

Phenomenology as a Research Method for Social Work Contexts: Understanding the Lived Experience of Cancer Survival

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Abstract

Cancer survival is a profound and complex human life experience. This article provides an overview of phenomenology and demonstrates its applicability for researching cancer survival. An historical account of phenomenology is provided, as well as an overview of key Heideggerian concepts. After setting the theoretical context and rationale for the study, the article then presents the methods and a brief overview of findings from the author's study of cancer survival. Implications for social work are discussed throughout. It is hoped that this article will encourage social workers to consider phenomenological approaches to research and practice contexts.

Keywords: Heideggerian phenomenology, cancer, survival, research, social work

Introduction

My purpose in writing this article is to provide an overview of Heideggerian phenomenology and how it can be used to understand the lived experience of cancer survivorhood. A further purpose is to highlight connections for social workers wishing to further understand this significant life experience.

By way of illustration, I present an account of the methods and a brief overview of findings from my recent doctoral research exploring the lived experience cancer survival (Pascal, 2006). The study was conducted in Bendigo, Victoria, Australia, where 15 participants with a range of diagnoses of cancer and prognoses volunteered to share their experiences during two in-depth interviews, spanning a six-month interval.

The interviews were audio-taped and then analysed using phenomenological interpretation. This interpretation involved a process that was informed by phenomenological theory. First, the hermeneutic circle process was employed (Ezzy, 2002). That is, data was analysed by moving between theory and lived experience, and also between part (lines

of transcript) and whole (entire interview or between interview transcripts) data sets. Secondly, Heideggerian theory provided a perspective for understanding cancer survivorhood and a lens for seeing the data. For example, temporality was a key concept to emerge from the data and was informed by Heideggerian understandings (Pascal, Endacott and Lehmann, 2009).

Furthermore, it should be noted at the outset that there are many “phenomenologies” and that I have chosen an explicitly Heideggerian approach. As such, I consider the methodological underpinning to the study to be interpretive and hermeneutic, rather than following Husserl’s more descriptive and eidetic methods (Hoy, 1999; Guignon, 1999). For the purposes of clarity, it is important to note that I use the term “hermeneutic” in relation to Heidegger’s hermeneutic turn, and not in allegiance to any particular hermeneutic school of thought (see Schwandt, 1994, for full discussion). Thus, a Heideggerian, interpretive phenomenology was the basis of the study.

First, I present phenomenology as a theoretical framework for undertaking research. I provide an historical overview, as well as a discussion of key Heideggerian concepts. Second, I briefly discuss the application of interpretive phenomenology as the ontology and epistemology for my research into cancer survival. Third, I outline the methods of the study including the aims, data collection and analysis process and participant profile, as well as ethical concerns and methodological limitations. Finally, I present a brief overview of the findings from my research project, focussing on the significance of temporality and relationships of care for cancer survivorhood. Implications for social work knowledge and practice are discussed throughout.

Theoretical Framework

An historical overview of phenomenology

Historically, phenomenology evolved as an alternative to scientific methods traditionally used within the social sciences. Radically for its time, phenomenology emphasised the notion of the humanities differing from natural sciences and thus requiring differing approaches. These differences arise at both the ontological and epistemological levels. Ontology is understood here to refer to assumptions concerning the nature of being and reality, whilst epistemology refers to assumptions about the nature of knowledge (Crotty, 1998).

Husserl is acknowledged as the founding father of phenomenology, although the term had been used earlier by philosophers such as Kant and

Hegel (Moran & Mooney, 2002). Husserlian phenomenology sought to explore the conscious lived experience of phenomena; particularly ways in which phenomena are perceived in everyday life (Moustakas, 1994; Crotty, 1998). Husserl was concerned with understanding the participant's life world (*lebenswelt*) and famously declared the way to knowledge was "back to the things themselves" (Holden, 1997), that is, back to the experiences of everyday life.

Importantly, Husserl posited that through bracketing (keeping a distance from one's own subjectivity), it becomes possible to analyse the object (for example, an experience, story, or participant) as it appears to us as a researcher. A full understanding of phenomena can then be gained. In one sense, this was liberation from researchers' prejudgments. However, bracketing raised the spectre of Cartesian mind-body and subject-object dualism, thereby favouring the intellect over experience (Heidegger, 1996, 2000) and assuming objective researcher knowledge. This became a major criticism of Husserl's thought (Heidegger, 1996, 2000).

Additionally, bracketing assumed the researcher can, and should, separate knowledge from experience. Martin Heidegger, Husserl's pupil, challenged this assumption. Heidegger claimed that a person, as a Being-in-the-World, could not be separated from the world. Meaning is co-developed through our shared humanness and life experiences. Heidegger believed it was not possible to bracket experiences, but rather, through reflection, we could become aware of our assumptions. Further, to bracket our experience we must shed our experience, therefore losing our capacity to understand through shared experience and meaning. This concept was understood as Heidegger's ontological difference, and formed the basis of his hermeneutic turn (Cohn, 2002; Heidegger, 1996, 2001; Guignon, 1999) Thus, Heidegger and Husserl developed differing positions regarding phenomenology. Nonetheless, Husserl's phenomenology and mentorship provided the impetus for Heidegger's thought.

The Heideggerian Context

Heidegger's analysis of Being (*Dasein*) is the focus of his seminal work, *Being and Time (Sein und Zeit)*. Heidegger used the word *Dasein* to express the uniqueness of human beings, as opposed to other animal, or inanimate, existence. The literal English translation of *Dasein* is "there being", thus the implication is that we exist as an individual, but also within a social context. Heidegger believed *Dasein* to be rooted in the world as world beings. To separate the person from their experience through objectifying their experiences was erroneous (Heidegger, 1996,

2000). This inseparability from the world is known as Being-in-the-World and is in keeping with the social work concept of person-in-context, and systems theories more broadly. That is, Heidegger explicitly stated that the world and individuals are indivisible; no world, no being and no being no world (Heidegger, 1996, 2000).

Heidegger claimed *Dasein* is essentially temporal (Heidegger, 2000; Korab-Karowicz, 2001; Watts, 2001). That is, we exist as human beings within our own personal and social historical context. Temporality can be understood as the past, present and the future and how these shape human existence. In everyday life, the past is revealed to us through our moods; the present is made manifest through language and meaning; and the future is projected as indefinite where we run up against our final horizon; death (Watts, 2001). Thus, temporality illustrates being-in-time as developmental and historical, as well as highlighting the impermanence of our existence.

Furthermore, Heidegger posited that we are a thrown project (Heidegger, 2000; Watts, 2001). Heidegger uses the metaphor of human beings akin to clay being thrown upon a potter's wheel, and that we find it difficult to imagine beyond the very randomness of our Being. This thrownness shapes our entire existence including past, present and future. Watts (2001) interprets Heidegger's meaning as:

So, I can never create myself anew, as I have to work with what I have been and what I am now, in order to become what I want to be in the future. Consequently there is a continual struggle between the drive to actualise my potentials and the influences or restraints of my thrownness (p. 35).

Beyond *Dasein* as an individual, Being-in-the-World entails a constant relating to the "they" world (*das Man*). There is controversy within the literature as to whether *das Man* is a necessary set of shared community practices, or a constraining force of mass society needing to be transcended (Boedeker 2001). I do not aim to resolve this controversy here but rather, I follow Crotty's (1998) interpretation of *das Man* as the socio-cultural expectations that we all conform to, in some degree, to make our lives meaningful and comprehensible. Often, these socio-cultural expectations remain at a subliminal level of awareness. According to Heidegger, this leads to a "they-self", a self that is inauthentic. This inauthenticity makes us prey to fallenness; described by Heidegger and Watts as absorption with the superficiality of the world such as gossip, trivia, mass media, fashion, and consumerism. This serves to have a numbing, or tranquilising, effect. Nonetheless, Heidegger (1996,

2000) points out that inauthenticity serves a purpose. The inauthenticity of the they-world serves as a means of protecting us from our existential angst.

Our inauthenticity is thereby revealed to us through our moods. We are always in a type of mood, most often an “everyday” mood that allows us to perform our everyday tasks. It is when we experience heightened moods, such as deep anxiety, that the nature of our being is called into question. This anxiety (not to be confused with anxiety disorders), or *Angst*, can allow us to redefine whom we are in the world, what relationships and tasks we will sustain, where we devote our time and energy. In short, anxiety can lead to authenticity, to developing relationships of care for ourselves, for others and the world (Heidegger, 1996, 2000).

Whilst profoundly disturbing, *Angst* can thus be a way of revealing authenticity and can be an enlightening event. Nonetheless, it is intensely disturbing as *angst* reveals the nothingness at the centre of human existence. This nothingness centres on the possibility of our own non-being (Watts, 2001). To see death as a possible mode of existence breaks the denial of death and frees *Dasein* from inauthenticity. To face death and its possibility can lead to a richer appreciation of the time and being we have in the present. Death reveals the sobering truth that life and death are grounded in time (Watts, 2001). This awareness of the inevitability of death is an essential condition of human freedom.

In summary, Heidegger extended phenomenology to include temporality, thrownness, fallenness, care, authenticity and angst and the interpretation of meaning. In common with social work approaches, Heidegger’s central concerns were essentially humanistic, locating the individual in context of their life-worlds. Heidegger’s work also located the social and historical context of individual existence, therefore taking a structural, rather than personal, perspective. He emphasised the broader influences at hand, avoiding a pathologising stance. Furthermore, temporality extends beyond historical contexts, and reminds social workers of the developmental unfolding of life, including the finitude of death. Grief, loss can be understood as *Angst*, but also possibility (Heidegger, 1996, 2000). Thus, Heidegger’s work has implications for social work by extending the key concepts of structural social work; offering a non-pathologising context; highlighting developmental contexts and reframing grief and loss.

Phenomenology as ontology and epistemology for understanding cancer survival

Keeping in mind Heideggerian theory as outlined above, I will now discuss the application of phenomenology as a theoretical framework for my doctoral research that explored the lived experience of cancer survival. Phenomenology provided the ontological and epistemological rationale for the research.

Lived experience of the everyday world, as revealed through consciousness, is the primary focus for phenomenological inquiry. Lived experience presents to the individual the many truths and realities of life. It is through accessing lived experience that researchers may gain understanding of the meanings and perceptions of another person's world. This forms the basis of an interpretive, or Heideggerian hermeneutic, approach to phenomenology. Steeves noted

A basic premise of the hermeneutic phenomenological method is that a driving force of human consciousness is to make sense of experience. In general, people try to reach this understanding by interpreting their lives as they occur by treating them as narratives that are unfolding (p. 59).

Thereby phenomenology was applied both as a research method and a philosophy that can illuminate survivorhood.

As stated above, Heidegger was concerned with the question of Being (Frede, 1999; Heidegger, 2000). Similarly, my study was concerned with Being a cancer survivor. Following Heideggerian theory, I was interested to explore the temporal experience of survival; that is, how survivors understood their past, present and future after a cancer diagnosis. My study did not concern itself with mental health pathology, or normative coping strategies. Rather, I was (and remain) curious about the meanings survivors ascribed to this unfolding process. Thus, cancer survival was conceptualised as an ontological question of Being.

As a study of lived experience, I decided not to operationalise the concept of "survival", but rather to understand and include participants' self-definitions. This is an important distinction that I shall explicate here. I did not operationalise survivorhood as a measurable variable based on medical prognosis, tumour or node status, stage of illness (e.g. metastases) or years of survivorhood. Further, empirical research in clinical randomised trials uses various measures, such as two or five years post diagnosis, to delineate survivorhood status. By contrast, Little

et al. (2001) defines survivorhood more subjectively as when the person believes they have a reasonable chance of survival. As mine was a study of lived experience, and following Little et al.'s more inclusive definition, I was interested in the participants' self-definitions and perceptions. Thus, several participants, who self-defined as survivors, revealed poor prognosis, metastatic disease and several died subsequent to interview. These participants, seemingly not survivors by more traditional definitions, nonetheless added a richness and complexity to understanding perceptions of survivorhood. Epistemologically, I assumed an inductive, theory generating approach, rather than a deductive, theory driven approach. Thus, the participants' own perceptions assisted to generate theory.

Extensive literature reviewing revealed there had been little previous research that conceptualised or theorised cancer survival (Little et al., 2001; Zebrack, 2000). Although there is a vast body of work exploring cancer and illness experience more generally, much of this work has explored the patients' experience (see for example, earlier work by Benner, 1994 and Munhall, 1994). By contrast, I intended to develop understanding about the substantive phenomena of survivorhood, not illness per se, and to expand the theoretical agenda (Zebrack, 2000).

Phenomenology, as a theoretical framework, had methodological implications for my study. Firstly, the issue of cancer survival is a fundamental existential issue. Survivorhood is at once pragmatic, presupposing existence, as well as metaphysical in that it calls into question the possibilities of both being and non-being. Survival raised issues about life and death and the nature of being, thus calling for both description and ontological reflection on the nature of being (Heidegger, 2000).

The second methodological implication was that of subjectivity, or rather the Heideggerian notion of intersubjectivity, as epistemology (Inwood, 2000). Intersubjectivity assumes a co-created and mutual research relationship between the researcher and the researched. This decreases the object-subject divide within the research relationship and acknowledges intersubjective experience, of both parties as a significant source of knowledge. Thus, Heidegger's assertion of an intersubjective existence liberated cancer survival from dichotomies such as: mind/body connections and disconnections; medical objective knowledge as oppositional to subjective lived experience and privileging cognitions over feelings or embodied experience.

Furthermore, Heidegger conceptualised and expressed Being-in-the-World as a holistic phenomenon (Heidegger, 2000). Being-in-the-World can then be understood as the intersubjectivity of interconnectedness and

interdependence of human relationships (Cohn, 2002). Translated as a research methodology, this includes an exploration of phenomena such as temporal, relational, spatial and corporeal life worlds (Munhall, 1994). Being-in-the-World encourages research exploration of holistic life experiences, including, where appropriate, those of the researchers.

By way of summary, Heideggerian phenomenology provided an ontological and epistemological foundation informing the methodology of my study. Key phenomenological concepts included the interpretation of lived experience as a means of accessing Being-in-the-World. Such a theory sought to acknowledge the embodied, emotional, temporal and socio-cultural experiences of participants, thereby was holistic in its investigation, in keeping with social work approaches as discussed above.

Overview of the methods of the cancer survival study

What I demonstrate below is how phenomenology informed the methods and findings of a cancer survival research project. This section commences with a statement of aims and overview of the methods and design of the study. This is followed by a brief presentation of key findings from the study, with a particular focus on temporality and relationships of care. Lastly, a phenomenological interpretation is offered and implications for social work knowledge and practice are discussed throughout.

The aim

The aim of my study was to explore the lived experience of cancer survival from the perspective of the people who have experienced the phenomenon. Lived experience was explored through:

- (a) Revealing the phenomenon of cancer survival as it appeared in everyday Being-in-the-World,
- (b) Understanding the meanings survivors ascribed to their lived experience of the phenomenon of cancer survival.

The over-arching interview question was; “What is your experience of cancer survival since the initial treatment you received?” with further exploration of issues such as everyday life, thoughts, feelings, actions, meaning-making, awareness of survivorhood status, changes over time, uncertainty and death.

Data collection: In-depth Interviews

Zebrack (2000) claimed that cancer survivors’ accounts enhance the understanding of the survival experience. He stated, “Cancer survivors

own narratives shed light on cancer's social impact, and often in a manner that illustrates in profound and evocative terms a *lived experience* of cancer" (p240). With this in mind, fifteen self-reported cancer survivors were interviewed on two separate occasions over a six-month period, with an interval of approximately three-months between the first and second interviews.

The first interviews allowed me to iteratively construct questions for further theoretical exploration. The preliminary analyses then informed subsequent first and second round interviews. In second round interviews I was able to give informal feedback to participants about emerging themes, check the direction of my interpretations, and clarify my assumptions. In this way, interviews provided access to lived experience and allowed survivors to tell and retell, construct and reconstruct their thoughts and reflections upon feelings, emotions and temporal perceptions of their experiences. Thus, multiple interviews provided a stronger basis for creating nuanced understanding; and the emerging analysis directed data gathering, self-corrections and analysis, and expanded the research process (Charmaz, 2002).

Situating the researcher

I chose in-depth interviews as a data collection method for their methodological accord and because I am a professional social worker who is experienced and comfortable with the interview process. As a cancer survivor myself, I felt familiar with aspects of participants' stories of lived experience, so my empathy was genuine. Nonetheless, I remained cognizant of attending to the confusion and tensions of multiple roles, as well as the inherent misunderstandings in any human communication.

The role of the researcher is not confined only to the interactions with participants in the interview context. The role of the researcher influences the entire research process; not even in quantitative studies is there a neutral observer. The researcher's background affects the choice of question and research design (Moustakas, 1990).

According to Lowes and Prowse (2001), a defining characteristic of Heideggerian phenomenological interviews and research is the acknowledgement of the researcher's beliefs, experiences and preconceptions, which are considered a legitimate part of the research process. According to Matelrud (2001), the question is neither whether the researcher affects the process nor whether such an effect can be prevented. A commitment to managing these methodological issues demands reflexivity.

In seeking to define the term "reflexivity", the literature offered contested and multiple interpretations. Given these varying meanings, I

concur with Matlerud's (2001) metaphor of the knower's mirror. Matlerud (2001) described reflexivity as the attitude of attending systematically to the context of knowledge construction, especially the researcher effect, at every step of the research process. Grbich (1999) provided further clarity. She stated reflexivity is: "a process of self awareness that should clarify how one's beliefs have been socially constructed and how these values are impacting on interaction and interpretation in research settings" (p65). Bias, then, is what is hidden; as it cannot be eliminated it can be accounted for (Matlerud 2001).

As a phenomenological researcher, I translated the epistemological concepts of intersubjectivity and reflexivity into research practice beyond the interviewer role. Following Moustakas (1990, p16), I engaged in self-dialogue aiming to acknowledge the "place and unity of intellect, emotion and spirit" and my tacit knowledge driving my passionate commitment to the topic. This self-dialogue took the shape of a fieldwork journal, memos and a reflective diary, as well as personal meditation about phenomena. Further, I engaged in dialogue with my supervisors, other postgraduate colleagues and oncology social workers, as well as participants' themselves, regarding my values and assumptions about the research process and emerging findings. Moustakas (1990) encapsulates my personal research experience as I believe I had a "personal desire to know, and a commitment to pursue a question that is strongly connected to one's own identity and selfhood" (p41).

A reflexive stance is in accord with Heideggerian concepts of both intersubjectivity and hermeneutic understanding. Intersubjectivity acknowledges values, experience and knowledge the researcher brings to the research as not only unavoidable, but with the capacity to enhance the research relationship (Benner, 1994; Cohn, 2002; Crotty, 1998). An objective bracketing, or a removed epoche is not in accord with Heidegger's stance (Moran & Mooney, 2002; Moustakas, 1994). Rather, intersubjectivity creates an interpretive space. This interpretation focuses on multiple meanings, what is revealed and concealed and goes beyond mere description of phenomena (Watts, 2001).

Ethics

According to Kellehear (1993), ethical concerns include the principles of privacy, informed consent, confidentiality, protection from harm, and avoiding deception. These broad principles were adhered to during the conduct of the present study. Ethics approval was obtained from the La Trobe University Human Research Ethics Committee (HREC) prior to the commencement of the study, ensuring that what was proposed for this

study was within the national statement outlined by National Health and Medical Research Council (NHMRC, 1999).

As the researcher, and because this study was located within regional or rural communities, I was particularly concerned about confidentiality. To protect participants, names of people and places were altered to pseudonyms during transcription and analysis, and all data were de-identified: no participant details were stored with transcripts. Thus confidentiality applied to the presentation of the data, as well as recruitment. All electronic data were stored in password-protected computer files and hard copies in the La Trobe University Health Sciences Office safe.

Additionally, with regard to ethical recruitment strategies, I was concerned that members from the Cancer Support Group, where I was formerly the facilitator, might perceive pressure to participate due to a previous personal or professional connection. To avoid this, I requested the current facilitator include the flyer in a newsletter and provide information sheets when requested. I attended the Cancer Support Group only when invited to provide further information and the majority of members were unknown to me. I had direct contact with members only at their initiation to request further information or to volunteer. Further, I recruited beyond the Cancer Support Group, ensuring a broader representation of participants.

I was also concerned with participants experiencing distress due to the personal and sensitive nature of talking about cancer survival. Included in the ethics application was a letter of support from a Community Health Centre willing to provide counselling and debriefing for participants. I also contacted La Trobe University Student Services for counselling and debriefing, in the event that I required personal support.

Ethical concerns go beyond guidelines that are set out by committees and national frameworks (Ezzy, 2002; Kellehear, 1993). There is a personal and moral obligation on the researcher to treat participants with respect for their knowledge, experience and human rights. To this extent, phenomenological intersubjectivity enriched the ethical research relationship.

Participants

Fifteen participants, who self-reported a diagnosis of cancer, were recruited from support groups and community health centres in the Bendigo region. Participants had a range of stages and types of cancer, including early stage and palliative experiences, of breast, prostate, ovarian, lymphoma, lung and invasive skin cancer. Participants' survivorhood status was self-defined, even if this contradicted medical

opinion. This complexity of perceptions was of interest to my study. Disease-free survivorhood ranged from 12 months to 15 years post diagnosis. In keeping with phenomenological methods, the participants were recruited using purposive sampling, a non-probability sampling technique (Sarantakos, 2001).

Data Analysis and Interpretation

I chose abductive data analysis for its harmony with the reflexive role of the researcher, but also for its dialogic reflexive arc with both the data and theory (Ricoeur, 1995). Put simply, abductive analysis involves testing ideas with both deductive logic and inductive empiricism. It is in keeping with the phenomenological hermeneutic circle of interpretation (Hoy, 1999). This circle involves a continuous movement between theory, data and experience, whole and part, and assumes phenomena can never be absolutely known.

Following Moustakas (1990), I went through a process of using my intuition to develop depth, substance and meaning in the data analysis process. This necessitated a period of “indwelling”, or turning inward to understand the nature of human experience of cancer survival. I then became focused on more deeply exploring the questions, contradictions and themes arising from the data. I became immersed in the data (Moustakas, 1990). The immersion phase was particularly exhausting, but led to illumination of new dimensions of the data. From these illuminations came abductive explications. Thus, this process of intuition, indwelling, focus, immersion and explication, I formed tentative themes that influenced the later coding of the data.

To assist with the management of the lengthy transcripts, I utilised the NVivo data analysis package (QSR International, 2000). I was initially hesitant about using computer software for analysis, imagining it to be linear, positivist and objectifying the data (Ezzy, 2002). I also feared it might distance me from the data (Dickson-Swift, 2004) and be in contradiction to my phenomenological aims. Such fears were unfounded when I realised that NVivo is a data management tool (albeit sophisticated), I remained responsible for the analysis process as NVivo manages but does not conceptualise data, so I used it to enhance my own phenomenological analytic style.

Moustakas (1990) process of intuition, indwelling, focus, immersion, illumination and explication is not fey, but rather, calls for emotional courage. The process of immersion in data of cancer survival was at times painful and distressing. Many times I had to stop due to sadness, anger or awe at the participants’ stories. Although painful at the time, I now believe my emotional response enhanced my thinking and

reasoning about the analysis (Campbell, 2002). Thus, data and theory, as well as my intuitive processes informed the codes for the findings interpretations. The process of writing and rewriting the findings further assisted my understandings (Cohen et al., 2000).

Methodological Limitations

There are challenges in every methodological tradition (Creswell, 1998). Within the present study there were limitations with sampling. Firstly, using a purposive technique I was seeking “information rich” participants and, initially, recruited from Support Groups and Health Centres. It is possible that participants were already in a supportive network, thus felt more confident with discussing personal and social experiences. Locating participants who experience social isolation posed recruitment challenges of access and equity to participate.

Additionally, there were limitations in participant demography. Although not seeking representativeness, I was intending a balanced sample. There was a balance of age groups, treatment regimes and diagnoses (given Australian national survival rates). Nonetheless, of the 15 participants, 11 were women. Thus, there was an imbalance of gender, perhaps reflecting service user trends. Further, there was only one participant beyond 10 years of survival. It is possible that the recency of the experience motivated participation. Additionally, poorer prognosis for some diagnostic groups may have precluded participation for longer-term survivors. Further, not seeking generalisability, the sample size was small, limited to a particular geographic context (Bendigo region of Victoria), largely Anglo-Saxon or European in cultural heritage. However, a larger and more diverse study may have uncovered a greater breadth or depth of experiences of survivorhood.

There were also limitations in the role of the researcher. As a PhD candidate, I was not working in a research team and was subject to the pitfalls of the lone analyst (Patton, 1999). I maintained a reflexive and ethical commitment to the data collection and representation; nonetheless, no interpretation is value free and a commitment to rigour and trustworthiness may be insufficient to eradicate bias. Further, a commitment to intersubjectivity and co-creation of research knowledge, does not eradicate power imbalances between the researcher and the researched, however ‘emic’ my experience as a survivor might be. That is, as a researcher from a university, and the author of this PhD thesis, there was power in my professional role.

Findings and Interpretation

The Lived Experience of Cancer Survival

My study found cancer survival to be a complex personal, social and meaning- making phenomenon that persisted beyond the acute stages of medical treatment. Changes to body, state of mind, temporal understanding and spiritual meaning were manifest in everyday Being-in-the-World. As such, survival can be understood as pervasive throughout all aspects of lived experience. The table below presents a brief overview of the key themes and findings from my doctoral research.

Table 5 <i>Overview of the Key Findings</i>			
Physical	Attunement	Temporality	Spirituality
everyday body	emotional roller coaster	The Past - das Man - previous experience	Why me? solace in communion
treatment body	feeling Fear	- family-of-origin	benevolence
sexual body	thinking positive uncertainty	The Present - the call - care for self and others	religious spirituality
		The Future - dreams and hopes - anniversaries - being for death - compassion - authenticity and care	

It is beyond the scope of this article to address each section in-depth; nonetheless, what is presented below are selected brief excerpts from the original findings demonstrating these everyday changes, with a particular focus upon temporality and relationships of care. Pseudonyms, rather than numbers, have been used to give a human voice to the participants' words, and at the same time preserving their confidentiality.

A highly significant finding in my study was that temporality and relationships of care were intimately entwined as sites of meaning-making

and self-identity. These findings are expanded upon in Pascal, Endacott and Lehmann (2009). To summarise here, the re-evaluations of the world before cancer and the influence of previous adverse life experiences were especially important. Overwhelmingly, my study found that family of origin experiences were of major importance. Family of origin experiences were reflected upon as an historical connection with one's past relational self, a site of potential resolution for painful relationships, and an historic, genetic and familial site for the experience of living or dying from cancer. Agnes explained

I lost family members you know; my father, step-father, grandfather, a sister. For me just knowing that I could have died and I didn't.

In turning to the present context of temporal experience, my study found cancer survival to be described as a wake-up call, leading to changes in the nature of relationships of care for self and others. As Frank said:

My outlook has been that what I was doing before couldn't have been that beneficial to my health. It gave me a big wake-up.

Again, family relationships were important for cancer survivors, both as temporal and relational sites of meaning-making. These relationships included partners, dependent and adult children and grandchildren. Miriam described her husband's shock-like response:

I don't think it had really sunk in. I think my husband was with me and he was more upset than I was. I think he thought it was the end of the world.

Nonetheless, after the shock there is a heightened awareness of, and appreciation for, the tenuous nature of human existence; including vicarious insights for family members as well the survivor themselves. Joy said:

It's made them more aware that everyone is vulnerable. And that's made me feel that way too. Nobody knows what is going to happen tomorrow and your life can be changed just in the blink of an eye. You just have to make the most of what you have got.

Dreams, hopes, anniversaries and anticipated personal milestones were part of the imagined future temporality of cancer survival. Here too,

family relationships, especially those with children, were significant as temporal connections with a past, present and future self in relationships of care. Frank explained:

The main resolve that I was going to see my daughter's 21st Birthday party. No matter what I did, that was the thing that kept me going. She was three months when I got diagnosed. I am going to see you at your 21st. That's a long-term goal.

The survival experience within the social and relational context was not unproblematic. As well as love and support, relationships facilitated feeling not at home with one's relational self as personal and social roles and expectations changed in unspoken ways. These changes, at times, led to rethinking relationship and perhaps disconnection or abandonment, particularly in the transition of early survivorhood. Darcy recalled:

I found that some of your friends couldn't talk about it. They would skirt around it or not even mention it and they would drift off a bit as if you had the plague.

Temporality and relationships of care were significant and entwined aspects of survivorhood. A further key finding was that, beyond the self and immediate family and social context, cancer survival entailed seeking a future of compassionate and ethical community relationships, including spiritual and religious communities.

Further, this revelation of the importance of care created a reflective space for questions about personal and social ethics, and what it is to lead a "good life". This metaphysical question about a good life was not answered in terms of the acquisitive Western social and personal constructions of positivity, problem solving, work, income, or consumerism. Kaylah provided further insight. She explained

People think that happiness is this thing that comes in the future when they have paid the mortgage off and they have got this BMW in the driveway and this fabulous job and 2.5 children in their designer clothes and it's not. People get there and they are not happy.

Relationships of care, including spiritual communion, were seen as providing meaning that replaced previous socio-cultural norms. There was a revisioning of life that encompassed changed attitudinal and behavioural dimensions. Thereby, from a Heideggerian perspective

cancer survival could be understood to be a temporal authenticity of care. Some examples of this included Grace described not wanting to be caught in the *das Man* of the working world:

From a work perspective I don't take it quite as seriously. I'm not very ambitious anymore. You know I enjoy it, and I'm very lucky that I enjoy my job, but I certainly don't want to go any higher. Life's too short for that stuff.

Kate explained she had become

a more kinder, compassionate person. I hope that as you get older you let go of all your insecurities and that's what I'm looking forward to just going 'stuff it' this is the way I am.

Robert decided to become an organ donor. He explained:

On my licence now, I've donated every part of my body to whatever they want within a reasonable period, then I want to be cremated.

Frank made the change to live in a rural community, returning to a childhood dream:

So it will be pleasurable sources there, like selling chook eggs or food from the vege garden, supplementing our need to buy veges. We'll just grow them ourselves and that's something that I find really healthy and enjoyable. So it's just a way of changing it around.

As stated previously, these changes were not unproblematic and created feelings of both meaning and meaninglessness. Frank expressed his confusion at what might come next in the survivorhood experience. He wondered:

OK, I've got through that first stage, now what the hell am I going to do? It was a bit like, 'well, what do I do next?' I've actually found it quite upsetting or distressing. I've gone through depression about it.

These feelings of *Angst* bear similarity to uncertainty, distress and liminality (Breaden, 1997; Holland, 2002; Little, Jordens, Paul and Sayers., 2001; Nelson, 1996), rather than diagnostic mental illness.

However, when understood from a Heideggerian perspective, these feelings of *Angst* were welcomed as a space for understanding Being-in-the-World. As Ruth explained:

I think the death experience actually makes you feel more alive, it makes you think, 'right, life's absolutely bloody amazing!' ... How much beauty there is out there, how much experience there is yet to have. I feel like there is actually not enough time. Even if I'm going to be well until I'm 80, there still isn't enough time.

I do not wish to imply that cancer does not precipitate mental illness or acute emotional anguish: the literature indicates approximately 30% of those diagnosed with cancer may also be diagnosed with anxiety, depression or PTSD. However, even for 30% with a mental health diagnosis, *Angst* may predominate. Further, such estimates do not fully inform us about, or adequately explain, the cancer survival experience. Thus, Heideggerian *Angst* is a powerful re-interpretation of diagnostic anxiety as a space for understanding temporal authenticity of care.

A Heideggerian Interpretation of Cancer Survival: Relationships of Care and Authenticity

The Heideggerian notion of “care” is not restricted to the description of “caring for”. That is, care does not only denote looking after another person by tending to their need for food, clothing, companionship or medicine. Nor is care worry, willing or wishing on behalf of another entity (Heidegger, 2000). Rather, care is what has significance for us as human beings: care for our own existence (Watts, 2001). According to Leonard (1994), “we exist existentially because of the things we care about, the for-the-sake-of-which... we exist in terms of what matters to us” (p. 54).

There is an essential connection between Being-for-death and care, as *Dasein* is always concerned about its own Being. From a Heideggerian perspective, the *Angst* of uncertainty of survival can be understood as caring about one’s mortality, as one’s individuality is disclosed in the *Angst* of Being-for-death (Heidegger, 2000).

The Heideggerian structure of care can further be understood ontologically as care for self (*Selbstsorge*), care for others (*Fursorge*), and care for projects or things (*Besorge*) (Inwood, 2000). Firstly, the findings demonstrate participants’ care for themselves. Participants undertook medical and self-treatment, managed their physical and emotional health, underwent changes to attitudes and values, and re-

prioritised working and family relationships. The meaning of this uncertainty can be understood as *Unheimlichkeit* (literally translated as not-at-home or unfamiliar) and *Angst*, which served to reveal *Dasein's* fundamental aspect of care for its own being (Heidegger, 2000). Beyond self-care, *Dasein* can be viewed as relational and caring for others. Overwhelmingly, participants described the significance of caring relationships as making meaning of personal identity, role and temporal connections. Family of origin, partners, children, adult children, friendships, support groups, and informal care relationships all contributed to survivors Being-in-the-World as care.

These relationships were not only about survivors receiving support from family and friends, but also revealed the significance of those relationships as a means of survivors giving support to others, thereby enhancing self-identity and finding meaning. These relationships, at times, were challenging, painful and did not always survive the survival experience. Whilst most participants experienced caring for others as a shared journey, several participants experienced distance from, or even abandonment by family or friends. The lack of relationships of care, in these instances, further highlighted the ontological and temporal significance of reciprocal relationships of care.

Having a passionate commitment to a project beyond one's self and family was important for survivors. It was demonstrated that the wake-up call of cancer was a call to conscience to lead a good life (Heidegger, 2000; Morton, 1996). This conscience awareness revealed metaphysical and ethical questions for survivors. Through a redefining of relationships, survivors found they wished to transcend the acquisitive demands of *das Man* and return to a more compassionate Being-in-the-World. Most participants wished to make a contribution to their communities. Pragmatically, this was demonstrated in volunteer work, cancer support group attendance, organ donation, animal aid and more time spent with family and friends. Furthermore, *Besorge* (caring for projects) gave a sense of purpose to the cancer experience, with participants using their experience of suffering to assist the wider community. This pedagogy of suffering (Frank, 1995) was translated into pedagogy of survival. Cancer had taught survivors fundamental lessons about care as a connecting and unifying temporal experience for *Dasein*.

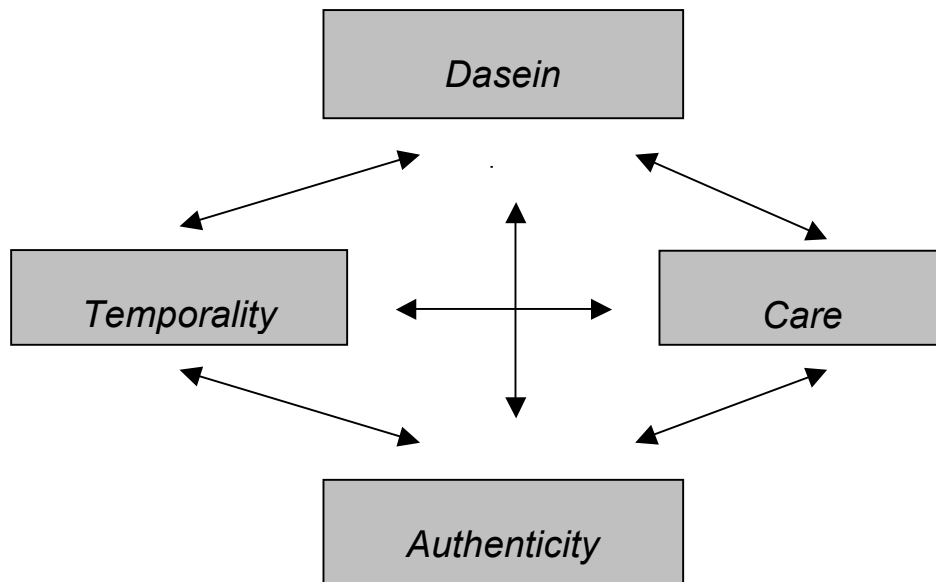
Conclusions

This study pointed to the temporal significance of relationships of care as a site of meaning-making throughout cancer survival. Within this historical and relational context, *Angst* facilitated a reflective space for

gaining understanding of this complex personal, social and ethical life experience.

Cancer survival is not an illness and requires its own analytic frameworks. Using Heideggerian phenomenology, my study has extended normative and developmental problem solving approaches to illness, and their implications for survival experiences. Through understanding lived experience, Heideggerian phenomenology critiques, as well as contributes to, the inchoate survival discourses. Survival can be interpreted, not as a linear journey, an emplotted narrative, or a disease trajectory, but rather as a hermeneutic space for understanding temporal authenticity of care (see figure 1). Such an interpretation contributes to extending existing social work, medical and therapeutic contexts.

Figure 1
The Ontological Structure of Cancer Survival



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