talked about whilst growing up and therefore, apart from deaths due to illness, I had not experienced or encountered other types of deaths. While some researchers have identified the value associated with having similar

experiences to participants (Rolls and Relf, 2006), I believed my lack of death experiences enabled me to be more open to new experiences.

My assumption before starting the research was that death was considered a negative experience. It evoked images of negativity, pain and anxiety for me. This was largely due to my upbringing and cultural context. I discovered that I had a double standard when it came to physical presence at the moment of death. When imagining the future death of family members, I found that I wanted to be physically present at the moment of their death. My presence would act as a kind of support for the dying person as well as exerting control over the situation. It felt important to be able to say goodbye to a dying person, so that being absent at the moment of death represented the inability to say farewell to the dying person. The image that came to mind when thinking of being present at someone's death was that of being in a hospital setting, where the dying person was ill from natural causes and I was physically present and active throughout the whole dying process. On the flipside of this, I also found myself contemplating my own death and having people physically present. Despite not wanting to feel alone in death, I also realised that I wanted to protect others from death and therefore would have to question what purpose having someone present at my death would bring. It also made me think about the relationships I had with people and whether or not I felt they could support me.

My earlier assumptions had led me to believe that other people who had experienced deaths due to illness would feel similar feelings and I had not taken into consideration the fact that being physically present at the death of someone could be a positive and relieving experience. During the interview and analysis stage I needed to still remain inquisitive to participants' experiences that resonated with my assumptions as their attempt to make sense of the phenomenon would be different to my sense-making.

As I am at the beginning of my career as a counselling psychologist I would ideally like to work within the field of palliative care, end-of-life conditions and bereavement. My investment in this research is directly linked to wanting to follow this area of counselling in the future.

Methodology and Procedures[21]

This chapter is intended to lead the reader through the design of my research, which aimed to explore bereaved people's embodied experiences at the moment of death in the context of them being present or absent. It will explore the adoption of a qualitative research design leading into Interpretative Phenomenological Analysis (IPA). The chapter will then look at the procedural elements of my research, such as sampling, the semi-structured interview, the process of analysis and the writing up of the analysis.

Methodology

Qualitative research design

In determining the appropriate research design for my research question, I first needed to consider whether to use a quantitative or qualitative method. Quantitative research begins with the underlying assumption that there is an objective truth that can be known. Some of the research in the area of bereavement (such as the study mentioned in the previous chapter by Furer and Walker (2008)) attempt to predict outcome. However, they do not take into consideration the process behind an individual's way of experiencing an event, which is often complicated and overlapping. Qualitative research is designed to explore the participant's account as a whole which prevents the research playing down their experience (Willig, 2008). This approach suits the aim of allowing participants to tell their story of how they experienced being physically present or not at someone's death.

Rationale for adopting interpretative phenomenological analysis (IPA)

Alongside IPA there are several other qualitative methodological approaches which were given serious consideration. The first being grounded theory (GT) (GT, Glaser and Strauss; 1967), which forms a theory through data analysis. One of the strengths of using the GT method is that "it offers a foundation for rendering the processes and procedures of qualitative investigation visible, comprehensible and replicable." (Bryant, 2007, p.4) GT is based on the belief that the themes that emerge from the data are independent of the researcher and therefore will be apparent to everyone. GT is concerned more with the

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[21] This chapter has been written in the first person to address the reader directly and also to show my relationship to the research.

processes of social phenomena rather than the phenomena themselves. The main premise upon which GT is based upon is that of generalisability. GT claims to be able to generalise findings based on theoretical saturation and large samples that are heterogeneous.

The main reason that I disregarded GT as an approach for my research, was because of its emphasis on building theory. Although there have been several GT studies about bereavement and dying (e.g. Groose and Shakespeare-Finch, 2013) and from the perspective of those counselling the bereaved (Dunphy and Schniering, 2009), they have focused on creating a theory based on the common themes that emerged in order to inform specific areas for counselling. The death of someone can be such a profound experience for individuals that to turn their experience into a generalisable theory seems to fail to capture the full extent of the individual's experience. Referring back to the research question for this study, IPA would therefore enable a focus on the individual experiences of physical presence or absence at the moment of death and how those people made sense of their experiences.

Following on from this, the other approach that was considered and then rejected was that of discourse analysis (DA). As reflected in its title, this approach is heavily based upon the underlying assumptions of language, where talk is the medium for communicating information and knowledge. Discourse is seen to construct reality and not reflect it. One of the branches of DA is Foucauldian discourse analysis (FDA, Foucault; 1972), which focuses on the power that language holds. FDA believes that words can be used to build the social world and hold power over conduct in society (Willig, 2008). DA intends to be able to generalise across speakers as it deals with society as a whole. What DA appears to lack is the cognitive and affective reactions that IPA can include in the process of research. Referring back to Merleau-Ponty's holistic view of the self and the embodied experience, this brings back the existentialist ideas of existing in the world and that we cannot be separated from our mind and body.

Shinebourne (in Frost, 2011) stated that, since IPA "often concerns topics of considerable existential significance, it is likely that the participants will link the specific topic to their sense of self/identity" (p.45). I felt that bereavement, which is concerned with life and death, was a topic in line with the individual's existential significance.

Epistemological stance

Unlike other approaches, IPA does not have a distinctive epistemological position but rather an openness that stems from its philosophical, ontological and theoretical influences. IPA recognises that we cannot access an individual's life world directly as there is no direct route to access that personal world (Eatough and Smith, 1996). IPA aims to gain an insight into the person's thoughts and beliefs which are manifested through their experience of the phenomenon (Willig, 2008). Despite this realist view, IPA also recognises the interpretative element in which the researcher attempts to interpret the experience based upon his/her own history. Knowledge therefore is relative and incomplete. This view of knowledge made sense in terms of contextualism and constructionist epistemology. Jaeger and Rosnow (1988) put forward the basic assumption that human activity does not happen in isolation but rather in the context of the socio-historical and cultural environment. Both the participant's and the interviewer's backgrounds will constantly be changing the development of the relationship. To further clarify, "human actions are embedded in a context of time, space, culture and the local tacit rules of conduct" (Jaeger and Rosnow, 1988; p.66). This means that the knowledge that is discovered from the research interviews as well as the analytic process is a reflection upon both the participant's and the researcher's perspectives. As 'reality' is placed in context, it is something that is continuously changing, developing and active. A change in the context means a change in the meaning and vice versa. To be able to understand more of the participant's experience, it is important to look at both its context as well as my own context. IPA therefore places a large significance upon the role of the researcher in the research process.

The epistemological stance that best suited the foundation for this research was that of contextual constructionism. This position is most relevant because it believes that the participant and the researcher are both active, interpretative beings in the context of their worlds (Madill, Jordan and Shirley, 2000). All accounts are therefore subjective. Henwood and Pidgeon (1994) addressed four main dimensions that could affect the production of knowledge. These include the participant's understanding, the researcher's interpretations of the understanding, cultural systems which both participant and individual are a part of, as well as being aware of judgements from within the scientific community. I felt that a way to manage these dimensions was to bring to the forefront my own personal assumptions,

positions and experiences which could affect the account. This has been discussed briefly in the reflexivity section in the previous chapter and shall continue throughout the research.

IPA – Overview and philosophical underpinnings

Interpretative phenomenological analysis (IPA; Smith, 1996) is a qualitative approach founded in psychology. It is concerned with personal lived experience, the meaning of the experience to the participant, how the participant makes sense of that experience and the idea that people themselves are meaning-makers. Smith (1996) reflects that there are three main epistemological underpinnings in IPA: phenomenology, hermeneutics and idiography.

Edmund Husserl's (1859-1938) phenomenology is the philosophical study of "how phenomena present themselves to consciousness" (Giorgi, 2012, p. 6). The phenomenological researcher therefore attempts to provide a rich and detailed account of the other person's experience. By finding out about the experience, we find out more about the world. With this new way of approaching events, we are encouraged to step back from the world which we take for granted and instead go 'back to the things themselves' where we look at the experience before our consciousness starts thinking, interpreting, or assigning meaning to it. For example, what makes a tree a tree? What is the essence of a tree? Our consciousness is always directing us towards something. Therefore, the phenomenological approach is a more reflexive move away from assumptions towards our individual perceptions. In order to do this, Husserl believed that we needed to 'bracket' off our past/theoretical knowledge, culture, background and history so that we can get to the essence of a given phenomenon as it presents itself to consciousness.

Following on from the work of Husserl, Martin Heidegger (1889-1976) moved away from the study of consciousness towards that of 'being'. He questioned what it is to *be* in the world. Where Husserl believed that 'bracketing' was an essential element in understanding essence, Heidegger believed that we are immersed in our surroundings and therefore we cannot disentwine ourselves from it. Heidegger (1962) believed that "the meaning of phenomenological description as a method lies in interpretation" (p. 37). In addition, "Whenever something is interpreted as something, the interpretation will be essentially founded upon fore-having, fore-sight and fore-conception. An interpretation is never a pre-

suppositionless apprehending of something presented to us…understanding always pertains to the whole of Being-In-The-World." (Heidegger, 1929/1962 pp.191-192,194, cited in Finlay 2008: p.12). Taking the example of the tree, we can only understand a tree because it is in relation to something else. It is our interpretation of a tree that makes it a tree for us. This forms the basics of what is known as hermeneutics, the theory of interpretation. This will be dealt with in more detail later on.

The other two significant contributors to the hermeneutic/existential phenomenology were Merleau-Ponty (1908-1961) and Sartre (1905-1980). Merleau-Ponty, like Husserl, placed great importance on the process of interpretation. His was a more holistic viewpoint; he believed that we often take our bodies for granted and therefore explored the relationship of the body to the world. This is especially pertinent when we think of the 'other' in relation to ourselves. As Smith et al. (2009) comment: "The lived experience of being a body-in-the-world can never be entirely captured or absorbed but, equally, must not be ignored or overlooked" (p.19). Sartre continued the work of existential phenomenology by emphasising how human beings develop. He believed that we are always becoming ourselves and therefore always developing. He did not view the self as an already existing entity but rather something more fluid and ever-changing. He also believed that we are embedded in social relationships and that this affects how we experience things. Our experience is reliant upon the presence or absence of our relationships with other people. This aspect of existential phenomenology is extremely relevant to that of death and dying as it brings to light our relationships with people whilst they are alive and how these can change when they are dead.

As mentioned before, the hermeneutic approach is one of the major components of IPA. In order to understand anything we must first start by understanding ourselves. Understanding is a circular process, in which we move from the whole to the individual parts and then from the individual parts back to the whole. This is known as the hermeneutic circle (Debesay, Nåden and Slettebø, 2008). We cannot understand anything without taking into consideration our prejudices and pre-understanding in the present. We acquire new knowledge constantly, which allows us to move around the hermeneutic circle and re-evaluate previous understandings in order to understand in a different way (Gadamer, 2004). With this type of thinking we move away from the pure phenomenological search for

essences and move towards what it is like for an individual to experience something. This can be done through interpretations. IPA is an iterative process which moves back and forth between the whole and the parts, as opposed to being linear in progression (Smith et al., 2009). The researcher is actively involved in relation to the text and it is the researcher's previous experiences and pre-judgements that can offer different part-whole interpretations. The reason why interpretations are so important in IPA is because they involve both grammatical and psychological elements (as first discussed by Friedrich Schleiermacher). This means that the author would have originally assigned a meaning to the text, which is then interpreted by the reader. The reader can also be attuned to not only their own interpretation of the text but also to the wider context in which the text was originally produced. IPA aims to understand not just the text itself but also the person behind the text.

Finally, IPA is concerned with the idiographic approach, which means that it aims for an in-depth focus on one case until the reader obtains a degree of 'closure' and then moves onto the second case. Once all of the cases have been read, the researcher then attempts to create a cross-case table of themes, which looks at both the convergence and divergence (Smith, 2004). An in-depth story of reflections and similarities of meaning is created from the shared experience (Shinebourne, 2011). This contrasts greatly with the nomothetic quantitative research that aims to look at relatively large samples so the findings can then be generalised. IPA claims to help the reader build upon the existing nomothetic research, as opposed to completely disregarding it.

IPA and counselling psychology

As a trainee counselling psychologist, I felt it was important to choose a methodological approach that not only fitted with my identity in the profession, but would also help me with my practical counselling experience. Counselling psychology, like IPA, moves away from the positivist medical model ideas of psychopathology and encompasses a more humanistic and holistic emphasis on the here-and-now (Orlans and Van Scoyoc, 2008). Within counselling psychology is the approach of the humanistic-existential tradition where the focus is on the individual's existence in the world and what it means to be a human. The phenomenological nature of IPA is similar, in that the researcher tries to make sense of the

participant who, in turn, tries to make sense of both their individual and social world (Smith, 2004). As Finlay (2011) suggested, phenomenological research is of value to therapists as it "deepens our understandings of the lived experience" (p. 261) which, in turn, helps "us grow and enriches our work as practitioners" (p. 261).

Counselling psychology's humanistic value base stems from the core conditions for change that Rogers (1980) puts forward as being empathy, unconditional positive regard, congruence and communication from the therapist of the conditions to the client (Cooper, 2009). I believe that these conditions can also be translated into the interviewing process with the participant, where the first step is to establish a relationship with the participant. By gaining trust within the relationship through empathic listening, this can enable the interview to develop to a deeper level where further insights can arise and, in turn, the participant will be more willing to be open. Then there is the attempt to understand their experience whilst maintaining an unconditional positive regard position, as well as showing empathy towards their situation. Finally, by being congruent with the participant, this ties into building trust and taking a step back from the idea that 'researcher knows best'. The researcher puts the participant as the fountain of information and the researcher is engaged in learning from the participant and their experience.

Reflexivity

With the rise of feminist scholars and critiques in the 1960s, 1970s and 1980s, authors such as Nancy Hartsock (1983a), questioned the positivist research norm of the time with her feminist standpoint theory (Hartsock, 1983a). In her book she put forward that the field of science was sexist because it was dominated by men who believed in research objectivity. Hartsock (1983a) and Harding (1986) believed that it was impossible to separate the self from the phenomenon that was being researched and that, by being reflexive and taking embodiment into account, we could engage in other subjective perspectives (Assiter, 2000). Woolgar (1988) saw reflection and reflexivity on a continuum. At one end of the continuum is the reflection, which has a positivist view of distinction between object and representation and which is therefore an 'accurate' account. At the other end of the continuum is where neither the participant's account nor the researcher's account can be valued over the other. Reflexivity is the 're-flexivity' or re-thinking about oneself and there is a constant engagement of meaning in a holistic approach (Shaw, 2010).

Methodological, epistemological, personal and embodied reflexivity

Although Gergen (1973) refers to the possibility that reflexivity can become "feedback and static" (Shaw, 2010; p.3), Willig (2008) counterclaims this, suggesting that there are two types of reflexivity: epistemological and personal. Whilst epistemological reflexivity asks us to reflect upon the assumptions of what we know and can know, it also encourages us to look at our general assumptions of the world. Personal reflexivity asks us to look at how our own experiences, values, morals, beliefs, concerns, identities, background and culture have formed the research. Methodological reflexivity is concerned with how the researcher affected the research design, outcome, data collection etc. Within IPA lies Gadamer's notion of horizons, the idea that the pre-suppositions of the researcher can both help and hinder the interpretations of the participant's lived experience. Finlay (2005, 2006) adds to Willig's (2008) reflexivity by including an extra dimension of embodied reflexivity which "involves engaging, reflexively, with the participant's lived body, the researcher's own body and the researcher's embodied inter-subjective relationship with the participant (Finlay, 2005; p.272).

Throughout this research, my reflexivity will be acknowledged, as I am fully aware that I cannot be separated from the research process. I am conscious that everything from the recruitment to the data analysis has been influenced by my personal experiences.

Validity and quality

The existing validity and quality criteria, which are used in quantitative studies, are not appropriate for use in qualitative research as they are intended to respond to different underlying goals (Finlay, 2011). Due to the increasing amount of qualitative research that has been produced over the past few decades, authors such as Elliott, Fischer and Rennie (1999), Yardley (2000) and Finlay and Evans (2009) have put forward the need for guidelines as to what constitutes good qualitative methodology, as this has largely varied between researchers. They believe that it can help contribute towards legitimising qualitative research, in order to create better quality studies, to encourage further developments and to ensure valid reviews of the research. Smith (2011) also provided an IPA-specific characteristics guide for good qualities to be found in IPA research. I have chosen to roughly

follow the seven criteria[22] that Elliott et al. (1999) set forward, as they provided clear guidelines for the novice researcher. I also added features from Yardley (2000), Finlay and Evans (2009) and Smith's (2011) papers to increase the overall validity and quality of the study.

The first criterion that Elliott et al. (1999) spoke of was that of 'owning one's perspective'. The researcher can demonstrate this by specifying their theoretical, epistemological and personal position. Elliot et al. stressed the importance of an iterative process in which the researcher reflects upon these things throughout the research. I believe I have demonstrated my reflexivity throughout the research process; I have regularly explained to the readers my personal stance in relation to the topic, to the participants, to my assumptions and beliefs and to my interpretations. My personal reflexivity also links with what Yardley (2000) described as 'sensitivity to context'. She mentioned the importance of awareness of the socio-cultural setting, as the data that emerges from the research reflects the context from which it was taken. For example, my experiences and interpretations around bereavement are based upon my socio-cultural context, which in turn, will be different from each participant's context.

'Situating the sample' as discussed by Elliott et al. (1999) involves providing a detailed review of who the participants are, in order to help the readers understand them better and the impact that that might have on the phenomenon. To situate my sample, I have provided not only the table of demographics but also the stories of the participants' lived experiences in the analysis. In terms of 'sensitivity to context' (Yardley, 2000; p. 219), the reader should feel that they fully understand the convergence and divergence between the participants and that that can be demonstrated by the analysis.

Also related to the analysis stage is the 'grounding in examples' (Elliott et al. 1999) criteria, which develops an understanding of the participants from the data and analysis. This lies very much within Smith's (2011) criteria for a good IPA paper in that it should be rigorous.

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[22] Elliot et al.'s (1999) seven criteria include owning one's perspective, situating the sample, grounding in examples, providing credibility checks, accomplishing general vs. specific research tasks and resonating with the reader.

He explained that the extracts that have been selected for the themes should give the reader a breadth and depth of interpretations. He believed that, in keeping in line with epistemological underpinnings of IPA, the paper should show not only the similarities but also individualities amongst participants as this puts forward commonalities, as well as allowing the individual stories and experiences to be heard.

As Elliott et al.'s (1999) criteria were written for the broad spectrum of qualitative research, I believe that the notion of 'credibility checks' fundamentally goes against the underlying assumptions of IPA. Elliott et al. believed that the researcher was required to check with the participant to make sure that the understandings of the account were accurate. As the IPA stance believes that there is no one accessible truth, checking the accuracy of the individual's account was not what I intended to achieve. Looking at bereaved people's experiences of embodiment at the moment of death in the context of them being present or absent, I was more interested in the perceived significance in experiences of the individuals rather than how accurately they were able to recall these experiences. I chose not to send the transcripts back to the participants as I felt that they might want to edit them and this would include social biases of what they thought they 'should' be saying. The interview was an in-the-moment co-creation of data and I did not feel that allowing the participant to change the data would be fitting. What the participant felt about their experience on the day of the interview might be completely different if they were to read through the transcript weeks later.

Instead, I member-checked the credibility of my analyses and interpretations by asking IPA colleagues and my supervisor to see if they could understand my train of thought with interpretations and themes. I also did not feel that asking my colleagues and supervisor to come up with their own themes was relevant, as my immersion in the data was how I came up with the interpretations and therefore it would be irrelevant to use someone else's interpretations. This was where the role of reflexivity became apparent, as it showed the reader my personal background and how decisions were made along the way that could have affected my interpretations of participants' experiences.

'Coherence' (Elliott et al., 1999) was demonstrated by providing a clear depiction of themes which were shown in the table for super-ordinate themes and themes which emerged from

the data. Following on from this, I added a coherent verbal narrative to the data as each of these themes were presented and elaborated in the written analysis section.

Creating research that 'accomplishes general vs. specific tasks' (Elliott et al., 1999), ties in with what Yardley (2000) described as 'impact and importance'. Finlay and Evans (2009) also talk about being able to take from the data something that can be used to move things forward in the world of research. With my research on physical presence or absence at death, this topic has a practical impact in that it can be used by practitioners working with the bereaved to gain more insight into the phenomenon of dying and bereavement. Although it is not intended to be generalised, it can still inform those within the medical and counselling professions as to how to work with people pre- and post- bereavement. The specific tasks of this research included adhering to the foundational elements of carrying out IPA research.

Finally, the criterion of 'resonating with readers' can be taken subjectively like most qualitative research intends to. It is about the researcher bringing the participants' experiences to life so that their stories may be heard. As mentioned previously, this can be shown both by the demographics table within the sample section as well as in the analysis stage of the research. Thus, my interpretation of the data aims to increase an appreciation of the participant's story and provide new knowledge of their experience.

There has been a great amount of criticism put forward about the guidelines that Elliott et al. (1999), Finlay and Evans (2009), Yardley (2000) and Smith (2011) have introduced, as many researchers feel that they can be taken as checklists or create rigid boundaries which would inherently stifle and go against the fundamentals of qualitative research. To counterclaim this, all the authors stressed that these criteria should be used in a tentative way where researchers adapt the criteria to their individual research purposes. They believed that this would "win wider recognition and acceptability for qualitative approaches to psychological inquiry, as well as to encourage qualitative researchers to exercise greater self-reflectiveness in their conduct and reporting of investigations." (Elliott et al., 1999; p.225). To this end, I used these criteria as a rough guideline and adapted them to my specific research question.

Procedures

Sampling

My research was carried out with nine participants. Reid, Flowers and Larkin (2005) raised the issue that IPA challenges quantitative research where more participants equal greater value to the data. In line with the idiographic principles of IPA, a small sample size was obtained as I was not aiming to make general claims about a large population (Langdridge, 2007). Hefferon and Gil-Rodriguez (2011) give a rough estimate for a professional doctorate level study using between four and 10 participants. Within the texts of Smith (2004) and Smith et al. (2009), it was stated that it is possible to do an IPA study using a single case study, as this would provide a specific detailed account in regards to the phenomenon. The reason why this approach was not chosen for this particular study was because my aim was to show how individuals manifest the same theme in convergent and divergent ways (Smith, 2011). This could provide counselling psychologists with different avenues to explore in applying the knowledge to client work.

Few studies to date have used focus groups in IPA research (Dunne and Quayle, 2001; Flowers, Duncan and Knussen, 2003). Whilst it can be useful to use focus groups to produce a larger amount of accounts, as well as taking into consideration the group as a whole, Tomkins and Eatough (2010) put forward a compelling argument that often when using focus groups, the individual's experience is not heard. The specifics of what a particular person said can often be lost within the group setting. They also stated that the potential difference in the content of the individuals can be altered depending on the group dynamics. For example, some participants might not share the same viewpoint as another individual in the group and therefore refrain from stating their differing point of view due to societal norms or other reasons. For these two major reasons, I decided against using a focus group for the participants in my study.

Inclusion criteria

By keeping in line with the idea of the homogenous sample in IPA research (Smith, et al. 2009), the participants in this study could take part if they were over the age of 18 years old and had experienced bereavement. There were no exclusion criteria in terms of the relationship to the bereaved (e.g. parent, child, grandparent, etc.) or the type of death (e.g.

health-related, suicide, violence-related, etc.) as the focus of the study was around the significance of the phenomenon of physical presence or absence.

There was no limit set in terms of how long ago the death had taken place. Previous ongoing debates in bereavement research have been concerned for ethical reasons about seeing bereaved people as 'vulnerable' and 'needing protection' (see Rolls and Relf, 2006; Buckle, Dweyer, and Jackson, 2010) and researching bereavement can be considered a sensitive topic (Parkes, 1995). I felt that the self-selected participants could make informed choices for themselves as to whether or not they perceived the time and topic was right for them to share their experience or not.

I debated whether or not to include a time frame as to when participants could take part in the study. Previous studies that have interviewed bereaved people have ranged anywhere from two months (Asai, Fujimori, Akizuki, Inagaki, Matsui and Uchitomi, 2010) to 13 months (Wilson and Supiano, 2011) to nine years (Goodwin and Ogden, 2006). My concern lay in an assumption that interviewing participants too soon after the death of someone would be unethical and would cause the participant unnecessary emotional stress. The reason why I decided not to include a time frame was partly because I felt that this could come across as a socially expected time where participants could or could not take part in the study. For example, if I had given a time frame of between six months and 20 years this would be my presumption that anything before or after that time would not be valuable for the data. This would not have been in line with the underpinnings of IPA, that all knowledge from an experience is valuable as it comes from the individual making sense of their world.

Exclusion criteria

As I currently work in a bereavement service, I felt it would be inappropriate to interview past or present clients because of the client-therapist relationship and confidentiality agreements. I felt that this would create confusion for both myself and the participant between my roles as therapist and researcher.

I chose not to interview family members or friends I considered to be in my close circle. Although I still would have obtained a certain degree of connection between myself and the data, I believed that this would be too emotionally close for me to reflect upon. For

example, if I had interviewed a family member the chances were that I would have known the person who had died. Despite bringing reflexivity into the research, I personally would have found it emotionally and ethically difficult to analyse and interpret that data in the later stages of the process. The same could be applied to close friends.

Finally, I deliberated over whether or not to exclude people who had had bereavement counselling in the past. My assumption to begin with was that people who had received therapy would have 'worked through' their experience of death and therefore, by the time they came to the interview, would give an intellectualised account of the experience rather than an 'in the moment' one. On the flip side of this, the fact that they had processed the experience in therapy meant that the possibility of accessing the death would be less raw and emotional and therefore less overwhelming for them (or me) in the interview. In the end, I decided to leave this criterion open so that people who had or had not received bereavement therapy in the past could take part in the study. My rationale for this was that we are constantly attempting to make sense of experiences and, in line with IPA's iterative viewpoint, I felt that participants would constantly be attempting to make sense of their experience, regardless of whether they had attended therapy or not. If a participant had been in therapy, this would be something I could address in the interview by asking them (should it have arisen) how they made sense of their experience before and after the therapy or whether/how change had occurred.

Recruitment

The first step was to recruit participants who had all experienced bereavement, as this would be the homogenous factor in the IPA research. I created a website specifically for the purpose of recruiting participants which would reach a large population of people irrespective of culture or background. I also spread the word about my research through social media sites such as Facebook and Twitter, which are powerful networking tools. Another medium that I used was word of mouth as I felt that this was also a powerful tool. Whilst attending a British Psychological Society (BPS) Division of Counselling Psychology conference, I created a poster[23] to display my research and recruit further participants.

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[23] See Appendix 1: Recruitment poster.

In the end, five people were recruited through word of mouth, three contacted me from seeing the advert on a social networking site and one came from the BPS conference. Two other people contacted me; however, before the interview, they decided that they no longer wanted to take part in the research.

Participants

Of the nine participants, four were male and five were female[24]. Their ages were between 20 and 40. Of all the participants that were interviewed, only one person was physically present at the death of someone; everyone else was not present.

The first participant that was recruited was initially only used as my pilot interview, just so that I could test out my interview schedule and interviewing techniques. After transcribing the first interview and showing it to my supervisor, he did not have any concerns with the technique. I therefore included this pilot interview in the analysis and continued the same approach for the remaining participants.

Interview schedule

After gaining ethical clearance from the ethics committee at City University[25], I began to construct the interview schedule,[26] which would form the basis of my semi-structured interviews with participants. The interviews took place either in a room within the university, or at the participant's home, or, as with one participant, at her workplace. When I interviewed participants in their homes, I set up a safety procedure with my research supervisor. I would let him know in advance when and where the interview would take place and I also contacted him afterwards to let him know that the interview had finished. Although several potential participants enquired whether Skype interviews were possible, I chose not to do this mainly for practical reasons. I could not ensure confidentiality over the internet, nor could I obtain a fully signed consent form from the participant. I could also not guarantee the quality of the recording of the interviews and therefore did not want to risk the potential loss of any data. Another major reason for choosing not to conduct online interviews was because of the absence of embodiment. Having chosen a phenomenological

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[24] See Appendix 2: Participant demographic information.
[25] See Appendix 3: City University ethics release form.
[26] See Appendix 4: Semi-structured interview schedule.

approach to my research, it would be important to observe the body in the interviewing process (Finlay, 2006). As previously mentioned, the embodied reflexivity is part of the research process. Online interviews lack a physical connection to the participant that can add to the overall experience. Also, as death is heavily related to the body and embodiment, I felt this was an important aspect within the research that I did not want to exclude.

Kvale (2008) points out that the nature of a semi-structured interview allows the researcher to access the lived experience of a participant which fits in line with the aims of IPA. The participant can use their own words to describe their own world. Although Smith et al. (2009) describe the interview as being a one-way conversation, it still involves a two-way collaborative process (Valentine, 2007) and needs to maintain the elements of professionalism and structure. The other benefit of using a semi-structured interview is that it is participant-led. Although I constructed a rough schedule, some questions could be changed or omitted depending on where the participant wanted to go.

The reason why using a structured interview was not appropriate was because it went against the epistemological stance of my research. The structured interview, for example, has a pre-set order of questions and it is standardised so that every researcher will be asking every participant the same questions in the same order. This standardisation would have implied that there would be a fixed truth and that it had a more positivist view. The study's stance however, is that there is no fixed truth. Structured interviews lack depth and are constraining in terms of the responses. Therefore, the research question could not be answered using a structured interview schedule.

At the other end of the spectrum lies the unstructured interview. Although this may have also been a good type of interviewing approach for this type of IPA research, I felt that the lack of pre-determined questions would not have been appropriate for me as a novice interviewer. Although I acknowledged that it could allow conversations to be completely participant-led and could therefore provide deeper and richer data, I did not feel confident enough to use this technique. For these reasons, I adopted the semi-structured interview approach.

The purpose of constructing an interview schedule was for me to think about the type of content I wanted to cover in the interviews (Smith and Osborne, 2008). The first step was to

think about the topics I'd read about in previous research, which I wanted to explore further within my own research question. The two main areas I wanted to look at were physical presence or absence at the moment of death and its significance in terms of how people made sense of the event and also people's views on death/dying/life in relation to this. I felt that these topics had not been covered in past research, specifically in related to bereavement counselling and they were very much related to my research question. I ended up with eight questions, each with a few prompts to help participants answer the questions if needed. The questions were constructed using some of the different kinds of questions suggested by Smith et al. (2009) for in-depth interviews.

Semi-structured interview questions

The following section provides a break-down of the questions used, to give the reader a sense of the different types of questions explored with participants and the rationale behind them. All of the questions were asked to all participants although they were not asked in any specific order. I was able to take cues from the participants to allow a more natural flow of structure. These semi-structured questions were used merely as a guide.

The first question was deliberately broad in order to help ease the participant into the interview and to help create a rapport (Smith et al., 2009). Building a foundational relationship with the participant is an important factor in establishing a trusting environment. This allows their experiences to be heard (Rowling, 1999). The first question involved getting the participants to think back to the experiences they had had, generally, about death. As the interview progressed, the questions became more sensitive and thought-provoking so that, by which stage the participant would have eased into the interview and would be more willing to speak about these topics.

The second question was also fairly broad and asked the participant whether they had anyone in particular they wanted to share with me in the interview. If they had not thought about it beforehand, it was a chance for me to see what the participant wanted to bring and share. Within this question, there was the opportunity for more exploration around the circumstances of the death(s) and the event(s) leading up to the death.

Question 3 looked more specifically at how participants experienced either being present or not present at the death of the person/people that they mentioned in the previous question. This question aimed to uncover the lived experience of how they felt, thought and acted in their absence or presence at death.

Question 4 aimed looked at the coping strategies around being present/not present at the death, then and now. By using this more reflective yet comparative question, I wanted to see whether the participants' experiences had evolved over time and whether their sense-making of the experience had changed.

The next question went back to the topic of physical presence and whether they felt it was important to be there or not. This evaluative question aimed to look at the overall emphasis that the participant placed on physical presence at death.

To gain a greater understanding of how the participant experienced the presence or absence of being there when the person died, Question 6 aimed to be circular so that it asked what advice they would give someone who was going through a similar experience to what they had been through. I wanted to explore what meaningful learning there had been or what they took away from their experience and what they would share with others.

Also related to how their experience could be shared with others, Question 7 aimed to look at whether the experience of someone else's death had then influenced their own views about death and dying. With an evaluative approach, it looked at how/if people imagined their own death and if they would want people to be/not be there when they died.

Finally, Question 8 asked participants to consider how the experience had affected their views on life, death and dying. It aimed to explore whether any changes had been made in terms of the way participants viewed their own life or death after the experience of having been physically present or absent at someone else's.

Although it was not a formal question on the interview schedule, at the end of every interview the participant was always asked whether or not they wanted to share anything else with me before the recording ended. This was an opportunity for the participant to

state anything that I had left out or that they wanted to continue talking about within the interview. For some participants, it was also a chance for them to state how the interview had affected them and their ongoing processing of the death(s).

As part of my ongoing reflexivity, once I had completed the interview schedule, I asked a researcher colleague to interview me using my own schedule. This helped me to not only experience the flow of the schedule but also to gain a greater understanding of the assumptions that I brought to the research. This was discussed in the reflexivity section in the previous chapter.

Interview procedure

When participants contacted me via telephone or email, I briefly outlined the basic premises of the research, the rough length of interview, the fact that it would be recorded and that it would be transcribed. Once the participant informally consented to this, an exchange took place, in which I offered them some suggestions for times and locations where the interview could take place. The length of the interviews ranged from 42 minutes to 63 minutes.

Before the interview commenced, I gave the participant a consent form,[27] which I discussed with them, before asking them to read and sign it. The consent form stated a brief aim of the research, the approximate length of the interview, the tape recording and anonymisation of data and the participant's right to withdraw from the study at any point. After the consent form was signed and there were no further questions from the participant, I began the interview using the interview schedule.

Once the interview had finished and the recording was stopped, the participant and I had a verbal debrief about how they found the interview and if they had any comments or suggestions. Participants were also given a written debrief,[28] which gave more information around the aims of the study. If any participants felt distressed after the interview, the names and contact information of two organisations were listed so that they could seek appropriate support if needed.

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[27] See Appendix 5: Consent form.
[28] See Appendix 6: Debrief form.

During my work with bereaved clients, I have often heard people say, that because others do not want to talk about or listen to others talk about death, they do not always get the opportunity to speak openly and freely about the topic. I was offering this opportunity for people to talk, given that they don't often get one. Participants were not given any money or vouchers for taking part in the interview, as I wanted people to come forward who genuinely wanted to share their experiences, rather than for any monetary gain or reward.

Ethical considerations and dilemmas

Within this research, there were several ethical considerations and dilemmas that I encountered, which affected both the participant and myself. Whilst authors, such as Parkes (1995), focused on ethical considerations from the perspective of the participants, there have been an increasing amount of studies that have focused upon the harm that can come to the interviewer. As the research interview is co-created, the space that both the participant and researcher share needs to be ethically sound.

Authors such as Parkes (1995) and Rowling (1999) emphasised the need for researchers within the field of bereavement to consider ethical issues for participants. This is to ensure that the participants are protected from harm whilst maintaining scientific value. Bereavement is seen as a 'sensitive topic', which implies the possibility of risk to the participant (as they could experience intense emotions and distress related to their loss) and the researcher (as they, too, could be emotionally impacted by the interview) (Rowling, 1999). It was therefore my duty as researcher, to ensure the safety of participants taking part in the research by preventing possible harm. At the heart of my research is the participant trusting the interviewer with private information that will inevitably become public. With this trust comes responsibility and so it is vital for the researcher to gain and maintain this trust (Long and Eagle, 2009).

Parkes (1995) gave suggestions and guidelines to ensure that researchers do all they can to minimise potential harm to participants. These included explaining the research aims and methods, obtaining informed consent, not pressuring people to take part, allowing the participant to withdraw at any point, being supportive in the interview and maintaining confidentiality. In addition to these, Buckle, Dweyer and Jackson (2010) also mentioned being aware of only going as far as the participant wants to go, gaining ongoing consent

from the participant, treating each case individually, researcher reflexivity and, finally, being aware of the benefits that can come from the interviews. To my knowledge I felt that I upheld these qualities of ethics whilst interviewing my participants. The difficulty with these criteria and guidelines is that they cannot account for every interview.

If we are to take Buckle, Dweyer and Jackson's (2010) awareness of treating each interview individually then there can be no blanket guideline for ethics, but instead a great amount of responsibility lies on the researcher's own ethical stance. Authors, such as Long and Eagle (2009) and Brinkmann and Kvale (2005), stress the importance of reflexivity and the researcher's inner guidelines rather than universals as ethical issues are situation dependent.

The other aspect of being ethical in my research was being reflexive over my actions and the different roles I undertook throughout the research process. I related very much to the articles by Rowling (1999), Valentine (2007) and Long and Eagle (2009) in which they explored the negotiation between different roles the researcher encounters. More specifically, these authors examined the ethical dilemmas that confront researchers who also hold a role as psychological therapists. Rowling (1999) articulated what she classified as the 'researcher I' and the 'counsellor I' (p. 172) and described how she often felt a discordance between maintaining a distance as the researcher yet at the same time attempting to elicit experiences from participants and caring for them. Lavis (2010) called for researchers to maintain a fluid identity, which meant being able to judge with each individual case how to be within the interview. I struggled to do this with all of the participants in the interview process. I was aware that I was using some of my counselling psychology skills and they enabled me to create trust and empathy within the interviews. However, when participants became visibly upset I needed to first and foremost make sure that no harm was being done to them. With some participants, they requested to take a small break by getting some water or by remaining silent for a minute. Using my counselling skills and awareness, I was able to recognise the difficulty that some of the participants were experiencing in recounting their bereavement. One of the benefits of having gone through a counselling psychology training was that I felt able to provide specific support during emotional stages of the interviews, rather than being over-protective throughout the interviews for fear of doing harm (Rowling, 1999).

My dilemma as researcher during these moments was checking with the participant whether they felt able to continue or whether they wanted to withdraw from the interview. Coming from a counselling background, it was often challenging for me to ensure that I was not intervening on a therapeutic level (Long and Eagle, 2009). After the debrief at the end of the interviews, I provided the participants with a list of organisations they could contact should they feel the need to speak to a professional due to the content that emerged. I also provided them with my own contact details and those of my research supervisor in case they had specific feedback or questions regarding the research. I felt this gave the participants the resources to seek help should they have needed to.

Having worked through these ethical dilemmas I realised that just because a self-selected participant had given consent to take part in the research, it didn't automatically imply that the research would be ethically sufficient. Stroebe, Stroebe and Schut (2003) discussed the importance of the selection process in bereavement research, saying that it was essential to allow participants to come willingly to take part in the study. I recognised that this was just the first step in maintaining an ethical stance throughout my research and that I needed to continue to ensure the safety of my participants from recruitment through to the interview stage.

Due to the semi-structured nature of the interview questions, I acknowledged that the participants could only be giving limited consent to take part in the research. They, nor I, could have anticipated the specific responses that the participants would give (Long and Eagle, 2009). I therefore did not assume that participants giving consent at the beginning of the interview meant it was ethically enough to continue the interview without checking throughout to make sure they felt able to continue. I felt that this was an example of Buckle, Dweyer and Jackson's (2010) suggestion to obtain ongoing consent throughout the interview.

Although IPA requires a degree of interpretation from the interview to the write-up, it also acknowledges the inter-connectivity of the researcher's background influencing the interpretations. I experienced the difficult negotiation between a counselling and researching role. Long and Eagle (2009) articulated that when coming from a therapist background, therapist-researchers can often be more sensitive to interpretations. As they

observed, "the therapist-researcher may be over-sensitised to become the keeper rather than the teller of secrets" (p. 37). Coming from a therapist background, I was particularly aware that I found it difficult to interpret the interviews, as I was unused to sharing people's experiences. Confidentiality in a therapy setting is very different from confidentiality in a research interview. On the one hand I felt protective of the experiences that were shared during the interviews. On the other hand, I knew that I needed to share the voices of the participants because I was researching their experiences. I also recognised during the analysis stage, that I had become protective towards not just the participants but also the dead people that were brought into the interviews. For example, I noticed that I found it very difficult to interpret the interviews as I felt that over-interpreting would lose a sense of the dead people that had entered the interview space. If interpreting is about obtaining an understanding of the participant's experience (Willig, 2012) to what extent should I interpret? As a novice researcher it was a challenge for me to know how much of the analysis I was over-interpreting or under-interpreting. I related to Valentine's (2007) description as she explored the appreciation and negotiation she felt towards both the presence and sense of loss of the dead that had entered the interview space.

In order to monitor the ethical issues and dilemmas I faced, such as the difficulties in interpretation and the unpredictability of the interviews, I kept a research journal[29] that included my thoughts, feelings, questions and experiences. Researchers such as Rowling (1999), Finlay (2002) and Valentine (2007) recommended keeping a journal or taking field notes. This journal reinforced my ongoing hermeneutic reflexivity as I became more aware of my fore-understandings and how they continued to affect the various stages of the research (Shaw, 2010).

The research journal also supports a new emergence of literature that has begun to look at the impact of emotional interviews on researchers and consequently the importance of protecting the researcher from harm (Kellehear, 1989; Rowling, 1999). My main concern before embarking on the research interviews was that, due to my own previous experiences of loss and bereavement, there might have been some unresolved issues that could surface whilst the research was being undertaken. The precaution I took was to inform my research

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[29] See Appendix 7: Extract from reflective diary.

supervisor or my personal therapist when anything distressing arose. I felt that this, in addition to my reflective journal, enabled me to explore whether some thoughts and feelings belonged to the participants or to myself (Long and Eagle, 2009).

A major ethical consideration for both the participant and myself was the fact that out of the nine participants that I interviewed I also knew eight of them personally. Five participants were fellow psychology trainees, two were people I knew from a previous school I attended, one was a work colleague and the other person was connected to professional contacts. The multiple roles that I held as psychology colleague, work colleague, old acquaintance and someone within the same field meant that I needed to be especially sensitive to confidentiality and boundaries. The participants had *only* agreed to information being obtained within the interview and, therefore, I consciously made an effort to bracket all prior knowledge about the participants as it would be irrelevant to the research question. As there was a possibility with most of the participants that I would have some kind of interaction with them in the future, I was aware of not bringing up the content of the interviews with the participants when I saw them again. The semi-structured interview was designed specifically to enable the participants to speak about their experience of the moment of death (Willig, 2013). The interviews captured an in-the-moment experience that also included the verbal and non-verbal communication of the participants. I felt that speaking about the interview with a participant at a later date could add further interpretations that were not established during the initial interview.

Although their paper was intended for the nursing community, McConnell-Henry, James, Chapman and Francis (2009) looked at the issues of interviewing people one knows. They explored the benefits and disadvantages of qualitative interviews with people with whom one had had a pre-existing relationship. I agreed with their idea of it being easier to interview these people as you did not need to worry about the time it would take to build a rapport because it had already been established. I struggled slightly though because I had to take on the role of researcher. This meant separating my prior knowledge of the participants and listening to their experiences with an open frame of mind. It also meant I had to emphasise to the participants beforehand that I would be seeing them as a bereaved person and not within their roles of 'psychologist', 'trainee', 'friend', or 'colleague'. Both the

participants and I understood the importance of the confidentiality agreement and that breaking it in any way would be a sign of mistrust.

Referring back to the guidelines that Parkes (1995) suggested, in regards to conducting ethical research, another reason why I provided the participants with a contact list for support post interview was so that the participants would not see me within the role of 'therapist'. Given that I knew the participants in different contexts, I wanted to maintain boundaries and so I did not feel it was appropriate for them to contact me for psychological support following the interview.

What is apparent from the papers on ethical considerations in qualitative research is that it is important for the researcher to "cultivate one's phronetic skills" (Brinkmann and Kvale, 2005, p.177). Due to the unpredictability of interviews, this means being able to develop the skills to make moral and ethical judgements by contextualising each situation. Lavis (2010) stated that there is no ideal ethical researcher and that the best we can do is to continue to gain awareness of each interaction and to be flexible enough to negotiate with our roles and identities (e.g. researcher and therapist). I believe that through reflexivity and maintaining overall ethical guidelines I was able to prevent harm from coming to the participants who took part in my interviews.

Transcription

All interviews were recorded on an Olympus digital recorder (VN-6800PC). The original recordings were then stored in a password-protected folder on my laptop as well as backed up onto a virtual storage space. Once my research thesis has been assessed, then these original recordings, as well as the transcripts, will be destroyed.

The recordings were transcribed verbatim in order to get as accurate an account as possible of the participants' experiences. The transcriptions included "hmm's", pauses, false starts and stutters. Non-verbal communication was also transcribed such as hand gestures, crying and laughing. This was done in order to bring to life the participants' accounts and also being mindful of Finlay's (2006) bodily disclosure in research. In order to protect anonymity and confidentiality, the participants' names were changed as well as other names and places that were mentioned throughout the interview. A list of the participant's actual

names and their corresponding pseudonyms were kept separately to any transcripts and will be destroyed after the completion of the research.

Analytic strategy

The aim of my research was to gain a greater understanding of the experiences of physical presence or absence at the moment of death. The aim of the analysis was to abstract themes which occurred both within and between the participants (Smith et al., 2009). Although Smith et al., (2009) emphasised that the steps they talked about in their book were not to be used in a prescriptive way, I found them incredibly useful to use as a starting point. Being a novice IPA researcher, I did not know where to begin or what to do, so it felt incredibly overwhelming.

After completing all the interviews, the first step in the analysis stage was to read the first transcript whilst listening to the recording. This enabled me to fully immerse myself in the data and the participant's world. By reading the transcript through a second and a third time (without listening to it), I was then able to hear the participant's voice in my head and helped their tone, pace and overall personality come alive in the text. Smith and Osborne (2008) pointed out that new material would emerge after each reading allowing the researcher to gain more insight into the participant's experience. At this stage, I did not make any notes or comments on the text as, for me, it was simply about 'hearing' the participant.

Once I had done that, I moved onto the initial notation of the first transcript[30]. The transcript consisted of three columns; the right column was used for initial notation, the middle column was a transcription of the actual audio interview and the left column was used for themes. The initial notation phase was broken down into three different types of notation: descriptive comments, linguistic comments and conceptual comments (Smith et al., 2009).

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[30] See Appendix 8: Example transcript notation.

Descriptive, linguistic and conceptual comments

Descriptive comments refer to the actual spoken content of the participants' responses. Whilst reading through the transcript, I asked myself questions such as 'How can this sentence/phrase/idea be summarised?', 'What experiences are being described/claimed?' and 'What are the key features of those experiences?'. These questions ensured that I focused on what was being said on the surface level, rather than interpreting the responses.

Having gone through the entire transcript looking at the descriptive comments, I then listened to the audio recording again to focus on the linguistic comments. At this stage I asked myself 'How are they saying what they're saying?' Some of the linguistic elements of the transcript included things like hesitations, pauses, tone, intonation, stops, etc. Listening to them brought the participant's words to life. I then asked myself 'Is there a shift in tenses or pronouns?' so that I could begin to think about what this might have meant for the participant. I also looked for any metaphors, interesting phrases, or particular words that stood out for me. These comments, in particular, brought out the more subjective nature of analysis, as I was aware of certain areas that I was drawn to whilst listening to and reading the participant's experiences.

The final notation involved looking at the conceptual comments. This stage allowed me to develop the interpretative side of my analysis; I asked myself questions like 'What is the participant trying to say?'; 'What's underlying what's being said?'; 'So what?' and 'What's missing or not being said?'. During this process I found myself writing more questions about the participant's experiences than comments as I didn't want to make assumptions about what the participant was trying to convey if it didn't have a solid basis within the text. I struggled immensely in juggling both not being too descriptive and being too interpretative. I found the freedom that these comments asked for very challenging as I felt a connection and loyalty to the participant's words.

Having completed these three types of comments for the first transcript, I then moved onto the subsequent transcripts and commented in the same way.

Process of developing themes

In the previous stage, the analysis was focused on the line by line data. The next step of developing emergent themes required me to look at bigger chunks of text in order to discover themes. As a novice IPA researcher, this was the stage that I struggled with the most. It required me to "speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual." (Smith et al., 2009; p.92). I began to look at the right hand column which contained my initial notation and comments, as well as the transcript so that I could combine the columns into themes. The part that was most difficult for me during this stage was the notion of finding the 'psychological essence' of the piece. Having a background in psychology, I felt that I needed to think back to theories and models in order to find a theme label. I then realised that this would be more my imposition of theory onto the text, as opposed to something 'popping out' at me. Although in the end this occurred for some themes, the majority of themes were, I felt, basic human concepts, rather than purely psychological classifications. At this stage, many emotions were extracted from the notation as these, too, reflected a 'psychological essence'.

Once I had gone through the transcript and written down the themes that had emerged in the left column, I then typed them up in a separate document in chronological order[31]. Due to the sheer number of themes that had emerged, I condensed the list by looking at whether I was calling the same theme by different names.

These emergent themes were then grouped together into what essence and experience they were speaking to. This clustering of themes formed the beginnings of what would later be called 'sub-themes'. Having grouped the sub-themes together, I generated a list in a table [32] where the sub-themes could be matched with a direct quote (including page and line number) to back up the sub-theme. In doing this, I discovered firsthand the iterative process, which involved going back to the theme, checking with the original transcript and then double checking that the title for the theme reflected the essence of the text.

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[31] See Appendix 9: Example list of emergent themes from a transcript.
[32] See Appendix 10: Table of sub-themes and direct quotes.

Having done this with all the participant transcripts, I then wrote out, on individual pieces of paper, all the sub-themes that emerged and clustered those together to try and further group the sub-themes until they could be condensed no further[33]. I felt that this was exactly what Smith et al. (2009) referred to when they spoke of a magnetic pull that some themes would have to each other in the process. This was a fluid process that constantly changed as I kept referring back to the original quotation within the transcripts.

Once I was satisfied with clustering them together, I then came up with a super ordinate theme name that attempted to encompass all the sub-themes. An initial master table [34] was created that showed the convergence and divergence across and between participants that is reflective of IPA research.

Writing-up process

The writing-up process began once, I felt that I was satisfied with being able to capture the themes within the super-ordinate themes by linking them to the direct transcript quotes. Even during the writing-up process the master table was constantly changing and being re-worked to reflect the dynamic and iterative nature of the process. It was only as the analysis chapter was being written that final decisions needed to be made in terms of sub-themes, themes and super-ordinate themes.

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[33] See Appendix 11: Picture of clustering sub-themes from all participants together.
[34] See Appendix 12: Table of initial master themes.

<u>Analysis</u>

<u>Overview</u>

This chapter presents IPA data from the participant transcripts. After introducing the three super-ordinate themes, it then proceeds to illustrate these themes with quotes from participants. What follows is an interpretation and analysis of the participants' experiences of the physical aspect at the moment of death within the context of them being present or absent.

The analysis in this chapter is presented by referring only to the participants' extracts; it does not link to the current literature – this will be explored in the following chapter. I felt that by allowing the participants' stories to be the main focus of this chapter, it would give a voice to the individual experiences and give the reader a sense of how I experienced immersion in the data.

<u>Super-ordinate themes</u>:

1. **Connecting to the body and emotions**

   i)   The person and their body

   ii)   Sensing the moment of death

   iii)   Negative affect at the moment of death

   iv)   Death anxiety

2. **Putting the moment of death into the wider context**

   i)   The choice to be present

   ii)   Whose death is it anyway?

3. **Endings and beginnings**

   i)   Goodbyes

   ii)   Incorporating the death into life

The first super-ordinate theme is 'connecting to the body and emotions'. This theme encompasses the different aspects of the deceased person that the participants related to when they were physically present or absent at the moment of death. The connection for

participants was with their own body and emotions, as well as to the dying/dead person's body and emotions.

The second super-ordinate theme is 'putting the moment of death into the wider context'. This theme combines the choice to be physically present with the experience of understanding who the presence was for. As death does not occur in isolation, this theme explores the moment of death and how participants tried to manage their physical absence or presence.

Finally, the third super-ordinate theme, 'endings and beginnings', explores the change process that occurred for the participants. For some of the participants, there was a strong emphasis on the actual goodbye that occurred between them and the dying person. Overall, there was an element of change that occurred, either through a process of making sense of and incorporating the death into their lives, or making a change for the future based on the experiences of the past.

It is important to note that, although the super-ordinate themes and themes have been presented separately, these themes overlap significantly within the transcripts. They have been presented this way for the purpose of clarity only.

Super-ordinate theme 1: Connecting to the body and emotions

The first super-ordinate theme of 'connecting to the body and emotions' reveals the interconnectedness of the participant's and the dying person's bodies as well as their emotions. There are four themes within this super-ordinate theme, including: Theme 1: the experiences of the person and their body and, Theme 2: being in touch with their own bodies and having a sense of the death before being informed of it. Themes 3 and 4 explore the emotional side of presence or absence at the moment of death; Theme 3 focuses on the negative affect that comes with the actual moment, and Theme 4 on the death anxiety which is evoked.

Theme 1: The person and their body

The participants reflected upon the complicated and multi-faceted nature of death in their experiences. For some participants, there was no clear separation between the dying person and the dying person's body.

Klaus was not present at the death of several people in his life including aunts and a friend. When he talked about the moment of death, he encapsulated the struggle of seeing the person for who they were and not just the illness that they were dying of.

> *I I think there's something about you know being remembered for for that more healthy kind of full person. Whereas you know people often get totally you know very broken down both emotionally and physically and everything else from big diseases like cancer and things like that. And I think (..)[35] there's almost that aspect of you know if you don't see them in that state you you have a more happy memory of them. Whereas otherwise you can't help but think about all the misery they were going through in the last last moments right.*
>
> *Klaus – 22:1–12[36]*

Klaus introduced the words "full person" when describing someone who was healthy. This denoted a complete connection between the body and mind of the dying person. He then went on to describe the effect that a disease would have had on this 'full' person, which put them in a different "state". It appeared that he found it difficult to "see" the person in this new way of being as it felt like something was missing for him. Also, the fact that he was using his senses to "see" the person and their illness meant that he could not deceive himself into believing that death was not occurring. In other words, 'seeing is believing'. Klaus stressed how important it was for him to be able to remember the person in a complete state of mind and body connection. Perhaps seeing the "misery" at the end was something that was difficult for him to have been left with.

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[35] See Appendix 13: Table of transcription symbols.
[36] Key to notation: Participant pseudonym – transcript page number: line number – (transcript page,) line number.

Kristina, who was absent at the moment of her grandfather's death, recalled what it was like seeing his body the day before he died.

> *Um and then--. So then Tuesday morning we then went to the hospital to see him. Um: or to see his body. Um (…) because I still kind of wanted to wanted to see him. One of the things actually that I didn't um--. What another thing that was also very different about when I first saw him on the Saturday was that he was very he was very swollen. And it: it didn't really look like my Granddad anymore. He looked quite different. And the same thing when he, you know, when we went to see his body (.) it it didn't really look like my Granddad anymore so it wasn't (…) it wasn't the sort of the man that I would like to remember or that I'm going to remember now because I'm gonna, you know, of course that is still very much in my head what those last few days--. But I would like to think in the long term it's all the other things that that you know the great (…) [Yeh]³⁷ (…) things about his life that I'm gonna remember more. Um. Yeah, so we went to see his ummm to see his body in hospital then um (…) and yeah (..) that was (..) that was the last time I saw him.*
>
> <div align="right">*Kristina – 18:10–19:3*</div>

Kristina highlighted the conflict that she experienced between seeing her grandfather versus seeing his body. Although she was left with the images and memories of the deteriorated body of her grandfather, this was not how she wanted to remember him. She interchangeably used "him", "his body", and "it" when referring to her grandfather. It was possible that she was in a state of confusion of him being like the grandfather that she used to know yet not physically looking like him. As the death of her grandfather occurred three weeks prior to the interview, this could have contributed to Kristina's interchangeable terms as she was still becoming accustomed to the fact that there was a part of him that she connected to that was no longer alive. There is a tone of endings in this passage; she was working through an ending to both her grandfather and his body. She mentioned that even his body looked different as a result of the swelling and so she was already in the process of saying goodbye to the body that he used to have.

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³⁷ [Text] indicates my speech in the interviews.

Both Klaus and Kristina seemed determined to remember the dead person for how they used to be both physically and emotionally. I noticed they both used the word "see" several times and there was something almost negative about what their eyes were telling them compared to how they remembered the dead person in their minds. Perhaps both of them did not want to remember this changed person as they felt that at the end, it was not 'them' anymore.

Like Kristina, Simon expressed a struggle in separating his views about the dying from the dead person. Simon, a trainee counselling psychologist, who was also not present at the moment of death, was able to imagine what it would have been like for his client at the moment of death.

> *I almost really imagine what it would be like and um maybe not sure if I imagine the person still being there you know if they're actually in the process of dying (.) if it seems almost like (…) I dunno something left of biology. If they're just--. You're just the physical (…) kind of gasping for air. I imagine their eyes would be closed so um (…) yeah I maybe think this is almost like a reflex thing now maybe they've already gone. But I would probably wonder or look for some signs that that wasn't the case. Some, you know, kind of hope that they were still there.*
>
> *Simon – 14:20–15:5*

For Simon it appeared that in the dying process and in the moment of death, once the person was gone, the only things left were the biological responses. Simon moved back and forth between seeing the person for who they were and the biology of a human being. For Simon there appeared to be a dichotomy between the physical biology representing something negative and the person representing something positive. As Simon talked about the "gasping for air" and "reflexes" I got the impression that he was describing them in a negative light as they both represented something uncontrollable. By contrast, when talking about the person, he used the word "hope", which denoted something more positive.

Where Simon and Kristina both experienced a continuation of the biology of the dying person, Patrick's experience was more connected to the disintegration of the human body.

> *When I was <laughs> um when I was travelling um from--. So we flew back with her body and like in a in the normal place and um we were going to from Dublin to Belfast and I was driving in the kind of Hertz car with the driver guy and he was saying--. He started telling me how you know, it's your eyes that go first when you die it's cos they're so much made of water that they kind of disintegrate. And then he started talking about more what happens to your body after and I was like (…) I guess he must get into this if you're--.It must be a weird job to do but to talk to somebody whose girlfriend has just died about how her body is going to disintegrate is not necessarily--. I didn't--. They weren't the kind of questions that I was wondering…*
>
> *Patrick – 33:7–23*

Patrick's girlfriend died suddenly when he was in his 20s and the cause of death is still unknown. As he was in a completely different country when his girlfriend died and was also not present at the moment of her death, he was left with many different questions. As he stated at the end of his quote however, how the body of his girlfriend disintegrated was not one of those questions! He described the different perspectives of the same person depending on the relationship: a body/corpse, a girlfriend and a human with body parts. Patrick still wanted to maintain that personal connection to his girlfriend as he used the words "her body" as opposed to 'the body'.

There was a slight resonance with Simon's quote where, when the biology of a human was broken down, there was a large part of them missing – the person part. There was also the sense that the conscious human part disappeared instantly, whereas the body still lingered and took a while to die.

Koji, a Japanese man in his 30s, described the importance of a funeral irrespective of whether someone was present or absent at the moment of death.

So yeah I think that that's the process (…) [Mm](…) they go through and it's a way of saying goodbye and seeing the last, you know, face for the last time. Although yeah they're gone but you still get to see the body. I mean in a way yeah it probably--. A Japanese person would say or I would say the spirit is gone but the body is there…

<div align="right">

Koji – 19:11–20

</div>

Koji believed that at the moment of death the person was gone, however the body was still left on earth. The funeral was therefore a place to say goodbye to the body as it was assumed that one had already said goodbye to the person at the moment of death. Koji also introduced the idea of the spirit, which could be interpreted as something separate from the person and their body. He recognised a difference between "they're gone" and "the body". Although he could not 'see' the spirit of the person, he still acknowledged that it was there. There was some lasting element of that person that continued.

Thinking reflexively, I was very aware that Koji and I shared a Japanese background. I wondered whether he was able to be open in his experience with me because we had this in common, or whether it was a hindrance because of shared social expectations or assumptions. I was left wondering whether he was referring to me when he said "probably a Japanese person would say", as if there was an underlying cultural ritual. However he then clarified his statement by saying "I would say".

Theme 2: Sensing the moment of death

For Patrick, Kristina and Karen, it was not only about getting in touch with the dying person and their body but also about feeling a connection within their own bodies to the death of their loved ones.

I can picture walking up the little driveway of our house and opening the front door and feeling like something was horrendously wrong. My parents were both there and um (..) yeah, I knew something was--. Something devastating had happened.

<div align="right">

Patrick – 4:20–25

</div>

Um we weren't--. I was actually in the hospital at the very time when he died. Um I woke up in the morning and it (…) in a weird way I did kind of wake up and I thought

to myself ok now I think Granddad has actually died because you know on Sunday morning and on Monday morning I didn't have that same feeling but on Tuesday morning I did kind of have that feeling.

<div align="right">*Kristina – 14:13–29*</div>

But I woke up and I never wake up in my sleep. I'm a really heavy sleeper. Woke up kind of almost on the dot of midnight kind of (..) I don't know whether I'd had a nightmare or what but I just sat bolt up in bed like <inhales suddenly> "where am I? What's going on?" you know, all the rest of it. They said they'd phone me if anything happens and they haven't so I'll go back to sleep. And then my phone rang at six the next morning. My Dad said "Oh, your your Nan died at midnight" <makes a sound and laughs>.

<div align="right">*Karen – 30:3–13*</div>

What the participants were describing was a 'sense' or a 'feeling' that they somehow knew that the death had happened before they had been informed. When asked more about these feelings, none of the participants could put into exact words what they felt, which implied that it was a body reaction or something pre-verbal. As someone who is not spiritual or religious, I found this a difficult experience to make sense of, especially as participants were unable to articulate their feelings. What came across from these participants was something about the need to be present at the moment of death. This presence did not only need to be physical but could also be spiritual. Despite not being there physically, there was some sort of connection of their bodies to a metaphysical presence and connection that existed.

Simon, too, acknowledged that there were some things that could not be explained about the moment of death itself.

So it's just this person (…) [yeh] (…) and they're gonna reach the end now and (…) the times when I've heard about it is when people have been there is that everybody seems to know that. So everyone says "and we all knew. And then it happened." Um. So, yeah it seems like there's some weird expectation so some (…) um (…) kind of

communal understanding that people people know this or acknowledge it at that point.

<div align="right">

Simon – 20:2–12

</div>

Interestingly, Simon used the word "expectation" when describing the sense that people knew that the moment of death was approaching. To 'expect' implied the cognitive ability to know something and anticipate something in advance. Where Patrick, Kristina, and Karen talked about having a felt sense about the moment of death, Simon believed that there was an unspoken communal understanding. The understanding was more connected to the mind's interpretation of the moment of death as opposed to the body's physical felt sense. Yet at the same time, the moment of death is something unknown both physically and cognitively that cannot be explained. With Simon using the words "everyone" and "communal understanding", there also appeared to be an element of wanting to understand this phenomenon and be a part of the experience of knowing about a moment of death. By contrast, the other three participants seemed to want to share their experience about sensing the presence at death.

Theme 3: Negative affect at the moment of death

All the participants, both those who were physically present and those who were absent at the moment of death, described this experience in a negative light. Their emotions were described as terror, pain, guilt, hurt and fear. Despite the difficulty of the negative emotions, some of the participants were able to get in touch with such feelings and shared them in the interviews.

This was the case for Kerry in particular, who was the only participant who was present at the moment of her grandmother's death.

Terrified of being there. Yeah it was horrible. It was horrible. Um (…). You you've got this strong person (…) the matriarch of the family who just suddenly in this bed you know about to take their last breathe. Experiencing that moment when somebody is well somebody is dying they're never gonna be there again (…). Death is just um (…) is just disturbing. It's terrifying. So the whole thing is just--. I think I tried to shut out my terror about it because I was--. Yeah of course all I kept saying to myself was that

I had to be there. I knew that she'd want me to be there. I knew that my Mum

needed me to be there. (…). It's uh (…) it's the worst experience ever so. There's no,

for me, there's no comforting (.) you can't you can't get any comfort out of it.

There's--. How can you? There's no comfort to get out of it.

Kerry- 12: 21–13:2

Looking at the repetitions of Kerry's speech in combination with the pauses, it could be interpreted that she was trying to emphasise how difficult, terrifying, distressing and horrible the experience of being present at the moment of death had been for her. The way in which Kerry described her process appeared to go backwards and forwards between an ambivalence of wanting to be present for her grandmother, yet at the same time experiencing a powerful feeling of terror. She mentioned having to keep telling herself that she had to be there, as if persuading or forcing herself. I was left feeling that Kerry was really trying to show me her discomfort by the amount of times she used the phrase "you" or "you know". Kerry, at this point, was connecting to the person (her grandmother) who was dying as opposed to seeing her as a body. Therefore there appeared to be a link between realising that the person was "never gonna be there again" and this "terror" that she talked about. There was an element of finality and perhaps this was something terrifying for Kerry. The actual moment of death was the moment of realisation that the person was no longer there.

As the research question was left open for participants to interpret, Adriana also spoke about the pain of not being there when her dog and cat died whilst she was in London and they were in a different country.

So it was very painful to not be there. I felt like I had let them down like uh: like uh: I

had abandoned them uh. Because somehow they were like my adopted uh children

or something like that (…) [Mm] (…) so that that was hard. Like the part of not--.

Maybe then maybe then it was important that I was not there when they died. Even

if it was not for the last (..) moment or whatever just being there in general for them.

I don't know I just--. Thinking that they never knew what happened to me you know

whether I just abandoned them (…) [Mm](…) or not that was really really kind of painful for me.

<div align="right">

Adriana – 34:5–22

</div>

The fact that they were pets did not take away from Adriana's personification of them as she gave them the human attributes of consciousness and awareness. Having never owned a cat or a dog myself, I struggled to make sense of the idea that animals recognise what we consider feelings of abandonment. However, by sticking with Adriana's humanisation of them, I could better make sense of her experience. The negative effect of pain that Adriana spoke of appeared to have come from her being unable to connect to the pets in a physical or emotional way, not just at the moment of their deaths but also in day-to-day life. It would suggest that Adriana struggled with the idea of death being the epitome of the unknown, as she mentioned the fact that "they never knew what happened to me".

When Adriana said "Maybe then maybe then it was important that I was not there when they died", I got the sense that there was an ambivalence in her; part of her wanted to be present at the moment of death while another part of her did not. This also sounded like Kerry's "*worst experience*" of being present yet at the same time making herself be present for her mother and grandmother.

With Patrick, there was a different tone in him describing wanting to be present at the moment of death of his girlfriend.

And of course I wished I had been there and there was part of that was blame and you know, kind of blaming yourself and thinking God, she really needed help maybe at the moment and I wasn't there for her. Um <pause and begins to have tears in his eyes> you know it still hurts to say that, but I don't really believe that that's true anymore. I think in some ways I was spared the possibility that maybe I had of been there and she would have still died. Imagine what I would have felt like then if I was in the same room or something like that but I hadn't woken up or(...) Um: But yeah, it hurts a lot. I wish that I was--. Wish that I had been there um (…) and cos I can't--. I guess it's the narrative that I have used to make sense of it is true that she just wasn't feeling well then I've got to believe she would have woken me up and it could have been avoided

but <pause and deep breathe taken> I also--. I don't have much heart for that kind of thinking anymore because I can't, you know, I can't control how I can't--. I guess that's a lot of what (...) um a lot of what you're forced to deal with is the realisation that you can't control these things you can't--. You're not in control of lots of things no matter how important they are to you.

Patrick – 16:1–27

Patrick took us through a journey from the guilt and blame of not being physically present at the death, to the pain of this realisation, to imagining what he could have been able to do if he was there, to creating his own narrative that made sense of the event, to accepting the lack of control he had in death. The intense emotions that he felt came across not just in the content of what he was saying but also in the tears, pauses and deep breaths that occurred whilst he was talking.

The pain, blame and hurt that Patrick talked about would seem to have come from the unknown. As he still did not know how she died, Patrick was left with many questions as to what happened in her moment of death. As he mentioned, perhaps she needed help and he was not there to provide her with any. Like with Adriana, there was a sense of letting the dying person down by not being present, which Patrick went on to state was associated with feeling like he could have done something about the situation had he been present. Patrick then came to the conclusion that perhaps even if he had been present, the outcome would have been the same. It could be interpreted that the negative emotions he was left with were not only about being absent at the moment of death. Through this experience, Patrick had come to the realisation that death could not be controlled no matter how much he wanted it to be. He commented on being "forced to deal with the realisation", which suggested that there was a part of him that did not want to deal with the death. Patrick displayed a struggle of emotions, which were complicated and inseparable from one another.

Whilst Patrick spoke of the guilt that he felt in relation to not being present because he felt he could have changed the outcome of his girlfriend's death, Koji spoke of a different kind of guilt about not being present at his grandmother's death.

So um although I was told straight away that she had passed away (…) [Mm] (…) you know that doesn't change the fact that I actually wasn't there when she died and also I wasn't there when she was struggling to be alive. And yeah it--. I feel as guilty. I feel as terrible but perhaps it feels stronger and it comes up in my head a little bit more often than what happened with my Grandfather because there are so many things that remind me of her starting from my mother who I'm really close to.

Koji – 12:10–22

In this passage, Koji mentioned that when his grandfather died he was informed not only of the death but also the funeral a week later. Koji's grandmother, on the other hand, had an illness that deteriorated over a significant amount of time and therefore he was aware that the death was approaching.

As with Patrick, I got the sense that Koji's guilt came from the powerlessness of not being present at the moment of death. For Koji, however, it was the dying process culminating in the moment of death about which he felt guilty. Although Koji did not explicitly state it, it could be interpreted that Koji's presence at the moment of death could have added something to that moment. Where Patrick felt he could have changed the course of death, Koji focused on the importance of his presence during the 'struggle' as well as the moment of death. He did not mention anything that he would have wanted changed about his grandmother's death, apart from him being there. Perhaps for Koji, his presence at the moment of death would have allowed him to be helpful and supportive in some way. Maybe it was simply the mere fact of <u>being</u> there that would have made a difference. Koji was consequently left with the guilty feelings of not being present, which were evoked more when he thought about his mother who reminded him of his grandmother.

Theme 4: Death anxiety

With some of the participants being left with negative emotions around the moment of death, death anxiety also entered into the interviews when talking about the subject. Death anxiety could be seen as a blanket term as each individual described different fears, worries and anxieties related to the moment of death.

As Simon stated:

So if I had've been there it's: this is happened, you can't ignore it because you were there.

Simon – 17:2–4

People handle anxieties in different ways and Simon chose the word "ignore" which made me believe that there was a part of him that ignored death to begin with. If you are physically present at the moment of death it means that you cannot argue against the facts and you cannot disregard it. Perhaps for Simon the fear was the realisation that death was unavoidable. If Simon were to "ignore" death then he would be consciously choosing not to notice it . This implied that there was a part of him that found it too difficult to think about and to sit with. By using the words "it's", "this", and "it" he did not mention the actual word 'death' which also led me to believe he found great difficulty in speaking about death in general. To ignore death was a way to try and calm his anxieties.

Koji described more specifically his worries and fears at the moment of death.

Of course I'm still thirty so I would like to think there's a long way to go but when you think of that moment and (.) I guess I'm thinking of the fact that I wasn't there for them so I'm thinking of the fact lots of people might not be there or there may not be many people fullstop when I actually die. And that thought makes me pretty worried and scared I guess…

Koji – 28:13–21

Koji had previously mentioned that he was a homosexual man who would therefore not be having any children. This implies that he might not have many people in his life at the end. Koji's statement highlighted that thinking about who would be present at one's death was also linked to continuing generations. What came across from Koji's worry was the not knowing who would be there when he died and therefore questioning if he would die alone. As with Koji's previous account, there was the underlying question of what significance being physically present at the moment of death could have for someone. Again, Koji did not mention people being there at the moment of his death in order to do anything; there was more of an element of simply being there to not feel alone. It could then be interpreted

that for Koji, the moment of death was a scary prospect and therefore he might gain some comfort from someone being there with him. The worry at the moment of death was of dying alone.

The theme of death being the unknown appeared to be an underlying fear for both Adriana and Kerry.

> *And although it was just a dream and that it wasn't real at the time it can be quite scary to: to: to: not know (..) what's happening. The not knowing what happens after you die (…) with certainty.*
>
> *Adriana – 10:13–17*

> *It is terrifying yeah. Yeah. Nobody can tell me for certain what happens when you die.*
>
> *Kerry – 17:10–11*

Adriana talked about a dream she had had where her grandmother, who had just died, was in purgatory. Both Adriana and Kerry talked about this fear of the unknown. It could be interpreted that everything up until the moment of death was something known to them and therefore not worrying. As soon as the moment of death occurred, they entered the unknown and that was the "terrifying" and "scary" element. What they both could have been demonstrating was that, no matter whether one was physically present or absent at the moment of someone's death, the commonality was the not knowing exactly what happens after death. It was also perhaps, the fact that they would never know what would happen until they themselves experienced the moment of death.

Perhaps the link between death anxiety and the moment of death is that of a lack of physical connection. For those participants who brought up the fear around the unknown and death, it was maybe linked to not having a physical connection to anyone or anything.

In summary, the participants all spoke of a connection between the dying person, their body and the participant's own body in presence or absence at the moment of death. This was highlighted by the inter-connectivity between physical presence, the body, the mind and emotions. The moment of death was just as embodied, affective and intersubjective an experience even when the bereaved person was physically absent.

Super-ordinate theme 2: Putting the moment of death into the wider context

The second super-ordinate theme, 'putting the moment of death into the wider context', combines the choice of physical presence with the experience of understanding whom the presence is important. As death does not occur in isolation, this theme explores the moment of death and how participants attempted to manage their physical absence or presence within a wider context.

Theme 1: The choice to be present

Almost all of the participants felt that had they been given the choice to be there at the moment of their loved one's death, they would have taken it. This would have given them the opportunity to feel more in control of death and to respect the relationship with the dying person. Some participants focused on choosing the scenario that would have been ideal for the moment of death, which involved the presence of themselves or others.

From the experience of not being present at the death of his girlfriend, it had not only brought Patrick the awareness of his parent's eventual death, but also the inability to control the unknown.

> *What was hard after um--. Part of what was hard afterwards was kind of constantly worrying what was going to happen next. And, you know, worrying about my parents and um (…) but (…) Yeah. I suppose given the choice I would like to be there when they die.*
>
> *Patrick – 32: 9–15*

As he went from mentioning the worry about the uncertainty of the future, he then talked about having a choice about being present when his parents died. It would suggest that having an awareness of others' mortality meant that he could gain some control over their deaths or at least being present when they died. Being present would have been a way for him to control his worry, as it would have meant he would have known what had happened compared to the unknown of not having been present. This, it would seem, would have made a big difference to the way he experienced their deaths.

Patrick made it very clear that being present at the death of his parents was something that he knew he definitely wanted. On the other hand, when asked about whether or not she had wanted be present at the death of her grandmother, Emily talked about the romanticisation of the moment of death and she brought a different perspective in her account.

I don't know how many people get the luxury. In an ideal world like what I wanted to do was to go home to stay home and to be there the whole time. [Yeah]. But I don't know that there would have been--. I guess it's about not romanticising. Cos the family dynamics side of it would have been there. Like (.) there's a reality in life.

Emily – 33:1–9

For Emily, the choice of being present at the moment of death was not as clear-cut as it was for Patrick. Emily, like the majority of participants, had emigrated to England and so the choice to be present at the moment of death was a difficult one, simply because of physical distance. Emily described being physically present at the moment of death as a "luxury", which denoted an indulgence. She was also aware of the conflict between the ideal situation of wanting to be present versus the reality of family dynamics getting in the way. I got the sense that had she had the choice, there was a part of her that would have wanted to be there, as she stated "in an ideal world". Yet at the same time, given the choice, it was uncertain if it really would have been what she wanted. Psychologically, there could have been a split, tension or ambivalence which she was very much aware of.

Simon also used the word "romanticisation" when he described what he would have ideally liked his deathbed scene to look like. This followed on from Emily's use of the word "romanticisation"; however, it was used in a different way.

Yeah I guess it's when normally--. Think of someone dying and people being around it's definitely always in a bed. Maybe it's in a hospital bed. Um: And it seems it's odd to say this word but I have to say it anyway (…) like a romanticised version about it seems like it's all very quiet and peaceful and then that's it.

Simon- 25:3–10

111

Simon painted an idyllic image of the deathbed scene and the moment of death: the dying person was in a hospital bed with people around and there was a sense of tranquillity and calmness. It could be interpreted that if he had been given the choice, this was what he would have liked a moment of death to look like. This reminded me of my interpretation of Simon's difficulty with death and him now wanting to paint a "romanticised" version of it in order to make it less scary.

The theme of choice that ran through the participant transcripts was not just about their own choices (or lack thereof) but also the choices that they considered the dying person to have had. Karen began to describe the physical and emotional difficulty of being present with her grandmother, waiting for her death.

> *But um, I ended up on the Thursday night going back to <name of place> because I was absolutely (…) absolutely exhausted. Umm, and you know when you kind of think: I can't actually remember how long I've been awake at this point and you know your eyes are sore and your head's sore and physically from just sitting in one position next to a bed for ages think oh God I can't do this, you know ↑. And I went back to < name of place>. The staff there kind of said you know ↓ "look, however often you stay, the minute you go you know if she wants to die she'll die. If she wants you to be there she'll know. Just do what you need to do and you know obviously if anything happens we'll let you know." Um: so I must've got back dunno maybe around 9 o'clock in the evening something like that and kind of got into bed exhausted and just fell asleep immediately.*
>
> *Karen – 29:14–30:3*

Karen shared the conversation she had had with the hospital staff giving her permission to put her self-care first. The staff attempted to convey the message that her grandmother had the choice of dying, so there was no point in making herself ill in the process. It would appear that Karen struggled to put herself first and it was only by someone else allowing her to leave that she felt able to do so. Perhaps there was also a sense of relief that the entire responsibility of being present at the moment of her grandmother's death was taken away from her and placed partly on the hospital staff; they would keep her informed if anything

happened. I got a sense of the discomfort that Karen was in both physically (as she listed the sore eyes and head from sitting in the same position) and emotionally, as afterwards her thoughts turned to "oh God I can't do this".

For Karen, it seemed as if sitting through physical discomfort for her dying relative was a way to demonstrate the importance of their relationship, her loyalty and her determination to not abandon the person. However, eventually the difficulty of her situation came to a head and she was left waiting for death with no certainty as to when the actual moment of death would occur. She chose to go home that evening as she did not know when her grandmother would die and the consequence was that she was not physically present at the death.

Where Karen could take some comfort from the choice of the timing of her grandmother's death in relation to her presence, Simon felt that the lack of choice he encountered around being present at death was not comforting.

> *Cos I had worked with them for two years and um: and they were in and out of hospital after having a stroke and um: and then further strokes and um: and then I just got an email from uh this lady's CPN saying "just to let you know so and so has died. The funeral's tomorrow." And um, and then that was it.*
>
> <div align="right">Simon – 4:5–8</div>

From the way he described how he had been informed of his client's death, he did not have the choice of being present. He described the moment that he found out that his client was dead and the lack of acknowledgement from the community psychiatric nurse (CPN) about the death. Simon began talking about how he had been with his client for two years, expressing the relationship that he had with her, to the abrupt ending of finding out that she had died. A possible interpretation from what Simon said could be that, had he been given the choice to be present, it would have signified the acknowledgement from others of his relationship with her. It would have held significance and value towards the previous years he had spent with her, as opposed to the factual information that she had died and the funeral would be the next day.

The choice, or lack of choice, of the presence at the moment of death appeared to have had an effect on the way that the participants interpreted the event. For the majority of participants, the element of choice was taken away from them as they were physically not in the same country. For others, the person died whilst they were sleeping. From the way they described their experiences, having the choice was not always easily achieved, as the participants needed to put this decision into the wider context of what was going on for them at the time. For those envisioning the choice, they felt that they definitely would have liked to have been there and painted an idealised picture.

Theme 2: Whose death is it anyway?

The theme, 'whose death is it anyway?' attempts to explore the participants' awareness of the different people who had a stake in the death other than the dying person. The participants experienced trying to understand who the presence was for. They also explored the importance of the roles people have at the moment of death.

As Kerry was present at her grandmother's death, she recollected that in actuality there was more to it than met the eye. Kerry's father had died unexpectedly when he was in his 50s and she assumed that he had died in pain and alone, as she was not present at his death. Although the person that Kerry wanted to focus the interview on was her grandmother, she also brought her father into the room.

> *Whereas my Dad I don't I don't feel that at all. I feel like he probably died in pain and alone. And um (…)--. So that was important for me to be there. So probably yeah there was quite a bit of it for me then: although I didn't know it at the time to be there for my Nan but it was probably quite a lot to do with my Dad.*
>
> *Kerry – 11:20–27*

There was a connection between the death of her father and her grandmother, as she felt that she was being present at the death of her grandmother partly for her but also for her absence at her father's death. The presence that she experienced for her grandmother was to attend to the absence of her father's death. Although she stated that it was important for her, she went on to state that it was important for her grandmother as well as her father.

Kristina, who attempted to wait for the death of her grandfather, described the struggle she faced with balancing her needs and her grandfather's needs.

> *Um:, but then and that day--. Then that day was really difficult for me to leave the hospital cos I was like then I was like I really want to be there you know↓ I want to be here when he when he passes away. When it then had gone on for three days (…) I almost kind of felt that it was kind of (.) you know we wouldn't have been able to sit there for (…) whatever you know um: 62 hours straight you know that that physically would not have happened. Um (…) so (…) yes it was sad, you know yes I do think it's sad that no one was there with him when it happened.*
>
> *Kristina – 17:15–26*

From the passage one can infer that Kristina wanted to be there when her grandfather died; however, after realising that she did not know when he was going to die, she had to put her physical wellbeing first. Her presence at his death was something that she valued as her repetition of wanting to be present came through from changing location "I really want to be <u>there</u>" to "I want to be <u>here</u>". This could signify the struggle she faced in making a decision about staying or leaving. The difficulty arose when she realised she had to leave and consequently there was a possibility that he would die alone. Despite starting off by saying that she wanted to be there, the focus of the death shifted to her grandfather and that being present would be for him. This then left her feeling sad that "no one was there with him". As she placed an emphasis on her sadness at the end, it suggested her presence at his death was so that he would not die alone. Kristina did not mention what being physically present would have given her, apart from the reassurance of being there for him. Being present at the moment of death, for Kristina, could be seen as both a moment where she would be with her grandfather so as not to leave him alone, but also for her as a kind of duty. Her role, therefore, was to keep her grandfather company and make sure that he had somebody with him when he died.

As Koji and Klaus talked about the importance of being present at the moment of death, they raised the point that it was not always easy to distinguish who being present at the moment of death was for.

I think you want to be because--. I again I didn't have that chance I talk about being there at the funeral but if you had been together all the way through I can only imagine it's so: so important to be there when they actually go (..) you know when the dead (..) you know when the person dies you want to be there cos I think for those people that's the end of the journey isn't it↑ And if you care about the person I think you want to be present in that moment. But (…) yeah: yeah I think so. I think so. And for the person who's dying as well.

<div align="right">*Koji – 21:1–13*</div>

I think one is if (..) if the person is (..) close or close enough or or you know someone you're um: (..) emotionally close to enough um (…) then prioritising to be there is quite important I think. Um, within the reason of that person. Cos some people as you know↓ some people just don't want um: want that. Um. But even then (..) even if it doesn't--. If you can't be there at the death then prioritise to be there at the funeral. You know make that priority if it's--. If you fee= if you think they're close enough cos it will likely be--. You know help you to process through that.

<div align="right">*Klaus – 30:10–22*</div>

Koji, who was not informed until a week later and therefore not present at his grandfather's death in Japan, began by saying that being physically present at the moment of death was for the dying person, as they were coming to the "end of the journey". He then went on to say that "if you care about the person I think you want to be present in that moment" followed by "and for the person who's dying as well". Koji acknowledged that it was a joint moment where being present was for both the bereaved and the dying person. By Koji being present, it would have suggested that it was a given that he should have been there, as he stressed the importance of being with the person all the way through to the end. It could be interpreted that, for Koji, being present was a sign of respect for the dying person and something that 'should' be done. What was left up to interpretation was who being present was for. This could have been a combination of being present for society, for one's parents or for the moral self. It would have appeared from Koji's de-personalisation and repetition of "you" that he could have been speaking to those different parts of himself within the

experience. He then added at the end that it would not only have been for him but that the dying person would have benefitted as well. This could suggest that the role of presence was mutually significant, as in Japan there is a cultural valuing of mutuality.

There were some similarities with Klaus as he, too, believed that being present was a sign of how emotionally close you were to someone. Klaus also added that being there at the moment of death was both for the dying person and the other. He realised that it could have been quite a difficult balance to strike, as he was aware that some people might not have wanted someone to be present at the moment of death but that a priority for him was to be there. Both Klaus and Koji stressed the importance of the relationship to the dying person and believed that their closeness was a motivating factor for being there. They also both said that if you could not be present at the death, then the next best thing would be to have attended the funeral.

Where Koji focused more on what he and the dying person would have gained from him being present, Klaus seemed to focus more on how his presence might help him process the death. Klaus did not mention how having someone present could benefit the dying person, which highlighted the Western value of individualism.

Related to the awareness of roles that the participants had at the moment of death, Simon shared his views on what it would have been like if he had been there at the moment of death of his client.

> *I couldn't have cried though I think (…) I don't know if uh--. If I did it probably would not have been maybe about that one person. It might have been about--. Because I wasn't there out of the times of my own life when people have died. So, yeah that would have been majorly inappropriate. But um (…). I dunno, if I was able to I almost feel like I would have had to have been outside of a work role…*
>
> *Simon – 18:23–19:4*

Simon highlighted the different parts of himself that he was aware of when interacting with people. As he was in the role of trainee counselling psychologist with his client who had died, he felt that he needed to have behaved in a certain way. In this example, Simon's presence would have been for the people who had previously died that he could not be

117

present for. There was a similar link with Kerry's previous quote on a relationship between the current death and previous deaths. Perhaps there was an element of regret coming through, which meant that being present was a way to make up for a previous lack of presence at death. When he mentioned that he did not think he could have cried, it made me wonder (as, a trainee counselling psychologist myself, also aware of the different positions I hold) where the line was between Simon as 'person' versus Simon as 'other role'? There was a sense that, as a trainee, he would not have been allowed to cry had he been present at the moment of death of this client. On the other hand, he was aware that the "inappropriate" crying would have stemmed from previous losses as opposed to the current death. Being present would have put him in the challenging position of not knowing what "role" to act in and consequently who the death was really about.

Emily, too, spoke about putting the death into a wider context and being caught between different points of view.

> *What was so gut wrenching about it I guess where--. Were a few things that make it more difficult I guess um because she was older. Like societally it is that stereotype where people think that it doesn't matter cos they're older. And that was part of the thing when she was in the hospital the first time (.) like the doctors and things were saying "oh well she's old" almost like it didn't matter if she died. And she lived another three years and was vibrant. And so I don't know (.) I felt like that's been a hard thing here of um--. I notice that I didn't tell people who it was that had died. I just said I lost someone close to me because I didn't wanna say Grandmother cos I didn't want it to be dismissed↑ And then the other thing people say is "well did you go home for the funeral?" and it's like somehow if you've not done that: well then your bereavement isn't significant because if it was you would have gone home.*
>
> *Emily- 13:7–26*

Emily appeared to have made a conscious decision not to tell people who had died, as there was an underlying stereotype that, because it was her grandmother and she was old, her feelings and experience would be disregarded. I felt that when Emily talked about the "gut wrenching" feeling, this was partly the internal struggle she faced of dealing with the death

118

of her grandmother, but also that of not being able to share it with others for fear of their reactions. Although she was aware that the presence at the moment of death would be for her grandmother, there was a sense that it would have also been to appease society's expectations. As she was not there for the death of her grandmother, people then placed an assumption that she would go back for the funeral, highlighting the significance to them of someone not being there for the death. She stated further on in the interview that, for her, it was more important to spend time with her grandmother whilst she was alive, as opposed to seeing her grandmother in a coffin at the funeral. With the extract from Emily, I got the sense that she was finding a way through the social norms that worked for her. Her absence at the moment of death was highlighted through societal norms and expectations and therefore she was attempting to balance her personal feelings with external and, arguably internal voices. Emily was feeling the difficulty of not being present at her grandmother's death, which was exacerbated by society's assumptions and judgements concerning presence, absence and attending the funeral. Even though Emily was aware of society's views, part of her conflict arose from the fact that she was also a member of society and not separate from it.

Both Simon and Emily appeared very aware of the different roles that they had in life which consisted of the relationship to the dead person as well as their connection to a wider society. They were aware of the reactions of their presence/absence at the deaths from other people. The presence would not only have been about themselves but would also have reflected the norms and values of their society.

For Koji, the absence at the moment of death mostly brought up the feeling of guilt, which he discussed.

> *So I still feel I do think about the moment and think about the whole process or the journey of it sometimes (.) especially when I'm not feeling great about myself or when I'm feeling quite guilty about what I've done or what I haven't done in life. Nothing to do with the actual event (…) [Mm] (…) there you know↑--. Sort of the image of me not being there does come back sometimes.*
>
> *Koji – 11:11–20*

Koji seemed to be aware of and attempted to manage the expectation (both personal and social) that he should have been there. As this was not the case, he was left with feelings of guilt, as he did not fulfil those expectations. Despite him saying that he thought about not being there at the moment of death when he was feeling guilty about something unrelated, he continued to say that the image of him not being there came back, which suggested that it was very much related. Despite not having had the choice of being there at his grandfather's death, he still felt this guilt even if he said it was unrelated. Like Simon and Emily, being absent at his grandfather's death highlighted Koji's perceived role as a member of society as well as within his family.

As humans, we have the capacity to decide and choose certain things and are faced with having no control over other events. The participants described what it was like to have been physically present and also what experiencing an absence was like. It brought to light just some of the roles that were involved in the moment of death. The moment of death could not be viewed in isolation but rather was embedded within the wider context.

Super-ordinate theme 3: Endings and beginnings

Within this super-ordinate theme is the theme of 'endings and beginnings' which brings about an air of change. Some participants expressed the importance of the final goodbyes they had with their loved ones or goodbyes that they would have liked to have had. For presence or absence at the moment of death, participants had to incorporate the change brought about by the loss into their lives which also meant creating a narrative for the deaths. Finally, for some of the participants, the experience of being physically present or absent at the moment of death had a direct impact on how they changed their lives from that moment.

Theme 1: Goodbyes

Those participants who were physically absent at the moment of death felt that it was important for me to hear their experiences of the final moments that they remembered with their loved ones. Although it was not the actual moment of death, it was still the final moment they shared with that person.

As Emily lived in a different country to her grandmother, she described the two types of goodbyes that she experienced: being physically able to say goodbye and saying goodbye on the telephone.

> *So probably the most absolutely gut wrenching experience of my entire life and there've been <starts laughing> quite a few <stops laughing> but the most gut wrenching one was having to leave {} but the leaving was um--. I had to tell her <begins crying> I had to tell her goodbye. And um (…) yeah. I'm so glad that I went.*
>
> <div align="right">*Emily – 11:7–24*</div>

> *I called and my sister put her on the phone (.) and she couldn't talk anymore (.) then and I just said "I love you Grandma. I just want you to know that I love you very much." <Begins crying>*
>
> <div align="right">*Emily – 16:1–5*</div>

She later went on to say:

> *Pure is the word that comes to mind like (.) yeah. Yeah. That it was between--. It was a moment just between she and I. And even though it was a phone and my sister was standing there (.) it was like there was a silence and it was just (.) yeah.*
>
> <div align="right">*Emily – 18:12–16*</div>

Her grandmother died a few days later. From the way that Emily described her experiences of saying goodbye, there was a part of her that knew that she would not have been able to be there when her grandmother died and therefore she felt it was important to say her goodbyes both physically (during her last visit) and also over the phone. In saying goodbye, there was an acknowledgement that change was occurring.

Adriana, who was also absent when her grandmother died, described the way that she said goodbye in her last moments alone with her preparing the body for the funeral.

I felt like (.) like I knew how she liked to do her make-up so I thought better that I do it than somebody else (…) [Mm] (…) so I did feel quite protective in a way. And um. Yeah. So so I did that and and it was also like a nice (…) well yeah (…) feels odd saying it but it was like a nice way of of saying goodbye to her as well. Because we had a moment together and uh: where we were only me and her and it was like a kind of like a goodbye. Um. And then (…) after that she (…) yeah she was taken away and then the--. We had the funeral.

Adriana – 13:22–14:5

Adriana had previously described the difficulty of being with her grandmother whilst she was alive because she was in physical pain and was suffering. After the moment of death, Adriana was surprised at finding herself able to cope better and take charge of the situation. It could have been too painful for Adriana to see the final moment of death and therefore she preferred to say goodbye afterwards once the pain and suffering had been taken away. Adriana was physically taking care of her grandmother's body and by the way she described the process, it suggested that her grandmother was still 'present' for her. She knew how her grandmother liked her make-up done, she still felt the connection of the relationship in saying goodbye, and she referred to the body as "her". It sounded like it was important to Adriana that she had that experience of preparing her grandmother for the funeral, as this was her way of a final goodbye to both the body and the person.

As Kerry sat with her grandmother after she died, there appeared to be a part of her that did not want to say goodbye.

And I didn't want her to feel like she was alone. Um (…) so <pause whilst crying>. Just by touching and stroking her hand and her arm and her face you know. I was trying to tell her that you know she wasn't on her own really. [Mm]. (…) <stops crying> And then I went back up and sat with her until the doctor arrived. So I was there for about another half an hour (.) three quarters of an hour cos I didn't wanna leave her on her own.

Kerry – 22:13–23

Being there for her grandmother was important; she didn't want her grandmother to feel alone. By the physical contact and also talking to her, Kerry was trying to reassure her grandmother (even though she was already dead) and perhaps herself, that she was not alone. Throughout the passage, I was unclear as to whether Kerry did not want to leave because she feared that she would then be alone. At the end of the passage, where Kerry re-emphasised the point of not wanting to "leave her on her own", I got the sense that she was still in the death moment. By leaving her grandmother, Kerry would have had to acknowledge that her grandmother was no longer alive. As Kerry had previously shared the terrifying feelings that death evoked in her, it made sense that she would have wanted to avoid that feeling for as long as possible by staying in the current moment. Perhaps for Kerry there was no need for a formal goodbye per se but the mere act of 'leaving' was in itself an acknowledgement of a goodbye.

Emily, Adriana and Kerry emphasised the aloneness of being with their loved one and saying goodbye in those moments. There was something about them taking the time to say their goodbyes. There was still some part of them that was aware that the dead person was still with them, which brought to light the difference between a biological death and a social death.

With the previous participants, there was an element of a goodbye being final. With Koji, however, it was more of a transitional state that occurred.

> I think I have two minds about it. So I think in talking about saying goodbye yes it does feel really final but yeah it does feel like this is the last opportunity for me to do something in relation to the dying (…) [Okay] (…) however I also think they are up there somewhere watching over us but there's no connection between us (.) so they might be looking at me now doing this interview and smiling about it I don't know. But it doesn't mean I can see them doing--. I don't know, having tea or whatever…
>
> *Koji – 30:9–21*

Koji separated out the different kinds of goodbyes that took place. The first was a goodbye where he had the opportunity to do something for the dying person – fulfilling some kind of wish for them. The second was saying goodbye to the person (human and body) as he knew

them. In saying goodbye to the person, there was an acknowledgement of a kind of spirit that carried on existing which could not be connected to in this world but was still out there. Not only was he not present at the moment of death but he was also absent in being able to say goodbye, which was why he was imagining what it would have entailed for him.

Theme 2: Incorporating death into life

The theme of 'incorporating death into life' dealt with the participants attempting to make sense of the death and processing it into their lives. It was about carrying on living without the dead person.

For several of the participants, there was the underlying question of how you knew someone was dead if you weren't physically present to have witnessed the death.

Klaus described his difficulty in trying to incorporate into his life the fact that someone was dead, having not been present at the moment of death.

> *You know, I always feel like there's a--. There's that moment that (..) the whole definition of someone being dead is: is sometimes as an emotion quite difficult to (..) define what it's supposed to be or you know↑ You kinda think well (..) is it the fact that you you're sad that you can't call them↑ Or that you can't be with them↑ But equally I have so many other people in my life that are alive that are almost similar so then (..) for me at least it's quite difficult. I think if you live in one place your whole life and you kinda always see almost everyday these people around you then you fee= then the difference strikes you really really hard and you kind of have a clear definition of what death means. But actually, there are probably many people that would fall under that similar category if it's purely just defined that you don't see them day-to-day that would (.) quote-on-quote be dead in my life just because I don't happen to see them for a while. But actually they're never really dead to me. I know I can still turn up somewhere else in another country and I'll see them again. And (...) I dunno um with that whole aspect of I'm I'm quite (..) I don't define things on 'oh: I haven't seen you so you're no longer my friend' or things like that right↑. So for me (...) I dunno I struggle with the definition of of you know, is someone dead or not I*

think. You know I find it I find it hard to really nail down what the emotional state of

that--. All that is.

Klaus was attempting to do two things at once: define death in a cognitive factual way, whilst trying to understand the emotional aspects of death. As he mentioned, there was the physically seeing someone again as a way to define death. He discredited this way to define death as it was hard for him to separate someone being dead from just not seeing them in a different country. At the same time, there was a feeling of sadness at not being able to call someone as this would indicate that they had died. He also discredited that, as he had experienced the same thing with people who were still alive. Klaus highlighted a contradiction as a feeling or emotion could not be defined cognitively. There was an underlying assumption for Klaus that death could be defined and that the emotions of death could be 'nailed down'. Klaus appeared to have been struggling to make sense of death and to find closure as he had no way of incorporating it into his life that would have taken the death into account.

I believed what Klaus was trying to say, that for people who did not travel or move around as much as he did, it was easier to acknowledge the death as it affected them on a more day-to-day basis and the loss would be more visible. However, if someone died whilst you were in another country, it was harder to incorporate the loss because the effect of the death was less noticeable.

Klaus went on to say:

To me (.) I dunno I find that the only way to get the definitive kind of punctuation (..)
on death is to be there.

As Klaus had never been present at the moment of death, he was imagining that in order to get that 'nailed-down' feeling and definition of death, he needed to be present. In order for Klaus to be able to fully acknowledge the death of someone, being physically present was

vital; it would have allowed him to incorporate the death into his life and he would not have mistaken them for simply being in another country.

Adriana voiced a similar experience of finding it difficult to keep the death of her grandmother in mind, as she had not been present at the death.

With this Grandmother my dreams were about her still being in her house um: and not knowing that she was dead. Uh:. So I dunno--. Could be maybe I was the one who didn't want to admit that she was dead↑. I think (…) yeh because nowadays when I go back to <name of place> I find it difficult to to (…) to remember that she's not there anymore.

Adriana – 25:1–8

Adriana experienced dreams about her grandmothers after they had died, which could be interpreted as her way of processing their deaths. In the above passage, she mentioned that when she went back to her home country, she still needed to remember that her grandmother was not alive anymore. Like with Klaus, perhaps being physically present at the moment of death would have given her clarity around death and therefore she would have been better able to have processed the non-existence of her grandmother.

There was something about the physical presence at death that, from the perception of these participants, would have allowed them to have 'known' that the person had died.

Like Klaus and Adriana, Patrick also wondered how one knew that someone had died.

I don't know how you would believe it's real↑ I think there is something about even after the moment of death seeing somebody's body to me is important actually. It's dreadful, but it's important. As part of a yeah↓ it's real actually…

Patrick – 32:29–33:5

From what Patrick was saying, the moment of death was not enough for him to believe that the death had happened. He also needed to be able to <u>see</u> the dead body to actualise the death. As he mentioned the word "real", there was a sense of being able to come to terms

with the death. Linking this back to Patrick's experience of wanting to see the body of his girlfriend, there was importance and significance behind it because by seeing the dead body, he would have been able to start processing the death and made it part of his reality. It was the end of his previous life as he knew it and the beginning of a different one.

For some of the participants, their presence or absence at the moment of death changed the way they lived their lives and therefore their sense of self and identity. This was most predominantly seen through Koji and Kerry.

> *And I think also the whole experience has contributed to the fact that I would like to relocate back to Japan relatively soon because now my parents are in their sixties, they're not getting any younger so it feels like I'd rather be closer to them physically just in case something happens (.) and if my mother gets sick of whatever then I'd rather be there to care for her which I never got a change to do (…) [Mm] (…) for my Grandparents. So in that sort of sense it's made a--. It made a big impact but good few years after the actual events.*
>
> *Koji – 38:17–39:6*

In Koji's, the physical distance of being away from his family, especially in moments of death, appeared to have been difficult for him. Having become aware of his parents' mortality, he did not want to have the same experience he had had with his grandparents of not being there when they died. In an attempt to change the way he lived his life, he was making a decision to move back to Japan to be closer to them when the time came. Thinking back to what he mentioned earlier about feelings of guilt about not being there at the moment of death, one could assume that he did not want the same thing to happen again. He appeared to have integrated the experience of being absent at the deaths of his grandparents into his life and made a change in response to it.

Similarly for Kerry, she described a change that occurred for her after her father's death.

> *I think experiencing death from people close to me (…) definitely made me appreciate my life more. I was quite a--. (…) Um: sort of depressive person I suppose↓. Not depressive but um (…) I could be quite (…) quite morbid at times I suppose. Yeah*

bouts of depression and stuff and uh (…) yeah things definitely changed after that for me. Definitely changed. I felt like I had to. In fact there was quite a sudden change in me. Um: sudden well within a few months when my Dad died I was like okay↓ (…) it's time to pull yourself together. You can't go on you know (…) so um yeah definitely. (…). The last ten years have definitely changed a lot for me and that's probably what helped me to cope with being strong when my Nan died.

Kerry – 33:7–23

Like Koji, it could be interpreted that not being present at her father's death had had a significant impact on her life. So much so, that she felt like she "had to" change. I got the impression that she experienced a transformation in herself after the death of her father and no longer felt like the person she was before he died. There was a reflective tone in her account as she repeated the words "definitely changed"; almost as if she was thinking back to the person she used to be and recognised how different she was now. The change that occurred enabled her to be more present and cope better when her grandmother died. Thinking back to Kerry's earlier account of needing to be present at her grandmother's death because she was absent at her father's, I was led to believe that, had she not experienced being absent at her father's death, she would not have felt the need to change. Furthermore, she might not have felt the need to be present at her grandmother's death.

For some participants, it was difficult to incorporate the death into their lives, as they were still unsure whether the person was actually dead. Despite being informed, some of them expressed that the physical presence at the moment of death could possibly have solved that. For others, the physical presence or absence at the moment of death resulted in a change to the way they lived their lives following the event. The change symbolised the end of one way of being and the beginning of a new one which ultimately had an impact on their identity and sense of self.

<u>Summary</u>

In summary, the analysis has sought to bring out the lived experiences of bereaved people of the embodied aspect of the moment of death within the context of them being present or absent. The themes of connecting to the body and emotions, putting the moment into

the wider context, as well as endings and beginnings are presented in this study separately whereas they appeared to be very much entwined. The interconnectivity of the themes showed the complexities of the phenomenon, which the participants experienced.

Discussion

Having analysed the participants' stories in Chapter 3 (analysis), this chapter now sets out to place the findings within the context of the existing literature. It then goes on to explore how the findings can be implicated in advancing knowledge, not just specifically within the field of counselling psychology, but also from a wider healthcare and societal context. The limitations of the current study will also be evaluated in this chapter and suggestions will be made for further research. Finally, my methodological, personal and embodied reflexivity will be discussed.

Contextualising the findings

My research study looked into bereaved people's embodied experiences at the moment of death within the context of them being physically present or absent. Their stories highlighted their very different perspectives on life and death and so were very much context dependent. The participants shared their journeys, which often involved intense emotions that ranged from sadness, anxiety and confusion to guilt, anger and relief. Overall, there was a sense from the participants that their physical presence or absence at the moment of death played an important part in how they created a narrative for the death of their loved ones. It consequently also affected how they negotiated their relationship with the concept of death.

One of the most striking aspects about conducting this research was the number of participants that came forward who had been physically absent at the moment of death. Eight out of the nine recruited participants had experienced physical absence at the moment of death. As the recruitment was left open to people who were both present or absent, either being physically absent is a more common occurrence or participants experienced more psychological significance in being absent.

By looking at this significance in the context of the 'good death' and 'bad death' literature, one possible interpretation of physical presence at the moment of death could be that by being absent, the death was experienced as a 'bad death' by some participants. It could be seen as a struggle between their lived experience of being physically absent at the moment

of death, versus their perception of a 'good death' in which they would be physically present. As Seale (2004), Kehl (2006) and Shneidman (2007) highlighted, a common social discourse was that dying alone was considered a 'bad death'.

Furthermore, in both Eastern and Western societies there is an expectation and assumption that people should be physically present. This might lead to people feeling less inclined to discuss their absence for fear of others' negative perceptions. By allowing a more open and exploratory standpoint, my research enabled people to come forward and share their experiences even if they were physically absent at the moment of death.

On the other hand, the experiences of the participants in this study did not always correspond with Seale's (2004) and Kehl's (2006) findings regarding a 'good death'. Despite being physically absent at the moment of death, Emily, Klaus, Simon, Adriana and Karen all focused more on the importance of the time they spent together with the dying person whilst they were still alive. For the participants in this study, just because someone died alone did not necessarily make it a 'bad death'. The findings resonated with Masson's (2002) questioning of the labelling of the terms 'good death' and 'bad death', as there is no idealised situation and an individual's negotiation around death will reflect their context and situation at the time. A death that works for one person at a particular time might not work for that same person at a different time due to various factors, including the surrounding circumstances.

As there have been only a handful of studies that have focused solely on the aspect of being physically present at the moment of death and none that have looked at physical absence, this study has begun the exploration of physical presence or absence as a phenomenon. Previous research (Donnelly et al., 2006; Donnelly and Battley, 2010; and Williams et al., 2013) has focused on the moment of death to improve hospitalised care. My research has attempted to step away from ways to advance or change medical healthcare policies. It has moved towards taking a more holistic approach to how this phenomenon can have a deep impact on people's lives and working with these findings in therapeutic practice. The moment of death was recognised by participants as a powerful defining moment, which brought up many thoughts, images and emotions. Despite this significance, the moment of death is not widely recognised in counselling research and therefore highlights the gap within bereavement theory and practice.

The following discussion focuses on the three super-ordinate themes that emerged and their relation to the existing literature. It should be noted that each of the super-ordinate themes, although presented separately, are interlinked and have been portrayed this way for structural purposes only. Based on the findings of participants' experiences of presence or absence in the moment of death, the discussion also offers specific implications for counselling bereaved individuals.

Super-ordinate theme 1: Connecting to the body and emotions

Overall, when reflecting on physical presence or absence at the moment of death, the participants felt a strong sense of connection, not only to the dying/dead person's body but also to their own. Merleau-Ponty's (1962) phenomenological perspective of the 'lived body' was that we cannot be separated from our bodies; we do not just *have* a body, but we also exist and *live* in our bodies. Therefore, a death is not just a death of the body, but also of the person connected to that body. Using Lawton's (2000) observations of 'body-subject' to 'body-object' was not necessarily a helpful way to make sense of the participants' experiences. The moment of death (and the dying process) was not as clear-cut as this, even if participants were present or absent at the moment of death. Despite the assumption that throughout the dying process the body goes from a 'subject' to an 'object', this was not the case for all of the participants. Participants described the death of their loved ones days, weeks and years after the actual death and still found it difficult to find such a clear-cut distinction of the deceased being the person they knew to the sum of body parts that functioned or did not function. There was a sense of the participants continuing a non-linear transition of how they viewed the dead person before, at the moment of death and after. The participants fluctuated between describing the people they used to know whilst simultaneously describing a corpse. Overall, the participants in this study did not adhere to the Cartesian dualism of the mind and body seen separately. The findings fell more in line with Gudmundsdottir's (2009) study, which recognised the different perspectives that exist in relation to the mind, person and body.

Working therapeutically with clients could therefore focus on the changing relationship that clients present when describing a loved one's death. Therapists are encouraged to have an awareness that the death of a person is more than a physical embodied death but can also

132

encompass the death or continuing presence of a person they used to know. When someone physically dies they may not be necessarily dead to those that are left behind.

An aspect of the experience that emerged strongly from some of the participants' transcripts was the notion of sensing the moment of death before being told it had occurred. Although, as far as I am aware, there are no studies that look specifically at sensing a moment of death without being present, these findings closely related to Fielden's (2003) study that explored the lived experiences of people bereaved by suicide. In the lead-up to the suicide, the participants in Fielden's (2003) study described sensing that death was occurring without having been informed. This sense of premonition was also evident in my research, with participants describing their own physical absence at the moment of death. The participants *felt* the death in a bodily reaction. Despite not all of the participants in this research being present at the moment of death, their need to feel a relational bond fell in line with Klass et al's. (1996) continuing bonds understanding of grief. Although there is an assumption that Klass et al. (1996) were talking more specifically about continuing a relationship bond, there appears to be no reason not to include a non-physical spiritual connection as well.

Some of the participants described seeing the deceased in dreams post-bereavement but none of them experienced seeing or hearing the dead at the exact moment of death. Bennett and Bennett's (2000) study explored experiences of feeling, seeing or hearing the actual dead person. Whilst participants in that study described feeling like the dead person was with them, the participants in my research experienced a change in their bodily sensations as a kind of warning of the death. They did not perceive this change in bodily sensations as the deceased's way of trying to communicate something to them. In fact, none of my participants provided an explanation for what that sense of another presence was.

Bennett and Bennett (2000) also highlighted how the context of their research played a part in their findings. They noticed that their participants tailored their narratives to the researchers fearing how the researcher might interpret the experience (e.g. a fear of not being taken seriously, being seen to have a mental health condition or being unacceptable).

The same could be applied to my participants; although they did not express the experience of hearing or seeing the deceased at the moment of death, they could have been moderating their experience for fear of what I might think. Another factor could be that the vast majority of my participants were working within a healthcare environment. The medicalised environment does not favour spiritual explanations but rather looks for rational understanding, therefore the participants could have been making sense of their experience through 'rational' rather than 'supernatural' discourses. The participants in my study described a change in the relationship with the deceased at the moment of death. They sensed that something was wrong or that the person had died, but could not describe actually sensing the person.

The findings relating to an embodied sense of the moment of death fully support the emphasis that counselling psychologists (Shillito-Clarke, 2008; Feltham; 2008) have placed upon seeing and working with people in a more holistic way. This view includes not only the mental and emotional aspects of a person, but also the often forgotten corporeal aspects. In some bereavement theories great emphasis is placed on the mental processes that occur for the bereaved individuals (as seen in the DPM and task model) while they adapt to change following a death. What the participants in my research have shown is that there is importance placed on their changing relationship to the dead person's body. The loss of a relationship to someone is not just the emotional connection but also the physical relationship from one human body to another. If people are attuned to their bodies in everyday life (such as the participants *feeling* within their body the death of someone before being informed), then the same should be applied within a counselling framework as the body plays an important role in the way we live our lives. Greg Madison (2010) has introduced an emerging approach to counselling which emanates from the philosophical underpinnings of Eugene Gendlin in combination with experiential-existential therapy. With greater emphasis on the interaction between the body and the environment, Madison (2010) puts forward that counselling should attend to the in-vivo bodily experiences of both the client and the therapist, therefore reflect the importance of the body within the world and also in relation to the remembering the dead.

Participants who were either present or absent at the moment of death expressed more negative emotions than positive ones. Terror, guilt, blame and feeling out of control were felt by participants irrespective of whether they attended or did not attend the deathbeds of those that had died. As neither the physical presence nor absence at the moment of death has been discussed within counselling research, it appears that a significant experience is being neglected within counselling practice. By recognising the importance of physical presence/absence, therapists can be aware of the potential for feelings such as fear, guilt and shame around the moment of death that are not currently being explored in sessions. A possible explanation for the lack of discussion around negative emotions within bereavement counselling could be the perceived effect it might have on a dying person's care. For example, if a relative expressed negative emotions to a medical healthcare professional, they may fear that the care of the dying might be jeopardised. If people are not encouraged, by those working with the bereaved, to speak about both positive and negative emotions, then they may feel ashamed.

Some participants also spoke about their ambivalence around wanting to be present at the moment of death, whilst at the same time not wanting to be present. They were able to evaluate the significance that being physically present or not being present would have entailed, which left participants with negative emotions. For example, they were able to acknowledge that they felt guilty about not being there but also realised that had they been present, it would have been very difficult. Counselling psychologists should be aware that being present or absent is not as straightforward as some of the assumptions in the 'good death' literature indicated.

The negative and positive emotions that participants described should also be of note to healthcare professionals. With the awareness that people experience both positive and negative emotions at the moment of death, professionals could facilitate discussions that enable people to express themselves and normalise such feelings.

Some of the studies that explored presence at the moment of death focused on the participants 'doing' something for the dying person (Donnelly et al., 2006; Valentine, 2007; Donnelly and Battley, 2010 and Williams et al., 2013). With the recent advances in technology, which have resulted in people living longer, there is an underlying assumption that we as human beings need to do everything we can to prolong someone's life, as for

135

someone to die before their time would be considered a 'bad' death (Seale, 2004). Some of the participants in my research were left with negative feelings because they had not done everything they felt they could have done. In their accounts, Adriana, Patrick and Koji expressed that their absence in the moment of death signified the incapacity to do something that otherwise their presence would have allowed them to do. For some, it was to provide reassurance; for others, it was asserting more control over the situation; whilst for others, it was an opportunity to be part of the dying person's journey.

In other words, the analysis from participants who were absent at the moment of death began to uncover the assumptions around the significance of being present. For healthcare professionals working with the bereaved and talking through their experience of the moment of death, it is therefore vital to explore with people the specific importance of being physically present and what it might mean if they were absent.

In being able to share negative feelings associated with the moment of death, participants also revealed some death anxiety around the moment of death of others as well as themselves. Participants spoke about their fears at the moment of death, which could be linked to the existing literature around death anxiety. Thinking about the very moment of death brings about death anxiety in people. The participants experienced a common feeling of anxiety, however it manifested itself in different ways.

Throughout the participants' experiences, there was a fear that arose from thinking about the moment of death. For some, it was the fear of the unknown from life to death; for others, it was the fear of being alone in those moments, or ceasing to exist as a conscious being. These findings would be consistent with Yalom (1980), Kastenbaum (1971) and Levi (1998), who stated that there are different kinds of anxieties that can arise from thinking about death. What, therefore, is significant about the moment of death? Perhaps a clue to answering part of the question lies with Simon saying that if you are present at the death of someone, you cannot ignore it. This brings up the idea of Heidegger's (1967) *Dasein* and being-in-the world. An existential given is that we are thrown into the world without having choices about a variety of situations (e.g. our birth or death). As death can be viewed as 'the end', the way that we manage this on a day-to-day basis is to find ways of avoiding confrontation of the fear of death (Becker, 1973). The terror management theory asserted that people actively suppress fears of their own death and this activates defences

(Greenberg et al., 1986). However, if someone is present at the moment of death it is much harder to consciously suppress the fear of death as it brings the awareness of death to the forefront. Kastenbaum (2000) stated that the moment of death is a reminder of the person going to eternal mortality. Participants described what happened at the moment of death of the people they cared about and it would appear that thinking about the moment of death was enough for some death anxiety to arise.

As the theme of death anxiety emerged strongly in my research those counselling not just the bereaved but all clients need to think about how to work with it. To date, there is no existing literature around bereavement counselling and exploring death anxiety within therapy sessions. What my study in the experience of physical presence or absence at the moment of death has highlighted is that death anxiety is very much at the forefront of people's minds. These findings are contrary to what Kasket (2006) and Yalom (1980) asserted when they spoke about those working with death anxiety never encountering it in its original form but rather through defences and reactions. The participants in my research very clearly stated their specific anxieties around death, which were not masked by defences.

The presence or absence at the moment of death and its link to death anxiety has implications for counselling. The moment of death is a complicated experience, which can bring up different kinds of worries about one's mortality. Healthcare professionals of all disciplines discussing presence or absence at the moment of death need to be aware that it can bring up anxieties. These anxieties are, for example, around death being an unknown, being alone and no longer being conscious.

Super-ordinate theme 2: Putting the moment of death into the wider context

The existing bereavement and cultural research has explored people's experiences that were context dependent. The participants in my study adhered to previous cultural research as they could not be seen separate from the environment in which they live. The element of choice at the moment of death was an experience which participants discussed as being context bound and often involved the participants having to think about their choice of wanting to be physically present within the wider context. What made choice

difficult was the fact that they did not have control over death; however, they did (sometimes) have a choice over presence.

Some participants ultimately realised their lack of control in death and also being physically present at the moment of death. Although not scientifically researched, it is fairly common for people to pass away without a relative, friend, carer, or hospital staff member in the room. This was the case for some of the participants. However, participants felt comforted by the realisation that they had no choice over being present at the moment of death. This could suggest that had they been present, the importance would have been around the relationship with the dying as opposed to carrying out specific tasks.

The relational significance ties into the counselling psychology research, which values the importance of the therapeutic relationship (Mearns and Cooper, 2005). As with some of the current participants, the emotions that surfaced were related to the loss of the relationship, as opposed to participants needing to do something. Grieving a relationship is not often talked about in some bereavement theories, where often the focus is on the client doing something to work through the loss (e.g. Worden's (1991) task model). As Van Deurzen (2009) mentioned, a death brings about the loss of possibilities. Very little attention is paid to the foundational relationship that was lost and therefore the findings from this study urge practitioners to further explore the lost relationship, rather than working through the grief.

For the majority of participants, the choice of being physically present was taken away from them as they either did not know the person had died or could not physically get there. The feelings that they were left with ranged from guilt, loss of control and sadness, to blame, disappointment and anger. These emotions echo the Begley and Quayle (2007) and Fielden (2003) studies on bereavement by suicide, where participants were left with similar emotions. What this could indicate is that when choice is taken away from participants around being present at the moment of death, it has a significant impact on the way they experience the event. The emotions associated with choice (and lack of choice) were also related to the meanings that participants attributed to the moment of death. For example, for Koji, the moment of death signified the end of the journey for the dying person and the fact that he was absent at that moment left him with feelings of guilt. From these findings,

the suggestion for working with bereaved individuals would point towards the direction of, existential therapy for example, which works with the meaning of choices and lack of choices within a certain context (Oliveira, Sousa and Pires, 2012). As we do not live in isolation, it is important to acknowledge the client's wider context as this will significantly influence their experience.

Physical presence or absence in the moment of death was not just about the participant, but involved a much more complicated network of relationships. This brought up the question of 'who is being present at the moment of death for?' For most of the participants, it was a combination of being present for themselves and being present for the dying person. With other participants, it was apparent that the social context in which they lived influenced the way they viewed their presence or absence. The roles that participants felt they played in being there at the moment of death contributed to their understanding of who the death was for. This included being there so the person would not die alone, to carry on with tradition, or to be present at the death of one person as they had been absent in another's.

Some participants mentioned that their physical presence at the death of someone would be a way to make up for an absence at the moment of death of someone else in the past. Despite this interconnectivity, no previous research has explored this aspect of bereavement. Seeing this experience through the lens of continuing bonds (Klass et al., 1996), bonds from previous deaths are constantly being re-visited and re-negotiated through the most recent death. As participants were absent at the moment of death of a loved one previously, this meant that their current experience was greatly influenced by that one as they wanted to be present for the more recent death. Participants expressed that deaths could not be viewed in isolation but in relation to previous deaths and losses. In addition, during the interviews participants did not only focus on one person who they were present or absent for but mentioned at least one other death and their physical presence or absence in relation to that death. Therapists offering counselling to those that are bereft should be aware that the physical presence or absence at the death of one person can also bring up previous experiences of presence and absence in deaths and losses.

For several reasons, the findings from my research regarding the roles people took at the moment of death do not fully support those of previous studies that have looked at presence at the moment of death (Williams et al., 2013; Donnelly and Battley, 2010 and Valentine, 2007). Firstly, with the exception of Valentine's (2007) study, the previous studies looked at participants who had had a relative die in a medical environment. This in itself highlights a different aspect of people's experiences, as the role of relatives in medical environments was seen to be trying to control the situation, as well as advocate on behalf of the dying person. As the majority of participants in my research were physically absent at the moment of death, the way they made sense of their experience was that they wanted to find comfort for themselves as opposed to advocating on behalf of the dying/dead person.

This study also highlighted the different assumptions that the previous studies were based upon. With the Williams et al. (2013) and Donnelly and Battley (2010) studies, which focused on dying within a medicalised environment of either hospital or hospice, the participants in their studies depicted an experience which was medically bound. By contrast, the participants in my research (either because of their absence or because there was no medical environment involved) were more aware of the dying person's phenomenological experience. When speaking of their presence or absence, none of my participants mentioned wanting to be there to relieve the suffering of the dying person; rather their focus was on their relationship with the dying person. In other words, the role that the participants in this study saw themselves fulfilling was simply to be present and not necessarily to do or change anything. The importance of the relational experience resonated with the findings of Pierson et al.'s (2002) study, that having someone present at the moment of death helps the dying person to not feel alone.

For some participants another powerful aspect of the moment of death experience was becoming aware of grieving within the society they inhabited. Although physical presence or absence was a universal experience, the manifestation of the experience was different due to the unique cultures of the participants. Everything from the dying trajectory, to the moment of death and the handling of the dead body was all made sense of through a 'cultural lens'. Participants like Simon, Koji and Emily, found that their experience of being physically present at the moment of death was not just for them and the dying person but that it was affected by social norms. Some of the participants were caught between making

sense of their grief on an individual basis yet trying to interpret their experience in a wider context that did not conform to social norms. Emily for example, described deliberately not mentioning her lack of presence at both the death and the funeral of her grandmother as she was aware that this would be considered unacceptable in terms of her social norms. Emily's experience resonated with the participants in Valentine's (2013) study of individuals negotiating their bereavement experience on an individual and societal level. If Emily had been from a Chinese or Japanese background where there is a greater cultural emphasis on respecting the elderly in life and in death, she might not have encountered the need to avoid telling those around her that her grandmother had died. Emily's experience as well as those of other participants, highlighted the effect that cultural assumptions have on the grieving process. What was different about Emily's experience, compared to the experiences from Valentine's (2013) study, was that Emily did not try to justify her experience in order for it to be more socially acceptable. Although Emily mentioned that she struggled to grieve publicly about her grandmother for fear of how others would react, she did not attempt to defend her absence at the moment of death.

The same could be said for Koji's experience where he was aware that in Japanese culture it is important to be physically present at the moment of death to see the peaceful face of the dead person (Valentine, 2013). Koji, who was absent at the death of both his grandfather and grandmother, did not see their faces when they died but rather than justifying his absences (like the participants in Valentine's 2013 study) he expressed his feelings of guilt and sadness. A possible interpretation for the difference in findings from Valentine's (2013) study could be that Koji was a Japanese man who still had his Japanese culture embedded into his mentality yet he was living in the United Kingdom. Koji could have acquired some of the individualistic Western mentality whilst living in the United Kingdom, which would consequently affect the way he interpreted his experience of absence. The Japanese participants in Valentine's (2013) study were interviewed in Tokyo therefore their cultural experience of grief on an individual and societal level would be different to that of Koji's.

The findings from my research are an example of Bonanno and Kaltman's (1999), Becker et al.'s (2007), Hardy-Bougere's (2008), Paletti's (2008) and Zeiler's (2009) emphasis on the individuality of grieving seen both between and within societies and cultures. Often the discordance between social norm discourses and their experience was what surfaced in the interviews. The importance of the wider context meant that participants related their

individual experiences to the experiences of others. Fundamentally, the participant's cultural values and assumptions impacted the way they made sense of their physical presence or absence. The expression of the disparity was more prominent for those who were absent, as there is still a cultural script in both the Western and Eastern societies that implies people 'should' be physically present at the moment of someone's death. The diverse participant group that took part in my study meant that a wide variety of cultural scripts, assumptions, values and practices surfaced throughout the interviews as a means for the participants to make sense of their presence or absence.

With culture playing such an important part in the way that participants made sense of their embodied experience at the moment of death, there should be a greater emphasis on exploring with clients in therapeutic settings how their cultural background affects the way they view the moment of death. What are the expectations both individually, culturally, and societally in terms of being physically present at the moment of death? Despite the NICE guidelines (2011) and other governmental bodies emphasising the need for healthcare professionals to demonstrate equality for all patients, the guideline appears unclear for specific therapeutic interventions for practitioners. In light of the findings from my study, I would stress that practitioners working in the field of bereavement ask their clients questions aimed at eliciting their personal and cultural assumptions and expectations with regards to the moment of death, and how their culture may view physical presence or absence when someone is dying. By asking these sorts of questions, some of the emotions associated with the moment of death can be explored and normalised within therapy sessions. The questions can also be used by medical staff working with patients and relatives pre-bereavement to facilitate discussions around advance care planning and respecting the wishes of the dying. Although the medical field is becoming more considerate towards different religious beliefs and rituals as a whole, current bereavement research lacks any discussion of the moment of death and people's choices and preferences associated with it. Having people present or absent at the moment of death should also be a choice, when possible, for healthcare professionals to consider when providing person-centred care to the dying and their relatives. The only way to establish a person's choice is to be culturally sensitive and aware.

Super-ordinate theme 3: Endings and beginnings

After looking at the existing literature surrounding 'good deaths', 'bad deaths' and trying to understand the concept of death, the qualitative studies have shown that one of the important tasks that people like to do before they die is to say goodbye to their loved ones (Weintraub, 2007). Despite the participants in my research being physically absent at the moment of death, they still managed to say their farewells at a different time in often difficult and emotional ways. According to Kastenbaum (2000), the goodbye is a way to preserve the encounter with death even if not being physically present.

The physical connection to the dying/dead person's body is one of the more specific aspects that has not been focused on in previous studies looking at death farewells in bereavement therapy. Adriana described an experience of spending time with the dead body when she spoke about doing her grandmother's make-up for the funeral as a way to say goodbye. Perhaps this suggests that, as Merleau-Ponty (1945) wrote, we not only live through our bodies but we are our bodies. The death of the person also means the death of the body; therefore, the participants were saying goodbye to both elements that could not be separated. Kerry and Karen also described the time they spent and the importance of touching and stroking their grandmothers' bodies. They were saying goodbye not just to the person, but to the relationship they had to another human body. Perhaps a continuing bond is not necessarily just the bond one has with the person but also the bond that exists between one body and another. The participants' goodbye experiences echoed Ribbens McCarthy and Prokhovnik's (2014) idea of embodied relationality after death. Participants described an embodied relationship that occurred after the biological death of their loved ones. Saying goodbye was a way for participants to continue the bond after the moment of death.

Physical presence or absence at the moment of death could influence how one incorporates the death of both the person and the body they knew into their lives. Klass et al. (1996) did not distinguish between the loss of attachment of the emotional and physical relationship after a death. The findings further support the work of Shillito-Clarke (2008), who emphasised that counselling psychologists should bring the body into sessions, as it is an area often neglected. The fact that my participants spoke about their presence and absence

in relation to saying goodbye to another human being's body, opens up a vast area for further exploration in therapeutic work with clients.

Participants focused on the lack of a corporeal connection at the moment of death. For example, Emily described how saying goodbye to her grandmother over the telephone lacked the physical connection of being present to say goodbye. Despite Kasket (2012) proposing that technology (more specifically, social networking sites) can break down physical barriers, it lacks the embodied experience of saying goodbye to someone. Participants still described the lack of a physical body to connect with.

Weintraub (2007) focused on the importance of saying goodbye after the moment of death. However, what the participants in my study emphasised were the emotions that came up around knowing they were saying goodbye to someone before the person actually died. They described feelings of terror, pain, blame and guilt. This insight allowed for a greater understanding around saying goodbye both for those that were physically present and those that were physically absent. On top of dealing with the sadness of the actual death, the participants were left with a range of emotions relating to either being physically absent or present at the moment of death. Although Kübler-Ross (1969) in her five stages of grief model described a range of emotions that bereaved individuals might feel after the death of someone, the participants in this study did not describe stages that they went through in dealing with the bereavement. Their experiences appeared to coincide more with the dual process model of bereavement (Stroebe and Schut, 1999) where, in the presence or absence, participants moved between dealing with the practicalities of the situation to processing the emotions of their presence or absence. Processing still occurred during the interview, as some participants' corporal experience of the emotional coping came through in the interview.

As bereavement counselling explores the loss a person has experienced, it is therefore vital for counselling to focus on the therapeutic ending with clients, as previous loss narratives can re-surface. After hearing the participants' different experiences of endings, it would suggest to the counselling world the importance around exploring what endings symbolise for clients. Fredman and Dalal (1998) explored the importance around the stories and beliefs that clients, therapists and other professionals held with regards to endings. The benefit of mutually ending a therapeutic relationship is that there is an embodied goodbye,

which is what participants felt they lacked in their physical absence at the moment of death. Those counselling the bereaved should be aware of the discourses around the client ending therapy. Therapists should explore the endings that their clients were perhaps unable to experience at their physical presence or absence at the moment of death.

From the way that the participants described their bereavement experiences there were two main types of incorporating the death into their lives, which signified an end to one way of being and a beginning of a new one. The first was in relation to the participants trying to make the death an integral part of their everyday existence. The DPM (Stroebe and Schut, 1999) could be a way of understanding the participants as they acknowledged a loss and tried to adjust cognitively and emotionally but also physically without the person being alive. The presence or absence at death meant that the participants had to adjust to a life without both the person and the dead person's body being in the world. The adjustment was particularly apparent for some of the participants who were not physically present at the moment of death, as they expressed a struggle between receiving the information that someone had died but found it difficult to interpret the death emotionally. It was as if they had received some news but did not know how to emotionally process it. It seemed as if they were asking the question 'how do you know when someone has died? And how will my life be affected?' Acknowledging the corporeal death of another human being was the aspect that appeared to be missing from the participant's experiences.

The other way in which participants incorporated the death into their lives was by making changes to their future, which resonated with the personal growth following a bereavement research (Heidegger, 1962; Yalom, 1980; Muller and Thompson, 2003 and Cadell and Sullivan, 2006). Although Yalom (1980) talked about death leading to different kinds of anxiety, it also had the capacity to move a person into a different state of awareness, which enabled a positive contribution to their lives. For some of the participants, the physical presence or absence at their loved one's death was a life-changing event and contributed to them taking more control in making decisions. Despite the negative emotions that arose for some participants when thinking about the moment of death, they were used in a constructive way. Thus in an attempt to avoid feeling guilt in the future, participants envisaged asserting more control over their present decisions about the moment of death.

As previous literature has shown, control was seen to be an important factor surrounding death (Kehl, 2006) thus supporting my participants experiences.

As seen through Koji, Patrick and Kerry, the moment of death for them was a shift in the way they viewed their present and future. It was also an event that fundamentally changed who they were as people. The participants described the process of change they went through after physical presence or absence at the moment of death, where they did not recover from the bereavement but rather grew as a result. Kerry, for example, spoke about how she, as a person, changed in terms of her way of being in the world. She described going from being a depressive person to someone who changed her focus to carrying on living. Kerry's example supports Sartre's notion that the 'self' is not a constant object but rather something that is continuously changing and developing (Pearce, 2011). Counselling psychologists working with the topic of bereavement should consequently continue to question the term 'recovery', as the participants in this study focused more on growth and change as a result of physical presence or absence, as opposed to recovery.

Overall, the findings from this theme could be beneficial in thinking about its applicability pre-death. In 'good death' studies (Kehl, 2006) giving people choice was seen to be important, therefore making people aware of the choice they have to be physically present or absent needs to be considered. Participants learnt that they could make small changes in the present, for example moving countries to be physically closer to relatives, in wanting to be present at future deaths. Having seen the importance that participants placed on choice, counselling psychologists, as well as those working with the dying and bereaved, should take this factor into consideration pre-death.

Practical application

This section discusses how the findings of this research can be applied to various practices. The experiences overall, can be applicable for counselling psychologists from a client's perspective, as well as from a practitioner's perspective. Finally, the findings can be beneficial within a wider educational context.

Implications for counselling psychology

Many of the participants in this study mentioned that it was helpful to take part in the research as it allowed them to see their experience from a different perspective. Some of the participants mentioned that they learnt something new: "I think it's always helpful to talk about it. Still, there's always something kind of new to be learnt" [Patrick – 34:10–12]. Others saw it as an opportunity to continue processing: "I do think that maybe I can see how this interview will have an effect on how I'm gonna continue thinking about death" [Adriana – 50:1–4]. For some it was merely an opportunity to share their experience: "I don't think I've told anybody about this actually which is really quite weird doing bereavement counselling but realising that nobody's ever really asked me to go through the whole story" [Emily – 8:10–15]. From what the participants said, taking part in the interview helped them to process and engage with the death in a new way. They implied that it was an ongoing process, where the understanding and relationship to the event was constantly being re-examined.

This research was inspired by my personal clinical observations of working with the bereaved, which brought to my attention a lack of understanding in terms of working with physical presence or absence at the moment of death. Pugh (1998) recommended that researchers listening to participants (and subsequent clients) can therefore help continue the research to practice and practice to research cycle. From a counselling psychology practitioner's point of view, the implications of this study echo what Muller and Thompson (2003) mentioned in terms of the benefits of qualitative research within the field of bereavement. More specifically, listening to qualitative experiences around the moment of death has brought to light the different embodied experiences, assumptions and expectations participants had in regards to physical presence or absence.

These findings can also be applied to counselling psychologists working within a number of different contexts. For example, those working specifically within a hospital or hospice setting can explore with clients the choice of wanting to try to be present or absent at the moment of death of a loved one who is being looked after within the medical environment. For counselling psychologists working in GP surgeries or other community settings, this therapy can address presence and absence at the moment of death if the dying person is not located within a hospital or hospice. This type of counselling would have been particularly pertinent for those participants that were not able to be physically present at

the moment of death because they were living in a different country. As my research has demonstrated, the choice, or lack thereof, may be an issue wherever people live. A potential avenue for exploration in therapy is what it might be like to know that the choice of being present has been taken away. Or the importance the client places on physical presence and as a consequence what it might be like for them to be physically absent at their loved one's death.

Due to the ongoing epistemological struggle between the positivist and phenomenological views around bereavement theories and within the counselling psychology profession, the individual's experience can often get lost. Researchers are beginning to become interested in exploring people's phenomenological experiences of physical presence or absence at the moment of death. However, the discourses around the moment of death still largely sit within a medical framework. Counselling psychology should therefore continue to challenge medicalised discourses and remain open to phenomenological experiences in order to discover assumptions around physical presence or absence at the moment of death.

Implications in a wider context

The NICE guidelines (2011) state that holistic and multi-disciplinary care for the dying and bereaved should be utilised when a person is in palliative and end-of-life stages. The findings from this study need to be applied in a wider healthcare context outside of the counselling psychology field, because professionals from different disciplines (e.g. medicine and social work) are also involved with continued care. The experiences that the participants from my research described can be educational to all healthcare professionals, as there is value in encouraging a discussion with both the relatives and the dying person concerning physical presence or absence at the moment of death. As the 'good death' literature suggested that having someone physically present at the moment of death is a generalised assumption (Kehl, 2006), the participants' experiences challenged the assumption that everyone wants to be or should be physically present. The findings from my research urges those working with the relatives and dying person to explore and discuss the subject, as physical presence at the moment of death is an individual choice and cannot necessarily be fulfilled.

Having known what they know now after their experience of absence at the moment of death, some of the participants in this study emphasised a change in their decisions. These changes involved them doing their best to be physically present for future deaths. This is educational for those working with people who are imminently dying, as it gives the potential choice to friends and family members that they otherwise might not have had regarding being physically present or absent.

The participants spoke of the dying trajectory (Glaser and Strauss, 1965), not just a single moment in isolation. The idea of providing holistic care was re-emphasised not just from a psychological perspective but also from the medicalised viewpoint. My research further supports practitioners from all disciplines to recognise that the continuation of care for those who are bereaved, starts pre-bereavement (if possible) and goes right through to the moment of death and eventually post-bereavement.

Implications to the end-of-life care context

In recent years, end-of-life care has become a topic of interest to dying patients, family members, healthcare professionals, researchers and policy makers (Guo and Jacelon, 2014) because there is still a lack of consensus around what constitutes the best provision of care. According to the British Social Attitudes survey (2013), an overwhelming majority of deaths in the UK follow a 'predictable' trajectory, indicating a need for society to examine end-of-life care. In end-of-life care, the moment of death is a transitional moment between providing support for the dying person and their relatives and the grieving period afterwards. The current trend in Western societies is that more deaths occur in acute care settings such as hospitals, hospices, nursing homes and care homes (Phillips, Halcomb and Davidson, 2011) yet people's overwhelming preference is to die at home (Dumont, Dumont and Mongeau, 2008). The participants who stated that their preferred place of care and death was home, said that their reason for wanting to remain at home was to be around family and friends (British Social Attitudes survey, 2013). In other words, the relationships that people had were prioritised when considering preferred place of death. Policy makers are still unaware of the importance that people place on being around loved one's at their death because more people are dying in acute care settings rather than their preferred setting at home. My findings from exploring participants' experiences at the moment of death further support the significance of relationships at the moment of death over, for

example, being in a pain-free environment. Policy makers should therefore consider the barriers that are associated with caring for the dying at home so that the wishes of the dying can be met.

Looking more specifically at the role of practitioner psychologists working in the provision of end-of-life care, Golijani-Moghaddam (2014) noted that historically there has been a lack of psychological therapists' input despite recognition of their importance. She brought to light the fact that many of the bereavement theories lacked links to clinical practice as not many psychologists actually worked with end-of-life care. Many theories did not 'fit' with clients' experiences as they were not based upon clinical practice. Golijani-Moghaddam (2014) went on to state that psychologists working with people in their final stages of life could contribute towards theoretical models and interventions in clinical practice. For instance, Dumont, Dumont and Mongeau (2008) heard through qualitative interviews that some participants did not feel prepared for the actual moment of death and were therefore left with disturbing images post-bereavement. Practitioner psychologists could therefore provide psycho-education and emotional exploration around the moment of death in pre-bereavement work. The findings from my research further support the need of psychological input from practitioner psychologists in end-of-life care as working with some of the participants pre-bereavement would have enabled them to explore their understandings around the anticipated moment of death. Expectations, assumptions and difficulties could be examined with people who knew that they would not be able to be physically present at the moment of death, as well as those who intended to be. Furthermore, practitioner psychologists can also help in service developments, training, supervision and raising public awareness (Golijani-Moghaddam, 2014).

Limitations and suggestions for further research

One of the main limitations of this research was the participant sampling. Although it was not intended to specifically target this type of participant, all of the participants who came forward were of a mixed background, which often meant that their relatives did not live in England. The implications of this meant that there was a higher probability that the participants would be physically absent at the moment of death. As the topic of research was concerned with the significance that bereaved individuals held about physical presence or absence at the moment of death, it transpired that the overwhelming majority of

participants were not present. To counterclaim, the non-homogenous sample of participants actually offered an opportunity to consider the cultural diversity of experiences and expectations of the moment of death. Although the part that culture played would have been seen irrespective of the participant sample, the fact that the participants were very culturally diverse made different assumptions and expectations more apparent.

Another limitation with regards to the participant sampling was the lack of homogeneity. My novice understanding of a homogenous sample was that participants had to have shared the same experience, which in this case was the significance and meaningfulness of being physically present or absent at the moment of death. Having reviewed the IPA literature from Smith et al. (2009) and Smith (2011), I realised that my participant sampling could have been more specific and therefore more homogenous had I used more exclusion criteria. Because the participants' experiences were all slightly different with regards to when their bereavement happened, what their relationship was to the bereaved and what kind of death they had, the only homogenous factor was that they had all felt a significance around their presence or absence. The idea of homogeneity in sampling is that it focuses on a specific group of people who are representative of a perspective, rather than a population (Smith et al., 2009). Each of the participants had a different relationship to the deceased, which meant that different perspectives came through; one participant described the death of a grandparent while another described the death of a partner. Studies emphasising the importance of the context of the loss (such as Bonanno and Kaltman, 1999) have shown that the type of death (i.e. parental, conjugal, child etc.) are experienced differently by the bereaved. The relationship that the bereaved has with the deceased taps into different ways of making sense of the death. Further research could focus on presence or absence from one particular perspective (e.g. the death of a partner). Concentrating on one type of relationship would allow for a greater variability psychologically within the group, where the analysis of convergence and divergence can more easily be seen.

Overall, from the findings, further research that looks into presence or absence at the moment of death pre-bereavement is a possible avenue for exploration. There are no studies to date that specifically focus on counselling pre-bereavement. This might be because the general public is not aware that pre-bereavement counselling is available. Or

because of the lack of research in providing therapy for anticipatory grief, counselling practitioners do not know how to work with issues pre-bereavement. Some of the participants from this study indicated the emotional difficulties they experienced in knowing that their loved ones were imminently dying and the fact that they could not be physically present at the moment of death. Research exploring how people make sense of knowing that they cannot be physically present at the death could ensure that therapy becomes a journey from pre- to post- bereavement.

The participants in my research stated that physical absence at the moment of death was an experience they rarely spoke about. Further research looking specifically at this phenomenon would be beneficial as absence was clearly deemed to be an experience the participants wanted to share in making sense of the moment of death. Different factors such as managing feelings and expectations, as well as the embodied relationship could all be explored in further detail.

Methodological, personal and embodied reflexivity

Several authors (Finlay, 2002; Shaw, 2010; Pezalla, Pettigrew and Miller-Day, 2012) have stressed the importance of reflexivity in qualitative research, as it is the uniqueness of the researcher that can influence the collection of information through the researcher-participant relationship. As stated at the beginning of this research, my starting point was that of having no previous qualitative experience, an interest in the field of death and dying as well as assumptions about what might be found. How my process could have impacted upon the study, despite being open to the participants' experiences (Finlay, 2008), is now discussed.

Methodological reflexivity

This section on methodological reflexivity explores how the choices made in the design process could have affected the data that was collected for the analysis. It begins by looking at the sampling and participants before moving on to the interview schedule and the analysis phase.

Upon reflection, the interview schedule could have affected and limited what the participants brought to the interview. There was an element of naivety in creating the interview schedule early on in the process, as at that stage I had only done a preliminary literature review, as opposed to an in-depth one. Once I had thoroughly researched all the studies related to presence at the moment of death, I was better able to see where gaps in the literature lay. Perhaps this is one of the reasons why some of the experiences that were shared in the interviews were previously mentioned in other studies.

In terms of the actual interview schedule, the first question that I began with was "Have you had many experiences of people dying?" Without realising it at the time, I was placing an emphasis on the word "many", which could have set an assigned value and comparison to the participant's bereavement. Only after transcribing the interviews, did I notice that several participants had placed emphasis upon the word "many", by saying they did not know what it meant. The emphasis could have influenced the interviews from the beginning, as it could have suggested a judgement in terms of an acceptable amount of bereavements to be considered "many". As some participants were particularly aware of social norms, they could have been more attuned to my assumptions around bereavements. I could have changed this question to "What are your previous experiences of people dying?" which leaves much more freedom for the participant to speak.

I found it very difficult to keep my focus on what the participant was saying as I was also thinking of what to ask next. Having a schedule helped me to keep my focus. When possible, I found it much easier to stick to the schedule order, as this had been thought through in advance. With more practice in interviewing, I believe that I could have been even more flexible with the interview schedule and focused more on the participant's responses rather than feeling I had to try to cover all the questions in a certain amount of time. I have now learnt, by going through the experience of conducting a semi-structured interview, that there is no 'right' or 'wrong' in terms of the experiences that people bring to the interviews. I was very much concerned with participants moving away from the topic of physical presence or absence at the moment of death yet wanting to hear more about their overall experience. I now realise that everything they brought to the interview was relevant.

After listening to the interviews, I realised that my interviewing characteristics were neutral like those seen in Pezalla et al.'s (2012) study. My verbal contribution to the interviews consisted mainly of "hmm", "yeah" and "okay". These neutral words allowed the participants to share freely with few interruptions. Being aware that I wanted to build a rapport, and consequently trust with the participant, my interviewing was a more conversational approach (Roulston, 2008). My minimal responses allowed participants to openly respond to questions so that their lived experience could be heard. The times when I contributed more, verbally, to the interview was when I took a more naïve stance in trying to elicit further details from the participant about their experience. By reflecting back to them what had just been said, this could have appeared to be more in line with the Rogerian counselling approach. On the one hand, it could have facilitated a closer interpersonal connection with the participant by allowing them to feel like I was open to understanding what they were communicating, however, it also could have created a therapy-like environment.

Being caught between the roles of researcher and therapist was something that I realised I struggled with during the interviews. Having previous experience of working with bereaved clients, I felt this was both a help and a hindrance for the research process. During the interviews, there were some emotionally charged parts, which brought out strong emotions not only for the participants but for me as well. My previous experience helped me to not become overwhelmed or panicked by what the participants brought to the interview. The difficulty arose when realising, that in a different context, I would have asked more questions about specific areas that would have been inappropriate and unethical to do during these research interviews. Conducting this research has made me become more aware of the overlap between my role as counselling psychologist and that of qualitative researcher as the two often overlapped.

During the interviews I noticed that I had entered the world of the participants as I empathised with their experiences. The difficulty I found during the analysis stage was that because I had empathised so deeply with the participants' accounts, I became protective over their stories. I noticed my feelings of wanting to shelter both the participant and the deceased who had entered into the interview space. I struggled with knowing how much interpretation was needed in IPA whilst wanting to stick as closely as possible to the

participants' accounts. Valentine (2007) expressed similar issues of protectiveness in her interviews and stressed the importance of her research journal in processing her reflexivity. Through the use of my own reflective diary I was able to 'let go' of some of the protectiveness I felt towards the bereaved and deceased as I realised that I would always be interpreting the participants. Drawing upon the hermeneutic circle, I recognised that my previous understandings would inevitably influence the way I made sense of the participant. In other words, I was constantly interpreting the participant whether I was consciously aware of it or not. In the analysis stage I still erred on the side of caution; rather than over-interpreting, I stuck to the participants' words as closely as possible.

Something that IPA is also keen to expand is the support that it offers fellow researchers, including beginners to this approach. Hefferon and Gil-Rodriguez (2011) mention in their paper the model for a Regional IPA Group, which provides support for researchers at all stages of their research and can increase reflexivity. I attended this group myself and found it insightful and thought-provoking for my own reflexivity. In listening to the experiences of others I could start to re-think and understand my own experiences towards my project. I also attended an IPA training course and joined the discussion forum to further my understanding of IPA.

Personal reflexivity

Due to the iterative nature of the research, it was only as I was moving through the hermeneutic circle that I became more aware of my prior understandings and assumptions. The constantly changing and moving process allowed me to gain further insight, not just into participants' lived worlds, but also insight into my own. One such insight was that of the importance that I placed around the physical presence or absence at the moment of death. During the research process, one of my relatives who had been ill for a long time, took a turn for the worse. As she lived half-way around the world, I needed to make some decisions in terms of wanting to spend time with her before she died or being there as she grew imminently closer to death. A large part of my decision-making process stemmed from the voices of the participants in this study having shared their experiences of their physical presence or absence at the moment of death. Having realised that I would rather spend time with her whilst she was alive than at her deathbed, I made the choice to visit her. Upon

my return, I went back to the analysis of the transcripts and recognised that I was much more attuned to the emotional content that the participants spoke about in their experiences. I believe my personal experience changed the way I viewed the analysis, as I focused less on psychological theories that were inevitably influencing my analysis and more on the emotional content. I felt a deeper connection to my research and to the participants' experiences, as I could relate to what the participants were describing.

Embodied reflexivity

As many of the participants mentioned the significance of connecting to the dying/dead person's body, I felt that attending to the participants' bodies and to my own was also important. Finlay (2005, 2006) noticed that there had been a tendency within research to focus on the spoken word, yet coming from a phenomenological point of view, "the body discloses to the world just as the world discloses itself through the body" (p.19, 2006). By focusing on the participants' bodily empathy and my embodied self-awareness, I now reflect upon how this gave insight into the research (Finlay, 2006).

The rationale behind retaining the non-verbal communication whilst transcribing the interviews, was to focus on the bodily expressions that the participants were communicating about their lived experience. For example, in my interviews with Kristina and Kerry, I noticed that when they became tearful in the interviews, they would reach for a glass of water. As a researcher, I became attuned to this, as it signified a point in the interview where I needed to see how they were and whether they wanted to continue with the interview. Although they did not specifically say anything, I was aware from their actions at that point in the interview they were becoming emotional. Being aware of the participants' emotions, I was able to add a layer of the lived experience to the analysis that otherwise would not have been explored.

Through an awareness of my own bodily reactions, I felt that I was being affected by the research. An example of this was during my pilot interview with Patrick, I was physically drawn to his reactions as he spoke about attempting to cope with the loss of his girlfriend. Patrick started to increase his energy when speaking about how he had been abandoned by his friends and family members following the death, as they attempted to help him 'move

on'. I found myself becoming increasingly fidgety in my seat and restless. Upon reflection, I recognised that I was becoming angry with the people that Patrick felt had abandoned him. This insight enabled me, during the analysis stage, to gain a greater understanding of what Patrick was experiencing in terms of the difficulties he faced.

Throughout the research process my methodological, personal and embodied reflexivity allowed me to explore how my choices and background affected the research. Having more awareness around how I directly influenced the findings demonstrated my interconnectivity to the research process. My awareness also enabled me to look at how I could do things differently in future research.

Conclusion

In conclusion, the aim of this research was to explore, in depth, the embodied experience of bereaved people who were physically present or absent at the moment of death. The interpretative phenomenological analysis of the findings suggested that participants negotiated their embodied relationship with the dead person, expressed emotions around presence or absence and managed their experiences of loss and change within a wider social/cultural context.

The findings ultimately challenged the cultural assumptions around people needing to be physically present at the moment of death in order for the death to be considered 'good'. Counselling psychologists and other healthcare professionals are urged to explore the significance of the moment of death with people as for some individuals, it is a significant moment in their lives which very rarely gets processed.

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Appendices

Appendix 1: Recruitment poster

Have you experienced the loss of some-one close to you? Did you feel emotions around being there or not being there when they died? If so...

I want to hear your story!

Hi! My name is **Lisa Dvorjetz** and as part of my Doctoral studies in Counselling Psychology at City University, I am looking into the individual experiences of people who felt that their presence (or lack of) at someone's death had a significance to them.

If you are interested in taking part or would like more information, please contact me at:

Lisa.Dvorjetz.1@city.ac.uk

or visit

http://presence-at-death.yolasite.com/

CITY UNIVERSITY LONDON

Appendix 2: Table 1 - Participant demographic information

Participant name[38]	Participant's age range	Main person/people /relationship talked about	Present at death	How long since death (at time of interview)	Other relationship mentioned
Patrick	30s	Girlfriend	No	10 years	Grandparents Pets Aunt
Kristina	20s	Grandfather	No	3 weeks	
Simon	20s	Client	No	2 months	Grandfather (maternal) Grandmother (maternal) Uncle Friend's parents
Karen	30s	Grandfather (maternal) Grandmother (maternal) Grandmother (paternal)	No No No	6 years 4 years 15 months	Grandfather (paternal)
Klaus	20s	Aunt Aunt Mother's aunt Friend	No No No No	Unknown Unknown Unknown 3-4 years ago	Mother's aunt's husband
Adriana	30s	Grandmother (maternal) Grandmother (paternal) Pets (dog and cat) Friend	No No No No	5-6 years ago Mid 20's 6 years 15 years	Aunt People went to school with Grandfather (maternal)
Emily	40s	Grandmother (paternal)	No	1 year and a few months	Grandmother Great Grandmother Ex-partner's father Grandfather
Kerry	40s	Grandmother (maternal) Dad	Yes No	5 years 10 years	Grandparents (paternal) Grandfather (maternal)
Koji	30s	Grandfather (maternal) Grandmother (maternal)	No No	13 years 12 years	Cousin

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[38] All participant names have been changed in order to preserve confidentiality.

Appendix 3: City University ethics release form

Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2009) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

D.Psych ☐

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

> How do people experience being physically present or not present at the death of someone?

2. Name of student researcher (please include contact address and telephone number)

> Lisa Dvorjetz
> Address: ▭
> Telephone number: ▭

3. Name of research supervisor

> Dr. Pavlos Filippopoulos

4. Is a research proposal appended to this ethics release form?   Yes

5. Does the research involve the use of human subjects/participants? Yes

If yes,

a. Approximately how many are planned to be involved? 8 participants

b. How will you recruit them?

> 1. Word of mouth
> 2. Posters/flyers
> 3. Website
> 4. Social Media
>
> Although the posters and website have not yet been created, they will consist of a brief explanation of the study as well as contact details for the researcher.

c. What are your recruitment criteria?
(*Please append your recruitment material/advertisement/flyer*)

> 1. Age 18 or over
> 2. The researcher will not interview clients (past or present)
> 3. The researcher will not interview family members

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent?   No

d1. If yes, will signed parental/carer consent be obtained?

d2. If yes, has a CRB check been obtained?
(*Please append a copy of your CRB check*)

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? (*If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification*).

> The participant will be subject to a recorded 30-45 minute face-to-face interview with the researcher. The interview will be semi-structured and will consist of questions such as "what was it like for you the fact that you were/ were not there when _____ died?"

7. Is there any risk of physical or psychological harm to the subjects/participants?
                                                                                                  Yes

If yes,
a. Please detail the possible harm?

> Due to bereavement and death being a sensitive subject, there might be psychological trauma involved or re-living and re-experiencing the death of a loved one.

b. How can this be justified?

Although psychological trauma sometimes occurs during qualitative bereavement studies, it is not the norm. There have been numerous studies in the past involving bereaved people, some of which have interviewed people days after a death has occurred. This study; however, will not occur immediately after a death.

The participant has the ability to withdraw from the study at any given point due to distress (or other reasons). Upon request, they may also receive a list of agencies (e.g. Cruse bereavement care) that deal with providing support or counselling.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes

If no, please justify

If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

All the interviews will be tape recorded and then transcribed onto the computer.

12. What provision will there be for the safe-keeping of these records?

Immediately after the interviews have occurred, the recordings will be saved onto the computer as well as an external hard drive and instantly deleted from the recording device. The computer and the hard drive shall be password protected.

13. What will happen to the records at the end of the project?

These records will be deleted at the end of the project.

14. How will you protect the anonymity of the subjects/participants?
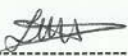
Once the recordings have been transcribed verbatim, pseudonyms will be created instead of using the participant's real name. Any identifying information associated with the participant will also be changed.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

On the de-brief form, there will be an explanation of the study as well as agencies that the participant can contact in case they feel that they need some support. These agencies will include the Samaritans, Cruse, local hospice bereavement services, and advice on contacting the participant's GP.

(Please append any de-brief information sheets or resource lists detailing possible support options)

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

Signature of student researcher --- Date 17/11/2011

CHECKLIST: the following forms should be appended unless justified otherwise

Research Proposal   ☐
Recruitment Material   ☐
Information Sheet   ☐
Consent Form   ☐

De-brief Information ☐

Section B: Risks to the Researcher

1. Is there any risk of physical or psychological harm to yourself?   Yes
If yes,

a. Please detail possible harm?

> Due to my previous experiences of loss and bereavement there may be some
> unresolved issues that surface whilst this study is undertaken.

b. How can this be justified?

> I have not had a bereavement or death in the family within the last 5 years therefore as
> far as I am aware, there are not major issues surrounding my past experiences of death
> that will be brought up immediately.

c. What precautions are to be taken to address the risks posed?

> If I feel that I am starting to become distressed due to the nature of the study, I will be
> able to speak to my research supervisor as well as a personal therapist.

Section C: To be completed by the research supervisor
(Please pay particular attention to any suggested research activity involving minors or
vulnerable adults. Approval requires a currently valid CRB check to be appended to this
form. If in any doubt, please refer to the Research Committee.)

Please mark the appropriate box below:

Ethical approval granted   ☑

Refer to the Department's Research and Ethics Committee   ☐

Refer to the School's Research and Ethics Committee   ☐

Signature -- Date 20/01/12

Section D: To be completed by the 2nd Departmental staff member
(Please read this ethics release form fully and pay particular attention to any answers on
the form where **underlined bold** items have been circled and any relevant appendices.)

I agree with the decision of the research supervisor as indicated above   ☑

Signature --- Date 20/01/2012

<u>Interview Schedule</u>

1. **Have you had many experiences of people dying?**

   Prompts: Who? Relationship? What happened?

2. **What did you want to share with me in this interview?**

   Prompts: Who? When? How?

3. **How did it feel that you were there/not there when they died?**

   Prompts: Thoughts? Actions? Feelings?

4. **How did you cope then? How do you cope now?**

   Prompts: What helped? Rituals? Thoughts? Actions?

5. **In terms of physical presence, do you feel it is important to be there or not be there?**

6. **What advice would you give someone who is going through a similar experience to what you went through?**

   Prompts: What did you learn/take away from the experience?

7. **We're all going to experience death, have you had any thoughts about your own?**

   Prompts: How do you imagine your own death? Would you want people to be there?

8. **Can you tell me how your experience has affected your views on life, death, and dying?**

   Prompts: Have any changes been made in terms of how you view death and dying?

Appendix 5: Consent form

CITY UNIVERSITY LONDON

Consent Form

The present study aims to look at the experience of bereaved people when they either have or have not been physically present at the time of someone close's death.

If you agree to this study, it will consist of a 45-60 minute interview surrounding topics of how you dealt with the death.

The interview will be tape recorded; however, all data collected will be anonymised. This means that any information that would make it possible to identify you will not be included in any sort of report. The raw data will only be accessible to those working on the project.

Your participation to this study is completely voluntary and you may request to finish the study at any point or refuse to answer any questions which make you feel uncomfortable. You may also ask the researcher any questions if something is not clear.

Statement of consent:
I have read and understand the above information. I, therefore, consent to participate in this study.

Name: _____

Signature: _____

Date: _____

Researcher: Lisa Dvorjetz	Research Supervisor: Dr.Pavlos Filippopoulos
Email: lisa.dvorjetz.1@city.ac.uk	Email: pavlos@city.ac.uk
Phone: 07934633003	Phone: 020 7040 4557

Thanking you in advance for your participation

Appendix 6: Debrief form

CITY UNIVERSITY LONDON

De-brief form

Thank you for taking part in this study.

The aim was to look at people's experiences either being present or not at the death of someone they cared about. This is a common lived experience, yet there are no studies specifically focusing on this subject.

Death and dying is still considered a taboo subject yet it is something that all of us will come across in our lives. By understanding the personal experiences in bereavement, it can allow us to become more aware of sensitive issues surrounding the death of a loved one.

Due to the difficult and complex nature of this topic, underlying issues surrounding the death might surface after the interview. If you would like additional support, please contact the following agencies who will be able to talk through some of the difficulties you might be encountering.

Cruse Bereavement Care
"A national charity set up to offer free, confidential help to bereaved people".
Telephone: 0844 477 9400
Email: helpline@cruse.org.uk

Samaritans
"Provides confidential emotional support 24/7 to those experiencing despair, distress or suicidal feelings."
Telephone: 08457 90 90 90
Email: jo@samaritans.org

Do not hesitate to contact your local GP for further advice and information on services that offer emotional support.

For further enquiries into this study, please contact either:
Lisa Dvorjetz (researcher)
Phone: 07934633003
Email: Lisa.dvorjetz.1@city.ac.uk

OR

Dr.Pavlos Filippopoulos (research supervisor)
Phone: 020 7040 4557
Email: pavlos@city.ac.uk

Appendix 7: Extract from reflective diary

Throughout this interview I was very aware of this person being both a participant and a work colleague. The realisation came as the participant's affect entered into the interview and I realised that I would not hear about this experience in our everyday work environment. I had a sense of privilege and responsibility as there was clearly trust involved. I constantly had to check-in with myself during the interview regarding my own fascination and interest becoming overbearing and consequently having to focus on the research question. I knew that if this had been a therapy session and she had been my client I would have explored completely different avenues which would have been related to linking thoughts and behaviours.

At one point in the interview there was a great deal of emotional content which felt like we were both processing the deaths together. Giving the participant space to feel the experience being brought back to life again felt very much like a therapy session. I was aware of feeling torn by my other role as counselling psychologist and having experience working therapeutically with bereaved individuals. I wanted to explore many different avenues which was something that I had not assumed would occur beforehand as I thought the boundary between research questions and therapeutic interventions would have been clearer. I felt like there was a part of me that was holding back however for the purpose of this study exploring certain issues would have been irrelevant and unethical. I felt connected and drawn into her describing verbally and non-verbally her experience. The experience all of a sudden became very real at this point as there was an emotional and cognitive connection that the participant and I felt. I acknowledged this to be a real co-creation of the interview and it felt like I was being taken down a path previously unexplored but that held intrigue that could bring new insights.

Both during and after the interview I was left with some food for thought regarding an ethical dilemma. The participant stated how she did not like to talk about death yet the entire interview was based around death. On the one hand I was aware that this participant self-selected to take part in an interview where she knew the topic was around death and bereavement. At the same time I was not sure whether checking-in with her throughout the interview how she was and whether she wanted to continue was enough. I felt a great sense of responsibility for the participant as I wanted her to feel safe but was aware I continued asking more questions around death. Was I somehow creating an expectation that she needed to continue with the interview despite giving her the option to withdraw at any point?

Appendix 8: Example transcript notation

Blaming self — *Effect of not being present*	And of course I wished I had been there and there was part of that was blame and you know, kind of blaming yourself and thinking God, she really needed help maybe at the moment and I wasn't there for her. Um (pause and begins to have tears in his eyes) you know it still hurts to say that, but I don't really believe that that's true anymore. I think in some ways I was spared the possibility that maybe I had of been there and she would have still died. Imagine what I would have felt like then if I was in the same room or something like that but I hadn't woken up or.... Um. But yeh, it hurts a lot. I wish that I was wish that I had been there um (pause) and cos I can't I guess it's the narrative that I have used to make sense of it is true that she just wasn't feeling well then I've got to believe she would have woken me up and it could have been avoided but (pause and deep breathe taken) I also don't have much heart for that kind of thinking anymore because I can't you know I can't control how I can't I guess that's a lot of what (pause) um a lot of what you're forced to deal with is the realisation that you can't control these things you can't...you're not in control of lots of things no matter how important they are to you. So um...	Blaming self for past. Expectations of self from self + other. Helpless — Let her down I didn't fulfill my roles/duties Come to acceptance of sorts. There's nothing I could have done ↳ accepting limitations of life - omnipotence? Inevitability of death.
Pain		Still nothing I could have done. ↳ fate / destiny? Wanted to be there.
Inevitability of death — *performing death.* *effect of not being present*		I would have been in Stay Charge if I had been there.
Sense making — *Making sense of the unknown*		avoidable? I wouldn't have suffered if this didn't happen. My presence could have altered this. CONTROL - and lack of
Lack of control ✓ ~~lost~~		Life is difficult when we want something to happens certain way and it doesn't. [Yalom]
	LD: Yeh	
Unanswered Q's unknown	PM: But yeh I I (pause) I think the unanswered questions and the never knowing obviously	Things would be different.

16

180

Appendix 9: Example list of emergent themes from a transcript

<u>**Transcript 1 emergent themes**</u>

Early experiences of death
Roles
Understanding death
Death is forever
Impact of death
Questioning knowing someone's dead
Sensing the unknown
Societal assumptions
Wanting a different outcome
Lack of control
Impact of others
Questioning existence
Multiple losses
Abandonment
Death of self
Similarity in others experiences
Impact of not knowing how someone's died
Attempting to find answers in the unknown
Value of time
Time (life stages)
Cultural norms
Effect of not being present
Re-framing death
Time (continuous)
Impact of being told
Changing attitudes towards self
Awareness of inevitability of death
Making sense after death
Effect of time on emotions
Allowing self to be
Broken self
Possibilities of the future
Re-gaining sense of identity
Practical coping
Self as worth caring for
Allowance of expressing self
Time (perceived differently)
Impact of permanence of change
Time (value of hindsight)
Awareness of own mortality
Impact of religion
Significance of moment of death
Awareness of other's mortality
Self as choosing agent
Person is sum of body parts
Impact of information from others

Klaus Anderson Table of Themes

Theme	Sub-theme	Page and line number
	Physical distance doesn't mean emotional distance	(2:11-21) (5:1-8)
	Being present as a sign of the relationship	(21:16-19) (30:11-23)
	Death seen as a relief	(13:1-14) (16:11-16) (16:18-28)
	Questioning the definition of death	(8:19-9:23) (11:25-28) (12:7-13) (32:28-33:9)
	Lack of not being present means lack of closure	(3:20-25) (15:20-16:2) (17:1-11) (17:25-18:1) (19:27-20:2) (20:6-10) (32:16-18) (34:6-13)
	Processing death to accept it	(16:4-15) (29:24-29) (33:18-34:3) (34:27-35:15)
	Talking about death to process it	(24:9-19) (24:23-25:1) (25:6-22) (30:23- 32:15)
	Difficulty of seeing physical decline	(5:6-16) (5:28-32) (21:11-19) (22:1-12) (22:24-23:7)
	Finding a way through social norms	(7:27-8:4) (24:1-5)
	Grieving the loss of a future	(10:28-11:11) (14:11-17)
	Living life differently as a result of awareness of own mortality	(23:28-31) (26:21-27:12) (27:16-26) (28:10-33)
	Awareness of others mortality	(28:4-7)
	Re-connecting with dead person	(9:27-29)
	Remembering the person not their body	(10:5-28) (19:4-21)

Appendix 11: Picture of clustering sub-themes from all participants together

Appendix 12: Table 3 – Initial master themes

<u>**The endings and beginnings**</u>

1. **Goodbye's**
   Saying goodbye to the person (Adriana)
   Saying goodbye to the body (Koji)
   Sadness of saying goodbye (Emily)
   The pureness of the final goodbye (Emily)
   Final memories of dying person as wasn't present (Koji)
   Providing the dying person with a farewell process (Koji)
   Leave no things left unsaid as a goodbye (Emily)
   Saying goodbye to person in this world (Koji)

2. **Processing death**
   The funeral as the next step (Karen)
   Allowing self to feel grief (Simon, Adriana)
   Rituals as a way to process death (Adriana)
   Levels of difficulty in accepting death (Kristina)
   Process of making sense of death (Karen)
   Death is not a single loss (Adriana [x2], Patrick, Kristina, Simon)
   Balancing practicalities and emotions after death (Adriana)
   Creating a narrative to make sense of death (Patrick)
   Conflict of logical and spirituality (Adriana)
   Re-connecting with dead person (Klaus)
   Interview used to help process death (Adriana)
   Carrying on living after death (Karen)
   Death involves a closing process (Emily)
   Processing death to accept it (Klaus)
   The funeral as closure (Emily, Koji)

3. **Awareness of the future**
   Questioning own existence (Patrick)
   Awareness of own mortality (Kristina, Karen, Emily, Koji)
   Awareness of death/mortality (Simon)
   Death brought out awareness of life (Emily)
   The awareness of others' mortality (Patrick, Kristina, Simon, Klaus)
   The fear in awareness of others' mortality (Adriana)
   Funerals heighten own mortality (Kristina)
   Living life differently as a result of awareness of own mortality (Klaus)
   Not letting history repeat itself when others die (Koji)

Appendix 13: Table 4 – Transcription symbols

Symbol	Explanation
(.) (..) (…)	Three tiered pause system: one dot (<1 second), two dots (1-3 seconds) and three dots (>3 seconds)
Cos, dunno, gonna, gotta, kinda, wanna and yeah	Transcribed orthographically in their dictionary accepted way
=	Indicates a truncated word
:	A colon is added at the end of a word to indicate that the last syllable is lengthened
<starts laughing> <stops laughing>	Indicates voice quality
<coughs>	Indicates nonverbal vocal sounds
<picks up glass>	Indicates contextual comments
--	Double hyphen indicates interrupted sentence
<name of place>	Indicates data that should be anonymised
↑ or ↓	The up and down arrows indicate a rise or fall in intonation
{ }	Indicates editorial omission of non-relevant material

Part 3: Publishable Paper

Physical absence at the moment of death: The embodied experience of bereaved individuals

ABSTRACT[39]:   This article explores the embodied experience of bereaved individuals who were physically absent at the moment of death. The aim of a recently conducted study was to explore the lived experiences of bereaved individuals who felt that there was significance to their mind-body relationship at the moment of death. Nine participants took part in semi-structured interviews, which were analysed using interpretative phenomenological analysis. Eight out of the nine participants were physically absent at the moment of death so this paper will explore the three themes that emerged in embodied absence at the moment of death. These themes included 'making sense of the dying body, 'the body as a barrier' and 'the physical goodbye'. The findings illustrate the significance of the corporeal aspect for the bereaved that is largely neglected in bereavement theory and research. Finally, this paper challenges some Western assumptions around the moment of death and highlights the significance of conceptualising embodiment at the moment of death in bereavement. This paper also demonstrates the relevance of physical absence in a wider counselling context.

KEYWORDS: moment of death; embodiment; interpretative phenomenological analysis; bereavement; continuing bonds; counselling

Introduction

Despite bereavement counselling being a popular talking therapy (Gallagher, Tracey and Millar, 2005), the theories that underpin it have failed to explore the relationship between the role of the body and bereavement counselling[40]. This article begins by reviewing the existing research into counselling's relationship to the body from positivist, medicalised and phenomenological viewpoints. The literature review then explores bereavement theories and, more specifically, the continuing bonds theory which has engaged with the body and the moment of death. An analysis of semi-structured interviews showed that participants in this study experienced an embodied relationship in physical absence at the moment of death. Finally, the experiences of these participants will further contribute to reconceptualising and challenging the way bereavement is seen, by focusing on embodied experiences of absence at the moment of death.

Understanding the body and mind

Dating back to the Greeks and Romans, the body has always taken precedence over the mind when it comes to advances in science (Rangell, 2002). The view that the mind and the body could be split was further developed by René Descartes (Burkitt, 1999). The positivist Cartesian dualism asserted that the mind and physical body were two separate entities which could be viewed in isolation. One of the themes that the philosopher Michel Foucault commented on in his observations of medicine in the 1960s, was that the body became an objectified site. Disease occupied space inside the patient yet the patient's subjective experience was ignored (Peerson, 1995). He viewed the separation of body and person as a

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[39] See Appendix 1 – *Mortality Journal* instruction for authors.
[40] The term 'counselling' has been used to encompass both counselling and psychotherapy.

detriment to the 'whole' being, yet the positivist biomedical view dominates and influences the current Western medical world.

More recently, a new development has emerged in understanding people's experiences that step away from the medical model. This other school of thought is the humanistic-phenomenological perspective. The school of thought view the mind and body in a more holistic relationship where these two elements cannot be separated and can only be viewed as one. In his philosophical writings, Merleau-Ponty suggested that the body both holds and creates meaning (Moreira, 2012). Working with the holistic concept within counselling means that therapists will gain invaluable information from establishing a greater awareness of the client's body, as by changing the body, the client's lived world will also change (Leijssen, 2006). Lawton (2000) affirmed this perspective from her clinical observations of dying patients and their carers. She noticed that the physical deterioration of the patient's body changed the relationship between the patient and carer. As the dying person became more incapable of doing things, the carer began to take on the role of the dying person, which included physically doing things for them or verbally expressing wishes on their behalf. The sense of self of the two separate individuals became enmeshed within the physical body of the non-dying person.

Bereavement theories

It comes as no surprise that the conflicting views of the positivist and humanistic views are exemplified in bereavement theories. As the development of psychology emerged in the early 1900s, Sigmund Freud's view on grieving involved the process of letting go of attachment bonds to the deceased in order to 'recover' from the bereavement (Paletti, 2008). Early psychoanalysis has suggested that grief, the reaction to a bereavement, has been medicalised and described as a 'disease' (Granek, 2010). There has been an assumption that grief can be placed on a continuum from 'normal' reactions to 'pathological' so people who did not achieve letting go of the relationship were considered to show pathological symptoms (Bonanno and Kaltman, 1999). As Freud was most notably a psychiatrist, his links with the medical world set the basis for the subsequent domination of his biomedical view for the majority of the 20th century.

Stemming originally from Freud, bereavement theories aim to understand and conceptualise the experience of grief, therefore, counselling has typically been aimed at recovery for bereaved individuals. In their qualitative study, Payne et al. (2002) interviewed 29 practice-based counsellors about their strategies for counselling the bereaved. They found that counsellors often resorted to the bereavement stage (Bowlby and Parkes, 1970) task (Worden, 1993) and phase (Marrone, 1999) models to understand grief, despite recognising that it was an individual process. The results from Payne et al.'s (2002) study indicate that the counsellors did not challenge the underlying Western assumptions around bereavement. Therefore, the theories that counsellors were resorting to were restricting them from different understandings of bereavement.

One of the most used theories in bereavement counselling is that of continuing bonds (Klass, Silverman and Nickman, 1996). Contrary to Freud's belief that mourning entailed loosening one's attachment to the deceased, the authors proposed that, bereaved individuals maintained a relationship with the deceased which was healthy rather than pathological (Field, 2006). In the medical environment, seeing or hearing the deceased is a sign of a pathological or mental health condition (Jackson, 1957), whereas the continuing bonds theory asserts that this experience is a common occurrence in the bereaved. There is a growing amount of research that supports the notion that bereavement is undoubtedly contextual (see Lalande and Bonanno, 2006; Valentine, 2013; Neimeyer, Klass and Dennis, 2014). As can be seen in the case of Freud's theory and the continuing bonds theory, culture plays an important role in mediating the bereavement experience. For example, the Japanese cultural practice of worshiping ancestors is seen as acceptable in Japan yet from a Freudian perspective would be seen as pathological.

The continuing bonds model focuses heavily on the relationship to the deceased from an emotional and cognitive perspective. What appears to be missing from the literature is what happens to the physical bond or relationship between one human body and another when a person dies.

To begin to answer the question of relationality in bereavement, Ribbens McCarthy and Prokhovnik (2014) drew upon the theoretical and personal experiences around understanding death as an embodied relational experience. They questioned whether the biological death was also the death of the self. They believed that a shift was needed from the Western medicalised view of splitting the body and person to a focus on the relationship. The authors argued that the self is always embodied and social. Therefore, the biological death of another human being is not the end of the embodied relationship as parts of the other still remain within the bereaved. Experiences of embodied relationality after death were illustrated in accounts of people who physically experienced the pain of loss. Other studies such as Gudmundsdottir's (2009), who interviewed 15 bereaved family members about their experiences of losing a child due to sudden or unexpected death, also suggested that participants experienced embodied grief. This grief was individualistic and context bound, yet they all described aches, pains and a sense of something missing within their body. Other phenomenological studies that have looked at embodied responses have also reported similar findings to the Gudsmundsdottir (2009) study where the body experienced pain (Bugge et al., 2012), tiredness and loss of energy around death anniversary dates (Hentz, 2002).

Ribbens McCarthy and Prokhovnik's (2014) paper in conjunction with the qualitative phenomenological studies exploring embodied grief have demonstrated that there are other ways to make sense of bereavement experiences which step away from the Cartesian dualism assumption.

The moment of death within 'good death' literature

The moment of death is a transitional moment from being alive to being dead. In Western culture, there is an assumption that great importance is placed upon being physically present

at the moment of death as this is considered to be a 'good' death (Valentine, 2007). With the relatively recent emergence of the hospice movement, which encourages medical healthcare professionals to provide individuals with an opportunity to die in the way they choose (Saunders, 1996), importance has been placed on providing the dying with a 'good death'.

Pierson, Randall, Curtis and Patrick (2002) interviewed patients with AIDS on their personal understandings of a 'good' and 'bad' death. What they found was that participants mentioned a total of 15 domains, all of which were considered to be what constituted a 'good death'. The most cited domain was that of having people physically present at the moment of death, as it would mean that they would not die alone. Pierson et al.'s (2002) interviews indicated that people perceived that the physical presence of another human being provided comfort, reassurance and support at the moment of death.

The moment of death has also been explored in studies conducted by Donnelly and Battley (2010) and Williams et al. (2013). These studies placed a greater emphasis upon the roles that these relatives felt they held at the moment of death, which included advocating and negotiating on behalf of the dying person, continuing family and cultural deathbed traditions and generally looking after the dying person. All of the studies mentioned the importance that bereaved individuals placed on saying goodbye to the dying person. Despite all of these studies focusing on the physical presence at the moment of death, there was no exploration around the embodied experience of being there. Putting the Donnelly and Battley (2010) and Williams et al. (2013) studies into context, a possible explanation for the lack of embodied experiences in their studies could be due to the medical context within which they were researched. The studies were mainly conducted by medical doctors whose motives would have been based on the positivist epistemology rather than the phenomenological.

Coming from a sociological perspective, Valentine's (2007) article on the moment of death discussed the relationship that participants described between the self and the other through embodiment at the moment of death. In essence, she illustrated that the bereaved individuals held on to an embodied relationship with the dead person. Valentine (2007) concluded by recognising that the relationship that bereaved individuals have with their own body, with others and within a wider social and cultural context is full of complexities.

There have been no previous studies that have specifically explored physical absence at the moment of death, which means that there have been no challenges to the cultural assumptions around physical presence at the moment of death. This would be beneficial to explore from a counselling perspective as being absent is a common experience and could therefore broaden the awareness of the moment of death.

Method

Participant recruitment

Recruitment flyers, social media sites, a psychology conference and word of mouth were used to obtain the self-selected participants. Once participants had shown interest in taking part in the study, they were contacted to arrange a suitable time and place for the face-to-face interview. Ethical approval was granted by City University using the British Psychological Society (BPS, 2010) research ethical guidelines. Researchers, such as Parkes (1995) believed that bereaved individuals were particularly vulnerable when taking part in research. He therefore articulated some ethical guidelines in order to maintain the rights and respect of the participants and to protect them from harm. Some examples of the guidelines that I adhered to whilst interviewing participants included obtaining ongoing consent throughout the interview (Parkes, 1995), using empathic counselling skills to be attuned to the potential distress of the participants (Rowling, 1999) and keeping a research journal (Valentine, 2007) that enabled me to be reflexive in continuously monitoring issues that arose. Following the interview, a verbal and written debrief was conducted with the participants and information was provided if they encountered distressing feelings and needed additional emotional support.

Participants' demographics

The four male and five female self-selected participants in the original study were in their 20s, 30s or 40s. None of the participants were originally from London, where this study took place, and many of them were of a mixed background. Two were Irish, one was British, one was Swedish, one was Swedish/Mexican, one was Mexican, one was American and one was Japanese. As eight out of the original nine participants were physically absent at the moment of death, one participant has been excluded from this article. The reason for this was to increase homogeneity within the sample and to focus specifically on physical absence at the moment of death.

Interviews

The guidelines used for conducting semi-structured interviews suggested by Smith (2008), Kvale (2008) and Smith, Flowers and Larkin (2009), informed the participants that the interview would be similar to a one-sided conversation although still involving a two-way process (Valentine, 2007). The semi-structured interview schedule acted as a basis upon which participants could build. The areas covered by the questions included exploring the general experience of the moment of death, the importance they placed upon presence or absence, as well as whether their views on living and dying had changed as a result of their experience.

Interpretative Phenomenological Analysis

Following the interviews, the audio recordings were transcribed verbatim and subsequently interpretative phenomenological analysis (IPA) was used to analyse the transcripts. IPA was chosen because its roots stem from the phenomenological approach of looking at participants'

in-depth, lived experiences whilst simultaneously being aware of the hermeneutic circle involving the researcher's interpretation of the participant's sense-making (Smith, 2004).

The transcript from the first participant was analysed with exploratory coding and then emergent themes were grouped together to form clusters. Once this was completed for the first transcript, the same approach was taken with the subsequent transcripts. Using an iterative process of revising previous themes, meant that connections were considered within and between the participants to form super-ordinate themes.

Findings

Although the participants entwined the analytic themes of 'making sense of the dying body', 'the body as a barrier' and 'the physical goodbye', the findings relating to each theme are presented separately for ease of reading. The first analytic theme of 'making sense of the dying body' explored the participants negotiating a relationship between the dying person being seen as a person, as well as a human body. The second theme of 'the body as a barrier' described the participants viewing their body and that of the dying person, as a hindrance, which was a reminder that the human body does not last forever. Finally, the third theme of 'the physical goodbye' looked at the different ways in which participants were able to say goodbye to the body of the dying/dead person and also how they said goodbye to the way their own body lived in the world pre-bereavement.

Theme one: Making sense of the dying body

The participants described the interchange between experiencing the dying/dead person as a person they once knew and a dying body. Kristina recalled the last time she saw her grandfather before he died.

> 'Um and then so then Tuesday morning we then went to the hospital to see him. Um, or to see his body. Um (…)[41] because I still kind of wanted to wanted to see him. One of the things actually that I didn't um--[42]. What another thing that was also very different about when I first saw him on the Saturday was that he was very (.) he was very swollen. And it it didn't really look like my granddad anymore. He looked quite different. And the same thing when he, you know, when we went to see his body it (.) it didn't really look like my granddad anymore so it wasn't (…) it wasn't the sort of--. The man that I would like to remember or that I (.) I'm going to remember now because I'm gonna, you know, of course that is still very much in my head what those last few days--. But I would like to think in the long term it's all the other things that that you know the great [ ][43] things about his life that I'm gonna remember more. Um. Yeah, so we went to see his ummm to see his body in hospital then um (…) and yeah (..) that was (..) that was the last time I saw him.' (Kristina)

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[41] Three tiered pause system: one dot (<1 second), two dots (1-3 seconds) and three dots (>3 seconds).
[42] -- indicates interrupted sentence.
[43] [ ] Indicates editorial omission of non-relevant material.

Kristina described the last time she saw her grandfather using words like "him", "his body" and "it". Kristina acknowledged that the change in her grandfather's body due to the condition of his physical illness meant that she found it difficult to recognise him for the person she used to know. Seen through her repetitions of the words "wanted to", "he was very" and "it", she was perhaps communicating the struggle and inner conflict in physically seeing a man whom she no longer recognised. Kristina made it clear that she did not want to remember this changed man due to his changed body. Her experience also reflected the body as a site of selfhood and agency in contemporary society.

Karen, too, experienced a change in relationship to her grandmother before she died.

> *'But then when I look back on it now (...) I suppose I I choose to think of my grandma's the grandma I knew before she went into the nursing home cos it's sort [ ] of feels like once she went in there she wasn't really grandma anymore. She was just kind of a bit [ ] of a <sigh>*[44] *it almost sounds awful but it was almost like she was a bit of a vessel with stuff going on that was making her brain not work properly therefore she wasn't grandma.' (Karen)*

Where Kristina struggled to negotiate seeing her grandfather as a person and a sum of body parts, Karen stated her awareness in choosing to remember her grandmother as the person she used to know before she went into the nursing home, as afterwards she became someone entirely different. In Karen's case, perhaps the "vessel" was her grandmother's body that contained a brain and body parts that were no longer functioning in the way they used to and that the essence of what made her grandmother a person was no longer there. For both Kristina and Karen, there appeared to be something difficult in remembering the dead person in those last few moments and it appeared easier to remember the relationship they had had with the dead person before their body died, turning them into someone unrecognisable.

Simon took this struggle of the dying body and person further by breaking down the person into a biological process. As Simon had only ever been physically absent at the moment of someone's death, he spoke about what he imagined being physically present at the moment of death would be like.

> *'but yeah I feel quite visual about it. I almost really imagine what it would be like and um maybe not sure if I imagine the person still being there (.) you know if they're actually in the process of dying if it seems almost like (…) I dunno something left of biology. If they're just you're just the physical (…) kind of gasping for air. I imagine their eyes would be closed so um (…) yeah I maybe think this is almost like a reflex thing now maybe they've already gone. But I would probably wonder or look for some signs that that wasn't the case. Some, you know, kind of hope that they were still there.' (Simon)*

It seemed clear for Simon that, when a person is dying, there are two elements: the person (that he referred to as "they") and the "biology" (as described through the "reflex(es)"). He

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[44] < > Indicates non-verbal communication

also spoke of the potential struggle that the dying person encountered, since he used the phrase "gasping for air" which denotes a fight or struggle to remain alive. He explored the feeling of hope in wanting the person to still be alive despite not knowing whether the person was still inside the dying body. Simon suggested that there was a struggle that both he and the dying person faced in the moment of death. For Simon, the struggle consisted of not knowing where or when 'the person' had left the body and, for the dying person, there was a struggle to remain alive.

Theme two: The body as a barrier

This theme encompassed how the participants experienced their body as a barrier to either allowing them to be physically present at the moment of death of a loved one or, in other cases, as a barrier to allowing others to be physically present when they die. There was also an element of the participants being more aware of their body and that of the dying person, as the body was preventing them from being somewhere or doing something.

As it is impossible to predict the exact time that someone will die, many participants found themselves 'waiting for death' by putting their own body under pressure so as to be physically present at the moment of death. One such participant was Kristina who wanted to be with her grandfather when he died; however, she found it difficult to predict when that time would be.

> *'Um, but then--. And that day then that day was really difficult for me to leave the hospital cos I was like (.) then I was like I really want to be there (.) you know I want to be here when he when he passes away. When it then had gone on for three days (…) I almost kind of felt that it was kind of you know we wouldn't have been able to sit there for (…) whatever you know um 62 hours straight you know that that physically would not have happened. Um (…) so (…) yes it was sad, you know yes, I do think it's sad that no one was there with him when it happened.' (Kristina)*

Kristina talked through the dilemma she faced at the moment of her grandfather's death: she wanted to be physically present but because she didn't know when he would die, she felt that her body could not physically sit there for an unlimited amount of time. The consequence of her leaving the hospital was that no one was physically present when he died. As conveyed in this extract, had Kristina not been constrained by her human body, she would have been able to be with her grandfather at the moment of his death. Her human body in this example, was a barrier to her physical presence at death.

Klaus spoke of his physical absence at the moment of death of several people. The absence brought about an awareness for him of the circumstances surrounding people being physically present at his own moment of death.

> *'Like if I die from an illness that you know slowly ripping me apart then (…) I dunno I suspect um (..) I probably wouldn't want that many people to see me in that state. It's kind of the way I look at it. If on the other hand you die and it's actually just old age*

and then I would probably want you know family, close friends, and things around.'
(Klaus)

Klaus pointed out that having people physically present at the moment of death would depend on the condition of his body at the time. He recognised that if his body was deteriorating due to a specifically violent illness, he would not want people to see him in that condition. The way he described a potential illness "slowly ripping" him apart suggested that it was possible for the person and their body to be torn into pieces. Klaus would not want his loved ones to see him in this 'incomplete' state. However, if he were to die from old age, then he would allow people to see him. Klaus assumed that dying of old age did not include suffering. For Klaus, it appeared that the need to protect his loved ones was important. He wanted to protect them from seeing him in a state other than what they recognised him as. In this example, the body's condition could potentially become a barrier to having people physically present at the moment of death.

Emily, like many of the participants, originated from outside the U.K. and so most of her family still lived abroad. Emily was unable to be physically present at the moment of death of her grandmother and so much of their communication was experienced over the telephone. In the following quote, Emily describes the difficulty of physically being in a different country from her grandmother and her awareness of non-verbal communication.

'And uh but I don't think I let more than like two days go by without calling. And um (.) she was still having all kinds of you know long conversations with me. I could tell that her breathing was more <inaudible>--. At one point could tell when it started changing but it's all that being here and the not knowing and the um--. And I didn't really know much about the dying process before even though I had people that had died I'd never watched even though I was here (.) I would still call it watching her die [ ] because I knew everything that was going on.' (Emily)

For Emily, it would seem as if her physical body being in a different country prevented her from experiencing other elements of her grandmother's death that being present would have included. When Emily said "it's all that being here and the not knowing" it implied that she was aware that she was in a different country, which had left her in a state of not knowing. As she relied heavily on telephone communication with her grandmother, she became attentive to the fact that her grandmother's breathing began deteriorating. Her grandmother's body became a barrier to their communication and relationship. If she had been physically present, she would have been able to use other modes of communication, such as touch, to relate to her grandmother.

Theme three: The physical goodbye

All participants experienced a form of saying goodbye to the person who had died, whether that meant saying goodbye to the person and/or their body. Additionally, for some other participants, the experience of being physically absent at the moment of death meant they wanted to have a reminder that their lives were permanently changed after the death. This

meant they were saying goodbye to the relationship they had with own body before the death, to a changed body after the death.

Participants, such as Adriana, expressed the importance they felt in saying goodbye to both the person that had died as well as their body. Adriana spoke of the way she said goodbye after her grandmother died.

> *'So at some point because they were--. Everybody was so upset so then I had to to prepare my grandmother for her to be taken. And so I did dress her and uh and yeah just prepare her and did her make-up and everything. [ ] I felt like (.) like I knew how she liked to do her make-up so I thought better that I do it than somebody else [ ] so I did feel quite protective in a way. [ ] Feels odd saying it but it was like a nice way of of saying goodbye to her as well. Because we had a moment together and uh where we were only me and her and it was like a kind of like a goodbye.'* (Adriana)

Adriana placed emphasis on saying goodbye to her grandmother that was experienced by her preparing her grandmother's body the way she knew she would have liked. At first, Adriana described having to prepare her grandmother out of duty because her family members were too upset to do so; however, it turned out to be a special moment of saying goodbye to the person and the body. Although Adriana constantly referred to her grandmother as "her", she was describing looking after the dead body. This suggested that Adriana still felt very connected to her grandmother, which included her body.

Koji, who was physically absent at the deaths of both his grandfather and grandmother, described the importance he attached to being physically present at the moment of death.

> *'It's--. I'm saying this it because I actually didn't get a chance and even if you know even if I had got a chance I would have probably said the same thing (..) I dunno but it just feels like I missed that opportunity to (…) yeah I mean rather than the grieving process it's more of saying goodbye when their bodies were still here.'* (Koji)

Koji felt that saying goodbye to the dead person's body was important because it was part of the person who died. As he was absent at the moment of death, he believed that saying goodbye to the body was an "opportunity", as once it was gone it was no longer possible to have a farewell.

Saying goodbye does not only have to be about saying goodbye to the dead person's body but can also be a way of saying goodbye to your own body as you knew it. Patrick described a choice he made in changing his body to reflect the changed life he was living after the death of his girlfriend.

> *'And so I got that tattooed on my arm, which is ok [ ] Um, but I was reading about--. I think what I read was that in some Native American cultures when your partner dies they cut off one of their fingers um as a sign of permanent change and loss actually that um (..) and that made a lot of sense to me. I didn't particularly want to cut off one of my fingers! [ ] But it made a lot of you know, the idea of it made complete sense [ ] so I wanted a permanent marker of [ ] change.'* (Patrick)

Patrick felt that getting a tattoo on his arm would symbolise the pain and change he was feeling after the death of his girlfriend. Getting the tattoo also related to the nature of the relationship with his girlfriend. He compared his experience to that of the Native American culture where they too, adapt their body to represent the loss and change that has occurred following a death. In this sense, Patrick wanted to say goodbye to his body as it was experienced before the death of his girlfriend; it belonged to a part of his life that had ended. The tattoo was a way for him to adapt his body to his new way of life that did not include his girlfriend in her physically alive state.

Discussion

The findings presented in this paper have shown the challenges and complexities of bereaved individuals negotiating a relationship between their body and the dying/dead person's body due to their physical absence at the moment of death. This complexity also reflects the socio-cultural frameworks they were negotiating. That is, it is exemplified in the way the participants were able to speak about their experiences. Although previous studies have focused on the physical presence at the moment of death and its importance (Donnelly and Battley, 2010 and Williams et al., 2013), the findings from this study would indicate that the experiences of those who were not physically present also played a vital role in the meaning-making of their bereavement. The experiences of absence at the moment of death therefore challenge the dominant Western biomedical assumptions around physical presence at the moment of death.

Participant's recollections included the difficulty of linking the person they knew with their dying body. The dying person's body impacted the way the participants saw and related to the person. These findings strongly echo Merleau-Ponty's (1962) view that as humans we are inseparable from our bodies. The constantly negotiating view of the dying person and the body was an important part of their sense-making. A change in the physical body of the dying person was seen to suggest a change in the relationship with the relatives, which further supports the interconnectivity between person and body. In bereavement counselling, there is a focus on exploring the loss that the individual is experiencing (Payne et al., 2002); however, there has been no research that has specifically looked into exploring the corporeal loss. The findings from this article suggest that counselling bereaved individuals needs to also include further exploration into the entwined nature of the human and the body. Although counselling psychologists, such as Feltham (2008), have argued the lack and therefore need for the body to be incorporated into theory and practice within counselling research, this study goes a step further to stress its importance with a specific focus on bereavement counselling research and practice.

Participants drew upon their cultural assumptions around illness, disease and dying where the body held considerable power in relationships. Some individuals described not wanting to have people physically present at their own death, as they recognised that, for others, seeing a deteriorating body would create a change in the relationship. Linked back to Lawton's (2000) observations that, a change in the body also changes the way a person is seen and experienced, participants recognised that they did not want people physically present at the

197

moment of their death if they had a serious illness, as it would potentially alter the way their loved ones viewed them as a person. Thus the body can be perceived as a potential barrier to seeing the person. This implies a tension between wanting to see and be seen in a holistic way (person and body) whilst recognising the potential for personal rejection due to the body's deterioration. From a phenomenological perspective, the findings from this study emphasise the relationship between the body and identity. The participants in this study described the extent to which the body's deterioration towards death impacted the way they viewed their identity and that of the dying person. Bereavement counselling should therefore pay more attention to the constantly changing and negotiated relationship that people have with their bodies as it can affect their experience of identity.

Participants often described their body and the body of the dying person as a barrier to maintaining the relationship. As death was unpredictable, many of them felt that their body could not sustain the 'waiting for death'. This notion of 'waiting for death' was also described by participants in previous studies (Valentine, 2007; Donnelly and Battley, 2010; Williams et al., 2013), which have looked into people's experiences of being physically present at the moment of death. The difference with this study is that some participants showed the predicament they were confronted with of wanting to be present for the dying person versus their own personal needs. As seen in Kristina's example, had she known exactly what time her grandfather was going to die, she might have pushed herself physically to stay by his bedside. What resulted was that her body could not wait for an unlimited amount of time and therefore she had to take care of her own needs. The embodied manifestation could have been a negotiation between the personal struggle versus the cultural expectations of wanting to be there and not being able to.

A challenge in communication due to the limits of the dying was another way the body was described as a barrier to the relationship. The participants voiced the difficulty of not only being located in a different country but also, in how they communicated with the dying person (e.g. over the telephone) as their body was deteriorating. For some, verbal communication was not possible. The inability of participants to connect to the dying person's non-verbal communication, for example, touching and gazing, meant that part of the relationship was not accessible to them. As Leiijssen (2006) pointed out, emphasis within the verbal psychotherapies is placed on talking as a form of communication. The participants in this study showed sadness and frustration when, due to physical distance, limited forms of communication were available. The implication in bereavement counselling but also in a wider counselling context would be that the body is often forgotten but plays an important part in the way people experience the world and communicate with others. Going back to Merleau-Ponty's proposition that the body both holds and creates meaning, the participants experienced an obstacle in relating to the dying person when they were unable to communicate and receive communication verbally. Focusing only on talking psychotherapies limits communication within the therapeutic space.

Previous studies have shown that one of the important aspects of being physically present at the moment of death is to say goodbye to someone (Donnelly and Battley, 2010 and Williams et al., 2013). The participants in this study not only stressed the importance of saying

goodbye but described goodbyes that incorporated saying goodbye to the body of the dead person. For some participants, the element of physicality was important in having a goodbye and described touch as a way to express themselves. For example with Adriana, as she knew how her grandmother liked to do her make-up, she felt that performing this act was a way of having a farewell. The holistic connection that participants felt to the dead person and their body meant that the body was an important part of the person that needed its own goodbye.

Finally, absence at the moment of death was a life-changing experience for some participants who felt that they wanted to change their body to symbolise the emotional pain and change. As demonstrated by Patrick's experience, the death of his girlfriend resulted in him changing an element of his body to permanently symbolise the emotional change he encountered. He was saying goodbye to the relationship with his body pre-bereavement. In qualitative bereavement studies, it is fairly common for participants to verbally describe the emotional pain that they felt (e.g. Wilson and Supiano, 2011; Hunt and Greeff, 2011). However, it is less common for that expression to be purposefully shown on the body. For some, expressing emotions verbally is rarely sufficient, which is why people find a variety of ways to memorialise the dead (Walter, 2008). The findings suggest that the idiosyncratic ways in which participants expressed their bereavement in relation to their body, needs to be reflected in counselling practice.

The overarching implication of this study is that bereaved individuals are constantly negotiating an embodied relationship to the dying/dead person particularly when physically absent at the moment of death. The body played a vital role in meaning-making for these participants therefore continuing bonds consisted not only of the emotional and cognitive levels but also an embodied level. Participants struggled to negotiate continuing bonds with the dying person, as a change in the physical body saw a change to both the dying person's identity as well as the participant's. For some participants, it was important to continue the bond to the dead person's body as in physical absence at the moment of death, they recognised that they wanted a physical connection to the dead person and their body. The embodied relationality that remained for participants echoed the findings from Ribbens McCarthy and Prokhovnik's (2014) paper, which highlighted an embodied relationship with the deceased even though they were not biologically alive. Instead, parts of the existing relationship still remained with the bereaved.

Limitations and further research

As with all IPA studies, the findings from this study cannot and do not intend to be generalised, as the combination of the researcher's and participants' backgrounds makes the findings from the study context-specific (Smith, Flowers and Larkin, 2009). Rather, the analysis aimed to show a different perspective into people's bereavement experiences.

What can be taken away from this study are the benefits of the role that counselling can play in working with bereaved relatives within a biomedical environment. Those working with the talking therapies do not aim to 'cure' people but rather understand bereaved people's experiences. Despite the values behind counselling being humanistic, in the sense that

therapists will respect the individuality of the client (Cooper, 2009), studies such as that of Payne et al. (2002) have shown that the assumptions counsellors held and therefore resorted to with clients reflected older stage and phase grief theories. The problem with these theories is that they did not include the body within bereavement counselling and therefore there still remains a lack of awareness of the subject. Highlighting to the research community that there are other ways to conceptualise bereavement, and in particular the moment of death, is further supporting Fulton, Madden & Minichello's (1996) call for widening the way Western society views and responds to bereavement. Further research could, as a result, focus more specifically on the role that culture and society play in physical absence at the moment of death. This could include participants' relationships on a family, cultural and societal level to look at the underlying assumptions and how participants made sense of their experience.

Conclusion

Overall, the findings from this study have supported previous research, which has looked into the phenomenological understandings of the interrelatedness of person and body. At the same time, the findings have introduced a new awareness around physical absence at the moment of death and an individual's relationship to their body within the context of bereavement. In making sense of the experience of absence, the bereaved person represented their own body as a barrier to being present and the dying person's deteriorating body as having a potentially negative impact on their relationship with the person. However, being absent did not prevent them from finding a way of saying goodbye, which they conveyed as an embodied, emotional and relational experience. These findings suggest bereavement counselling would benefit from an understanding of individuality, which includes the body, as without this focus embodied experiences in bereavement will continue to go unexplored.

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Appendix 2: Table 1 – Participant demographic information

Participant name[45]	Ethnicity	Age range	Relationship of deceased	Time since death
Patrick	White Irish	30s	Girlfriend	10 years
Kristina	White Scandinavian	20s	Grandfather	3 weeks
Simon	White Irish	20s	Client	2 months
Karen	White British	30s	Grandfather (maternal) Grandmother (maternal) Grandmother (paternal)	6 years 4 years 15 months
Klaus	Mixed Scandinavian and Latin American	20s	Aunt Aunt Mother's aunt Friend	Unknown Unknown Unknown 3-4 years
Adriana	Latin American	20s	Grandmother (maternal) Grandmother (paternal) Friend	5-6 years 10 years 15 years
Emily	White American	40s	Grandmother (paternal)	1 year and a few months
Koji	East Asian	30s	Grandfather (paternal) Grandmother (maternal)	13 years 12 years

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[45] Participant names have been changed in order to preserve confidentiality