Relational Narratives, Suffering, and Counselling Psychology

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Relational Narratives, Suffering & Counselling Psychology

Preface

This preface introduces three main components, making up my portfolio of training in counselling psychology. The first component is a research study, presenting an original narrative inquiry exploring online brain tumour caregiving stories. The second component is a clinical case study of work I conducted with a client within an integrated theory framework. The third component is a publishable paper on location of self (Jones, 2011), a technique that can be employed to enhance the therapeutic relationship between practitioners and clients. Together, these three interrelated components showcase a collective body of work, accentuating the centrality of the concepts of relational narratives and suffering in my learning and practice as a developing counselling psychologist.

My passion for stories can be traced back to my childhood in Kenya, listening to my grandmother's numerous tales, some humorous, others full of riddles, but the most captivating often described how ordinary characters transcended perceived weaknesses, overcame tragedies, performed heroic deeds that ended suffering and brought greatness to their communities. These stories invariably contained moral lessons emphasising relationships, community and cultural values.

This passion for stories was re-ignited during my first year in training. I was in placement with three different organisations working with: 1. Refugees and asylum seekers; 2. Survivors of rape and domestic violence; 3. Survivors of torture and human rights violations. What these organisations had in common is that they provided counselling to minority men and women from diverse backgrounds, mostly from Africa and the Middle East. There was great emphasis on providing a *safe space* for the client to *tell their story*. Practicing in both individual and group settings, I noted a distinct contrast in authorship or agency in the stories clients would narrate in individual therapy, in comparison to group sessions. Individual sessions, were often still and intense. The women would painfully narrate stories of atrocities

committed against them. These stories were foregrounded in a single narrative of vulnerability and suffering. By contrast, group sessions tended to be animated with laughter, choruses of understanding and affirmations, patting each other's backs, high fives, spontaneous clapping, and even celebratory ululations! In group sessions, new stories emerged, focussing on *what I did to escape/overcome/survive*. These stories exemplified courage and resilience. Gradually, it occurred to me that these powerful *narratives of survivorship,* might otherwise have been lost, were it not for the group. This was the beginning of my deep commitment to working relationally (Jordan, 2008) and narratively (White & Epston, 1990), with women diagnosed with Post Traumatic Stress Disorder (PTSD), multiple trauma, or complex trauma (DSM V, 2013), who simply described their experiences as "suffering". They had never heard of the word PTSD.

In my second year, working with HIV+ men and women in a national organisation, I once again had the opportunity to work in both individual and group settings. The organisational ethos was based on community psychology. I learned about the value of providing additional psychosocial support for clients alongside psychological therapy. Counselling psychology, and its multiple influences, rooted in humanitarian philosophies, emphasising the centrality of the therapeutic relationship, provided the epistemological base for my continued learning; a base from which I begun to engage with narrative theories, feminist relational theories and intersectionality. I learned that clients have countless of equally significant stories they could tell; however, the kinds of stories they chose to narrate, about what was ailing them or what brought them to therapy, were greatly shaped by the storytelling landscape and the relational safety provided, by both the organisation and the therapist. Hernandez & McDowell (2010, p.34) define relational safety, as "the co-construction of a dialogical context" in which "questions can be raised, viewpoints challenged, issues pondered, opinions confronted, ideas articulated and feelings expressed". Relational safety is not *blind validation*, but rather, the nurturing of *a caring relational environment* which can facilitate multifaceted,

multidimensional relational narratives; reflecting the complexities of human beings and their storied experiences.

By my final year in placement at the National Health Service (NHS), working within Improving Access to Psychological Therapies (IAPT) and engaging with Cognitive Behavioural Therapy (CBT) treatment protocols, I had internalised my practice of thinking narratively. This meant that, I often implicitly reflected on three key questions: 1. What is the storytelling landscape? 2. What kinds of stories are dominant or marginalised? 3. What resources does the client need to tell a different story? (Frank, 2012). Initially, I struggled in supervision, chided for not using the time allocated optimally, because I "told too many stories," and was reminded on more than one occasion that the therapeutic relationship was a secondary factor in CBT, "necessary but not sufficient" (Beck et al., 1979). My confidence was, however, restored when my outcome measures showed, that my clients and I were "exceeding expectations". I observed that, regardless of diagnosis, most clients interpreted their experiences relationally: the joys celebrated, the losses mourned, the sources of hurt and distress and what mattered most was relational. Even so, my placement with the NHS reflects a significant turning point in my own process of embracing the scientist-practitioner perspective (Corrie & Callahan, 2000) in my development as a clinician. While acknowledging the effectiveness of CBT, I could not deny the centrality of suffering to my everyday clinical work, irrespective of client group or setting. Ironically, the term suffering, as a construct/concept in counselling psychology theory, is hardly in use (Miller, 2005). In addition, my preferred model of psychotherapy, holds no currency in a market place being gradually eclipsed by evidence-based practice (James, 2013).

Nearing the end of my training and still thinking narratively, I have embraced counselling psychology's contradicting epistemologies, valuing both humanistic and scientific influences by practicing my reflexive stance. I have come to accept this conflicted framework as a

reflection of the complexities of human nature and experiences. Drawing parallels to the contrasting multidimensional stories that clients bring into therapy, I now see this as "an empty space of possibility" (Gergen, 2001, p.7), from which both client and therapist can benefit from the diverse multidisciplinary influences available in the field, through the practice of integration. Overall, I put forward that the themes of relational narratives and suffering, foreground my view of counselling psychology as a practice, first and foremost, embedded in relational care.

Research Study

This narrative inquiry research, guided by feminist relational epistemologies, asked the question: What kinds of stories do brain tumour caregivers narrate online? Using Arthur Frank's (2012) Dialogical Narrative Analysis (DNA), the research aimed to build story typologies. Story typologies have the potential to illuminate the conditions that cause suffering, shed light on psychological needs, improve professional listening and enhance therapeutic responsiveness. Narrating stories has been found to serve many therapeutic functions (or not) (Frank, 2012).

7 bereaved caregivers consented to the use of stories they had narrated online as research data. These stories were regularly narrated online, in "the heat of the moment" or retrospectively, within conversations (dialogical) and among communities (relational), throughout the brain tumour trajectory and post-bereavement. The long duration of story-telling (2-3 years) generated a large amount of data, both rich and copious. Email interviews, conducted with the participants, about their experiences of narrating stories online, provided a retrospective, as well as, performative aspect of stories and storytelling. DNA, a method which explores "the mirroring between what is told in the story – the story's content – and what happens as a result of telling that story – its effects (Frank, 2012, p. 71-72)", was deemed a good match to build story typologies, interpret, and analyse the stories. Five story typologies: Narratives of Disruption, Embodied Narratives, Moral Dilemma Narratives,

Narratives of Destruction and Narratives of Silence are presented. In addition, two core narratives: The Suffering of Caring and Woman as Healer, emerged from the interrogation of the story typologies and the storytelling landscape. Theoretical insights are discussed and suggestions are made on how counselling psychologists can work narratively with brain tumour caregivers and caregivers in general.

My interest in this topic comes from my experience as a caregiver to my beloved husband and partner of 28 years, father of my two teenage children, who was diagnosed with a terminal brain tumour at 45 years, six months into my counselling psychology training. I still have no words to describe this experience.

Professional Practice

The second component of the portfolio is a focus on professional practice, with the aim of demonstrating knowledge in theory, application and competence in the chosen therapeutic model. A clinical case study, illustrating the main aspects of the collaborative work between myself and a young male client, who is stateless and destitute is presented.

Writing for Publication

The last component of the portfolio is a journal article written for submission to Narrative Works, an online peer-reviewed, open-access, interdisciplinary journal. The aim of this article is to propose techniques that trainee counselling psychologists can employ in therapy to enhance the therapeutic relationship by addressing the power imbalance between practitioners and clients. Examples from location of self on how this can be managed appropriately are discussed. The use of experiential learning based on practice based knowledge is illustrated. Location of self is a unique technique, which can contribute to levelling the playing field between practitioners and clients in the therapy room.

Recommendations are made for counselling psychology researchers to explore different ways in which experiential knowledge can be applied in research to improve practice.

Reflections & Summary

This portfolio is intended to illustrate my competence to work with diverse clients presenting with a wide range of issues in different psychological settings in an increasingly fluid and dynamic environment for counselling psychology as a profession and counselling psychologists as practitioners. I hope it demonstrates my ability to balance practice based knowledge and theory led practice as these competencies demonstrate both scientist-practitioner and reflective-practitioner positions essential for practice. I hope the portfolio also demonstrates my humanistic values of placing the therapeutic relationship at the forefront of my practice, an awareness of the impact of socio-political processes in clients' lives, ability to practice with and beyond manuals of psychological theories. Integration within therapy demands reflection, theoretical knowledge, understanding and continual awareness of the reasons for using specific strategies within the framework of therapy.

Lastly, I spend much of my professional life listening to stories. What I find significant is not fitting the client in to a diagnosis (dominant narrative), but, to listen to the complex struggles, multiple relational narratives and suffering that clients bring into therapy. My experience has led me to presume that most therapeutic encounters begin with a relationship and a story or a story followed by a relationship hence my use of the term relational narratives. Like Wells (2011, p.162), I maintain that clinicians "trade in stories" and narratives "form our greatest currency."

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Part 1: Research

Woman as Healer: A Dialogical Narrative Analysis of Online Brain Tumour (GBM) Caregiving Stories

Abstract

A diagnosis of glioblastoma multiforme (GBM), a World Health Organisation (WHO) grade IV brain tumour, is devastating for patients and their families who bear the impetus of caregiving. GBM caregivers act as *de facto* health professionals when their loved ones are discharged prematurely from hospitals. Faced with complex healthcare needs, GBM caregivers report the highest psychological burden, and highest unmet needs of all cancer caregivers. Despite this, they rarely accessed rehabilitation services. Researchers hardly engaged with their stories. The current research on GBM caregiving is predominantly from a biomedical perspective, not only offering limited understandings of psychosocial experiences, but also, evidencing the need for caregiver stories in caregiving research.

The researcher recruited 7 bereaved caregivers, who had previously narrated stories online about caring for their loved ones diagnosed with GBM and; consented to the use of their stories as research data. These stories covered a period of between 1-3+ years, throughout the illness trajectory and post-bereavement. The researcher further conducted email interviews focussed on the retrospective perspectives of sharing stories online. Participants provided feedback on the preliminary findings of the DNA. The findings consisted of multiple layers of interpretations drawn from social constructionism, narrative and feminist relational theories, beginning with subjective stories, collective story typologies and core narratives, thereby illuminating the relationships between GBM caregivers, the stories they narrated and the event of narrating stories online. An additional layer of interpretation served to shed light on the relational, dialogical, performative and hindsight perspectives of storytelling and the storytelling landscape. This research decentres the dominance of biomedicine in caregiving research to present a perspective from GBM caregivers using their own stories, in their own voices, so as to inform counselling psychology research and practice.

1 Chapter One: Introduction

1.1 Background

In the United Kingdom (UK), the term "carer" is widely used to denote both formal and informal carers. Formal carers are professional employees, trained to provide support for patients with health problems; while, informal carers are mostly untrained family members, friends, and volunteers who provide similar care, and, are sometimes entitled to a statutory allowance. These differences mean that the use of the term "carer" is considered by some carers and researchers as not representative of all carers (CarersUK, 2017).

After careful consideration, I chose to use the term "caregiver to circumvent the controversies associated with the term "carer," while acknowledging that the word "care" remains the building block upon which the terms carer and caregiver are constructed. "Care" originates from the Old English term "wicim", which means "mental suffering, mourning, sorrow or trouble". Combined with "give", an Old English word meaning "to bestow gratuitously" (Gratuitous: free, spontaneous, voluntary), caregiving becomes the action or process of spontaneously and voluntarily providing support and emotional care to those who are suffering (Caregiving, 2010; Hermanns & Mastel-Smith, 2012). Thus, caregiving is associated with a willingness to give care based on an emotional connection.

In this research, the term caregiver infers informal caregivers or family caregivers; henceforth, simply referred to as caregivers. This does not mean that the term caregiver is unproblematic as there remains no agreed-upon definition of what caregiving means (Hermanns & Mastel-Smith, 2012). In other words, consensus about who a caregiver is has not yet translated into a global conceptualisation of caregiving.

Caregiving is a 21st Century multi-dimensional global phenomenon, with millions of caregivers worldwide. Rapid changes in population demographics, the development of medicine and new medical technologies, mean that people are living longer (Bruhn & Rebach, 2014). Traditionally, caregiving has been regarded as a lifespan experience associated with aging. However, research shows that caregiving is a critical and salient issue in the lives of individuals from all demographic, socioeconomic, and ethnic categories. Caregiving impacts children, adolescents, young adults, and adults, who care for family members with disabilities, illnesses and conditions that require special health care needs (APA, 2017).

Worldwide, the number of people requiring caregiving is expected to continue rising. Caregiving needs frequently exceed the resources available in families, communities and health care services. In addition, rehabilitation services and the provisions of palliative and hospice care rarely meet the demands of the population. It is common practice for patients to be discharged early from hospitals necessitating continued care at home. Caregivers increasingly bear major responsibilities for providing care and play an essential and indispensable role in health care systems worldwide (Bruhn & Rebach, 2014; APA, 2017).

Research on caregiving is multidisciplinary, vast and diverse. Important areas of research for psychologists have included prevalence, types of assistance provided, and the impact of caregiving on health, social life and finances. However, there remain several challenges in caregiving research, for example, researchers have acknowledged the complexity of caregiving for a loved one with Dementia and Alzheimer's Disease (Bruhn & Rebach, 2014; APA, 2017). These revelations have been eye-openers on the need to develop disease-specific supportive care interventions for caregivers (APA, 2017**).** It, however remains unclear how caregiving is the same or different for divergent cultures, age groups, genders,

types of diseases, disease stage, and disability (APA, 2017). The subject of this research is caregiving for a loved one diagnosed with Glioblastoma Multiforme (GBM), a World Health Organisation (WHO) grade IV primary malignant brain tumour (PMBT).

1.2 Overview of the Research Study

The above background section introduced Chapter One and is preceded by an overview of the research, which begins with a clarification of the caregiving context, followed by *a priori* reflexive statement outlining my personal engagement with the topic. A literature review, offering the rationale for research and identifying research gaps concludes with the research questions. Chapter Two introduces the research methodology and provides detailed accounts of the research process and participants. Chapter Three presents the research findings. Chapter Four is a discussion which links the findings to theory and draws together implications for counselling psychology. A final *a posteriori* reflexive statement concludes the study.

1.3 Context of Caregiving: Glioblastoma Multiforme (GBM)

GBM is a rare, progressive, degenerative, incurable brain cancer, with devastating effects on patients and their families (Ownsworth et al., 2016). It is a life-limiting condition, which unexpectedly strikes relatively young individuals (Philip et al., 2015). In the UK, 4900 people were diagnosed with brain cancer in 2015. Worldwide, diagnoses for brain cancer make up 1% of all cancers and the incidence rate is about 2 to 3 cases per 100,000/year (2013-2014). The rate is higher in males (7.7 per 100,000/year) than females (5.4 per 100,000/year). White and Hispanic populations have a higher incidence of brain cancer than Black and Indian populations (Cancer Research UK, 2017; WHO, 2016).

With the worst prognosis of all cancers, survival rates for GBM have not changed in the last 50 years unlike other cancers which have seen a significant improvement in treatments. Brain Tumour Research Online (2016, p.1) note that "stark inequalities in cancer research funding…correlate tragically with poor survival rates for brain tumour patients." The UK government spent just 0.52% of the total cancer research budget on brain tumour research (Cancer Research UK, 2017). Ironically, brain tumours are the highest cause of death among all cancers for people under 40 years. In addition, up to 25% of all cancers lead to a secondary brain cancer metastasis, making brain cancer one of the most lethal human diseases (Brain Tumour Research, 2017). The aetiology of GBM is poorly understood. There are no known risk factors. Prevention does not exist. Many environmental, dietary, and lifestyle influences which have been studied have produced no conclusive evidence to date (Holland, 2000). Population studies on cell phone use as a risk factor for brain cancer have provided conflicting and inconclusive evidence (Swerdlow *et al.*, 2011; Little et al., 2012).

Brain cancer diagnosis often follows a series of unexplained symptoms, such as nausea, headache or seizure. Standard of care treatment (SOC) is aggressive; beginning with a craniotomy to remove the tumour, followed by radiation and chemotherapy. Some tumours are inoperable for various reasons, such as size (too large) or proximity to essential areas, such as brain stem (Cahill & Armstrong, 2011). After surgery, Magnetic Resonance Image (MRI) is recommended every two to three months to monitor tumour recurrence. Due to limited treatment options, patients are encouraged to participate in clinical trials to increase their overall survival rates. The tumour inevitably recurs, making disease progression certain. Further surgical intervention, followed by more chemotherapy is recommended as long, as the patient remains healthy. Most patients average two to four surgeries, several chemotherapies and head radiation, until there are no more treatment options. Most patients diagnosed with GBM die within one year of diagnosis, despite undergoing multiple aggressive therapies (Holland, 2010; Ownsworth et al., 2015).

DIAGRAM 1.3: THE BRAIN AND ITS FUNCTIONS

Frontal Lobe
- Problem solving
- Emotional traits
- Reasoning (judgment)
- Speaking
- Voluntary motor activity

Parietal Lobe
- Knowing right from left
- Sensation
- Reading
- Body orientation

Occipital Lobe
- Vision
- Color perception

Temporal Lobe
- Understanding language
- Behavior
- Memory
- Hearing

Cerebellum
- Balance
- Coordination and control of voluntary movement
- Fine muscle control

Brain Stem
- Breathing
- Body temperature
- Digestion
- Alertness/sleep
- Swallowing

1.4   *A priori* Personal Reflexivity

The terms reflection and reflexivity are sometimes used interchangeably. In this research, reflection is defined as thinking about something after the event, while reflexivity, involves an ongoing self-awareness (Finlay & Gough, 2003). Reflexivity, therefore, involves engaging in *a priori* reflexivity (prior to commencement of research), *in situ* reflexivity (in-the-midst of research) and *a posteriori* reflexivity (towards the conclusion and post-research). Reflexivity is a dynamic process operating on multiple levels, and influencing actions and decisions taken throughout inquiry, analysis, and interpretation (Etherington, 2004). Below is my *a priori* personal reflexivity, as pertains to the research topic.

My first encounter with caregiving was with my beloved 96- year old grandmother. During her illness, I witnessed how my mother and aunts rallied around her, taking turns to care for her. She was never alone. Her dignity was fiercely protected. She was loved and kept comfortable. She died peacefully in her home surrounded by all who loved her. I grew up thinking that caregiving was a private family matter, intrinsic to women. When my beloved 45-year-old husband and partner of 28 years suddenly became incoherent and underwent an emergency craniotomy to remove a 6X5cm brain tumour from his frontal lobe, I went into functional shock. I was alone with our two teenagers, age 15 and 16, as other family members lived abroad. My husband, a pragmatic Swiss German man in his prime, received the prognosis of GBM in silence, and then went on with his life. A former lieutenant in the Swiss Army and a CEO of an international company, he never asked: "why me?" I, on the other hand, struggled with the senselessness, the unbelievability of it all. He was tall, strong and healthy, exercised painfully and religiously (jogged uphill with a 20kg backpack), ate nutritiously and was an avid *naturophile*. He was always cheerful and supportive; fiercely committed to family, and indeed the glue that held it together. We all adored him. He was my soulmate, my world. How could this happen to him? To us? Why? This was my second encounter with caregiving and the potential lens through which, I navigated my caregiving experience, including research.

1.5   Literature Review

Worldwide, brain cancer makes up only 1% of all cancers (Brain Tumour Research, 2017). As a topic of research, it is global and multidisciplinary in nature (APA, 2017). The sources of this literature review are predominantly from City University London Library, utilising mainly online resources. An electronic search of Ebsco, PubMed, Medline, CINAHL, PsychINFO, ScienceDirect, GoogleScholar, ProQuest and Ethos for unpublished dissertations was conducted using combined key words (a) glioblastoma, glioma, brain tumor, brain tumour, brain cancer, neoplasm, brain disease, astrocytoma; and (b) caregivers, carers, spousal

caregivers, relatives, family members, widows, female caregivers and yielded hundreds of articles. The scarcity of studies specifically mentioning GBM led to the revision of the search criteria to include primary malignant brain tumour (PMBT), malignant high-grade gliomas (HGG), brain tumour, brain cancer, combined with caregiver, carer, spouse, next of kin, and family caregiver, to capture as many studies as possible. Further, I mined the references of selected studies in search for more publications.

The global nature of the research uncovered studies from around the world, mainly Australia, Austria, Canada, Denmark, Germany, India, Italy, Netherlands, New Zealand, Norway, UK, and USA. The multidisciplinary nature of the research revealed an affiliation with Neuroscience, Neuro-oncology, Nursing, Disability and Rehabilitation, Brain Injury, Neurosurgery, Psychiatry, Hospice and Palliative Care. In addition, there was a large number of biochemical, neuropathological and epidemiological reports, too technical for this research. It was, therefore, prudent to be mindful of the scope of associated literature and the word count limitations in deciding what literature to include in the review. This enabled a focused and informative review of the existing knowledge most pertinent to the current study.

Green & Johnson (2006) advice, that a literature review is primarily an integrative endeavour, which aims to provide a "bridge between the vast and scattered assortment of articles" on brain tumour caregiving and the reader (Baumeister & Leary, 1997, p.311). The goal of this literature review is to offer a rationale for the research and research questions, supported by the available literature. Preliminary readings found the bulk of research on brain tumours did not differentiate between malignant tumours, which range from grade I to grade IV and non-malignant tumours. Grade I-II diagnoses generally received prognoses of 3-8 years while grade IV prognosis is 6-12 months. This was problematic. My aim was to illuminate caregiving for GBM, which is a grade IV tumour. It is possible that differences exist

in caregiving across tumour grades. In the absence of this differentiation, I decided to include any research on PMBT.

Research on brain tumours employed both quantitative and qualitative methods (Sherwood et al., 2004; 2006). Since, the aim of my research was to illuminate the GBM caregiving experience, the most pertinent articles were those which included interviews with brain tumour caregivers. A preliminary analysis of the selected publications identified a focus on emotional and psychological aspects of brain tumour caregiving (McCognigley et al., 2010), caregiver stress (APA, 2017), caregiver burden (Sherwood et al., 2004; 2006), family and interpersonal relationships (Sherwood et al., 2014), social support (Lobb et al., 2010), self-care (Ford et al., 2012), employment and financial status (Patterson, 2007),experiences within the healthcare system (Philip et al., 2015), quality of life (Moore & Brand, 2012), and end of life care (Lipsman et al., 2017).

Based on Green & Johnson's (2006) advice that a successful review is well structured, with available evidence organised in common themes, which convey a clear message; I grouped the information under the heading "psychosocial experiences of brain tumour caregivers," with three subsets, namely; psychosocial needs of brain tumour caregivers, psychosocial support for brain cancer caregivers and psychosocial impact of brain tumour caregiving. I adapted the term psychosocial, due to its broad use in majority of research to emphasise the close connection between psychological aspects and the wider social experiences (Woodward, 2015).

1.5.1 Psychosocial Experiences of Brain Tumour Caregivers

Psychosocial experiences include emotional, spiritual, social, cultural, political, economic, familial, community, and all factors that influence both caregivers and their loved ones.

Psychosocial experiences include the totality of individual experiences, rather than focussing solely on the physical or psychological aspects (Woodward, 2015). The guiding questions underlying this literature review were: a) What is the current knowledge on the psychosocial experiences of brain tumour caregivers? b) What are the significant theoretical and methodological procedures employed by researchers? c) What research still needs to be done and why? Due to the overlapping nature of psychosocial experiences, this review offers "critiques of groups of studies, rather than individual commentary on each study" (Baumeister & Leary, 1997, p.318).

1.5.2   Psychosocial Needs

Informational Needs: Brain tumour diagnosis often occurred in emergency circumstances. Caregivers reported events moving too rapidly for them to absorb information about the limited treatment options and poor prognosis. Post-surgery, effects of brain tumour can lead to neurological deficits, such as memory loss, aphasia, visual problems, motor dysfunction, paralysis, migraines, epileptic seizures, personality changes and poor social functioning (Arber et al., 2010, 2013). Quick discharges from hospitals and a rapidly evolving disease meant that caregivers were unprepared for the primary responsibility of supporting their loved ones at home immediately after surgery (Ownsworth, 2015).

The rapidity of events was reported by Janda et al. (2008), who used a cross-sectional survey via mail to assess supportive needs of 75 patients and 70 caregivers. A theme of "learning how to be a caregiver," which included the need for practical skills education, knowledge in providing safe care, managing seizures, cognitive deficit management, administering medication, end of life care and provision of services available was identified. A hospital case review of 70 patient records and their caregivers by Arber et al. (2010) also reported the deficit of information as a source of distress. While these studies were useful in

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highlighting the need for addressing the information needs reported by caregivers, a limitation is that participants were diagnosed with different tumour types, making it difficult to differentiate needs across tumour types. In addition, methods employed to collect data were cross-sectional surveys and case reviews of hospital records, thus lacking the direct perspective or voice of brain tumour caregivers.

Janda et al., 2008 and Arber et al., 2010 reported that the needs of caregivers and those of patients, were not always the same, making the case for interviewing caregivers separately. This was echoed by Ownsworth et al. (2015) who interviewed both patients and caregivers and found that they were not as forthcoming with information when interviewed together. Their needs were also different. For example, caregivers wanted to know more about long-term care or prognosis, while patients were concerned about their current symptoms. A limitation of Ownsworth et al. (2015) is that participants were interviewed at different points during the illness trajectory, making it difficult to ascertain how their needs shifted throughout the illness trajectory. Additionally, patients included in the study had mixed tumours.

Supportive Care Needs: Arber et al (2010) reported that caregivers needed support to manage symptoms, such as hemiparesis, cognitive deficits, mobility, and falls. A case review of 70 patient records found that both patients and caregivers were not routinely offered supportive services, such as physiotherapy or speech therapy, as was common practice with other cancer patients and their caregivers. Caregivers were also not given advance information on available rehabilitation services. The study did not seek the perspective of caregivers. Interviewing caregivers directly has the potential to provide more in-depth information regarding their supportive care needs.

Communication with Health Care Providers: Up to 25% of brain tumour caregivers were dissatisfied with doctor and nurse communication (Lidstone, 2003). In a qualitative study conducted in a hospital, Strang & Strang (2001) recruited 20 brain tumour patients, 16 family members and 16 nurses. They used an exploratory semi-structured interview, conducted at the patients' home or at the hospital. Data were analysed using interpretive phenomenological analysis (IPA). The study reported that relatives wanted more time with the staff to discuss the chaos they were going through, while nurses did not think this was a part of their duties. Nurses also reported that they did not have the training or time to address the complex issues raised by having a brain tumour. Relatives found the staff to be unapproachable and felt rejected. Ironically, relatives still felt rejected when the staff communicated. Widenheim et al. (2002) interviewed 3 families made up of 3 patients, 5 next of kin and reported that families lamented the directness of medical staff about the poor prognosis or perceived that majority of doctors avoided answering their questions. Families reported that negative unsolicited information was a source of anxiety and took away hope from them. Widenheim's (2002) sample was too small to offer generalizable information, but, nevertheless corroborated difficulties in communication with health care providers.

Decision-Making, Quality of life and End of life: Sabo (2014) conducted a literature review on intimate partners of brain tumour patients and highlighted the difficulties involved in discussing Advanced Care Planning (ACP) with relatively young patients. Similar to Widenheim (2002), findings divulged that caregivers rejected early discussions about death. Caregivers were faced with limited choices - between prolonging life or prolonging death, due in part to the aggressive nature of treatments, whose side-effects were considered worse than the symptoms of disease progression. Taking on the role of decision-making at such an emotionally charged time, in the face of disease progression (cognitive and speech deficits) was experienced as stressful by caregivers (Janda et al., 2006, 2008). Sabo (2014) recommended further research on how intimate partners of brain tumour patients coped with

the challenges of decision-making. In contrast, Fritz et al. (2016) recommended that medical practitioners engage early on with patients and caregivers via ACP before cognitive changes and communication difficulties made conversations more difficult. They advocated for the use of ACP in assisting caregivers in their roles as proxy decision makers. Difficulties between medical practitioners and brain tumour caregivers persisted throughout the illness, indicating a complex issue worthy of further research (Janda et al., 2006; Philip et al., 2015).

Spiritual and Existential Needs: Spiritual needs and existential questions were heightened with the diagnosis of a brain tumour. Adelbratt & Strang (2000, p.499) investigated death anxiety by interviewing 20 patients and 15 caregivers. A qualitative hermeneutic approach was taken using a content and context analysis approach. The study concluded that, even though death anxiety was a preoccupation with both patients and caregivers, it was overlooked, not expressed directly by caregivers and remained unaddressed by healthcare practitioners. This was echoed by Strang & Strang (2001) who interviewed both patients and nurses and found that existential issues were poorly understood by healthcare practitioners and difficult to manage in practice, due to lack of time, lack of knowledge and sense of inadequacy.

Salander & Spetz (2002) examined spousal communication patterns regarding discussions about death and dying. They conducted a series of interviews with 25 patients and their spouses at different stages of the illness trajectory. The interviews were analysed thematically and identified four distinct patterns: a) the patient is not aware of the gravity of the situation, the spouse is aware, but acts as if not aware; b) both patient and spouse are aware; the patient does not want to share and they drift apart; c) both patient and spouse are aware, they do not openly discuss the gravity of the circumstance, but share a united front; and d) neither seems aware, keeps living as before. These findings reveal communication

challenges are not between caregivers and health care practitioners only, but also affect caregivers and their loved ones. These studies also confirm the complex and subjective nature of living while dying (Ownsworth et al., 2010) which is not unique to brain cancer (Willig, 2015).

1.5.3 Psychosocial Impact

Psychological Distress, Uncertainty & Hypervigilance: Caregiving for a brain tumour patient had a devastating effect on the family (Sherwood, et al, 2004, 2014; Faithfull et al., 2005; Madsen & Poulsen, 2011; Ownsworth, 2015). Given the uncertain prognosis, the rapidly changing nature of the disease, the aggressive and protracted treatment and it's numerous and unpredictable side effects, coupled with the relative youth of the patient, families experienced high levels of distress. Symptom management, disease progression, fear of seizures, were described as ever-present and impacting day to day activities. The responsibility of being a watchful eye was persistent. Caregivers were afraid to leave their loved ones. Planning activities was difficult due to cognitive, personality, behavioural changes and the unpredictable nature of the disease (Gazzotti et al., 2011). Caregiving was described as intense and relentless (Ownsworth et al., 2015).

Family and Relational Changes: A diagnosis of brain cancer brought about immediate challenges to family roles and relationship dynamics between caregivers, their loved ones, family members, and friends. Caregivers made attempts to adjust to changes as their loved ones rapidly lost the ability to contribute physically, intellectually, emotionally, socially, and financially, due to cognitive and mobility deficits (McConigley et al., 2010). Edvardsson & Ahlstrom (2007) found that neurocognitive changes obliged caregivers to adapt to a new relationship that was quite different from the pre-diagnosis relationship. Caregivers lamented the change from a being a romantic partner to assuming the role of a caregiver. Such role

changes caused further distress. Caregivers had to face the reality of increased

responsibility as well as their partners no longer able to contribute relationally and intimately.

Levels of anxiety and depression were high. Whisenant (2011) investigated caregivers'

experiences of providing care and found that the care-recipient/caregiver relationship

changed dramatically across the short illness trajectory. Unpredictable and unreasonable

emotional behaviour was reported as most distressing for caregivers. Mood and behavioural

changes, such as anger, obsession, hallucinations, indifference, disinhibition and impulsivity,

all symptoms associated with brain tumour depending on location, caused emotional

distress, when their loved ones said and did cruel and mean things deemed uncharacteristic.

Whisenant (2011) recommended more psychological support for brain tumour caregivers.

Employment and Finances: Diagnosis and treatment brought about immediate changes

impacting employment and finances. Sherwood et al. (2008; 2009) interviewed bereaved

caregivers regarding their experiences and found that: a) Brain tumour patients lost the right

to drive immediately after surgery, which led to a new time-consuming task for caregivers –

driving to frequent long distance medical appointments; b) Brain tumour patients had more

than 53 doctor appointments in their first year of illness, meaning caregivers who were in

employment needed to make quick decisions about whether to give up work or to combine

work with caregiving. Appointments were rarely local and involved driving long distances or

flying; c) Not being able to work or cutting back on working hours meant loss of productivity

and less income. McConigley et al. (2010) found that it was a time of rapid change for the

whole family.

In a survey targeting 500 brain tumour patients and their caregivers, the National (American)

Brain Tumour Foundation (NBTF) concluded that "a brain tumour diagnosis is a financial

crisis," whose effects are long lasting for the household (Patterson, 2007, p.3). A total of 277

patients and 224 caregivers completed an online survey administered by SurveyMonkey, consisting of multiple-choice questions. The mean age of the respondents was 45 years. The survey described "the bleak picture of downward mobility" and burden of debt which extended beyond the patient's life. The survey did not provide further information on the impact of the financial hardship. Other studies have found that financial problems contributed significantly to the high levels of distress experienced by brain tumour patients and their families (Ekman & Westphal, 2005; Olesen et al., 2012).

Health and Well-Being: In telephone interviews with 95 brain tumour caregivers, Sherwood et al. (2006, 2007) described brain tumour caregiving as mentally overwhelming, relentless and physically exhausting. Even though caregivers were generally cognisant of the need for *self-care* while they were in the caring role, many found this difficult to achieve and prioritised their caregiving role. Sabo (2014) found that many caregivers struggled with self-care and resisted any suggestions to focus on own needs. Acknowledging stress or fatigue was perceived as a personal failure. Sabo speculated that this was likely based on gendered and sociocultural expectations that women bear *the burden of caregiving*.

Resilience: Caregivers expressed a sense of powerlessness as the health of their loved one declined, but, some found new ways of living. Strang & Strang (2001) found that caregivers expressed a sense of inner strength and resilience. Lipsman et al. (2007), found that caregivers felt grateful and privileged to provide care to their loved ones. Recommendations were made for healthcare practitioners to be trained in strengthening the resilience of caregivers (Sherwood et al., 2004, 2014, 2016).

Caregiver Stories: Using qualitative descriptive exploratory method, Whisenant (2011) recruited 20 patients and their caregivers from a national cancer institute and conducted

interviews using story theory. The study found that caregivers' commitment to their loved ones was sustained throughout the illness trajectory and recommended that researchers explore the use of storytelling to support caregivers. This is supported by Lipsman et al. (2007), who interviewed 22 caregivers using open-ended questions and found that participants were grateful for the opportunity to speak about their experiences.

Bereavement after Caregiving: Rohleder et al. (2009) matched bereaved brain tumour caregivers against healthy controls and then followed them for one-year, correlating measures of psychological distress with biomarkers. Bereaved brain tumour caregivers were at an increased risk of cardiovascular morbidity and premature mortality. Bereaved brain tumour caregivers are at a high risk for mental health problems, such as, clinical depression, general anxiety disorder (GAD), Post Traumatic Stress Disorder (PTSD) and complicated grief (Keir et al., 2009; Goebel von Harscher & Mehdorn, 2011).

Gender Differences: Keir et al. (2006) used questionnaires with 60 caregivers, aged 24-67 years, 20 males and 40 females, to determine which caregivers were at risk of experiencing elevated levels of stress. While there was no significant correlation between age and stress, male caregivers reported 43% more stress than female caregivers. What this implies is that there might be differences between how male and female caregivers respond to stress. Carlson (2001) reported that female brain tumour patients were 10 times more likely to experience separation or divorce during the illness trajectory than men with brain tumours. Female brain tumour patients had a higher vulnerability in comparison to patients with multiple sclerosis, Parkinson's disease and other cancers and "it's still the men who walk away" (p.63). The study advanced that "women by nature are more nurturing and tend to have a higher fidelity to the family," and that women recognised "the importance of the family unit and of standing by and helping with a profound health problem," while "males are more

likely to have a fear-and-flight response in such a situation" (p.63). The influence of gender in GBM caregiving has not been researched.

The Suffering of Caring: Collins et al. (2014) conducted a qualitative study using semi-structured interviews, which aimed to understand the supportive and palliative care needs of brain tumour caregivers at the end of life. Twenty-three brain tumour caregivers (15 current and 8 bereaved) recruited from two hospitals were interviewed. Thematic analysis informed by grounded theory was used to analyse the transcribed interviews. One of the themes emerging was the suffering of caring. It is not clear whether the suffering of caring is limited to end of life stage only, as no research has explored the full illness trajectory. Collins et al. (2013) concluded that brain tumour has a unique disease trajectory, different from the classic cancer trajectory and puts an enormous strain on caregivers. Ramkumar & Elliot (2010) referred to brain tumour caregivers as "de facto extensions of our health care system (p.105)" due to the scope, intensity and duration of their contributions to the welfare of their loved ones. There was an over-reliance on brain tumour caregivers by the health care system.

1.5.4 Psychosocial Support

Limited Provision of Services: Limited provisions of services and early discharge from hospital for brain tumour patients and their caregivers, in comparison to other cancers were reported (BTR, 2017; Ownsworth et al., 2010; Arber et al., 2013; Madsen & Poulsen, 2011). Brain tumour patients and their caregivers were not offered psychological services, as medical practitioners deemed they would not benefit from these services despite evidence to the contrary (Ownsworth et al., 2010; Salander, 1996; O'Donnell, 2005). Palliative care for BT patients was underutilised (Langbecker & Yates, 2016). The interface between treatment, neuro-oncology and palliative care was poorly managed. Aggressive treatments continued in

part due to the relative youth of brain tumour patients, which means caregivers provided high intensity rapidly evolving care without assistance from palliative care (Ownsworth et al., 2015; Philip et al., 2015). Medical practitioners were hesitant to recommend palliative care as these patients were not typical of the palliative care population (Philip et al., 2015; BTR, 2015). A limitation of the studies is that they are specific to end of life care and cannot be generalised to the needs at different stages of the illness trajectory.

Challenges Balancing Hope with Reality: Philip et al. (2015) conducted semi-structured interviews with 35 medical and nursing practitioners engaged in providing care for brain tumour patients. They found that caregivers "navigate a system of care which has many shortcomings" including lack of support and restricted services. Medical practitioners found it challenging to balance hope with reality for patients whose prognoses were dire and caregivers whose needs were complex. A medical oncologist was quoted:

> *It's an awful situation where you kind of hope that their tumour grows*
>
> *to the extent that they can be moved to the hospice because that's*
>
> *really the best place to manage them.*

This research is significant because it offers a rare window into healthcare practitioners' attitudes towards brain tumour patients and their caregivers.

Social isolation and stigma: Brain tumour caregivers value support, especially from family members, friends and medical practitioners (Strang & Strang, 2001; Sherwood et al., 2004; Janda et al., 2006). As the illness progressed, many reported being socially isolated. Treatment with corticosteroids and anti-seizure medication had many adverse side effects, such as "moon face" (Cushing's syndrome), weight gain, impulsivity, aggression, fatigue,

mood swings and personality changes. Caregivers reported fear of being stigmatised and having to protect their loved ones' dignity. Edvardsson & Ahlstrom (2011) found that stigma surrounding neurological and functional deficits in brain cancer contributed to the limitation of social contacts. There is no research on stigma and brain tumour.

Forgotten Voices: Sherwood et al. (2004) referred to brain tumour caregivers as the "forgotten voices" (p.67) and advocated for research to prioritise the perspectives of caregivers. This was echoed by Holge-Hazelton (2011, p.118) who referred to brain tumour patients as overlooked, invisible, vulnerable, marginalised and urged researchers to "challenge the traditional hierarchy of knowledge" by giving participants an opportunity to express their subjective experiences through their own preferred methods of communication. Hricik et al. (2011) found that as the disease progressed, caregivers often sought more support from people going through a similar situation, because they were able to relate to their situation and provide information on how to cope. Cashman et al. (2007) reported that 70% of 24 caregivers seen at a neuro-oncology clinic found it beneficial to share their experiences with other caregivers. Whisenant (2011) affirmed that caregivers in a group setting expressed value in "telling the story" of their experiences of caregiving.

Social support groups: Horowitz et al. (1996) and Sherwood et al. (2004) found that social support groups can mitigate negative impacts of caregiving, such as anxiety and depression. Research by Janda et al. (2006) reinforced the notion that support groups were a valuable source of information and hope. *Online Support Communities:* Caregivers sought information and shared supportive resources online. Caregivers relied heavily on brain tumour websites and other social network sites to ask questions, seek support, share experiences, and discuss concerns (ABTA, 2017). As the disease progressed, caregivers tried to find ways to cope and maintain hope (Whisenant, 2011; ABTA, 2017). 90% of caregivers, 20 males and

40 females, 24-67 years old, preferred support programs that were accessible from their homes (Keir et al., 2007), implying that online intervention programs have the potential for emerging at the forefront of supportive care interventions.

1.6   Rationale for the Research

The rationale for this research emerged and developed from the literature review which focussed on three inter-related areas: psychosocial needs, psychosocial impact and psychosocial support for brain tumour caregivers. The aim was to "pull many pieces of information together" in a cogent format, "bring certain issues to light" and present a focussed perspective on the topic of brain tumour caregiving (Green & Johnson, 2006, p.103). The first of the three underlying questions in the literature review was: a) *What is the current knowledge on the psychosocial experiences of brain tumour caregivers?* Research on the psychosocial experiences of brain tumour caregivers revealed that brain tumour has a unique cancer trajectory. Brain tumour caregivers have distinct supportive care needs unlike those of other cancer trajectories. Brain tumour caregivers reported the highest levels of psychological distress amongst all cancer caregivers. They also had the highest unmet needs. Despite this, health care systems relied heavily on them to provide complex care needs, such as intensive emotional and practical support on matters medical, which included seizures and neurological deficits without any training or preparation. In addition, brain tumour patients and their caregivers experienced inequalities in the provision of services, such as palliative and rehabilitation care which increased caregiver burden. Brain tumour caregivers felt invisible and ignored**.** *Post-bereavement* caregivers were more likely to suffer from anxiety, depression, PTSD and premature death due to heart disease (Catt et al., 2008). Caregivers continued to be at high risk for poor mental and physical health. A higher number of brain cancer caregivers (compared to other cancers) were referred for psychiatric evaluation.

The second of the three underlying questions stated at the beginning of the literature review was: *b) What are the significant theoretical and methodological procedures employed by researchers?* Research was predominantly from a biomedical perspective, and rarely included the direct experiences of caregivers. Instead, researchers used literature reviews, telephone interviews, online surveys, mail questionnaires, patient hospital records and semi-structured interviews to collect data. Most studies targeted large numbers of hospital patients with mixed tumours and tended to include caregivers, patients, healthcare practitioners, male and female, all in the same research. Further, not all studies specified the theoretical framework upon which their research was based. Burns & Grove (2009) state that theoretical and conceptual frameworks that clearly express the logic on which a study is based play a significant role in building upon past research. In addition, most studies derived from the disciplines of neuro-psychiatry, neuro-oncology, nursing, psychiatry, palliative and hospice care. Lastly, research on the illness trajectory was fragmented and skewed towards end of life care.

1.6.1 Gaps in the Literature Review

The last of the three underlying questions stated at the beginning of the literature review was: *c) What research still needs to be done and why?* This question speaks directly to the gaps in the literature. The challenges facing brain tumour caregivers are not conclusively dissimilar to other disabilities or cancer caregiver populations. However, when viewed in totality, it appears that brain tumour caregivers face one of the most challenging experiences in caregiving which remains undocumented in caregiving research (Collins et al., 2014; Philip et al., 2015; Langbecker & Yates, 2016).

Brain tumour caregivers are a population worthy of increased research and in particular a focus on illuminating the unique cancer trajectory would increase understanding and inform practice. There is a need to develop specialist supportive interventions to mitigate the high

unmet needs. Ignoring this research gap means that unparalleled expectations are placed on brain tumour caregivers to carry out complex medical, social, advocacy and emotionally supportive tasks beyond that of traditional caregiving, and undermining their own health in the process (Ownsworth, 2015). The research identified multiple gaps too numerous to be addressed in this study. The research proposes that the following lenses have the potential to mind the gaps identified in the literature review and bring them into consciousness, thus expanding our understandings of the psychosocial experiences of GBM caregivers.

1.6.2 Feminist Perspectives

Amaresha et al. (2015) tabulated the gender of all brain tumour research participants and found that women caregivers made up to 90% of research. Research on brain tumour caregiving has not interrogated this trend. Williams et al. (2017, p.6) investigated the gender of all caregivers and found that women bear constitute the majority of caregivers for the sick, disabled, chronically or terminally ill and were central to the provision of palliative and end of life care. The study concluded that women are "the cornerstone of care, although their role is often obscured by the euphemism *family care*" (p.6). Gender differences in responding to stress has received support in research (Keir et al., 2006; Carlson, 2001; Sabo, 2014).

Health psychologist Shelley Taylor (2000, 2002) argues that Hans Selye's (1956) universally accepted fight/flight response applies only to one half of the population – men. She argues that faced with challenging circumstances women view affiliation and cooperation as a more beneficial response. Tend and befriend theory (Taylor, 2000) proposes that women seek connections, nurture relationships and have the tendency to form alliances or come together in groups to respond to stressful life events. This implies there are differences between how male and female caregivers respond to stress. A feminist perspective on brain tumour caregiving provides an additional lens to counter the overwhelming biomedical perspective evidenced in the literature review.

1.6.3 Narrative Perspectives

Narrative perspectives centralise and give voice to narrators. Giving voice means "empowering people to be heard who might otherwise remain silent" (Bogdan & Biklen, 1998, p.204). The loud and authoritative voice of biomedicine, even though fragmented and aloof has suppressed GBM caregivers' voices, possibly resulting in loud, authoritative, fragmented and aloof care. Giving voice to GBM caregiver stories with a focus on subjective, collective narratives and the storytelling landscape has the potential to illuminate multidimensional, multifaceted, contextualised aspects of the psychosocial experiences of GBM caregiving that remain silenced when researchers use voiceless methods, such as hospital records.

1.6.4 Counselling Psychology Perspectives

Counselling psychologists have not explicitly engaged with the topic of brain tumour caregiving. Clinical themes emerging from the literature review which overlap with counselling psychology concerns were addressed solely from a biomedical perspective painting mostly a picture of pathology. This is problematic because philosophical underpinnings of counselling psychology acknowledge that the dilemmas of human existence are too complex to be explained solely by the medical model and empiricism (Strawbridge & Wolfe, 2010). A summary of what a counselling psychology perspective entails follows.

Counselling psychology as an applied discipline within professional psychology has its origins in existential-phenomenological and humanistic philosophies. Currently, counselling psychology co-exists with the medical model and holds both empiricist and subjectivist epistemologies (Douglas et al., 2016). Numerous debates have focussed on these conflicting epistemologies as a disadvantage, while others have suggested embracing

plurality as a pathway to engaging with subjectivity, diagnostic categories, while understanding the client holistically as a related being, embedded in a worldview (Hansen, 2005: Lane & Corrie, 2006; Milton, 2010).

A counselling psychology perspective, values feminist theories, which include a focus on diversity, intersecting identities, empowerment and social justice (Remer & Oh Hahn, 2012). *The Guidelines for Psychological Practice with Girls and Women (APA, 2007*) emphasises collaboration, diverse methodologies, self-reflection and the belief that theory and practice should always be evolving and emerging. A feminist perspective in counselling psychology does not infer homogeneity and in fact values multiple ways of knowing and being. In this study, a feminist perspective is based on sets of values which inform research and practice and are not exclusive to women, but rather embrace Adichie's (2016) stance that *We Should All Be Feminists.* In a sum, a counselling psychology perspective on brain tumour caregiving aims to honour subjective experiences as well as group experiences, while shedding light on the conditions that facilitate therapeutic encounters and foster resilience and growth. These themes are the bedrock of counselling psychology research and practice and feature prominently in the current edition of *the Handbook of Counselling psychology* (Douglas et al., 2016).

Counselling psychology, based on its multiple epistemologies does not assume one way of knowing and is influenced by a variety of positions, which have become known as scientist-practitioner-model, reflective-practitioner-model and researcher-practitioner-model (Corrie & Callahan, 2000; Strawbridge & Wolfe, 2010; Henton, 2012). This does not mean that the debate on this conflicted conceptual framework (Van Deurzen, 2002) or epistemological contradiction (Corrie & Lane, 2011) has been resolved. There is still a sense that counselling psychology by expanding its knowledge base betrayed its humanistic origins and failed to

forge a firm identity for itself (Hansen, 2005; O'Hara, 2014). This debate is ongoing (Cooper & Dryden, 2016).

Amidst the debates on conflicting epistemologies, I embrace Cooper's (2009) stance of "Welcoming the Other" and the 5 pathways he proposes counselling psychologists can use to synthesise their core values. These pathways are: a) developing the capacity to see beyond diagnoses, b) enhancing responsiveness, c) focusing more fully on the intelligibility of clients, d) taking a lead in giving psychology away, and e) developing the evidence base, by distinguishing counselling psychology from other practitioner psychology disciplines (the centralisation of the core humanistic values). This study engages with these core values throughout the research process.

1.7   Research Aims & Questions

DIAGRAM 1.7.1: RESEARCH QUESTION 1

Research Question 1

- **What kinds of stories do GBM caregivers narrate online?**

Aims

- **Illuminate individual stories**

- **Illuminate collective story typologies**

- **Illuminate the relationship between the events being narrated and the event of narration, that is: what happens, as, a result, of story-telling?**

Purpose

- **Shed light on the conditions that cause suffering by highlighting psychological needs**

- **Shed light on the storytelling landscape by highlighting the therapeutic nature of storytelling (or not)**

Goals

- **Enhance professional listening for clinicians by providing a "simple structure of what to listen for"**

- **Expand practitioners' sense of response-ability in how they might respond to what is heard**

- **Give voice to GBM caregivers and their stories**

Research Question 2

- **Looking back on the stories you shared online- Can you please tell me about the stories, the responses you received, and, whether, or not, you are still sharing stories online?**

Aims

- **Further illuminate the storytelling landscape by gaining a retrospective/hindsight aspect, either, supporting or disavowing the performative aspects of storytelling, including the research findings.**

Purpose
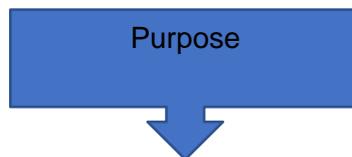
- **Give voice to research participants by providing an opportunity to contribute feedback on the research findings, either supporting or disavowing the findings**

Goals

- **Share ownership of the research with the researched**

- **Provide further credibility and authenticity of the research findings**

2 Chapter Two: Methodology

2.1 Overview

This chapter is concerned with four aspects of the research study; the research question, the ontological and epistemological stance, the theoretical perspective, and the method. The aim is to describe the research methodology in detail, while, the goal is to achieve transparency by providing a step by step rationale for the many decisions and choices made throughout the research study. I begin with research positionality and disclose my personal engagement with the research topic and subsequently discuss the ontological and epistemological basis for the research design and present qualitative research as best suited for answering my research question and Narrative Inquiry as the most suitable method for conducting my research. Next, I expand on the influence of social constructionism, feminist relational theories and narrative humility as intrinsic to my theoretical framework. I then present Dialogical Narrative Analysis (DNA) as the chosen method of analysis of data. A description of the research design, recruitment, selection criteria, participants, data analysis, ethical considerations and limitations of the study follow. Finally, I elaborate on the congruence between counselling psychology and narrative inquiry. Throughout the study, I consider the impact of my personal context upon the research process by holding the assertion by Denzin & Lincoln (2003, p.29), that behind "theory, method, analysis, ontology, epistemology, and methodology" (...) "stands the personal biography of the researcher." What this means, is that I endeavour to interweave reflexivity into all aspects of the research which begins with research positionality.

2.2 Research Positionality

Research positionality aims to make transparent the decision-making process which influence and shape the study throughout the research (Foote & Bartell, 2011). Herr & Anderson (2005) came up with several research positions along a continuum, the most

debated ones being insider/outsider positions. The positionality that I bring to this research is coupled with my experiential knowledge and central to the understanding of who I am as a counselling psychology researcher. Increasingly, counselling psychology researchers are advocating for a more participatory and reflexive practice, enjoining researchers and participants in a process of co-inquiry and co-construction of knowledge (Chou et al., 2016) or methodological pluralism (Cooper & Dryden, 2016). Debates about the merits and demerits of outsiders or insiders are ongoing (Hayfield & Huxley, 2014).

I take the position that it is not possible to be a complete insider or a complete outsider in counselling psychology research, because research is part outcome of the relationship between the researcher and researched (Clandinin, 2016). Kerstetter (2012) urged researchers to move beyond the insider and outsider merit and demerit debate to embrace "the space between" (Dwyer & Buckle, 2009) as all researchers fall somewhere between complete insiders and complete outsiders. Hayfield, (2014) suggests that all researchers ought to take responsibility for making transparent how their positionality affects the research process and its findings.

As a GBM caregiver, I considered myself an insider, because of my shared experiences with other GBM caregivers. However, I heeded Audre Lorde's (1984) caution that, even as I focus on what holds us together, I should be mindful of differences and reflect on what this means. I remained aware that "insiderness" may be eroded by factors such as race, culture, social class, sexual orientation, education, and religion; while the quality of relations I cultivated with my participants could potentially outweigh any perceived "insiderness" or "outsiderness." Aware of the dynamic nature of positionality, I engaged in several activities with an aim to reflect on how my so-called insider position was an impediment or a facilitator

in the co-construction of knowledge (Clandinin, 2016). These activities are elaborated on throughout the research process and addressed comprehensively in Section 4.9.

2.3   Research Design

Clandinin & Murphy (2009) assert that different research paradigms are linked to different ontological, epistemological and methodological perspectives to create knowledge. They argue that ontological and epistemological questions need to be situated in an expansive view, which begins with a clarification of assumptions around the research question and methodology. The research question is a statement which identifies the phenomenon to be studied. Methodology encompasses all the strategies, designs, plan of action and processes influencing the choice and methods, used to answer the research question; beginning with an explanation of the ontological and epistemological stance. The word ontology originates from the Greek word *ontos* "being", and *logos,* "study". Ontology is the study of the nature of reality and being, and the perspective which shapes the researcher's beliefs about reality. Ontological questions are concerned with "how things really are" and "how things really work" (Guba & Lincoln, 1994, p.108). Likewise, the word epistemology originates from the Greek word *episteme,* which means knowledge. Epistemology is the theory of knowledge and the nature of the relationship between what can be known between the researcher and the researched. Epistemology poses the question: How can I know reality? Ontology and epistemology, thus, provide the philosophical stance or theoretical perspective informing the methodology, and providing a context for the research process in terms of logic and criteria. Methods are the techniques or procedures used to gather and analyse data related to the research question as illustrated by the table below (Bloomberg & Volpe, 2008; Creswell, 2003; Crotty, 1998).

DIAGRAM 2.3: RESEARCH METHODOLOGY

| THE RESEARCH QUESTION | ONTOLOGY EPISTEMOLOGY | THEORETICAL PERSPECTIVE | METHODOLOGY | METHODS |
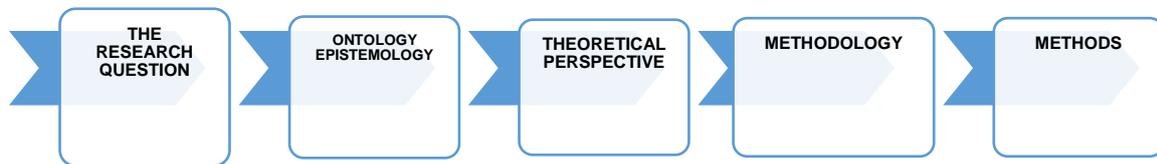
2.3.1 Rationale for Qualitative Research

Counselling Psychology is entrenched in both quantitative and qualitative research and embraces a pluralistic stance in research and practice (Cooper & McLeod, 2011). Quantitative methods have contributed significantly to psychology's scientific identity, while qualitative methods have been used to illuminate subjective experiences, making them both valuable tools for knowledge acquisition. Distinctions between quantitative and qualitative methods can be summarised by their contrasting perspectives about knowledge. Quantitative research is framed as positivist, realist, objective, deductive, and normative, and employs methods which aim to discover the truth/reality. Meanwhile, qualitative research takes a relativist, subjective, inductive and interpretive stance which seeks to explore phenomena in their natural environments (Bloomberg & Volpe, 2008; Willig, 2008).

Qualitative methods commonly used in counselling psychology research are Discourse Analysis (DA), Grounded Theory (GT) and Interpretive Phenomenological Analysis (IPA). I will briefly clarify why I did not use them. The focus of DA is on language and how it is used to represent social reality. The inquiry analyses speech or text within a social context and what it achieves as part of social action (Willig, 2008). My focus was not on units of speech *per se,* but rather, on the holistic understanding of my participants' stories. So even though my participants' stories could be regarded as text, DA was not considered a match for the research focus. I considered that GT was compatible with my research question, but after

familiarising myself with the details, it appeared that the most commonly cited reason for GT was discovery and generation of theory. This was not germane to my research question, which emerged from conducting a literature review on brain tumour caregiving research and identifying gaps in the literature. Further, my aim was to expand on what other researchers had described, which means I could have used IPA. IPA has a special standing in counselling psychology, as the preferred methodology, because of its emphasis on lived experience (Willig, 2008). The primary goal of IPA is to investigate how participants make sense of their experiences, which made it incompatible with my research focus, as my participants had already storied their experiences (Sarbin, 1986).

Willig (2012) advices researchers to reflect on their aims for the research before deciding on methodology. From the outset, my research question: What kinds of stories do GBM caregivers narrate online? - aimed to illuminate the GBM caregiving experience throughout the illness trajectory and post-bereavement. This would have involved descriptions and interpretations, making it more compatible with qualitative research (Crotty, 1998; Willig, 2013). Central to my research question were online brain tumour caregiving stories, which led me organically towards Narrative Inquiry as the chosen method.

2.3.2   Rationale for Narrative Inquiry

There is the contention that all qualitative research originates from the narrative (Sarbin, 1986; Bruner, 1991). Josselson (2014) discloses that she was "at pains to distinguish narrative analysis from phenomenology, discourse analysis, grounded theory or intuitive analysis," because, "narrative researchers often incorporate all these strategies in their toolboxes." She questioned whether narrative inquiry could be sufficiently discerned as a "unitary endeavour with homogeneity of approach and analytic strategy differentiated from other qualitative approaches" (p.146). In the next section, I highlight the characteristics that distinguish narrative inquiry as an autonomous research methodology.

Historically, stories and story-telling have been the means through which individuals and groups have provided day to day insights about their desires, motivations and actions. These stories are the means through which individuals and groups have created meaning and passed on knowledge since time immemorial. Narrative Inquiry emerged from the view that human beings, individually and socially, live storied lives (Sarbin, 1986). Their daily lives are shaped by the stories they tell about themselves; Their cultural selves are embedded in the stories they have internalised from families, relationships, communities and cultures. They experience and interpret the past, present, and the future by the use of the stories they tell (Josselson, 1996). Story is described as "a portal through which, a person enters the world, and, by which, their experience of the world is interpreted and made personally meaningful" (Connelly & Clandinin, 2006, p.477).

Narrative Inquiry is a cross-disciplinary study, which does not fit within "the boundaries of any single scholarly field" (Riessman & Speedy, 2006, pp. 426-427). Interest in Narrative Inquiry, as a human science, is a 20th-century development credited to the collective writings by narrative scholars in the mid-80s (Bruner, 1986; McAdams, 1985; Sarbin, 1986; Polkinghorne, 1988; Gergen & Gergen, 1988; Berger & Luckmann, 1966). These writings are credited with "the narrative turn", defined as: "renewed interest in narrative inquiry as a method of inquiry, distinct from other methodologies" (Riesman, 2008, p.14).

A proliferation of narrative inquiry research has resulted in multiple and contradictory views of what narrative is and what it does (Riessman & Speedy, 2006). Narrative Inquiry has been described as: A perspective within the discipline of psychology concerned with the "storied nature of human conduct" (Sarbine, 1986, p. vii); Theory of thinking (Bruner, 1986); Mode of meaning making (Polkinghorne, 1988); Process of shaping identity (McAdams, 1985); Social interaction (Gergen & Gergen, 1988); "The most developed social constructionist form of theory, inquiry and practice" (Gergen, 2001, p.29); A conduit to *give voice* to marginal

populations (Chase, 2005); Profound source of hindsight and retrospective thinking (Freeman, 2009); A "principal channel for listening to silenced voices" (Spector-Mersel, 2010, p.207); Therapeutic practice (White & Epson, 1990; Angus & McCleod, 2004); The study of experience as story, (…) and a way of thinking about experience (Connelly & Clandinin, 2006, p.477); A paradigm (Spector-Mersel, 2015); A Method of inquiry (Clandinin, 2016) and; A worldview (Clandinin, 2015). A worldview is defined as a framework of the basic assumptions about the values and beliefs individuals and groups hold about the nature of the world, and which they use to understand themselves, their environment and live their lives (Hiebert, 2008).

This research has adopted Sarbin's (1986) the definition of narrative inquiry as a worldview and an organising principle for human action by integrating; - Crossley's (2000) viewpoint of narrative as a structure for the flow of experience, which includes the way human beings think, perceive, imagine, identify, interact, act, and make moral choices - ; and, Chase's (2005, p.665) definition of narrative inquiry as "a conduit to give voice" to marginal populations. At the core of narrative inquiry are the concepts of relational being (Gergen, 2016) and narrative knowing (Bruner, 1985). Relational being is the position that: "People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context" (Clandinin & Connelly, 2000, p.2). Narrative knowing is described by Brunner (1986, 2004) as knowledge that is created and constructed through stories of lived experiences, because the listener can hear the suffering of the storyteller in their attempts to make sense of the unfolding events. Narrative knowing emerges from experience, to unravel the ambiguity and complexity of human lives by bringing together layers of understanding about personal values, beliefs, hopes, intentions, experiences, and how they are storied within time and societies to create meaning and change (Clandinin & Connelly, 2000; Clandinin, 2016).

Narrative Inquiry has multiple philosophical influences, the most pertinent for this research are social constructionism (Berger & Luckman, 1966; Gergen, 2009; Burr, 1995), feminist relational theories (Gilligan, 1982; Baker-Miller, 1976; Jordan,1991; Hill-Collins; 1991), and narrative humility (Tervalon & Murray-Garcia, 1998; Das Gupta, 2014). *Social Constructionism* is an epistemological stance underpinned by multiple theories for which there is no single agreed upon definition. Social constructionism can be identified by its underlying assumptions of anti-essentialism, anti-realism, knowledge as co-constructed and social action. Anti-essentialism, a critical stance towards taken-for-granted knowledge, challenges "the view that conventional knowledge is based upon objective, unbiased observation of the world," including categories we use to understand the world (Burr, 1995, p.2). Anti-realism advances that there is no such a thing as the truth, and all knowledge is historical and culturally specific, meaning that the way individuals and cultures are perceived is specific to periods in history. For example, the opening chapter of Michel Foucault's (1977, p.3) *Discipline and Punish* describes a scene in 1757 in which a condemned man is tortured before his body is "drawn and quartered by four horses" as punishment for his crime. Through international laws, conventions and treaties, there is nearly global agreement today against the practice of torture as punishment or otherwise.

Social constructionism also holds a critical stance on theories about human behaviours generated by psychology, arguing that they are cultural, time-bound and not be taken for granted. Social constructionism argues that knowledge is co-constructed, through social interactions and processes that people encounter daily. Knowledge and the knower are viewed as interdependent and embedded within context, culture, language, history and experience; emphasising relational knowing or the co-construction of knowledge. Lastly, social constructionism views research as a catalyst for social action (Gergen, 2009; Burr,1995).

Feminist relational theories have also contributed to shaping Narrative Inquiry. While I did not set out to recruit women only, all my participants are women. It can be argued that caregiving is a gender role (APA, 2016; United Nations, 2017). In this research, feminist relational theories are conceived from the works of Jean Baker Miller in *Toward a New Psychology of Women (1976);* Carol Gilligan's (1982) *Psychological Theory and Women's Development;* Nel Noddings (1984) *Caring: A Feminist Approach to Ethics & Moral Education (*Belenky et al.,1997) *Women's Ways of Knowing;* and Hill-Collins (1992) *Race, Class and Gender.* Feminist relational theories critique the promotion of individualism as a false premise, referred to as "the myth of the separate self," (Jordan, 2002, p.1) based on the Western ideal which promotes individuality and independence as the ideal goal for human beings to attain. Feminist theories place relationships at the centre of understanding and the conduit to human agency and empowerment (Jordan, 2001; Jordan, 2008). Feminist theories value multiple ways of knowing, collaboration, equality, diversity, and view research as an opportunity to engage in the promotion of empowerment through the dismantling of power relations between the researcher and the researched. Feminist theories aim to foster the use of reflexivity, humility, self-disclosure, intuition, metaphors and dreams in research (Etherington, 2004; Thayer-Bacon, 2011; Gergen, 2016).

This research also draws on principles espoused by *Narrative humility* (Dasgupta, 2014), which has its origins in Cultural humility (Tervalon & Murray-Garcia, 1998). Cultural humility emerged in response to critiques against cultural competence when Tervalon & Murray-Garcia (1989) pointed out that, while being culturally competent is desirable in our daily interactions with diversity, it is not enough in practice, because complete mastery of each culture's way of being is impossible. They proposed that instead, practitioners should adopt a stance of not knowing and allow patients to educate them on how little or how much culture is a factor in their beliefs and behaviours. Borrowing heavily from this, Dasgupta (2014) describes narrative humility as a stance that acknowledges we cannot become 100%

competent in comprehending other peoples' stories all the time. Dasgupta (2014, p. 980) explains that narrative humility means engaging in a relationship with stories, while "remaining open to their ambiguity and contradiction", which necessitates "constant self-evaluation and self-critique about issues such as, our own role in the story as listeners, our expectations of the story, our responsibilities to the story, and our ownership of the story." Narrative humility promotes the "very act of listening" (p.980) in a socially just manner to all kinds of stories, whether they are comfortable, familiar or challenging stories from the margins that are oftentimes silenced. This perspective compliments narrative inquiry in its support and exploration of multiple voices including "subject positions, social locations, interpretations, and personal experiences" (Chase, 2005, p.666).

In a sum, my understanding of narrative inquiry is as, an innate human impulse which permeates all cultures. It is both the method of inquiry and the outcome; both a process and a product; and both the means of gathering data and a type of data (Bruner, 2004) which provides researchers with a rich framework through which the storied nature of human experiences can be explored (Sarbine, 1986). A discussion on Narrative Inquiry would not be complete without some clarification on the distinction between story and narrative, sometimes used interchangeably (Reissman, 2008). This study adopts Frank's (2010) clarification that stories are commonly available resources within people and societies, that are used to construct narratives, while narrative is a term denoting the "collective storied wisdom" of people's individual stories", which is different from a single story" (Emden,1998, p.35). Narratives are generated from stories, which share recognisable plots and themes (Frank, 2010), for example, illness narratives (Kleinman, 1988) which are the subject of this research.

2.3.3   Illness Narratives

In this study, illness narratives are defined as stories written by" intimate others" or "proximate others" (Eakin, 1998, p.171) about the experience of caregiving for a loved one diagnosed with GBM. Illness narratives "offer an unmatched window into subjective experience" (Hyden, 1997, p.49). Cassel (1991, p.183) promotes the inclusion of "narratives by care-givers as authentic contributions to the understanding of illness experience". The term illness narratives originated from sociologist Arthur Kleinman's, *Illness Narratives: Suffering, Healing, and the Human Condition (1988).* In this seminal work, Kleinman differentiates between disease and illness; describing disease as a pathological and biological condition originating from the physical body and of primary concern to the medical fraternity; while, distinguishing illness as a personal and subjective innate human experience of suffering the social and cultural effects of living with disease. Illness narratives arose from the recognition that the focus of biomedicine was on technological and scientific advances and did not capture the effects of disease on individuals and their loved ones.

Illness narratives are driven by the desire of ill individuals and their loved ones to tell their stories. Illness narratives are a method of giving voice to the experiences of individuals and groups considered marginalised by biomedicine. Illness narratives evolved out of the increased medicalisation of illness, which, Foucault (1963) referred to as *the clinical gaze* which does not represent the ill, who as a result, need empowerment through the expression of their own stories (Kleinman, 1988; Frank,1995).

2.3.4   Rationale for Dialogical Narrative Analysis (DNA)

In Narrative Inquiry, stories are viewed as socially situated knowledge constructions, which can be analysed or interpreted using a variety of narrative analyses depending on the researcher (Hunter, 2010). Narrative inquirers have various frames for observation and

understanding which offer varying interpretive approaches that can be used to interrogate and elucidate data, with each researcher selecting different aspects of the story as their focus (Dibley, 2011).

Dialogical Narrative Analysis (DNA) was chosen as the method most compatible for interpretation and analysation of the data. DNA is a method which explores "the mirroring between what is told in the story - the story's content – and, what happens as, a result of telling that story – its effects" (Frank, 2012, p.71-72). DNA aims to illuminate the mutual dependence between story typologies (content) and the effects of storytelling. DNA emphasises the importance of exploring the relationship between the events being narrated and the event of narration.

RESEARCH QUESTION

i. What kinds of stories do brain tumour (GBM) caregivers narrate online?
ii.What happens as a result of storytelling ?

EPISTEMOLOGY

Post-Modernism - Post-Structuralism - Social Constructionism

THEORETICAL PERSPECTIVE

• **Qualitative Research - Narrative Inquiry - Dialogical Narrative Analysis -Feminist Relational Theories - Narrative Humility**

METHOD

• **Dialogical Narrative Analysis - Online Stories - Posts - Blogs - Email Interviewing - Focus Group - Reflexive Diary - Participant communication - Participant Feedback**

2.3.5 Congruence between Counselling Psychology & Narrative Inquiry

Despite sharing multiple similarities with counselling psychology, both narrative therapy and inquiry remain peripheral in practice and research (McLeod, 1998; Wells, 2011). Counselling psychology, like narrative inquiry, does not claim to discover "the truth," but rather, acknowledges the complexities of how individuals and groups create and are created by the societies in which they live (McLeod, 1998). This research study is influenced by the collective philosophies of social constructionism, narrative theories, feminist relational theories and narrative humility, all of which emphasise that the world cannot be understood through one over-arching system of knowledge, and instead allow for multiple possibilities, available to those who expand their perspectives, dig in deep, seek and embrace multiple realities.

Social constructionism has gained influence in counselling psychology, but not without raising some questions. Hansen (2005, 2011) critiques counselling psychology as having abandoned one of the most fundamental tenets of psychotherapy, which is to place a premium value on inner subjective experiences (ISE) of clients. Narrative researchers respond that ISE, like stories in narrative inquiry, do not emerge from a vacuum, but are embedded in social and cultural contexts which shape meaning (Clandinin, 2016). Narrative inquirers posit, that exploring ISE within social and cultural contexts has the potential to provide richer and deeper insights, which does not mean ISE is not important. At the core of both counselling psychology practice and narrative inquiry lie life stories, which have led to the suggestion by McLeod (2008) that all therapies are narrative, and counselling can be understood as a process in which clients tell, retell and re-author their lives.

This section aimed to illustrate a clear fit between the research question, counselling psychology, social constructionism, narrative inquiry, feminist relational theories, narrative humility and DNA. I espouse Kasket's (2012, p.65) standpoint of counselling psychology as distinguishable by its willingness "to expand its horizons to accommodate a plurality of viewpoints, a multitude of possibilities and an infinite variety of potential "truths".

2.4   Ethical Approval

This study complied with the core principles of human research ethics as outlined by *The British Psychological Society Code of Human Research Ethics* (BPS, 2014), the *Health and Care Professions Council's guidance on conduct for students* (HCPC, 2012) and the Association of Internet Research (AoIR) Ethics Working Committee on Internet Research (version 2), see http://www.aoir.org/reports/ethics2.pdf (Appendix T) which formed the basic readings for this study and the guidelines were followed rigorously. This study received ethical approval from the Psychology Department, Research Ethics Committee at City University, London, the details of which can be found in Appendices section as Appendix A.

2.5   Procedure

2.5.1   Recruitment

I created a website www.glioblastoma-narratives.org (Appendix B) and asked bereaved

GBM caregivers, who had previously shared their stories online, if they would be willing to

volunteer the online stories for research, in addition, to participating in an email interview. A

contact email was provided. All the necessary precautions were taken to assure potential

caregivers that their safety, privacy and well-being would be protected and respected. Even

though the website attracted more than 200 visitors in a week, only 4 potential participants

expressed interest. Given the low number of recruits, several advertisements were placed on

several online brain tumour community forums requesting interested participants to get in

touch via email.

Bereaved caregivers who expressed interest in participation were provided with the

participant information sheet (Appendix C) (encouraged to ask any questions, and allowed

time to consider their participation). Reminders were then sent a week later and those who

were willing to participate provided with informed consent forms (Appendix D). They were

reminded that they would be consenting to their online stories to be used as research data.

They were also informed of additional requirements: a) to participate in an email interview

regarding their retrospective perspective on their online stories (Appendix E), b) complete a

brief demographics questionnaire with basic questions: Name, Age, Geographical location

(Appendix F), and c) be open to providing feedback on the findings.

The responses to the recruitment were challenging and involved numerous back and forth

communication with potential participants. All four potential participants who had expressed

interest initially suddenly went cold. Reflecting on the reason with the remaining potential

participants, I was informed that my plan to use SecureSafe for communication was too

complicated. A request for an amendment to recruitment procedures allowing for the use of

PDF/DropBox was approved (Appendix G). Originally, 12 participants received information

participant sheets. 8 participants, all female, 7 spouses and 1 mother were briefed via participant information sheet and encouraged to ask any questions. 8 participants signed informed consent authorising the use of their online stories for research, in addition to consenting to participate in an email interview at a time of their choice and convenience. All participants completed demographic questionnaires. All participants were debriefed (Appendix H). All participants received information on psychological help (Appendix I). Initially, I had intended to recruit 9 participants, but this was later revised to 7 (Appendix J) when the first few stories trickled in revealing hundreds of pages. Most participants had written stories covering between 1-3+ years (Appendices K-Q).

2.5.2 Participants

Participants were bereaved caregivers who had already shared their stories online. These stories were shared within conversations with other brain cancer caregivers. I considered this suitable because my research aimed to capture the entire caregiving experience. I also considered it an advantage to gain access to unfiltered stories, devoid of the researcher's influence. Feminist relational research advocates for researchers to use their participants' preferred method of communication (Illingworth, 2001). I considered that caregivers, who had previously shared stories online and expressed willingness to participate would have experienced the benefits (or not) of storytelling, which is of interest to the research. The literature review suggested some gender differences in the experience of brain cancer caregiving for males and females. The literature review also showed that research with brain tumour caregivers did not prioritise the caregiver's voice. Since my research aim was to give voice to brain cancer caregivers, I considered it would be antithetic to exclude any participant based on gender. The question of how soon it is appropriate to ask bereaved caregivers to participate in research found no easy answer. Research showed variations from 3 to 6 months-post-bereavement (Stroebe et al., 2003). I decided on 12 months-post-bereavement based on several research studies, which showed a high rate of

decline/dropout and non-participation with bereaved caregivers at less than 12 months' post-bereavement (Stroebe et al., 2003).

2.5.3 Sample

A minimal amount of demographic information was collected. The sample consisted of 7 GBM caregivers, six spouses and one mother. There were no male participants. Participants were all professionals, except one who described herself as a housewife. Ages ranged from 32 years to 58 years old. Care-recipients were all male, 6 spouses and 1 son; ages ranged from 27 years to 58 years old. Participants were from USA, Canada, Australia and Asia. There were no UK participants. I did not consider this a disadvantage given the rare occurrence of GBM, the global nature of the literature review and the wide-reaching nature of online recruitment.

2.5.4 Inclusion Criteria

The inclusion and exclusion criteria for the sample were as follows:

Inclusion criteria

- 18 years and above
- Ability to give informed consent
- Already narrated stories online (posts, blogs, discussion forum) about caregiving for their loved one diagnosed with brain cancer from diagnosis to post-bereavement
- Willing to participate in an email interview
- Willing to complete a brief demographic questionnaire
- At least 12 months-post-bereavement

Exclusion criteria

- Participants under the age of 18
- Participants less than 12 months-post-bereavement

2.5.5 Briefing

Caregivers who expressed willingness to participate were provided with a Participant Information Sheet, clarifying the aim of the research. They were informed of their right to withdraw from participation at any time they wished.

2.5.6 Informed Consent

The Informed Consent Form made participants aware of all issues pertaining to participation in research. Following the signing of the Informed Consent, participants sent their stories via (DropBox/PDF). They also completed a demographic questionnaire and answered an open-ended email interview at their convenience. Participants also received a debriefing information sheet and an information pack on available online psychological support. All participants were offered the opportunity to provide feedback on interim findings (Appendix R). The researcher expressed gratitude to the participants for their courage and participation.

Caregivers	Age band & Gender	Years Married	Age of care-recipient & Gender	Relationship	Duration of illness in Months
Sharma	32-58 F	14	26-58 M	Spouse	13-22
Anna	32-58 F	18	26-58 M	Spouse	13-22
Heather	32-58 F	25	26-58 M	Spouse	13-22
Jasmine	32-58 F	11	26-58 M	Spouse	13-22
Rosemary	32-58 F	36	26-58 M	Spouse	13-22
Lilly	32-58 F	22	26-58 M	Spouse	13-22
Helen*	32-58 F	27*	26-58 M	Mother	13-22

*Mother and son

2.5.7   Confidentiality

Data security includes collecting, handling, processing, storing and destruction of data in accordance with the UK Data Protection Act 1998. Participants were assured that all data would be fully anonymised and stored in a password-encrypted memory stick. Any paper documents were locked in a cabinet to safeguard confidentiality and preserve anonymity. Pseudonyms were employed. Limitations of confidentiality and the procedure for breaking it was explained. The BPS recommends that data be retained for a maximum period of 5 years, after which it is disposed of securely in accordance with the university regulations for disposal of data (Moher et al., 2014).

2.5.8   Debriefing

Participants received a Debriefing letter in which they were thanked for participating and once again the reasons behind the research explained. An offer to share the findings was extended to all participants.

2.5.9   Online Stories as Data

Stories were defined as posts and blogs which included any message that provided a personal perspective, comment or a response to another post (Polletta, 2006). The stories covered a period of 1-3+ years and ranged from 30 pages to over 300 pages, far exceeding the data usually required for qualitative research.

2.5.10 Email Interviews as Data

Participants completed email interviews, providing retrospective perspectives on their experiences of sharing stories online. These stories ranged from 1-30 pages and formed part of the data collected.

2.5.11 Participant Feedback and Email Communication as Data

All participants received a summary of preliminary findings and provided feedback. The researcher maintained an open communication with all participants throughout the study and these emails formed part of the data collected.

DIAGRAM 2.5.12 SUMMARY OF PARTICIPANT RECRUITMENT PROCESS

Over 18 years old, Male/Female
Previously narrated stories online (Posts, Blogs,
Facebook, Brain cancer forum) about caregiving
for their loved one who died of brain cancer. Stories
should cover whole illness trajectory
Participants should be 12+ months-post-bereavement

Researcher created own website and advertised for potential participants to get in touch via website portal

Researcher advertised on several brain cancer websites and asked potential participants to get in touch via email

4 Participants expressed interest, all female

10 Participants expressed interest, all female

3 Participants signed informed consent forms and authorised their stories to be used as data for research and agreed to respond to email interview and complete demographic form

1 Participant did not respond

8 Participants signed informed consent forms and authorised their stories to be used as data for research. 8 participants agreed to respond to email interviews and completed demographic forms

3 Participants did not respond to email interview or complete demographic form

7 Participants completed email interviews and demographic forms

1 Participant did not communicate and later withdrew. Her story was not included.

Participants and their stories were not included in the research

7 Participants, their stories, email interviews were included in research

7 Participants received preliminary findings

7 Participants provided feedback on findings which was included in research

2.6   Data Analysis

2.6.1 Practising Dialogical Narrative Analysis (DNA)

This section is concerned with how I managed, organised and analysed the data I collected, in preparation for the write-up and presentation of findings. This begins with a step by step description of how the DNA was carried out. There are no fixed rules or procedures for practising DNA. Instead, there are proposed guiding questions, which can be adapted to the research question and objectives. DNA aims to preserve the stories in all of their complexities. DNA values both individual and collective stories (Frank, 2012). My analysis begins with the first research question, which was based on caregiver stories throughout the illness trajectory and post-bereavement.

> *Good luck with your data. I imagine you feeling like the Brothers Grimm story of the miller's daughter locked in a room full of straw, told she must spin it into gold. That's a good fairy tale for researchers…Art*
>
> (Appendix S: Email communication from Professor Arthur Frank).

2.6.2   Research Q.1: What kinds of stories do GBM caregivers narrate online?

Re-telling individual stories

The first task of DNA is to make the incoherent coherent (Frank, 2012). The initial data were copious, consisted of hundreds of pages, and was overwhelming. To gain a sense of control, I began with each story at a time. Majority of the stories were in response to other caregivers' stories, asking a question, providing information or responding to a conversation. Topics varied haphazardly from the medical to the deeply personal, making it a complex affair, at the same caregivers could post three or four stories on the same date, addressing different topics. I began by arranging the stories chronologically, beginning with the earliest posts.

Next, I re-arranged the stories, so there was a beginning, middle and end, corresponding to stories of diagnosis, treatment, end of life and post-bereavement. This exercise was time-consuming and tedious, as some stories were narrated *in the heat of the moment*, while others were retrospective; yet others were the same story with variations. Hundreds of stories involved condolences or supportive messages. Having completed the job of making the incoherent coherent, I kept each story aside.

Focussing on one story at a time, I read each story until I *was immersed in the data* (Frank, 2012). As I read, I also wrote down my impressions of what I thought was going on in and around the story for each participant, for myself and between us as the story unfolded. Next, I re-read the story with a purposeful search for my research question. DNA concerns are represented by questions which the researcher is at liberty to pick and adapt. The question I found most pertinent to interpreting and re-telling individual stories was: *What multiple voices can be heard in any single speaker's voice and how do these voices merge?* Focussing on multiple voices illuminated individual complexities as well as relationships: the personal, social, cultural, psychological processes and what else matters to each participant. Josselson (2011) cautions the researcher involved in the construction and retelling of the participant's story should be aware that "every aspect of narrative work is interpretive" (p.38). In an effort to preserve the individuality of each story, I paid attention to tone and emotion, using the notes I had written. I then began the process of drafting the story, using as many participants' metaphors as possible. In keeping with my feminist epistemology, I used Gilligan's (1984, 2017) Listening Guide to focus on the first-person voice as well as the voice that speaks directly to the research question. The goal of this stage of the analysis - the aim of which is to make the incoherent coherent - was considered complete when each participant's story was rendered orderly. Combining all the notes and drafts, I began the process of writing up the story. In retelling the story, I followed Chase's (2005) supportive voice which presents the participant's voice as central to the story. I repeated this process

for each participant, resulting in 7 highly individual stories, unique to each participant. Only one story made it to the main body of the research due to word count constraints. After some careful consideration, 6 brief introductory versions were included.

Story Typologies: Collective stories

The next stage of analysis directly responds to the research question and involved building story typologies. I relied on Frank's (2010) suggestions on how to build a story typology. I re-arranged the stories once again this time based on the illness trajectory across participants', stories narrated: a) at diagnosis, b) during treatment, c) at the end of life, d) and, post-bereavement stories. Keeping each category separate, I once again paid attention to tone, emotion and metaphors, aligning them next to each in search for similarities. As with individual stories, relationships are central to story typologies. This process was less tedious, as each participant's story was already summarised. Frank (2012) recommends the researcher keep asking: What does this typology do? For whom is it useful? I kept my research question close, repeating it with each reading. I remained opened to ambiguity and contradiction by adopting a stance of narrative humility (Dasgupta, 2014). I began with stories told at diagnosis and searched for shared experiences and commonalities. Keeping each category separate, I continued the search paying attention to metaphors. This activity was meticulously repeated multiple times, eventually leading to the construction of collective narratives (Richardson, 1990), referred to as story typologies. This process of constructing the first typology termed narratives of disruption is illustrated below:

DIAGRAM 2.6.2(1): THE PROCESS OF BUILDING A STORY TYPOLOGY: NARRATIVES OF DISRUPTION

Name*	Metaphors: Stories narrated at initial diagnosis
Sharma	**Our lives** came to a **screeching halt**…
Anna	All the **oxygen was sucked** out of the room ….**we** literally went from 100 miles an hour …….to **STOP** …
Heather	**A cruel twist of fate** …
Jasmine	**Our world** just **imploded**…
Rosemary	My **whole world stopped**…
Lilly	Like a **nuclear bomb** had gone off in **our house** …
Helen	Completely terrifying **life altering**….

*All names have been changed

DIAGRAM 2.6.2(2)

Name	Catastrophic, Disruptive: What kind of?
Sharma	**Sudden** loud violent onslaught thrown into **confusion**
Anna	Forceful vast **violent** no way out **trapped**
Heather	Unexpected underserved destined doomed **uncontrollable**
Jasmine	**Collapse** violently inward fail suddenly and completely unable to operate
Rosemary	**End** come to a standstill
Lilly	**Violent** forceful no way out the end
Helen	**Devastating**

DIAGRAM 2.6.2(3)

Name	Disruption: Where is the disruption?
Sharma	Physical, Family, Financial, work life, relationships,
Anna	Physical, Family, Financial, work life, relationships
Heather	Physical, Family, Financial, work life, relationships
Jasmine	Physical, Family, Financial, work life, relationships
Rosemary	Physical, Family, Financial, work life, relationships
Lilly	Physical, Family, Financial, work life, relationships
Helen	Physical, Family, Financial, work life, relationships

DIAGRAM 2.6.2(4)

Name	Disruption: What happens? (Behaviour, emotions etc.)
Sharma	**Shock chaotic, uncertain future**
Anna	**Helpless** despair, uncertain future
Heather	Helpless **despair,** uncertain future
Jasmine	Despair helpless **failure self- blame**, uncertainty
Rosemary	**Overwhelm confusion chaotic**, uncertainty
Lilly	**Fear** frightened, uncertainty
Helen	Overwhelming hopeless despair, uncertainty

DIAGRAM 2.6.2(5)

Name	Disruption: Where else? Physical manifestation Embodied
Sharma	Lump in my throat
Anna	My heart hurts
Heather	I am exhausted
Jasmine	I am crumbling inside
Rosemary	I am broken
Lilly	I feel nauseated
Helen	I wake up in a cold sweat

This exercise was repeated multiple times and resulted in 4 additional story typologies: Embodied Narratives, Moral Dilemma Narratives, Narratives of Destruction and Narratives of Silence.

Core Narratives

Building story typologies does not signify the end of the analysis. Frank, (2010) suggests the researcher continue to repeatedly reflect on the performance aspect of the story typologies. This involved asking: *What do these narratives do? What is the thread that holds them together?* Fastidiously interrogating the convergence of the typologies formulated the first core narrative as The Suffering of Caring. While the purpose of a core narrative is to illuminate the available range of resources to caregivers, DNA encourages the researcher to interrogate them further and continue reflecting on whether the narrative enhances the participants' capacity to exhibit resilience in the face of vulnerability. Researchers who omit this in-depth process risk limiting their participants' capacity to generate new narratives. Frank (2010, p.199) suggests the researcher listen for what he refers to as "the story that I

could not tell unless they listened." This stance can help the researcher to hear what is implicit in its absence. It requires the researcher to return "full circle to the interest that first animated the research". This rigorous process of continuous cross-examination generated a second core narrative as Woman as Healer. I next moved on to the email interviews.

2.6.3   Research Q. 2: What happens as a result of storytelling?

The participants had responded to email interviews, reflecting on the stories they had shared online. The research question was: *Can you please tell me about the stories you shared online, the responses you received and whether you are still sharing stories online?*

There was no time limit to answer this question. This meant I had to send some reminders, but, all participants eventually completed the email interviews. The first response I received acted as a pilot. The participant indicated the question was easily understood, and, also, allowed her to reveal only she wanted, due to its open-ended nature and lack of a word limit. Eventually, all participants provided feedback which was included in the research.

The point at which I had tentatively encapsulated my findings and shared them with the participants coincided with some email interview responses and feedback from participants, resulting in participants completing email interviews and providing feedback on the preliminary findings at the same time. A back and forth ensued with multiple, enriching conversations taking place simultaneously and organically. What this means is that the dialogue between the researcher and the research began, even as the dialogue between the researcher and participants continued, each engaging uniquely with the stories. Eventually, all this communication converged in the same place, at the same time, providing rich data (online stories, blogs, posts, email interviews, email communication, participant feedback) which included both in real time and retrospective reflections on the effects of storytelling.

Freedman (2009) advances that retrospective thinking has the potential to be a profound source of hindsight, thus illuminating, stories as well as the event of narration - "what happens as a result of storytelling?" is the focus of this analysis which begins with the storytelling landscape.

The Storytelling Landscape

Stories are influenced by multiple factors. Frank (2012) proposes several open-ended questions and advices the researcher to pick from amongst which they find most pertinent. I chose circulation and affiliation questions and adapted them to my research as follows: a) Circulation: Why choose an online brain tumour forum to tell stories among other expressive possibilities? Frank advances that circulation stories are the most expressive stories and "often remain told within only one community." Next question was: b) Affiliation: Why is the storyteller telling this story, at this time, and to this listener? Affiliation stories share a common understanding and often exclude others who are considered outsiders. I kept these questions close as I read and re-read the email interviews, email communication and feedback. Repeatedly asking these questions illuminated the storytelling landscape and the characteristics that enabled storytelling. Stories were told within relationships, in dialogue and within community, which generated the categories of Community of Storytellers, Relational Narratives, Dialogical Narratives and Narrative Performance. Hindsight Narratives emerged from *telling and retelling* (participants telling the same story over again, with little or great variations each time) and the retrospective email interviews. These are elaborated on in Chapter Three and Four.

2.7   Ethical Considerations

So far, ethical considerations have been made transparent throughout this research. *A priori* personal reflexivity pertaining to my relationship with the research topic was discussed in

Section 1.4. Research positionality pertaining to my relationship with my research participants was discussed in Section 2.2. However, narrative inquiry makes substantive demands on the researcher beyond what is recommended by Research Ethics Boards. Three types of reflexivity salient to counselling psychology research are personal, epistemological and methodological (Willig, 2008; Kasket, 2012). Personal reflexivity focusses on the self of the researcher to include an examination of how the researcher's experiences, values and beliefs potentially shape and influence the research. It also includes an awareness of how conducting the research has impacted the researcher. Epistemological reflexivity revolves around the assumptions and theoretical perspectives underlying the chosen research methodology. Reflexivity as pertains to the personal, epistemological and methodological are revisited in Section 4.9. This section is concerned with methodological reflexivity *in situ*, as it unfolded.

2.7.1 *In Situ*: Methodological Reflexivity

Methodological reflexivity requires that the researcher is transparent about how ethical issues are addressed throughout the research. It includes elaborating on the sets of activities the researcher engaged in during research. Engaging in methodological reflexivity illuminates how these activities influence and shape the research (Etherington, 2004). I address several pitfalls inherent in research with bereaved caregivers.

2.7.2 Recruitment of Bereaved Caregivers

Temple & Brown (2011) suggest that online researchers use multipronged internet-based recruitment strategies which: a) outline the aims and purposes of the research clearly, b) use language tailored to the population of interest, and, c) build rapport directly with potential participants. However, the most fundamental ethical principle a researcher is faced with, is

how to protect the dignity and well-being of the participants (Clandinin, 2016). Recruitment of bereaved caregivers presented significant ethical challenges, the first being, upholding the principle of *primum non nocere*, Latin for *first, do no harm*. Ensuring the psychological safety of participants includes data collection methods (Caserta et al., 2010). Feminists have long recognised ethical and political significances of engaging participants with a minimum of intrusion (Gilligan, 1982; Lorde, 1980). They point out that honouring the participants' preferred way of communication, whether song, artefact, or poetry, image or spoken language, has the potential to yield more complex multidimensional data (Lorde, 1980; 1984; Holge-Hazelton, 2011). I focussed online stories as my participants had already storied their experiences.

2.7.3   Online Stories as Research Data

Bereaved caregivers who participate in online research are vulnerable to exploitation and misrepresentation (Couser, 2004). Despite researchers going to great lengths to anonymise participants and protect their privacy, the current reality is that the internet has shrunk our world. There exists less privacy today, making it easier to identify others. If participant stories are rich and unique, they are also highly recognisable. It was, therefore, important to reflect on the merits of the research, and whether the potential for harm was outweighed by the needs of research. Couser (2004) proposes that researchers ask: Are my participants' interests equally served by this research - *Cui bono*? (Latin: Who benefits?) After all, I was the one pursuing an academic goal. There are no straight forward answers to these questions, evidencing the need for continued reflection.

2.7.4   Email interviews as Research Data

I chose email interviewing because it offered instant access to participants without geographical constraints. It was also user-friendly as participants were at liberty to choose when to respond. Boshier (1990, p.51) contends that email interview is a "democratisation of

exchange" which is non-hierarchical, non-coercive and an "ideal speech situation" which promotes equality and mutuality. My experience is that the use of email transcended traditional biases, such as race, gender, age and class. Email interviewing also reduced the influence of personal characteristics, such as shyness and so on. Emotional distress was also managed. This does not mean that email interviewing is unproblematic, as it requires good writing skills which might limit participation. Other limitations are discussed in Section 4.8.6.

2.7.5   Illness Narratives as Research Data

Illness narratives include stories written by caregivers, "intimate others" and "proximate others" (Eakin, 1998, p.171). However, writing about another person's illness and the experience of caring for them, particularly when this person is no longer able to tell their own story, raises certain uncomfortable questions, which I address below.

What is fair and right to write about someone else's illness?

In addressing the issue of what is right and fair to write about someone else's illness, Burke (2014, p. 29) observes that illness narratives can be a "troubling form of empathy" because stories can reproduce the erosion of dignity and helplessness that illness often perpetuates. She questions whether researchers are in "danger of unmasking their subjects" and participants a second time, by "re-enacting the violence and trauma" they have gone through. Eakin (1998, p.169) gives an example of Roth (1991) who writes about his father's illness and "explores every last crevice of a humiliating experience his father regards as the depth of shame and disgrace." Eakin laments that if Roth had reflected honestly on what is right and fair to write about someone else's illness, this so-called shameful episode would have been excluded from the book.

Whose voice is it?

In addressing this question, Eakin (1998, p.162) observes that a significant number of illness narratives are not patient-authored, and reflects on how different they would be if written by the patients themselves. Gerda Lerner (1989, p.49) in writing about her husband's inoperable brain tumour makes a similar observation: "We battled on separate battle-fields, each very much alone. Mine: to prepare myself for his death, to help him die a good death. His: to live". This statement implies a tacit acknowledgement that Carl Lerner might have written a different book. The question about whose voice it is poses serious ethical questions.

Whose story is it?

Eakin (1998, p.162) suggests that this question can only be answered by how individuals define privacy, which necessitates a debate about selfhood. Is the self "an autonomous, free-standing... distinct and clearly defined person who acts and is acted upon?" Or is the self a relational self, living a relational life? It appears that if the self is autonomous, then writing about another's illness has the potential to violate privacy. However, ethical determinations become more complex if identity is perceived as relational. Cassell (1991, p.183) explains that "the boundaries of illness are poorly defined," because illness "tend(s) to draw in others" and can "have destructive effects on their bodies and lives", and therefore, "to include narratives by caregivers as authentic contributions to the understanding of illness experience", is desirable. Eakin (1998, p.169) makes reference to "a relational life in which the story and self of the author are shown to be intimately and inextricably linked to the story and self of another person". However, the potential to reveal deeply intimate experiences, such as loss of neurological and physiological functions that brain tumour patients often experience remains. Brain tumour is a cruel disease, often eroding a person's sense of self, long before it takes away the body. There is some ethical unease about telling such a story. My husband was a highly disciplined, deeply private gentleman, who was devoted to his family and it was unbearably heart-breaking to witness the illness gradually steal away his

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sense of self and independence. After reading hundreds of stories, it became apparent to me that illness does not "draw in others" (Cassel (1991, p.183) equally and there is potential for tension amongst "proximate others" (Eakin, 1998, p.171), who might view events differently. This is my story, not my children's story. These issues warrant continuous reflection.

Burke (2014) notes that to write of another is necessarily to write of oneself because in writing, lives and selves become entangled. I agree that how we understand inner subjective experiences (ISE) (Hansen, 2005) in the context of illness narratives, is fundamental to the centrality of relational identity and the shared authorship of illness narratives. I acknowledge this is as much my husband's story as it is my own. It is important for participants to reflect on this as well. I argue that as long as the researcher remains cognisant of the multiple possibilities in retelling another's story and allows for their emergence, then the research can be worthwhile.

2.8   Evaluation of Qualitative Narrative Inquiry

Key determinants for the evaluation of research are the type of data employed and the goal of research (Willig, 2008). This researcher suggests the value of this research be judged by its fidelity to Narrative Inquiry, DNA commitments and their underlying epistemologies, which take precedence over general qualitative research concerns. Some Narrative Inquiry and DNA commitments have been addressed in Sections 2.3.2, 2.3.4 and 2.6, while others overlap with qualitative concerns interwoven throughout the research.

Clandinin (2016) identified criteria for judging narrative research based on a literature review of narrative inquiry publications. She proposed twelve touchstones, described as qualities "used to test the excellence or genuineness" of narrative inquiry research (p.212). These

are: *1. **Relational responsibilities**, 2. **In the Midst**, 3. Negotiating of Relationships, 4. **Narrative Beginnings**, 5. Negotiating entry to the field, 6. Moving from Field to Texts, 7. Moving from Field Texts to Interim and Final Research Texts, 8. **Attention to Temporality, Sociality and Place, 9. Relational Response Communities, 10. Justifications – Personal, Practical, Social, 11.** Attention to Multiple Audiences, 12. Commitment to understanding lives in motion* (p.212).

Relational responsibilities: Ethical considerations in narrative inquiry are referred to as relational responsibilities, to be negotiated with participants throughout the research process and beyond (Clandinin & Connelly, 2000). This study has shown considerable concern for the welfare of research participants. Relational responsibilities include steps that were taken to ensure participant well-being, such as reflecting on criteria for participation, for example, research readiness and preferred modes of communication to minimise inconvenience were built into the research design after negotiation with participants. Open email communication and feedback provided opportunities for the researcher to make attempts at balancing the hierarchy of information. Clandinin, (2016) advices narrative inquirers to "negotiate ways in which they can be helpful to participant(s)" (p.51). Negotiations with participants regarding a secure system to send stories resulted in changes in the research design, further evidence that this research prioritised relational responsibilities.

In the midst: Is the recognition that both the researcher and participants are in-the-midst-of-living their lives during the research. The researcher's life continues, as do the participants' lives. This awareness is paramount. Care and consideration have been taken to portray participants as living meaningful lives, which continue in the face of multiple challenges. Participants are presented as individuals, whose stories matter, for example, the analysis

resisted attempts to over-interpret stories, and instead increased the audibility of participant stories.

Narrative beginnings: Refers to the notion that all narrative inquiries begin with the researcher's personal experience (Frank, 2012). As a new caregiver, I had joined a brain tumour forum to seek information on how best I could support my young family. According to Frank (1995), this is perceived as the onset of fieldwork, which is recognised as having greater trustworthiness.

Attention to Temporality, Sociality and Place as common places of narrative inquiry: *Temporality* refers to an understanding of events being studied as transitional (Connelly & Clandinin, 2006). This is an integral part of the study which shows caregivers' stories over time, as seen from a rapidly evolving disease, from diagnosis to post-bereavement. *Sociality* involves paying attention to the researcher/participant relationship which is explored in Sections 2.2 and 2.3. *Place* is the storytelling landscape, which is central to the co-construction and containment of stories, as discussed in Section 3.6.1 and 4.5.

Relational response communities: Response communities in narrative research refers to trusted individuals or groups the researcher is surrounded with, to provide feedback and support. Response communities can be focus groups, supervisors, co-researchers and others, who provide "responsive, and responsible dialogue" about the researcher's emerging study discussed in Section 4.9 (Clandinin, 2016, p.210).

Justifications – personal, practical, social: Justifications for the research are covered in section 1.6. Narrative researchers "are expected to deepen understanding that can translate to practice" (p.211). This means addressing the *So What* and *Who Cares* debates regarding the phenomenon under study (See section 4.8). Limitations of the research are addressed in Section 4.8.6.

2.9   Summary

This methodology chapter was concerned with four aspects of the research study and began with a clarification of the research question, the ontological and epistemological stance, the theoretical perspective, and the method. This chapter has achieved its purpose which was to provide a detailed and transparent account of all steps taken in the research methodology.

3 Chapter Three: Findings

3.1 Overview of Chapter

Chapter 3 presents the findings of DNA of the online stories, email interviews and participant feedback. It begins with a brief introduction of the caregivers, followed by a presentation of the multi-layered findings. A reflection on the analysis and findings ensues. The final section summarises the chapter, and lays the foundation for the succeeding discussion chapter.

3.2 Introduction to the Caregivers

There is no Greater Agony Than Bearing an Untold Story Inside You. Maya Angelou

Caregivers were all female, age range 32 to 58 years old. There were 6 spouses, married for between 11 and 36 years, and I mother and son. Caregivers were from USA, Canada, Australia and Asia. One Caregiver described herself as a housewife, while the rest were professionals. All caregivers were members of a brain tumour forum. Care-recipients were all male, age range 27 to 58 years old, all professionals who were previously in good health. All care-recipients were diagnosed with GBM and survived between 13 and 22 months. All names are pseudonyms.

3.2.1 Sharma: He was my rock…

See Individual Story Section 3.3.2

3.2.2 Anna: I would have walked through molten lava for him….

Anna and Edward are both 49 years old and have been together since high school. They have no children. They are self-employed computer programmers who "had been working like demons" in preparation for their retirement in 10 years' time. Anna says she joined the

forum because: "*I knew precious little about brain tumours and I figured that at least some one there would understand what I was experiencing.*" Edward survived for 14 months.

Anna is still a member of the forum, checks in infrequently. She says she cannot handle it as:

> *everyone who was a patient when Edward was sick is dead – it is all a whole new crop of victims to this disease…I think I have PTSD from having been through this experience and the forums tend to make all the memories FLOOD back.*

3.2.3   Heather: We were a team, united in love….

Heather is a 52-year old researcher who has been married to 55-year old Arnold for 25 years and they have four teenage sons. Arnold is a physician. After the diagnosis, she says: "*As a physician, he knew the stats*". She joined the forum with:

> *that desire to put our story out into the world. Writing it helped me to process the story, especially in times when the emotions were excruciating. It also often provided validation that I was not going crazy and to see that others experienced similar things. It helped me to feel less alone.*

Arnold, who participated in various clinical trials was the longest surviving care-recipient. He died 22 months after diagnosis. Heather is still a member of the forum and responds, "occasionally to others," but, "mostly now I want to show my gratitude to the forum by offering expertise and support to others."

3.2.4 Jasmine: It was a gift and honour to have been part of (his) life …

32-year old Jasmine, has been married to 48- year old Andrew, a university professor, for 10 years. He has one daughter from his first marriage. Andrew was a caregiver to his wife who died of cancer after a four year "battle". Jasmine is an accountant. When Andrew is diagnosed with GBM, Jasmine joins the forum to look *"for help on what to look out for, to learn about the disease and its progression…to make sense of my new world that didn't make sense"*. Andrew survived 13 months. Jasmine is still a member of the forum, but doesn't "frequent the site very often. I did for a little while after my husband died, but it was too hard to read the posts."

3.2.5 Rosemary: He was my knight in shining armour…

Rosemary 57 and Peter 58 have been married for 36 years and have two grown up daughters, who are married with children. Rosemary, who is disabled, says: "I leaned heavily and completely on my husband for everything." Peter was very health-conscious, but, "after some research on the internet I knew that I would probably outlive him now." Peter passed away 17 months after initial diagnosis. Rosemary remains an active member of the forum and participates regularly in discussions. She is a frequent volunteer and organises various activities to raise funds for brain tumour research. She also mentors caregivers of newly diagnosed patients.

3.2.6 Lilly: His last kiss was 1 minute before he passed…

Lilly 52 and Paul 47 have been married for 22 years. Paul is a physician, while Lilly is an administrator. They have one daughter who is studying abroad. After the initial diagnosis, and dire prognosis, Lilly and Paul embark on an alternative treatment, which shows some initial success. Lilly joins the forum to share Paul's good news. She advocates for others who are "on borrowed time" to go on the alternative diet and "starve the alien matter" as

Paul's tumour has "disappeared." She says Paul's "recovery is nothing short of miraculous and stunning." She gains hundreds of followers. Paul survives 20 months after diagnosis. Initially, Lilly announced the intention to quit the forum as the stories were just too heart breaking, but when the time came, she decided to stay on. She is still a member and participates occasionally.

3.2.7 **Helen: He was precious…. our only child…**

Helen is 55 years old and mother to her only son Joshua, who is 27 years old. Joshua is "a professional trainer, health nut, natural food/supplement aficionado." Because of Joshua's youth and excellent health, his doctors were convinced he would "beat it." Helen joined the forum to motivate others, because Joshua was "in great shape and lived his life normally – apart from the annoying doctor visits." Joshua survived 19 months. Helen is an active member of the forum, a prolific writer and expert on all matters brain tumour. She continues to share information, provide support and care to brain tumour patients and their caregivers.

3.3 **Presentation of Findings**

3.3.1 **What kinds of stories do GBM caregivers narrate online?**

Each one of the 7 caregivers narrated highly unique stories. What brought them together on the same story telling landscape was the need to share their experiences about caring for their loved ones diagnosed with GBM. The stories they told evidenced their individualities, as well as their commonalities. The findings are presented in three layers as: 1. Subjective stories - Sharma; 2. Five story typologies - a) Narratives of Disruption, b) Embodied Narratives, c) Moral Dilemma Narratives, d) Narratives of Destruction and e) Narratives of Silence; and 3. Two core narratives - a) The Suffering of Caring and b) Woman as Healer. See diagram below.

DIAGRAM 3.3.1 THE STORY TELLING LANDSCAPE

Research Question 1: What kinds of stories do GBM caregivers narrate online?

1. **SUBJECTIVE STORIES: SHARMA'S STORY**

2. STORY TYPOLOGIES:

e) Narratives of Silence

d) Narratives of Destruction

c) Embodied Narratives

b) Moral Dilemma Narratives

a) Narratives of Disruption
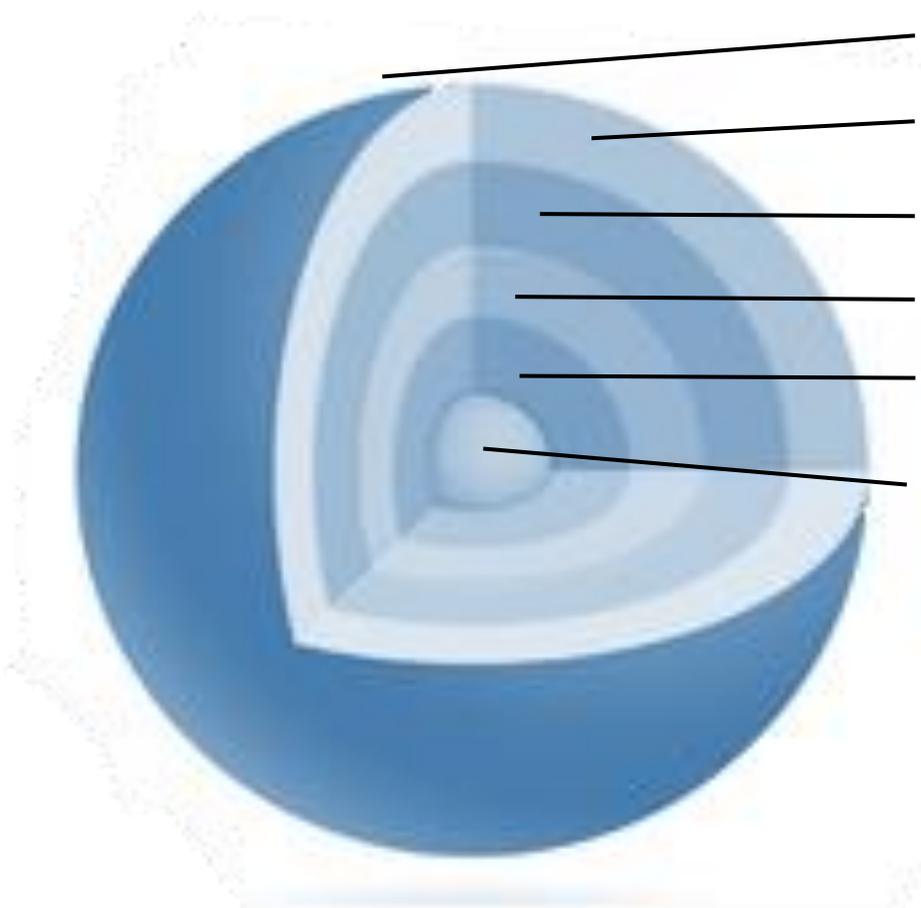
3. CORE NARRATIVES:
a) The Suffering of Caring
b) Woman as Healer

3.3.2   Subjective Stories

In re-telling each individual story, I was guided by Labov's (2013) proposal that "a fully developed narrative begins with an abstract, an orientation with information on persons, places, times and behaviour involved; the complicating action; an evaluation section, which

identifies the point of the narrative; the resolution; and a coda, which returns the listener to the present time" (p.5). In keeping with my narrative and feminist relational epistemology, I chose realistic pseudonyms and provided more details about participants' lives. The findings privilege the stories by using caregivers' words, sentences, phrases, and metaphors in the analysis and discussion. DNA does not promote the fragmentation of stories and advocates for "letting stories breathe" (Frank, 2012, p.43). Frank uses the term *phronesis* to infer "the analyst's cultivated capacity to hear, from the total collection of stories, those that call out as needing to be written about." All seven individual stories screamed out for audibility. In deference to the word limit, one story out of seven was randomly chosen for individual attention.

3.3.3   Sharma: *No Suffering Plz…*

Sharma made contact after reading my advertisement on a brain tumour website. She requested I send her further details in 6 weeks' time as she was not yet at the 12 months' mark. Sharma is a 38- year old woman from Asia, who has been married to 49-year old Anu for 20 years. They live in the capital city, where Anu is a successful businessman and she is a "housewife". She "married young" and was looking forward to joining Anu in the family business as their two boys have just started college abroad.

The story about Anu's diagnosis begins with a succession of rapid events. Anu's initial symptom is a dragging of the right foot. Sharma recalls they drove to the hospital feeling anxious, but not worried. Anu undergoes an MRI, which reveals a brain tumour. A biopsy is urgently needed to identify tumour type and plan treatment. She quickly signs the authorisation form. Anu recovers from the biopsy, but has trouble moving his legs. The diagnosis is GBM and the prognosis is dismal. Surgery is not an option because of the tumour's proximity to the brain stem (controls breathing). A week later, they are discharged from hospital with Anu in a wheelchair. Available treatment is chemotherapy and six weeks

of daily radiation (Monday to Friday). There are only two treatment centres with radiation facilities. Both require long hours of driving. There are only a handful of oncologists who specialise in neurology and the waiting lists are long. Anu is self-employed and has no health insurance. The recommended treatments run into thousands of US Dollars.

They mortgage their home to secure funds for treatment, because "if you can't afford it too bad, you can die." For the next six weeks, Sharma drives Anu for daily radiotherapy. The initial MRI scan after radiation treatment shows the tumour has continued to grow. More aggressive treatment is recommended. They mortgage their business to secure more funds. Five months later, Anu is confused, bedridden, incontinent and is slurring his speech. The oncologist advices there are no more treatment options and Anu should "put his affairs in order."

Confused and bewildered, Sharma joins the brain tumour forum for support and shares her struggle to understand why this is happening to them. She describes Anu as "the bravest and most determined and most dynamic person I know." Her stories have an intense urgency. She is angry and vulnerable at the same time:

> *Our medical system offers no help , no comfort , ….. I had to beg , bully and grovel , as needed for a bed for my sick husband . ....Really !!!!*
> *"i had to plead , cajole, scream, yell and fight for doctors appointments , for a hospital room, for radiation onco to start radiation ,to find genuine TMZ (medication).*

Her experiences contrast with other caregivers' descriptions about access to various services, such as Medicaid, Medicare, Rehabilitation services, Psychological services, Palliative and Hospice Care, including opportunities to enrol in clinical trials offering the latest innovative treatments at renowned world class hospitals. Sharma observes:

> *i just didnt get any good days or good moments, people write about making beautiful memories that did not happen to me, my days are lonely filled with anxiety….*

She receives numerous messages of support from other caregivers who offer ideas, hope and prayers. She remains inconsolable. She discloses that initially she spoke to her siblings, but as the disease progressed:

> *I felt out of sync with everyone else, I did not find any solace in any one's words, I felt they did not know what was happening neither did they try.*

When a relative tells her that: *"you had a fairy tale princess life, this is reality,"* she is genuinely perturbed and struggles to find meaning. She questions her past, but finds no answer:

> *is human apathy and indifference also incurable?? Ironically I was always the stronger and smarter one, who would back up others 100% … My relationship with my siblings has changed forever.*

She feels "deserted and isolated", but, undeterred reaches out to Anu's brother, who lives in another city. He visits only once after:

> *cajoling and sending him a return air ticket."* Finally, she resigns herself to being alone: "*You cannot force people to feel and care… i realized people have far more interesting things to do as their lives are full .....while ours has come to a screeching halt…….people like their comfort zones ...**no suffering plz**....well i am wiser but also numb.*

Her angry voice betrays the hurt beneath the surface even as she discloses that she has mastered the art of deceit by hiding her feelings. Her story, narrated in unfinished sentences, without full stops or capital letters, mostly trailing off into pauses, full of medical jargon, interrupted by half sentences, reveal her unfiltered emotions. She experiences no reprieve. Soon, she is compelled to hire lawyers to defend against numerous lawsuits filed by Anu's business partner for an unfinished project. At stake is the auctioning of their house. Feeling betrayed and overwhelmed by events, her anger is on full display as she vents and rants

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against her fate. She wonders how they got caught up with "this disease." Finding no solace in the present, she reminisces about their life prior to "this":

I do think of the times before we were hit by this .... how good life was ... the good times, funny moments, adventurous moments, and sweet moments…my husband loved life, very smart and very elegant man, it is sad to see him in such simple state, it is just so sad and simply heart breaking.

Devastated by events, she discloses:

…it feels as if an eternity has passed,… i am facing a lot of major issues and on daily basis have to make decisions that i have absolutely no clue of.......only person that i want to consult with is my husband and i cant .....so i keep doing what i think is right but there are days ,quite frequently when even a small glitch sets me off and (everything) comes crashing down in a second….

She is especially unprepared for the role of decision making:

we always rely on protection from father, from brothers, from husband, son…" She regrets that: *when he could speak he never told me what to do ...men find it really hard when they feel they cant take care of their family.......i feel so incompetent and so lost, telling myself that i am trying to do my best is no good because my best is still crap it brought no results. my husband never accepted his diagnosis , thought he will be just fine so never put anything in order. never discussed his wishes , treatment plan , did any research, gave any instructions, i had to do all that to the best of my abilities but i feel like such a failure. i feel i should be doing something more for him but i dont know what, surgeon says inoperable , second opinion still inoperable, …..only getting worse, maybe that was a wrong decision ,.....i dont know what to do,*

Her sons are abroad and she does not want to burden them with seeing their father in such "a simple state." But, this means that she is alone without support and relies more and more

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on the forum for advice and support on how to make changes in their home to make room for a special bed and other medical equipment needed to take care of Anu. As Anu's condition worsens she says:

> *he is neither here nor there, he is sleeping all the time and even when he is awake keeps staring at window, all my efforts to reach out to him on some level do not work , i still keep talking to him about everything." i know i did whatever i could do ,i was actually better when i was in doing mode , now i feel i go through the day with an aching heart and a lump in my throat...there is nothing i can do but watch him helplessly fade away and that really hurts , this has to be the worst disease to come down with , it does,nt just kill the patient but kills everything around him too.*

A sense of helplessness engulfs her as hope that Anu will recover continues to dwindle. She says:

> *it is really hard for me to face the fact that i can not change the outcome no matter what...i really fought for his life every step of the way , .i wish i could know what he feels ....does he know how i am coping.. I know i sound stupid but i wish he could tell me , i know you are trying your best and you are doing ok.....his approval always made me feel safe, i felt he had my back....*

She finds the whole experience senseless and is aggrieved by others who offer that "God has a plan" or "look at the bigger picture". She challenges the perceived universality within the forum of the use of the metaphor "journey" to describe caregivers' experiences:

> *Why do we call this disease a journey ??? we choose a destination before we start a journey .....we choose....we plan ..we anticipate...whereas this disease is a massacre , we did not choose it , we did not plan it and we certainly did not want to go to this destination.....this disease massacres every thing in its path, body ..soul..mind..not just the patient but routes every person it touches in any way....the helplessness*

> *....the despair...the desperate efforts to hold on to whatever you can and failing...this disease is not a journey it is a massacre.*

This comment attracts numerous responses resulting in a lengthy debate mostly in defence of the term journey. Incredibly, one of the caregivers who replies to Sharma is Heather:

> *We call it a journey as it has led us to many discoveries...about each other, about life, about what really matters. We know the grim statistics but we chose to travel this "journey" with optimism and hope...Heather*

Anu survives for 14 months after diagnosis. For 9 months, he was bedridden, speechless and incontinent. Sharma is still a member of the brain tumour community:

> *I am not ready to cut off from this community yet… it is heart breaking to read these posts …. so many human beings hurting. Maybe given some more time I would be able to help someone with my experiences.*

Sharma's stories reveal her heartbreak, helplessness, loneliness, anger, despair, disappointments, dilemmas, and struggles to get the best care possible for Anu. Increasing audibility for Sharma's story provides an opportunity for virtual witnessing. The reader is invited to contemplate how they would respond to her in a manner that recognises her suffering, but, also stands in awe of her *Coeur* Rage. *Coeur* is French for heart. Rage of the heart. Throughout, Sharma's devotion and commitment to Anu and their sons never waver. Later, when the sons return home, she describes how one day "coming back from another meeting to sort out property matters… her son told her, "mom i am proud of you" ..."now that was precious."

3.4   Collective Story Typologies

Similar to Sharma's story, all caregivers' stories were intensely personal. However, some form of homogeneity in the shape of story typologies was also evident from the idiographic accounts offered by the caregivers. Thus, whilst seeking to capture diversity, the analysis was also driven by the need to identify and foreground commonalities, obtain useful and usable information. The following five collective story typologies are presented: Narratives of Disruption, Embodied Narratives, Moral Dilemma Narratives, Narratives of Destruction and Narratives of Silence.

DIAGRAM 3.4: COLLECTIVE STORY TYPOLOGIES
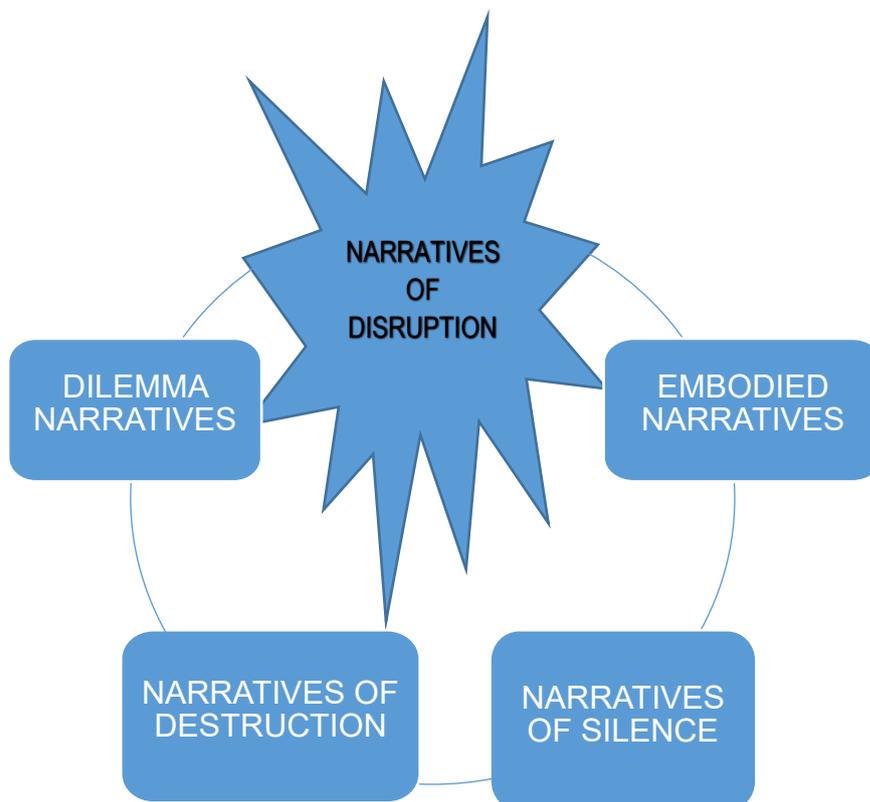
3.4.1 Narratives of Disruption

Narratives of disruption comprised stories surrounding the events of diagnosis, impact of prognosis and the attempts made to find meaning, adjust and cope with the disruption. The ominous implication of a GBM diagnosis was not lost on caregivers. Caregivers described the various perplexing symptoms, ranging from headaches, seizures, talking gibberish, limping, walking into a tree - to memory loss, which led them to the Emergency Room.

DIAGRAM 3.4.1

Name*	Narratives of Disruption
Sharma	**Our** lives came to a **screeching halt**….
Anna	Believe me all the **oxygen was sucked out of the room** ….**we** literally went from 100 miles an hour … to STOP …
Heather	A cruel **twist of fate**…
Jasmine	**Our** world just **imploded**……
Rosemary	And then **we** were **hit** with this… My **whole world stopped**…
Lilly	Like a **nuclear bomb** had gone off in **our house**…
Helen	Completely terrifying **life altering**… Situation…

*All names have been changed

All caregivers described onset of disease using metaphors depicting a violent life-threatening event as depicted above. These metaphoric, evocative and vivid descriptions capture the

devastating effect of the diagnosis. Anna's highly descriptive story which contains minutiae details records the gravity of the moment:

the ER doc said those dreaded words, "Mr. X you do not have a sinus infection, you have a brain tumor." That was at 3:30 pm on March 19, 2013[1]. Up until noon of that same day, we had been working like demons planning for and working toward our retirement in 10 years - he is 49 and I am 50. We literally went from 100 miles an hour with our business to STOP within 90 minutes. Everything in our lives changed from 1:50 PM, that day - when we headed to the ER with him nearly screaming of "head pain" - until the ER doc uttered those horrible words; all in just under 90 minutes. Every molecule of oxygen was immediately sucked out of that room. From that moment on, our lives were forever and sadly changed. I hate this disease…Anna

The disruption is relentless and is rapidly followed by other critical events, such as brain surgery, chemotherapy, and other treatment complications offering no respite; disordering family constellations, ushering in more responsibilities, complicating mutuality and reciprocity, throwing into disarray previously taken for granted beliefs and assumptions about life and the future. Jasmine, Lilly and Helen arrange to work from home with the support of their employers. Heather and Anna give up their jobs, while Sharma and Rosemary take over their husbands' businesses. Treatment after surgery is a challenge as care-recipients automatically lose their driving privileges due to the high risk of seizures. Lack of a driving license also means immediate loss of independence and livelihood. Families are challenged to mobilise resources to handle the disruption. Accessing brain tumour centres for treatment involves long distance travelling and overnight stays, adding to the caregivers' responsibilities and financial strain. Financial difficulties were reported by all caregivers,

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[1] Date changed

including those who had health insurance. The impact of the disruption is immediate and permeates all areas of life.

All caregivers described spending hours online searching for information on treatment. Helen refers to online information as "hate speech" or akin to "stepping inside medieval torture chambers" but, "in between horror stories, there were enough gems of data," such as: anti-cancer diet ideas; exercise, boosting the immune system; vitamins and other supplements. Her son Joshua is only 26 years old and in excellent physical health at the time of diagnosis. The family hold out hope and engage "brilliant doctors" and the best "cancer team".

> *From Day One, we spent very little time in Pity City …, and enlisted "every prayer warrior we could find, recognizing that the outcome of this battle ultimately rested in the hands of God…Helen*

Heather, who is deeply spiritual turns to her pastor and church community for emotional support. Her husband, who is a doctor, "had great support," from the medical community and was enrolled in a novel and innovative clinical trial which offered better chances of survival than the standard of care treatment. Even so, she admits that "control is an illusion" and "we must live in the ambiguity of the diagnosis." Lilly describes an unwanted conversation with her husband's neurosurgeon:

> *My husband's neurosurgeon coming out of the craniotomy tells me a hideous story of "what will happen next." I was stunned. I wondered if the man had blood or anti-freeze running through his veins. I vowed to not repeat his words to anyone, and get busy praying.*

She "reconnects with the Holy Spirit" by attending spiritual seminars and "charismatic prayer meetings," where her husband is "prayed over" to "bring the root cause(s) of the illness to

the surface for healing." She is finally led to a special diet and a special herb "in a dream" from God and the "Holy Spirit."

All caregivers used descriptions that marked the moments that their lives changed forever. They describe confusion amidst events that are moving too fast for reflection. A surreal feeling gradually evolves into a sense of dread and bewilderment, as the reality begins to sink in and the families try to adjust to "the new normal". All caregivers describe feeling helpless. Anna describes being thrown "into a storm without a lifeboat". She explains that from time to time the unbelievability of the situation hits that "you are no longer the master of your fate and nothing you do can change the eventual outcome". It is dread accompanied by turmoil, uncertainty, loss of safety and security. Disruption is experienced as profound and permanent. Lilly describes disruption to self:

> *What lies ahead for my husband XXX, only God knows at this point. He is comfortable today, praying and eating well. No matter what happens, we will never be the same. It's a weird feeling. I feel that part of me died when he was diagnosed. I feel like a different person….*

Hard pressed to find inspirational resources, all caregivers describe joining online brain cancer forums, where they connect with other caregivers through shared experiences. They exchange information about treatments, treatment side effects, symptoms, and everything else about how they can support their loved ones. Stories include their attempts at meaning making and coping with their rapidly changing circumstances.

3.4.2 Embodied Narratives

Embodied narratives are stories which used metaphors analogous to the physical body's capacity to independently register responses to experiences. I have referred to these reactions referencing strong physical sensations as embodied responses. Embodied responses were linked with various events, such as doctors' visits, waiting for MRI results, the appearance of new symptoms, witnessing a seizure, pain or suffering.

DIAGRAM 3.4.2

Name*	EMBODIED NARRATIVES
Sharma	I walk around with an **aching heart** and **a lump in my throat**…
Anna	this **rips my guts** out every second of every minute of every hour of every day. ….I am just **crushed** by the enormity of this ….
Heather	I … put on a brave face and then **fall apart**…This disease is **heart breaking**
Jasmine	That **hit me** so hard in the heart…I was **crumbling inside**
Rosemary	I feel I'll be **forever broken**…
Lilly	It **hurts** to see (him)… get scared… I **felt nauseous** (sp?) and had **chest pains…**
Helen	For … (close to) 500 days I woke up… **my blood like ice**… I could lose him… and then, the unthinkable happened. I feel **like ash inside**…

*All names have been changed

Embodied responses were interpreted in various ways. Anna's description implies a deep empathy:

> *I cannot even imagine what (he) goes through every day - it breaks my heart into 100000000000000000000000 pieces. Anna*

Descriptions were vividly and metaphorically associated with different parts of the physical body: heart, throat, gut, chest and verbs like breaking, aching, wrenching, shivering were commonly used. Helen describes her experience as follows:

> this horrible journey, where my blood just froze in my veins for long periods of time from shock and fear, and where to do just anything felt like I was dragging around a tarp filled with bricks … and where just about anything and any memory could make me cry from sadness, and where I kept searching the Internet for that one elusive clinical trial that never came.

Embodied responses were also associated with mental states, such as empathy, compassion, fear, anxiety, depression, sadness, anger, guilt, stress and anticipated grief. Caregivers also understood the negative implication of embodied responses on their physical health. Heather writes that being in a state of alertness was mentally and physically exhausting. Anna shares that:

> It was at least 7 months before I stopped shaking… Never have I been so scared…

Other caregivers associated embodied responses with hyper-alertness or hypervigilance and generally agreed on the advantage of being "alert" as being able to provide better care and advocacy for their loved ones. Lilly explains why:

> When my husband came out of craniotomy surgery, I found him moaning in agony. They couldn't figure out why he was in so much pain. The .... nurses said they put pain patches on him before leaving the surgery room . . . well, guess what? They didn't. My husband suffered so terribly until they looked to see EXACTLY where the

patches were . . . they were absent. I could have screamed …. It was so upsetting…

The moral of that story is . . .

Embodied responses were equated with intuition or premonition, a stimulus for reflection or a catalyst for action. Overall, embodied responses motivated the caregivers "to do something" to help their loved ones. Embodied responses were also interpreted as a deep connection or the ability to comprehend and respond to their loved ones' feelings and suffering. Caregivers were acutely aware of their own embodied responses and most used creative means, such as meditation, prayer, optimism, and good sense of humour to counter the effects. For instance, after receiving the news that her husband's tumour is growing again, Lilly writes:

this is scary - so we cried yesterday and then we laughed and then we drove to the medical marijuana dispensary so my husband could try a new strain. You can't make this stuff up…

Afterwards, she self-calms:

I'm reminded that the best thing for me to do is focus on this hour. This hour is a simple place with reasonable expectations, and boundaries I can live with. Staying within the hour is what got me through those first days and weeks after diagnosis. Staying focused only on the hour at hand allowed me to function and not cave into terror. So, I'm back there now - 1 hour at a time…

It is not clear what consequences embodied experiences have for health. Immediately after diagnosis Lilly lost 15lbs in 10 days. Heather, Jasmine and Anna complain about various ailments. Helen develops acid reflex. Both Lilly and Rosemary were diagnosed and treated for thyroid cancer.

What are the odds that we'd both get a cancer diagnosis???? Just yesterday I found

out that the cyst removed from my neck last week is thyroid cancer. I am a little

freaked but assured that it is very treatable.

Rosemary's thyroid cancer is diagnosed during her husband's remission and she forgoes treatment for a family holiday. Interpreting embodied responses is not straightforward. Caregivers seemed to have a wide range of benign and beneficial explanations, such as, attunement, compassion, empathy, and intuition.

3.4.3   Narratives of Moral Dilemma

Moral dilemma narratives are stories which involve responsibilities and decision-making regarding the right thing to do, and often resulting in emotional conflict and psychological distress. The most common moral dilemmas involved situations where caregivers believed that treatment and care decisions made on behalf of their loved ones went against their personal values and beliefs. Moral dilemmas also occur when caregivers believe they know what is the right thing to do for their loved ones, but are unable to attain their desired goal due to various factors, such as lack of resources. The responsibilities of caregiving weighed heavily on all caregivers. Situations that resulted in moral dilemmas were varied.

DIAGRAM 3.4.3

NAME*	NARRATIVES OF MORAL DILEMMAS
Sharma	i feel like such a failure. i feel i should be doing something more for him but i dont know what, surgeon says inoperable , second opinion still inoperable,…i dont know what to do
Anna	- even here at the end the punches to the face just keep coming. It shredded me to tell both these places that he was now on Hospice care. I will live the rest of my life with the WHAT IF's ---what if ??????!!!!!!!!!!!
Heather	I feel the weight of his care fall on my shoulders… We do many treatments blindly, not knowing how our loved ones will respond … sometimes, stopping chemo is the kindest most loving decision
Jasmine	The decisions are hard and really are life or death decisions. There is no cure. So why are we going through all these treatments whose side effects are just as bad or worse as the disease?"
Rosemary	I just wish I knew if he is really in there. He would be so upset to know all he's going through……The last 3 months robbed him of his ability to communicate…I always wondered what he was wanting to say…
Lilly	No offense to the docs, but if they REALLY knew so much about this, the mortality rate would not be as high as it is. They've "got to do something, offer something" and what is offered is woefully insufficient
Helen	What the doctors do not like to say, and we do not like to hear, is that at some point in treatment, the medical situation implodes on itself and we run out of options … we would be basket cases of grief if we were second guessing ourselves and thinking - "if only we had done this or that

*All names have been changed

Jasmine's moral dilemma lies in the knowledge that she is not fulfilling her husband's wishes. She recalls that his first concern was not to be a burden. For 4 years, he was a caregiver to his first wife who died of cancer. He was clear that he did not want to linger on, but, when the time came, Jasmine found that she was helpless and had no say in treatment decisions. For instance, the steroids prescribed for brain swelling, also caused muscle waste, Cushing's syndrome and lethargy. Despite his worsening symptoms, observed at home, his MRI scans showed a stable tumour, (a common occurrence due to hidden tumour tentacles invisible on the MRI), which meant the continuation of aggressive chemotherapy. Jasmine noted continued treatment was exhausting as they:

> *had to travel by ambulatory transport (he is bed ridden, so had to go on a stretcher), it's an hour-long drive to and from the hospital, and there is a lot of wait time at the hospital, so very long days for someone who likes to sleep most of the time. Besides it was also very uncomfortable for him because it was really hard for them to find a good vein to use…*

After two weeks of continued treatment he suffers seizures and internal bleeding, and she is informed that these are potential side effects of the treatment. She feels helpless and guilty, that she was unable to fight for him. She is torn between the opinion of the doctor and her husband's pronounced wishes. She explains:

> *His biggest fear when he found out he had a tumour was to be bed ridden, "useless" and a burden. He is bed ridden. He is not useless to me … and he is not a burden either though I have to do everything for him, but I know he does not want to live this way …*

He later develops cataracts in his eyes, which turn out to be a side effect of steroids. The neuro ophthalmologist recommends laser eye surgery, but the waiting time is 6 months. She

is tormented by the decision making, not wanting to think the "unthinkable" by acknowledging that he might not be around in 6 months:

> *There is no cure. So why are we going through all these treatments whose side effects are just as bad or worse as the disease? My husband's quality of life is more important then keeping on fighting a losing battle which is robbing him of everything: memory, sight, mobility, muscles, taste, continence, etc. It is a terrible disease.*

She concedes that:

> *there are days here and there where he has a resurge of energy and can hold a conversation...*

Those conversation days are bittersweet because he thinks it's 1996 and keeps asking for his late first wife. He thinks Jasmine is his nurse. She feels that her husband of 11 years is already gone and she is taking care of a stranger. She is overcome with guilt for this kind of thinking.

Anna, a fierce advocate for her husband, presents a sobering discussion on medicine:

> *What goal do we have? Health and good standard of life for our beloved. What is average doctor goal? Not being sued, comply with standard practices, avoid any risky procedures, also prescribe drugs from the company which invited him to Caribbean trip ;-) Don't you see conflict of interests?"*

Rosemary's moral dilemmas are complex. She believes she is the cause of her husband's GBM. She narrates her story:

> *Prior to my husband's diagnosis (7years ago), I wound up in the hospital…. for 3 months and was diagnosed with a rare xxx disease…. my husband was there every day, fighting my battles, feeding me when I couldn't feed myself. I left confined to a wheelchair where I am today. I could no longer work or drive… He took me to therapy, managed the house, paid the bills, bought the groceries and cooked the meals. He was my full-time care giver while holding his full-time job working from home. And then we were hit with his GBM diagnosis…… I know none of us know what causes brain tumors, but I can't help but believe the stress he endured contributed to it.*

She is haunted by treatment decisions she made. He initially responded well to treatment and they had "a 10-month honeymoon period." She promised him that if the tumour recurred, she would take him to a well-known cancer centre. When his tumour recurred, she "didn't bring it up" and instead signed off on a promising new treatment based on her research:

> *well, unfortunately, the tumour growth exploded, he wound up on hospice……I'll always feel guilty…I have to live with this decision …*

She also feels culpable for allowing the use of steroids:

> *for 3 months …. he was totally unable to communicate, was totally incontinent the whole time and was paralyzed. If the steroids kept him here in that condition, … I know he would not have wanted to be here in that condition…I hate that he may have been suffering and I didn't know it.*

Rosemary feels that she was not able to provide the best possible care her "knight in shining armour" deserved. Because of her disability, she received assistance from a team of rotating

nurses and did not provide the kind of "loving intimate care" that is described by other able-bodied caregivers on the forum. She says*:*

> *In many ways I feel like a fraud because I didn't do what so many spouses did. And*
>
> *for that reason, I feel I'll be forever broken…*

Another area fraught with moral dilemmas involved end of life care which necessarily brought to the fore discussions about quality of life. Medical practitioners were uncomfortable discussing end of life care with relatively young individuals and instead continued with treatment until there were nil options, at which point treatment was discontinued abruptly. Anna was dismayed when this happened. She narrates that her husband died a "horrible death". He was "restless", "agitated", "wide awake and hallucinating about people climbing on the roof." She had promised him that he would stay at home, but:

> *his pain was not manageable at home since the meds that were needed to keep him*
>
> *pain free …. can only be administered in a hospital/clinical setting*

She is shattered that they had to share "his transition" and guilt-ridden that she was not able to provide "the softest landing" for her husband.

Helen's description of her 27-year old son's death captures the paradox of prolonging life/death:

> *Before my son passed … he fell into a deep sleep/light coma for several days. Then*
>
> *suddenly, one day he woke up. For 40 minutes we could talk with him (he did not*
>
> *answer back), we could give him some water and chocolate protein drink. We could*
>
> *tell him we loved him and always had loved him. His eyes smiled even if facial*

expressions had long since left his face. After that, he went back into his sleep…

Memories of those 40 minutes are like stepping onto a beautiful island.

Caregivers reported that failing to attain their caregiving goals, such as keeping promises, being patient, being brave, and so on, resulted in feelings of shame and guilt. Inability to stand up for the values of their loved ones caused feelings of failure, self-blame, frustration, anger and depression.

3.4.4   Narratives of Destruction

Narratives of destruction are stories which depicted the piecemeal destruction of vision, hearing, speech, intellect, mobility, neurological and memory deficits, while keeping at bay symptoms, such as migraines, seizures, mood swings, erratic behaviour and personality changes. Narratives of destruction included the helplessness experienced by caregivers as they witnessed what Sharma referred to as "total annihilation" of everything that made their loved ones normal, ordinary, and unique. It does not help that medical literature makes frequent references to GBM as "the destroyer", "the terminator," and most "aggressive", "deadly", "lethal", of all cancers. Caregivers' experiences and the metaphors they frequently used to describe GBM formed part of the building blocks for narratives of destruction

DIAGRAM 3.4.4

NAME*	NARRATIVES OF DESTRUCTION
Sharma	This disease massacres everything in its path…
Anna	This disease is a brutal monster, evil and vile and foul and devastates everything it touches… - in the final days I watched (him) go down by the hour...... You read and read read and hope and it seems like the beast always always always wins.
Heather	I watched (his) physical ability diminish to what sometimes felt unrecognisable.. he stopped walking, talking, eating and finally drinking…
Jasmine	He lost his reasoning skills, and short term memory, he was just alive, not really living… So hard to witness….
Rosemary	This disease is just plain evil…. Watching this horrible disease ravage his body for months before it took his life… the inability to communicate was probably the worst.
Lilly	**On September 12th he was completely independent, September 13th he was cut down. There was (no) mercy .
Helen	The pace of his decline accelerates wildly.. ..Nothing worked. This is the most lethal and dangerous cancer known to mankind

*All names have been changed

**Dates have been changed

Jasmine says:

> *as he lost his reasoning skills, and short term memory, he was just alive, not really living. His beautiful spirit was always there, but he was no longer the man I knew, more of a shell with a spirit slowly detaching itself from the human body. So hard to witness the slow death…*

Helen sums it up as follows:

This disease robs us of our loved one and replaces them with a TUMOR; a tumor that talks and acts out in ways that our loved one never would have nor ever could have. You always have to remember that; the damned thing talks and usually does not speak nicely or even logically most of the time.

Anna concurs:

Nothing prepares you for what you see as a caregiver for someone with this disease. I watched my strong sexy healthy man deteriorate to someone I did not know - who did not look the same/act the same - nothing. It was like caring for a stranger in so many ways.

Destruction also referred to the rapidity and unpredictability with which disease progression advanced.

3.4.5 Narratives of Silence

Narratives of silence permeated the whole GBM caregiving experience. Narratives of silence were a complex mixture of stories known and unknown. Stories unknown engulfed the path of the future deviating from the taken for granted, pregnant with a void and emptiness threatening to spill over at any moment. It was the silence of impending loss. I have used the term *Asymbolic* narratives to define these stories that defied verbalisation or representation, because there was nothing in the caregivers' previous encounters or imagination to provide a guide for narration.   Silence was predicated on various experiences taking various forms: i) Care-recipients were silenced by disease progression; ii) There was silence between caregivers and care-recipients; iii) Silence from medical practitioners ill-equipped to deal with

the disease; iv) Silence in the family; v) Silenced by the insensitivity of others; vi) Silenced by witnessing suffering; vii) Self-imposed silence as respite.

DIAGRAM 3.4.5

NAME*	NARRATIVES OF SILENCE
Sharma	I felt out of sync with everyone else, I did not find any solace in any one's words, …I am silenced
Anna	There are parts of this journey I am aching to share and I am stopped by my own fear and desire to remain private, although I think sharing them would lighten my load and possibly help someone else in this position
Heather	His cognitive deficits make the experience very isolating and lonely since he was always the one I would talk to about things.
Jasmine	The whole experience was isolating. They kept telling me to put him in a facility so I wouldn't have to look after him all the time, but they didn't seem or want to understand that I was his voice and advocate. I knew what certain behaviours meant, and others didn't.
Rosemary	His inability to communicate was the absolute hardest. I wanted to talk with him but he was not able to respond to me.
Lilly	When my husband was diagnosed I truly feared for my own mental sanity, I was so scared I could barely speak
Helen	.. when I understood he was dying, I also said nothing to him. We just enjoyed each other's company, in a mutual silent conspiracy to ignore the T-Rex in the room, until he died

*All names have been changed

Stories known induced silence for various reasons and most were told retrospectively.

Silence in the period following surgery is ubiquitous. Recurrence period for GBM after surgery can be two weeks to twelve months and patients are routinely monitored every two to three months via MRI. Inevitably, the tumour comes back. This "dreaded period" which is referred to by Helen as "waiting for the other shoe to drop," and by Lilly as "the unthinkable" is never openly discussed "in the moment." It is only post-bereavement that caregivers describe their feelings of being terrorised by the omnipresent threat of recurrence, a taboo subject that remained unspoken.

Lilly remains silent because of her personal belief that "words have power" and to speak of her fear is to allow it to take shape. She confides that:

> *When my husband was diagnosed I truly feared for my own mental sanity, I was so scared I could barely speak…God is so good. I know I'll be given direction if I sit still, get quiet and put this whole situation in His hands.*

Many other stories remained unspoken. Anna reveals her reluctance to share some aspects of her caregiving experience, dissuaded by the "public even when private" nature of online communication. Caregivers were also reluctant to share intimate details that are part of the dignity-eroding GBM illness trajectory. Sharma's experience of silence includes feeling unsupported by relatives and medical practitioners. Jasmine echoes Sharma's experience regarding the isolating nature of GBM caregiving. Anna does not get on well with her in laws, who "second-guess" all decisions she makes. She perceives this as a lack of trust and eventually stops communicating with them, remaining silent. Silence serves to protect Anna and others from "uncaring and untrustworthy others".

Silence came in various other forms. There was silence among caregivers understood as a mutual understanding. Rosemary "wanted to be strong" for her daughters and kept away some "difficult" information. Caregivers also described their shrinking worlds as silencing. Anna describes how their lives became confined to their home as she watched her "once brilliant" husband move back and forth between his favourite *La-Z Boy* (recliner) and the sofa while flipping TV channels. Sharma, Jasmine and Rosemary' limited their social contacts due to aphasia (inability to speak) or dysphasia (loss of language comprehension) experienced by their loved ones who were also bedridden. Aphasia, Dysphasia and mobility deficits are common symptoms of GBM. Lilly's fear of seizures made them withdraw completely from social life.

All caregivers self-silenced for various reasons. Some expressed "the need to take a break," from dealing "with much more death." Sharma disclosed that: "I am silenced and I have read so many heart-breaking posts". Explanations were not always forthcoming and some absences from the forum remained a mystery. But, ultimately all caregivers experience the ultimate silence – the absence of further treatments and the elimination of all hope is experienced as the beginning of the final silencing event. For Helen, the thought that her son was dying was "the unthinkable," "the dread that could not be verbalised:"

> *When I understood he was dying, I also said nothing to him. We just enjoyed each other's company, in a mutual silent conspiracy to ignore the T-Rex in the room, until he died.*

3.5   Core Narratives

Core narratives are described as dominant narratives circulating exclusively within the GBM caregiving community. Two core narratives formed the third layer of analysis. They are: The Suffering of Caring and Woman as Healer.

3.5.1   The Suffering of Caring

The Suffering of Caring is a core narrative constructed from interrogating the convergence of the five story typologies: Narratives of Disruption, Embodied Narratives, Moral Dilemma Narratives, Narratives of Destruction and Narratives of Silence. The Suffering of Caring is the most dominant narrative in the storytelling landscape. I define The Suffering of Caring as a deep kind of empathy embedded in the caregiving/care-recipient relationship and in which the distress of a loved one is experienced as one's own distress, blurring the boundaries between caregivers and their loved ones. The Suffering of Caring represents an alliance between mutual vulnerability and mutual empathy.

Sharma's evocative description captures the essence of The Suffering of Caring succinctly:

> *This disease is total annihilation from word go, and I watched helplessly as it ate into my husband bit by bit, watching him lose his faculties was the hardest thing for me, from not being able to walk after biopsy to not being able to form sentences, from not being able to write to not being able to read ...or speak, being confined to wheel chair to hospital bed... for me protecting my husband, s feelings and dignity was paramount, nothing else mattered at that time for me. Only a person who has seen a degenerative disease up close and has been a care giver can understand what it is like, give it all one has got , fight on in the face of such hopeless and difficult situation, and when you have no hope given and becomes increasingly apparent what lies ahead ,this disease is relentless , it does not give you a respite anywhere, it*

requires adjusting to very fast changes in mental and physical abilities , sometimes in

days and sometimes in a matter of hours, it is a huge burden that the care giver

carries . Which is impossible to bear without the selfless and deep love I have seen

in all the care givers, what compels you to do that, in my case I felt just as protective

about my husband and felt the same tender love that I felt when I had my children.

Her eloquent perspective mirrors what other caregivers disclosed about their experiences of caregiving. She points to her relationship with her husband as the inspiration for selflessness and protective love which are the central ingredients of GBM caregiving.

3.5.2   Woman as Healer

Woman as Healer is the second core narrative, also arising out of the convergence of the five story typologies. Woman as Healer represents what is absent but implicit in the caregiver stories. The essence of Woman as Healer is exemplified by Helen's post:

Your posts deeply touch me and provide much consolation during this time. What is

clear from these messages is that none of us are alone as we journey through this

unspeakable trial. We all have each other to lean on - for knowledge, for hope, for

compassion - and I am grateful for each of your perspectives and contributions to this

Board, which I feel has made such a difference in my ability to better process this

awful outcome. You taught me and prepared my mind and heart for the worst pain

that a parent can ever experience. You explained what it means to be a caregiver - to

deal with the behavior issues and change diapers in the middle of the night on just 3

hours sleep and to do it all with love and patience and gratitude for one more hour,

one more day. You showed me how to be meaningfully human in the face of an evil

and inhuman disease. Thank you so very much for being there for me when I needed

you. Helen

This is echoed by Jasmine who reports that she learned how to listen and respond to others from the forum. She found strength and solace in her interactions with other caregivers, suggesting that underlying the stories presented in The Suffering of Caring were stories of love, strength and resilience which make up the core narrative of Woman as Healer:

> *i do his every little thing myself from bathing him , to changing him and feeding him , hoping he can register on some level that it is me and he is safe. Sharma*

> *When I look back at the beginning, I am still amazed that I made it through those first few weeks. Never have I been so scared. But as soon as we got home. I began researching - we have been to five brain tumor centers with phone/scan consults at three others; and I am still trying to find a cure/or at least make this a chronic disease - we are almost 13 months in an counting; but it is still hell, sheer hell. But I love him, he is my life and as long as I have breath in my body I will fight for him. It is hard at times it seems impossible… Anna*

These stories are at the heart of how brain tumour community members, not only care for their loved ones, but also care for each other. Woman as Healer is made up of inspirational stories, lessons learned and shared:

> *It is a completely terrifying, life-altering, heart-breaking situation you are in. So, how to get through it? Yes, hang onto hope...for now. A small percentage of individuals do beat this stupid disease. But, unfortunately, the largest percentage of people do not. So, the key is knowing when to drop hope as a life-preserver or else, should it become evident that hope is useless, you may be left in a pile of ash from anger. Since hope can eventually betray you, the better virtue to cultivate at this time is love. Helen*

I learnt more from the members of this forum then the doctors themselves, infact I learnt every thing here, about treatments to care giving… I read on this forum the single most important thing , be kind, that is what I would like to repeat, be kind . All empathy comes from kindness… we are all mortal and running scared from death will not make us immortal . the person who is facing this disease needs his friends and relatives more than ever, be there for them   Sharma

T H A N K Y O U EVERYONE - you are all gems, true gems. Thank you for the love, support, info and suggestions. Not afraid today, feel grateful, inspired and supported. My heart is with all of you in these terrible trials. I have had the good fortune to speak with a few of you around the country over the phone and it has been VERY helpful, very validating. I imagined that I would sign off this website for good at the 1st of this month, but find that I can not let go yet. Lilly

3.6   What happens as a result of narrating stories online?

The second research question was: *Can you please tell me about the stories you shared online, the responses you received and whether or not you are still sharing stories online?* The findings are presented in five layers as follows: 1. The Storytelling Landscape, 2. Relational Narratives, 3. Dialogical Narratives, 4. Narrative Performance, and 5. Hindsight Narratives, as depicted in the below diagram.

DIAGRAM 3.6 THE STORYTELLING LANDSCAPE

3.6.1 The Storytelling Landscape

Stories do not exist in a vacuum. In this study, the storytelling landscape is an online brain

tumour forum. I use the term storytelling landscape to infer the location and setting in which

dialogue takes place, the dynamics involved in the dialogue (telling and retelling), the topics

of interest, the central features and the culture surrounding members and membership. Story

as the medium of communication exists in a storytelling landscape that has a significant

influence on the stories created. The online forum where the stories were narrated are

central to the kinds of stories that were produced. Online GBM forums are global narrative

spaces created to share stories about brain tumours. They fill a crucial knowledge gap

identified in the literature review. The storytelling landscape sustains this research as well as

the stories narrated. The stories are specific to all matters GBM - types of treatments,

symptoms, medication, and care. Members are friends and relatives who are caregiving for a loved one with GBM. They come and go as they need, characterising fluidity.

The landscape contains all stories, past and present ensuring continued dialogue. Members decide whether to share their stories with members only or publicly. Stories are organised by topic and date. Old stories are archived and can be retrieved, which means that each story, not only, leaves its mark on the landscape, but, also continues generating responses in the future. Each story has the potential to attract hundreds of responses, endowing it with simultaneous multiple layers of meanings and interpretations of a single event. Each day, all members receive an email with the top ten topics of the day. Once a member responds to a topic they receive an email alert each time someone responds to the story. There are few protocols for participation: email address, username, geographical location and a voluntary short or long bio. Caregivers can join at different points, have access to all the stories, are free to participate or not, take a break and return or cancel their membership. There are no conditions for membership and no fees involved. Many caregivers confessed to being lurkers for months before posting their first story. The storytelling landscape is filled with all kinds of stories too numerous to locate, suffice to mention that underpinning the origin of most stories is the desire and hope to "save" a loved one from the fate of GBM as described by a research professor at Yale University:

> *Glioblastomas, you can say, are a total disaster… When you are hit with this diagnosis it is always a tragedy, because essentially there is almost nothing that can be done … The prognosis is about a year that you have to live. Furthermore, the current options for therapy provide very little in the way of extended lifespan. There have been few if any advancements in the treatment of glioblastomas. The state of the art (treatment) is horrible… Essentially, people get these tumors today and they die from them ….. (as) happened 20 years ago, 50 years ago, 1000 years ago. Virtually no difference (Bendesky, 2015).*

The storytelling landscape is imbued with numerous dynamics of storytelling, central for the co-creation of the collective narratives as caregivers resist their fate (as described by Bendesky, 2015) and support, encourage and inspire others:

> *You have - against your want and will - joined a club of parents, wives, patients and caregivers who have experienced or are experiencing what must be one of the most frightening nightmares known to mankind…. (it is) .. a very, very tough place. Helen*

Three distinct features of the storytelling landscape which emerged are relational, dialogical and performative.

3.6.2   Relational Narratives

Relational Narratives are stories narrated within relationships formed from shared experiences.

> *Your (sp?) are part of a big family now that I am sorry you were forced to join, but welcome, you get no judgment here 'cuz we know the drill sister, we know the drill. Hang on, it is bumpy and rotten!! But we got your back - VENT ANYTIME! Lots of love coming your way…Anna*

3.6.3   Dialogical Narratives

Dialogical Narratives refers to the idea that each story has a response and is therefore a continuous conversation.

3.6.4 Narrative Performance

Performative aspects of storytelling address the issue of what happens as a result of storytelling, that is, its effects. All caregivers narrated actions they had taken as a result of storytelling.

3.7 Hindsight Narratives

Hindsight narratives emerged from the email interviews. Participants were asked to reflect on their stories and the responses they received. Hindsight narratives provided retrospective perspectives regarding the storytelling landscape as follows:

> *It was a safe place where I could explore and imagine my future, getting information and support from both patients and their caregivers. I could ask others about their experiences, compare them to mine and feel like I was getting a better picture of the myriad possibilities of what was inevitably coming. Honest and candid foreknowledge of the possibilities of what was coming helped me to feel like I could emotionally prepare for the inevitability of my husband's death. Heather*

Jasmine also described how she found the forum useful:

> *I tended to respond when a post resonated with me, or where I thought an objective input might be helpful to the recipient. Sometimes the resonance was due to being at a similar stage in the journey, other times it's is because I felt the pain and fear as if it were my own, and wanted to offer a listening ear and a sense of not being alone. I know that not feeling alone was important to me, and wanted to provide that as others had provided me the same support. Sometimes posts were filled with so much pain that I didn't know how to respond, and didn't, but luckily their were others out there able to support those people…*

Hindsight narratives included stories narrated post-bereavement. Lilly considers the forum a safe space where she can share her feelings about her husband knowing that others understand.

> *I love looking at photos of XXX when he was a strong, strapping man with lots of physical strength. A man who liked to chop wood and dive into ocean waves. Some say time exists on other planes and realities. I like to think of the happier, healthier times, put myself in there with him and re-live it. Lilly*

Rosemary also shares her feelings about the loss of her husband:

> *I still talk to my husband. I still have crying spells. I will always have a hole in my heart where he was. But I am determined to ensure he will live on in the hearts of those still living. As far as the hole……, I don't believe it will ever go away**.***

3.7.1   Narrative Responsibility

Narrative responsibility refers to the multiple responsibilities weighing on caregivers and which influenced their actions. The theme of responsibility underlies most actions taken by caregivers throughout the illness trajectory and post-bereavement. Narrative responsibilities are discussed in Chapter 4.

3.7.2   Narrative Resistance

Narrative resistance refers to the stories and activities caregivers engaged in to resist the dominant *GBM the destroyer* statistics. All caregivers believed that their loved ones could "beat this disease" and did everything possible to achieve a different outcome. The theme of

resistance, like responsibility, underlies most actions taken by caregivers throughout the

illness trajectory and post-bereavement. Narrative resistance is discussed in Chapter 4.

3.8   Reflections on Analysis

The principle commitment of DNA is to engage the story in an ongoing dialogue, thus "letting

stories breathe" (p.10). Doing DNA, therefore, involves continuous interrogation of stories,

opening up the potential for multiple layers of findings. DNA also lays emphasis on individual

stories as well as collective narratives. Engaging in the analyses of 7 individual stories, in

addition to connecting the stories into collective narratives, followed by illuminating the

storytelling landscape demanded meticulous attention and patience. The hundreds of stories

located participants at the crossroads of many potential narratives enriching the findings, but

also, making it a challenge to address all the themes. Further, building story typologies

required singular focus to language, particularly, tone, emotion and metaphors. Frank (2012)

suggests that a good story typology brings together the individual and collective themes in

relation to each other in an explicit and meaningful manner. The integrity of each typology is

maintained when the listener can more readily identify the narratives, enabling an in-depth

understanding of psychosocial experiences. Story typologies provide the listener with an

opportunity to reflect on how to respond to GBM caregivers. Polkinghorne (1995) warns that

typologies can copy/paste experience in a way that does not capture the participant

holistically and serve only to support theories and conclusions. Thus, the DNA researcher

bears responsibility for continued dialogue, ensuring that analysis does not impose a

diagnosis or a narrow theoretical perspective to the stories. The DNA researcher stance is

that of being primarily a witness, which entails putting stories in dialogue with one another

(Frank, 2012). For the researcher, this entails asking for participant feedback which requires

time, demands sensitivity and further adds on to the complexity of the analysis. Participants

in this study were generous with their contributions. Their feedbacks validated and enriched

this study. Further, DNA aims to deepen the relationship between the research, the researcher and the researched as implied in the following correspondence:

Dear Susan,

I've been avoiding allowing my heart to shatter (or open fully) and feeling the depth of emotions for quite some time, but in answering your (email interview), I allowed myself to go there.   And as much as I am crying and feeling so much sadness, I've also discovered the great love that lies within this emotion. I don't know if I had ever realized or noticed before that it was there with the sorrow of loss. So thank you for your research...it has allowed me to discover more about myself! There is so much beautiful tenderness in the sorrow of loss, and being aware of it makes sitting in sorrow not quite so scary. I don't know if that makes any sense, but I'm grateful for the discovery, and thought I would share it with you. Much love, Jasmine

DNA works to enhance the quality of companionship between the storyteller and the listener. As a researcher, my initial interest was in story typologies which focus on the collective experience of stories. As I engaged with the stories further, it became apparent that each of the 7 stories was worthy of increased audibility. This resulted in a tension that I carried with me throughout the research – a tension of *unfinished business*, a feeling of not doing justice to the other six individual stories. This tension is best described as the researcher's *narrative responsibility* towards each story which needs to be balanced with the researcher's own academic mandate. The compromise I made was to include abbreviated versions of the other 6 stories. From a narrative perspective, this decision is perceived as *narrative resistance.*

Nevertheless, I acknowledge that it was not possible to comprehend and interpret my participants' stories with a universally accepted lens (if such a lens exists). I engaged the stories with narrative humility; recognising that not all stories are familiar, even though I shared so many similar experiences with my participants. I am also aware that these stories could have been analysed and interpreted differently, resulting in different genres (Riessman, 2008). Additional reflections are provided in Section 4.9.

4 Chapter Four: Discussion

4.1 Overview

Chapter Three presented the analysis and findings of the online GBM caregiving stories collected from participants, and the email interviews conducted. Chapter Four locates these findings into the wider theoretical frameworks of counselling psychology, the literature review, narrative inquiry, illness narratives, DNA, and feminist relational theories, guided by the research aims, questions and methodology. This discussion addresses each research question separately. Implications for counselling psychology are interwoven throughout the discussion, followed by a critique of current conceptualisations of caregiving and bereavement. Suggestions are made for reconceptualising GBM caregiving as a relational, embodied, moral and spiritual experience. Further suggestions are made on how counselling psychology can expand its response-abilities to suffering. Strengths and limitations of the research are discussed. The chapter concludes with a final *a posteriori* reflexivity.

4.1.1 Research Q.1 What kinds of stories do GBM caregivers narrate online?

The aim of this research question was to amplify brain tumour caregivers' "forgotten voices" (Sherwood et al., 2004, p.67) and learn from their psychosocial experiences of caring for their loved ones diagnosed with GBM. The focus was on three interrelated areas:
a) subjective stories b) collective story typologies, and c) core narratives. The expectation was that subjective experiences, story typologies, and core narratives would educate healthcare practitioners about the psychosocial needs of GBM caregivers throughout the illness trajectory and post-bereavement, particularly, the conditions that cause suffering. The presumption was that story typologies would enhance professional listening by providing counselling psychologists and other clinicians with "a simple structure for what to listen for" (Frank, 1995, p. 12) in their work with GBM caregivers. Engaging with story typologies and

core narratives has the potential to expand practitioners' response-abilities in their work with

GBM caregivers. The discussion is structured to systematically address each of the research

findings, beginning with: 1 a) Subjective stories: Sharma; b) 2. Story typologies:

a) Narratives of Disruption, b) Embodied Narratives, c) Moral Dilemma Narratives,

d) Narratives of Destruction, e) Narratives of Silence; and 3. Core Narratives: a) The

Suffering of Caring and b) Woman as Healer.

DIAGRAM 4.1.1 STORY TYPOLOGIES & CORE NARRATIVES
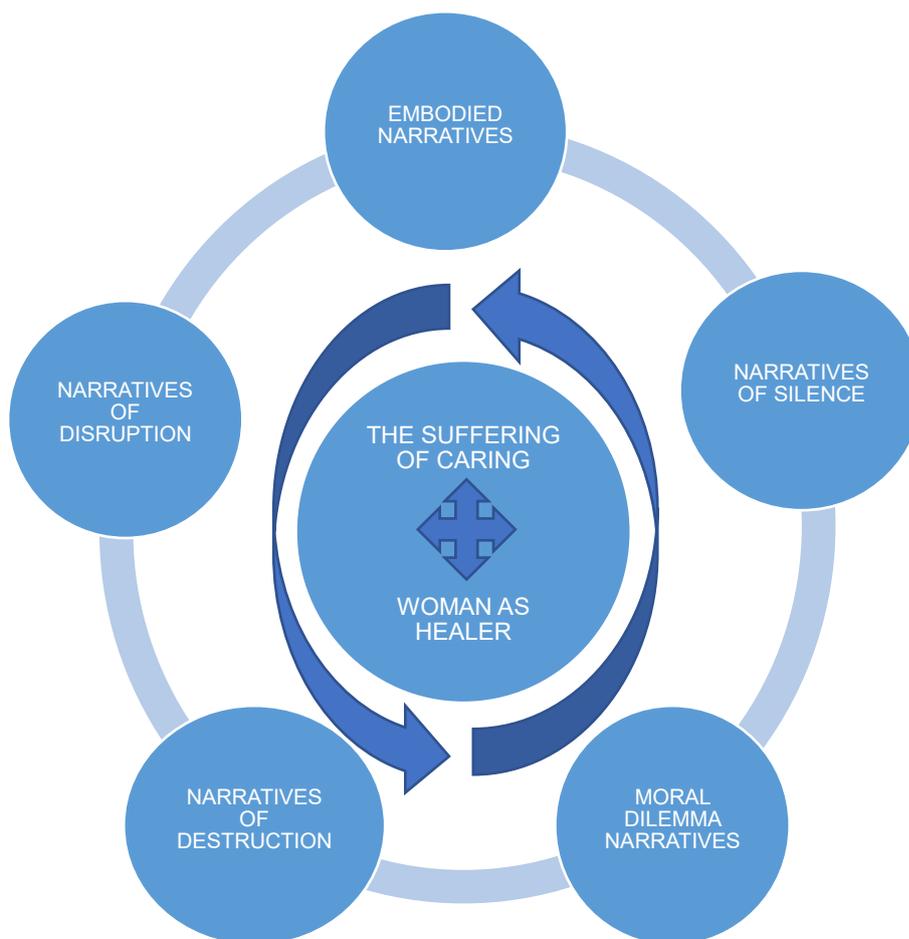
4.2 Subjective Stories

Even though, individual stories were *prized* (White & Epston, 1995) as authentic portrayals of *voice,* caregivers were perceived as "relational beings," embedded in their social and cultural environments (Gergen, 2011, p.1). Each caregiver narrated stories chosen from a collection available to them, depicting what mattered most to them, and what they elected to share or not (Frank, 2012). All the seven individual stories met the criteria for increased audibility and needed to be heard. One story out of the seven was randomly chosen.

4.2.1 Sharma: *No Suffering Plz…*

Sharma's stories corroborated most of what was presented in the literature review, evidencing high unmet needs, lack of resources, and lack of social support (Arber et al., 2010; 2013) including her perception of "apathy and indifference" from medical practitioners (Aoun et al., 2016; Philip et al. 2015). From the outset, Sharma was confronted with complex care needs, such as attending to mobility and neurological deficits immediately after premature discharge from hospital (Collins et al., 2015; Ownsworth, 2010; 2015). Sharma's descriptions of her life reveal a patriarchal society where "men, fathers, brothers, sons" take care of the women and she perceives Anu's illness as loss of protection. Her stories suggest rapidly moving events. Her incoherent syntax fits Frank's (1995) description of a chaos narrative in which, "one bad thing has led to another, and life is collapsing around this person. Efforts to stop the collapse are futile; everything has been tried, and each potential form of assistance is blocked" (p.48). Sparkes & Smith (2011) explored multiple responses to a chaos narrative told by a young man named Jamie (pseudonym) who suffered a spinal cord injury, and as a result requires artificial life support, breathes through a ventilator, has no movement or sensation below the neck and requires full-time care. The audience reported feelings of anxiety and discomfort in listening to Jamie's story, affirming Frank's (1995) stance that chaos narratives are hard to tell, hard to listen to, and "words necessarily fail" (p.98). Frank observes that "naming the chaos narrative opened a silence in clinical

practice " (p.12), suggesting that clinicians also found it difficult to respond to chaos narratives. Frank (2015, p.2) cautions that "listeners bring their own defences, including everyone's fear that the storyteller's troubles could become my troubles". In addition, clinicians resist "hearing about inadequacies of care". Smith & Sparkes (2011) reported that, most audience members responded to Jamie's story by attempting to immediately drag him out of chaos by suggesting the need for depression therapy.

In stark contrast, Sharma's chaos stories shared within a community of storytellers, receives numerous well-thought-out responses, offering empathy, compassion, support, and very useful practical advice on how to take care of Anu's mobility deficits. In this forum, chaos narratives beget more stories rather than anxiety and discomfort. Sharma credits this responsive community with supporting her, even though her circumstances are comparatively difficult. Sharma and Anu have no health insurance, no supportive health care team, no hospice, no palliative care, no social support, no clinical trials and yet, she is holding her own. Frank (2012) refers to holding one's own as the effort to "sustain the value of one's self or identity in whatever threatens to diminish that self or identity" (p.34). By continuing to participate in the forum, Sharma's voice is heard. With time, her stories alternate between advocacy and helplessness, portraying both resiliency and vulnerability, suggesting that suffering and healing are not mutually exclusive, and in fact often co-exist (Papadopoulos, 2002). This finding is in keeping with DNA ethos and social constructionist understandings of individuals as innately multiple (Frank, 2012).

Counselling psychologists would benefit from heeding Frank's (1995) suggestion that those who tell chaos narratives "can only be helped out when those who care are first willing to become witnesses to the story" (p.98). Based on this statement, I presuppose a preference for non-directive therapies, such as bearing witness which is largely non-verbal (Tatran,

1997). Bearing witness is described as a stance that values showing up, being there, and listening to another amidst discomfort, helplessness and anxiety. Bearing witness is "the choice to give the gift of a pure expression of love and respect — being a compassionate observer to the unfolding of another person's life or a particular moment or event" (p.86). For counselling psychologists, bearing witness includes providing relational safety and unconditional love for the Other (Levinas, 1987) by listening to their story without judgement. Chaos narratives call on us to respond by standing in solidarity, beside those in need. Sharing stories and having others bear witness enabled Sharma's chaos narrative to be heard.

Exploring the conditions needed for chaos narratives to be heard is a salient issue for counselling psychology. Frank (1995, p. 98) argues that it is both a moral and a clinical imperative that chaos narratives are heard. He reminds clinicians who work with chaos narratives that "chaos is never transcended but must be accepted before new lives can be built and new stories told," and even then, "chaos always remains in the story's background". Counselling psychologists who work with chaos would benefit from understanding that chaos narratives "can only be lived" (p.98). Yet, there is hope that if the voice of chaos is captured, it can potentially open-up the possibility that the story can be reconstructed. A counselling psychologist working with Sharma from a narrative and feminist relational perspective would interpret her reaching out to the brain tumour community as an attempt at connection (Baker-Miller, 1976; Jordan, 1995). Her decision to tell her story is interpreted as an attempt to make life narratable in the face of chaos. Her story is viewed as a *counterstory*, which is described as a form of resistance, enriched by her connection to other GBM caregivers (Frank, 2012). Sharma's vulnerability, shared on the forum with other vulnerable caregivers is transformed into mutual vulnerability, which occurs in relational safety. Thus, mutual vulnerability is recognised as a strength and a pathway for more integration and more

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responsiveness (Jordan, 2001; 2008). This interpretation is supported by Sharma's hindsight perspective from the email interview.

> *I found encouragement and learnt that there are many others who are going through this, and over and above I learnt to what extent human soul is capable of loving and enduring with such grace. Sharma*

Sharma's email interview recalls her most memorable post in the forum, when she questioned other caregivers' frequent use of the journey metaphor to describe their experiences. She discloses that she still rejects the journey metaphor and still perceives her suffering as useless and meaningless. The journey metaphor has been described by Frank (1995) as a Quest Narrative, characterised by the storyteller's belief that something meaningful and transformative will be achieved through suffering. Storytellers of Quest Narratives "meet suffering head on: they accept illness and seek to use it" (1995, p.115). In their research with bereaved individuals, Neimeyer & Sands (2011) found that the ability to make meaning from tragedy, contributed to a healthy adaptation to loss. A counselling psychologist, working with Sharma would benefit from being aware of the dichotomy between subjective stories and collective narratives. Subjective stories become part of collective narratives when they resonate, find validation and recognition, amongst other storytellers and similar story typologies. Sharma's narrative mirrors the two core narratives, balancing both suffering and healing in equilibrium. If allowed expression, these narratives can further illuminate the complexities of Sharma's experiences and the furtherance of narration as a potential pathway to reconstruction. Awareness of the debates surrounding meaning making in the face of tragedy can provide further insights (Neimeyer et al., 2006, 2010). It is prudent to remember that even Frankl (1984, p.9), who espoused the wisdom of "finding meaning" advised that no one can tell another what meaning is or how to find it.

Finally, Mahaffy (2015) notes that caregiving reveals our own vulnerability in the face of mortality and is potentially a source of discomfort for the healthy, thereby validating Sharma's experience of *No Suffering Plz…*

4.3   Collective Story Typologies

Each of the five story typologies represents an attempt to capture a frozen occurrence in time, and frame it as a representation of the event. Each story typology bears witness to collective experiences, which were narrated in relation, in dialogue, evoking multiple responses, resonating with multiple community members, and finding validation among them. These stories, thus, have a temporal value (Bruner, 1991).

4.3.1   Narratives of Disruption

Those suffering *disrupted lives* create meaning through storytelling (Hyden, 1998). Atkinson (1998) proposed that "we become fully aware, fully conscious of our own lives through the process of putting them together in story form … Telling our story enables us to be heard, recognised and acknowledged by others" (p.7). Narratives of disruption consisted of stories depicting the turmoil experienced by GBM patients and their families. Disruption comprised of the event of diagnosis, impact of prognosis, efforts at adjusting to the new normal, meaning making and coping with the disruption. Narratives of Disruption are supported by Hyden's (1997) findings that anxiety and uncertainty about the future obstructed ordinary life, blocked and revised plans and caused lives to be re-examined. GBM caregivers and their loved ones faced their new realities and made efforts to adjust and cope with their new normal. Much of what was described by the caregivers is validated by Bury's (1982) *Chronic Illness as Biographical Disruption.* Bury found that chronic illness impacted "the very foundation" of peoples' lives "causing discontinuities" and forcing them to look at the future

from "a different perspective with reduced options" (p.169) as life becomes confined and restricted. Additionally, "structures of everyday life and forms of knowledge which underpin them are disrupted" (p.169). Chronic illness laid bare the "resources (cognitive and material) available to individuals and modes of explanation for onset of disease" (p.167).

McConigley et al. (2010, p.474) reported that brain tumour caregivers' experiences differed from other cancer caregivers' because they faced "unique care-related issues and a shorter disease trajectory." "The rapidity with which changes took place" gave rise to a complex mixture of emotions and the disease's relentless ongoing nature, put brain tumour caregivers at high risk for poor mental health, particularly PTSD. Although GBM caregivers used analogous metaphors to describe the abrupt and violent nature of their experiences, their available resources were varied, as were their meaning making processes.

From a narrative perspective, disruptions are perceived as events which cause ruptures and can be reconstructed. Kleinman (1988) proposed that illness narratives are one way of coping with ruptures. Narratives of Disruption can be useful for psychologists because they often include the storytellers' meaning making processes and their responses to disruption, which situate individuals within their families, cultures and wider environments. Counselling psychologists would benefit from remaining aware that meaning making and resistance to disruption continue throughout the illness trajectory and post-bereavement. GBM caregivers found the opportunities to share their stories beneficial. In Narrative therapy, storytelling is interpreted as an effort to manage the biographical disruption. There is an understanding that there will be times when the sequence of events is not coherent. Awareness of the thin line between life and death whether spoken or unspoken is a useful stance to adopt at this time (Kleinman, 2008, 2009).

Based on Bury (1982), counselling psychologists working with GBM caregivers ought to be mindful that the disruption has likely ruptured the clients' "taken for granted assumptions" about everyday life and the future and, as a result is potentially undergoing a seismic shift in their explanatory system, resulting in "a fundamental re-thinking of the persons' biography and self-concept" (Bury, 1982, p.170). Assisting clients to mobilise resources is important. The presence or absence of a supportive network has the potential to make a significant difference in caregivers' experiences. Building on Bury (1982), Hyden (2011) put forward the concept of *Broken Narratives*, which refers to the notion that the structure and narrative stability of life has been disrupted and the projected future shattered**.** Broken narratives refer to the limits imposed on individuals afflicted with conditions, which limit their capacity for self-representation.

Narratives of Disruption have wide-reaching consequences for those impacted. Hyden (1997, p.56-57) avers that, narrating stories can mitigate the effects of disruption, because stories can reorient selves, create continuities by knitting together "the split ends of time", which fit the disruption into a temporal framework. It is precisely this relationship with time that undergoes a fundamental shift, when faced with a GBM prognosis. Offering GBM caregivers the opportunity to tell their stories can lead to reconstructing their personal life histories, an essential part of the therapeutic process. Psychologically, the ongoing nature of disruption and the complex mixture of emotions involved can be perceived as anticipated grief or trauma (DSM-V, 2013). Counselling psychologists working with Narratives of Disruption are advised to pay attention to all of the above.

4.3.2 Embodied Narratives

Embodied Narratives consisted of stories which linked the physical body to emotional experiences or other states of knowing. These narratives suggest the physical body's capacity to independently register responses to experiences. The participants identified

various events which triggered embodied experiences such as, doctors' visits, waiting for MRI results, the appearance of new symptoms, witnessing a seizure, pain or suffering. Embodied responses were interpreted in various ways, some implying deep empathy, attunement, compassion, anxiety, depression, fear, anger, despair, hopelessness, guilt, stress, peace and calm. Caregivers were aware of embodied experiences and used various means to interpret and respond to them.

Addams & Merleau-Ponty (2004) suggest that embodied responses are a means of communication through which important information between mind and body can be conveyed. The most cited embodied responses used metaphors, such as "feeling heavy" to convey an emotional state, such as anxiety. Mattingly (1998, 2010) made reference to embodied responses as a means for shared experiences, enabling empathy and compassion. Analysing stories told in the aftermath of the 2004 Tsunami in Banda Aceh, Frank (2013, p.2) noted that many people told their stories "through the body." He observed that the body is central to the experience of the event and to the storytelling about the event. Embodied narratives illuminated the various ways participants interpreted their embodied experiences. These included embodied responses as reactions to events such as, witnessing their loved ones in pain; a warning sign or cue for action; or, a link between emotions and physical selves. Embodied responses as a reaction to their loved ones' needs were associated with various aspects of being a good caregiver, such as being attentive, empathic, compassionate, attuned, intuitive and other modes of knowing. Embodied experiences as a warning sign, included symptoms akin to hypervigilance or hyper-alertness. These symptoms were often diagnosed as somatic disorders, anticipatory grief or trauma (Auon et al., 2016). By contrast, GBM caregivers often interpreted embodied experiences intuitively as helpful cues or warnings and premonitions about the welfare of their loved ones. The link between embodied experiences and action is supported by

Mattingly (1998, 2010) who suggested that experience and action are narratively structured. This viewpoint corroborates caregivers' perception of embodied experiences as a precursor for action. For example, Lilly felt her heart racing and immediately thought of checking on her husband. Upon checking, she found him "moaning in pain" and thereafter vowed not to leave him alone again.

Embodied narratives were also associated with grief. Gudmundsdottir (2009, p.253) described embodied responses as "emanating from the bereaved person's body" and "commonly considered to be psychosomatic reactions to loss". GBM caregivers continued to describe embodied experiences two to three years post-bereavement. They were noticeably different, and more likely to be described as "a gentle touch on my cheek", "a warm feeling," "a pat on my back or shoulder" and so on. McCarthy & Prokhovnik (2013) referred to these experiences as embodied relationality. They suggested that physical death is not the end of embodied relationality, meaning that embodied responses continue after death. Their writings challenge the assumption that "loss of the physical other is a loss of the whole other" (p.5). This perspective is shared by Heather and other caregivers:

> *I watched his physical body die, yet something remains inside of me. I don't know what happens after we die. It is a mystery. What I do know is that I feel a palpable presence …... Life and death are about love and connection even when that physical connection is gone.*
> *Heather, Three years post-bereavement*

In psychology, conceptualisations of embodied experiences as symptoms of maladaptive coping, often diagnosed as psychosomatic disorders or various other traumas best addressed in psychological or psychiatric care are common (DSM-V, 2013). It is, therefore,

significant to note the disconnect between the way participants in this study interpreted their embodied experiences and the literature review's stance of pathology. Counselling psychologists working with embodied narratives are reminded to pay attention to this dichotomy by engaging the client in dialogue about their interpretations of embodied narratives. Furthermore, counselling psychologists are familiar with embodied experiences in therapy, usually perceived as secondary trauma or transference/countertransference. Frank (2012) alerts clinicians to the interpretation of embodied experiences as normative events and not as symptoms of pathological disorders. Mattingly (1998) argues that the body's most innate desire is to share experience, enabling others to simply 'be-with' others. Samuels (2016) concurs that embodied experiences enable individuals to be more evocative by sharing experiences through their bodies.

Nina Papadopoulos (2014, unpublished seminar), a dance movement psychotherapist, teaches that regarding "the body as home opens up a number of important considerations as well as enabling helpful therapeutic applications." Counselling psychologists, who work with embodied narratives are advised to incorporate body movements in their work with physically fit clients. The body can be a source of strength and stability during disruptive times. Nevertheless, chronic embodied experiences can lead to serious illnesses. It is not clear whether embodied experiences were symptoms of illness. Lilly reported losing 15lbs in 10 days immediately after her husband's diagnosis. Heather, Jasmine and Anna reported varying experiences. Helen developed severe acid reflex. Both Lilly and Rosemary were diagnosed and treated for thyroid cancer.

> *What are the odds that we'd both get a cancer diagnosis???? Just yesterday I found*
>
> *out that the cyst removed from my neck last week is thyroid cancer. Am a little*
>
> *freaked but …. it is "very treatable." Lilly*

4.3.3 Moral Dilemma Narratives

Ethical complexities are inherent in GBM caregiving. Moral dilemma narratives were described as stories which involved emotional conflicts between responsibilities and decision-making. Moral dilemmas occurred when caregivers believed that treatment and care decisions made on behalf of their loved ones were against their personal values and beliefs. The most reported emotional reactions associated with moral dilemmas were frustration, anger, anxiety, guilt, self-blame, shame, remorse, regret, dissatisfactions and depression. All participants reported experiencing moral dilemmas throughout the illness trajectory and post-bereavement.

Brain tumour caregiving literature did not directly engage with moral dilemmas. Ethical issues were limited to end of life decision-making and did not focus on caregivers. I have therefore appropriated the concept of moral distress from nursing care literature. Moral distress was first defined by Jameton (1984) as a condition in which institutional constraints prevent nurses from doing the right thing. "The right thing" is guided by the nurse's own moral compass. Moral distress in nursing includes initial moral distress and reactive moral distress. Initial moral distress was described as feelings of frustration and anger when confronted with limiting institutional obstacles. Nurses identified 'prolonged, aggressive treatment as one of the triggers for moral distress (Jameton, 2013). Reactive moral distress involved regrets about not having acted upon the initial moral distress. Both initial and reactive moral distress lead to burnout in nursing care (Jameton, 1984, 2013). *Au contraire*, caregivers and care-recipients were not averse to "prolonged and aggressive treatments", provided there was a chance for improved health. They continually held hope *For One More Day* (Albom, 2006) and, consequently, repeatedly encountered situations that required difficult decisions often made under emergency conditions without time for reflection. They

often learned about negative side-effects of medications when the treatments had failed. GBM caregivers' stories included both initial and reactive moral distress. Reactive moral distress was prevalent post-bereavement.

Ironically, GBM caregivers perceived that healthcare practitioners contributed greatly to their moral distress, as illustrated succinctly by Gerda Lerner's experience (1978, p. 49). Gerda and her husband Carl had agreed that they would never allow either one of them to be "kept alive on machines" in case of a terminal condition. Their *entente cordiale* is put to test when Carl is suddenly diagnosed with an inoperable GBM. Gerda is immediately advised by the doctors that Carl has no more than six months to live. The doctors do not have the same conversation with Carl, and instead focus on cheering him up. Truth becomes elusive as one doctor advocates for it, while the other urges against it. Based on their previous discussions, Gerda is conflicted and "burdened by hiding the truth" from Carl. She describes how "an enormous load of anger and bitterness" (…) "build up inside" her (p.56). Finally, she reflects: "In truth, there is no equality with the dying, no sharing. A man learns he will die and that moment separates him from the living. There is no way to bridge that" (p.145). What this story brings to the fore is the complexity of moral dilemmas in GBM caregiving. Faced with impending death, both caregivers and care-recipients do not know how they will respond and doctors and nurses, relatives and friends further compound the situation. Treatment options available, described by Helen as akin to "voluntarily entering a medieval chamber of horrors," include chemotherapy (which does not cross the blood brain barrier BBB) and whole head radiation (which destroys healthy brain cells).

Johnstone & Hutchinson (2015, p.10) find the concept of moral distress in nursing controversial, conceptually flawed and "vulnerable to objection on grounds of being

philosophically flawed", due to its definition as "being a problem that primarily affects nurses" and does not address the experiences of patients and their families. Furthermore, the issues nurses find morally distressing differ from that of caregivers. It is also questionable that nurses care more about their patients than the patients' own "intimate others" and "proximate others." Moral distress as it is currently conceptualised, prioritising the values and beliefs of nurses make it unhelpful in solving the profound moral dilemmas which arise from GBM caregiving. It appears that moral distress is a complex phenomenon, which is multi-disciplinary in nature and would benefit from additional lenses. Moral distress has not been researched in GBM caregiving or caregiving in general (Johnstone & Hutchinson, 2015). Debates on moral distress are active in nursing, especially in end- of- life care (Jameton, 2013).

For counselling psychologists who encounter Moral Dilemma Narratives in their work with GBM caregivers, it is important to note that values and beliefs can potentially be "undermined by the pressing circumstances and the rapidly evolving situation" as decisions are often made "under emergency situations caused by unforeseen and uncontrollable events with unwanted consequences" (Johnstone, 2015, p.5). Miller (2005, p.330) theorises that the relief of moral distress can only come from "finding oneself back in a moral relationship in which the needs of both parties are taken seriously and respected". For counselling psychologists, this means that the therapeutic relationship is central to addressing moral distress. Moral Dilemma Narratives are the most debated stories on GBM caregiving forums.

4.3.4 Narratives of Destruction

There is going to be destruction: the obliteration of a person,

his intellect, his experience and his agency. I am to watch it.

This is my part.

Coutts, 2014, blurb

Narratives of Destruction described the piecemeal demolition of vision, hearing, speech, intellect, mobility, memory, in addition to debilitating migraines, seizures, hallucinations, tremors, potential changes in mood, personality and behaviour. These losses are ordinary symptoms of GBM. Caregivers described helplessly watching the "total annihilation" of everything that made their loved ones unique. GBM was experienced as a violent, cruel, and unforgiving beast which attacked mercilessly. The significance of the brain as the organ responsible for protecting "the intactness of the person", (Cassell, p.639) their intellect, personality and will cannot be underestimated. Paradoxically, the most common metaphors embedded in cancer language are those of willpower and warfare (Sontag, 1978). Implicit in the warfare language is that surviving cancer depends on characteristics, such as will power, optimism and positive thinking. Thus, the war on cancer metaphor influences the way cancer is understood and treated. When the organ impacted is the brain, many GBM caregivers and care-recipients agree that, perhaps the better attitude to cultivate is to live with it for as long as you can. Hauser & Schwarz (2015) agree that the use of enemy metaphors in cancer is not helpful and may indeed be harmful to some individuals who do not embrace the language of warfare. Furthermore, the effects of destruction are not limited to care-recipients only. Caregivers are "caught in between continuities and discontinuities" (Burke (2014, p.33), contrasting identities pre- and post-illness (Couser, 2009), and experiencing their former self-images "crumbling away" (Charmaz (1983, p.168).

Cassel, (1991, p.183) notes that "the boundaries of illness are poorly defined," and "draw in others" potentially having "destructive effects on their bodies and lives" affirming that Narratives of Destruction are devastating to caregivers and their loved ones. De Beauvoir's (1985) description of witnessing her mother's dying as "an epistemological crisis or breakdown (p.194) representing "a cry of pain," "as well as one of mourning" comes to mind. Cassell (1982, p.30) advices that "the intensity of ties to the family cannot be over-emphasised; people often behave as though they were physical extensions" of their loved ones.

For counselling psychologists, working with narratives of destruction, the understanding of identity as relational and embodied offers a useful platform from which relationships and identities can be explored as the pathways that will eventually lead to narrative reconstruction. Counselling psychologists who work with narratives of destruction are reminded that cancer warfare metaphors do little or nothing to energise the brain tumour population and instead might cause more damage. Philip et al. (2015, p.1522) quoted a medical oncologist who differentiated brain tumours from other cancers as follows: "I think the big difference compared to other cancers and general malignancies – is the loss of the person". This is an undocumented taboo in brain tumour caregiving literature. Indeed, only Collins et al. (2013, p.6) referred to "a form of biosocial death" which removes brain tumour patients from "the realm of meaningful social interaction" prematurely.

4.3.5 Narratives of Silence

Narratives of Silence permeated the whole illness trajectory and post-bereavement. There were various interpretations of silence. Narratives of Silence included stories about being silenced by uncaring others or insensitive others (friends, relatives, medical practitioners, communities, other institutions etc.), as well as, stories about self-imposed silence as

respite. These two types of silences, being silenced and being silent are supported by feminist theories. Being silenced is associated with lack of power and marginalisation; while, silence is interpreted as voluntary withdrawal (Fivush, 2010). Being silenced fits in with Sherwood et al.'s (2004) reference to brain tumour caregivers as "the forgotten voices", Ownsworth's (2011) use of the term "overlooked" and Holge-Hazelton's (2011) use of the terms "invisible and marginalised". These descriptions place being silenced in the realm of social isolation and marginalisation (George & Gwyther, 1986).

Silence as an act of voluntary withdrawal to gain respite was practiced by all participants, evidenced by their storytelling tendencies which were interwoven with intermittent silences. The benefits of silence listed by Carillo-Rowe & Malhotra (2012, p. 110) are: allowing for the space to breathe; freedom to pause before reacting or responding; opportunity to stand in silence with others; creation of a space of great healing; a space of fluidity and non-linearity; a sacred internal space that provides a refuge; a process that allows one to go within before speaking/acting. These functions of silence are compatible with GBM caregivers' stories, where silence is perceived as, a means to achieve deep contemplation and meditation, or a method used for the preservation of energy. Being silent implied agency as deliberative conscious focus for the purposes of maintaining or regaining control.

For counselling psychologists working with this population, being aware of the various interpretations of silence can be a useful tool in therapy. Silence as synonymous with lack of agency and marginalisation, contrasted with voice as analogous with power and privilege, represented the dominant narratives about silence in the literature review (Sherwood et al., 2004**).** This perspective is however, contested by GBM caregivers who considered themselves vocal through their collective narratives. They were active advocates for their loved ones through participation in numerous activities, such as fund-raising, education on

the latest treatments and care, in addition to providing support for other GBM caregivers. Carillo-Rowe & Malhotra (2012, p.110) challenged the idea that individuals and groups who are silenced need to "activate voice, in order, to resist and transform the conditions of their oppression". They argued that this expectation placed an undue burden for social change on "those least empowered," without demanding that those in positions of power learn to listen. This perspective validates GBM caregivers' who were agitating and shouting on behalf of their loved ones, but perceived that no one was listening. Frank (2012, p.48) illustrated this complexity by disclosing that "naming the chaos narrative opened a silence in clinical practice," meaning that clinicians remained silent because they did not know how to respond to the profound suffering laid bare by chaos narratives.

Narratives of Silence also affirmed that silence emanates from fear of the unknown and impending loss (Fivush, 2010). Helen described this silence as "waiting for the other shoe to drop." Research by Salander et al. (2000) and Arber et al. (2013) found that caregivers experienced silence due to fear, helplessness, despair, overwhelm and anticipated grief. Audre Lorde (1982) advised against silence due to fear because "Your silence will not protect you." She perceived that silence gave fear a bigger voice, also equating voice with agency.

Feminist relational theories advance that silence is an epistemological perspective, representing knowledge or experience that cannot be readily expressed or articulated (Clair, 1998) echoing the term *Asymbolic.* Frank (2001, p.355) takes this concept further to equate silence with suffering: *Suffering is the unspeakable.* Silence has the potential to provide "a space of possibility and transformation" countering the perspective of "voice as the only form of intelligible communication (Carillo-Rowe & Malhotra, 2012, p.225). Fivush (2010, p.89), suggests that "voice and silence are socially constructed in conversational interactions between speakers and listeners". Counselling psychologists working with GBM caregivers

are advised to pay equal attention to voice and silence. Picard (1998, p.25) suggests that "speech and silence exist simultaneously" and deserve equal attention. Counselling psychologists working with narratives of silence would benefit from interrogating how the spaces between silence and voice can be traversed. GBM caregiving stories function as bridges between silence and voice by bringing the silenced care-recipients' stories to light.

Counselling psychologists who work with GBM caregivers need to be aware of psychotherapy's long and chequered history with silence (Freud, 1912/1953; Zeligs,1960, 1961). Silence has been associated with resistance, regression, contemplation, separation, loss, trauma, secondary trauma, non-verbal communication, transference and countertransference among others, meaning it is a contentious topic. I interpret Audre Lorde's (1984, p. 110) proclamation that "the master's tools will never dismantle the master's house" as a challenge to counselling psychologists that we must continually interrogate our own practices by seeking new tools of engagement which might involve "wading into the fullness of silence" (Carillo-Rowe & Malhotra, 2012, p.225). Practitioners are urged to consider silence as a space of possibilities and not assume homogeneity in the experience of silence.

Overall, working with story typologies is not unproblematic. Each typology lays bare the caregiver's resources or lack thereof. Practitioners are warned not to assume an attitude of knowing and misuse story typology as a diagnostic tool (Frank, 2012). Typologies have the potential to act as educational tools and listening guides which allow practitioners to reflect on the function of the stories, consider the storytelling landscape, as well as imagine how they would respond to the story.

4.4 Core Narratives

In this research, core narratives were defined as a body of internalised stories that community members narrated about themselves. Narrative inquirers have not engaged with the term core narrative. I have instead appropriated literature on cultural narratives for this discussion on core narratives based on similarities between the two. Cultural narratives are stories which shape how a community identifies itself, its origins, history and *raison d'etre.* Cultural narratives act as moral guides, teach and reinforce values among community members (Riessman, 1994). Like cultural narratives, core narratives became the building blocks upon which GBM caregiving stories were formed, when they were repeated, over and over again. The origins of core narratives are both internal and external. They are reinforced by favourable environments. For example, the medical fraternity in using metaphors such as *GBM the destroyer*, perpetuate the dominant medical narrative, perhaps prematurely imposing it on patients (Philip et al., 2013). Sharing core narratives helps community members to understand the ways in which their stories contribute to their helplessness or strengths and resilience. A new-comer who did not know GBM was a terminal condition until she joined the forum remarks:

>*Don't get me wrong, I am grateful for this site, its info, and all you*
>
>*fine folks. But it wasn't till I got here I realized there is no light at*
>
>*the end of this tunnel.*

Core narratives have multiple functions too numerous to elaborate on. Two core narratives co-constructed from the story typologies are The Suffering of Caring and Woman as Healer. These categories are not mutually exclusive.

4.4.1 The Suffering of Caring

The Suffering of Caring is the most dominant narrative in the GBM storytelling landscape and includes all the five story typologies (Disruption, Embodiment, Moral Dilemmas, Destruction, Silence) already discussed. The Suffering of Caring was first mentioned by Collins et al. (2013, p.6) in interviews with brain tumour caregivers. It was described as: the exhaustion, grief, bewilderment, guilt, sadness and loneliness that results from caring in the context of PMG (Primary Malignant Gliomas), exacerbated by the unique challenges that this illness brings and the lack of support provided. Key aspects include: "the relentlessness of caring, the loneliness of caring and the ongoing suffering of bereaved carers." Similar to Collins et al. (2013), this research found that suffering dominated all caregivers' stories. In this research, The Suffering of Caring is described as a deep kind of empathy embedded in relational care, where the pain and distress of a loved one are experienced as one's own. The Suffering of Caring is an ethical responsibility (Levinas, 1987).

Frank (2012) advances that the dialogical test of a good typology is whether it enhances people's capacity to hold their own in circumstances of vulnerability. Focusing solely on the Suffering of Caring can be perceived as a single narrative whose weaving thread is helplessness. To avoid *The Danger of a Single Story* (Adichie, 2009), Frank (2012) suggests that the researcher ask the question: For whom is this narrative useful? The reasoning behind this question is that those who represent their lives only as sufferers are limited in resources which can assist them in imagining how their lives can get better and their story becomes a self-fulfilling prophecy. Internalising the single story can lead to narrative conformity further trapping the individual in their story. Narrative conformity in a community can stifle other members by isolating those who deviate from the single story. This is not to say that the Suffering of Caring is a dangerous narrative. It is a raw and authentic depiction of the psychosocial experiences of GBM caregivers, which deserves to be heard. Counselling psychologists who work with GBM caregivers who narrate stories about the

Suffering of Caring are encouraged to bear witness. Further, it is important to note that the meaning of suffering is co-constructed between the storyteller and listener and therefore, listening and responding offers opportunities to transform suffering from a monologue into dialogue potentially generating alternative stories (White, 2005; Frank, 2006). In Narrative Therapy, the Suffering of Caring is viewed as the dominant narrative, which permeates the storytelling landscape. White (2004, p.135) opposed all attempts to narrow down "human multiplicity to a single-voiced vision of life." This act of holding on to multiple stories concurrently enabled caregivers to disclose their suffering as well as offer comfort and hope to other caregivers contemporaneously. Caregivers learned to listen actively as well as respond compassionately.

4.4.2 Woman as Healer

Woman as Healer lies on the flip side of The Suffering of Caring. Every time a caregiver expressed their suffering, there were multiple responses from other caregivers: condoling, consoling, empathising, encouraging, validating, resonating and reassuring them, that they were not alone. They were a part of a community. The term Woman as Healer is borrowed from Jeanne Achterberg's (1990) book of a similar name in which she unearths the previously unacknowledged influence of women's contribution to the development of modern medicine. Her book is centred on the tragic history of the persecution of women mid-wives (often but not always), accused of witchcraft in the Middle Ages. Ehrenreich & Engish (2010, p.25) researched the role of women in the history of medicine and contend that:

> *Women have always been healers…*
> *They were the unlicensed doctors anatomists… abortionists, nurses, counsellors.*
> *They were pharmacists… midwives, travelling from home to home and village to*
> *Village… doctors without degrees… learning from each other, and passing on*
> *experience from neighbour to neighbour and mother to daughter. They were called*
> *"wise women" by the people, witches or charlatans by the authorities. Medicine is*
> *part of our heritage as women, our history, our birth right.*

Woman as Healer captures the selflessness, love and commitment GBM caregivers devoted to their loved ones and to each other. Achterberg (1990) defines Woman as Healer as women of a special calibre who view healing "not as something one does to another, but as a process that takes place through the healer/healee relationship" (p.4). Healing does not relate to a cure or to techniques, but rather to a way of being, an attitude that is life-giving and life-enriching for caregivers and their loved ones. The bond that is established between the healer and the healee is as comforting as Lilly's words to another caregiver:

> *Its good to cry, he is worth crying over. And you did amazing acts of love for him all the way. So many go through life never experiencing true love. Crying is very healing. Lilly.*

At the core of Woman as Healer are moral and spiritual groundings. The relationship itself is held in reverence, with the awareness that it is made of trust, love, and hope. Caregivers aver that they are working in sacred space (Achterberg, 1990, p.5). Kleinman (2012), who wrote about caring for his wife contends that caregiving is at the centre of what it means to be human and an indelible part of *relational being*. Woman as Healer narratives allow the suffering community to hold their own in a process that is the very essence of what it means to be human. Woman as healer is a narrative which challenges the dominance of the suffering narrative. It is a narrative which often remains unheard. Woman as Healer is an inspirational narrative which embodies the virtues and aspirations of the GBM community. Woman as Healer co-exists with the Suffering of Caring, illustrating the complexities of human beings and affirming our multiplicities.

Counselling psychologists who work with core narratives are invited to reflect on how powerful core narratives can be – they are made up of multiple building blocks (story typologies), which are difficult to dislodge. They are at the core of individual and collective

experiences, values and beliefs. It is important to note that there is no singular core narrative but rather, individuals and groups have capacities for additional core narratives, sometimes in conflict with each other. Based on my engagement with thousands of stories in the course of this research (story was identified as an online post) some assumptions about the functions of core narratives follow. Core narratives explain the past and act as a guide for community members on what to expect in the future; dispel uncertainty; teach community members how to listen and respond to one another; inform the attitude of the community; reveal available resources; create strength and resilience to name a few. Counselling psychologists who work with GBM caregivers are encouraged to reflect on the functions of core narratives by continually reflecting on *how well are individuals and groups served by the stories they tell* (Frank, 2012).

It is also important to honour feminist perspectives. *Guidelines for Psychological Practice with Girls and Women* (APA, 2007) states that Women's Perspectives are Valued. What this means is that GBM caregivers are not separate from their multiple roles, identities and social locations. As evidenced by their stories, participants in this study were socialised to nurture and support others, while also taking responsibility for their relationships. A feminist perspective is not exclusive to women and can be applied to male caregivers as well (Adichie, 2014; Remer & Oh Hahn, 2012). Indeed, suffering knows no gender, but recognises all of humankind and its vulnerabilities. The qualities of Woman as Healer include the "feminine principles of healing – subjectivity, relatedness, understanding (Achterberg, 1990, p.197). To follow in the tradition of Woman as Healer is to "work in sacred space, in places where the meaning of existence is constantly being confronted, where life and death in their awesome and terrible dimensions are being faced. Those who chose, or are chosen, to work in such space feel honoured and humbled to be part of the transcendent process, knowing full well that the demands are far reaching, sometimes overwhelming. Entering that

space requires passion and courage and knowledge that not a single moment is banal"
(p.197-198).

4.5   The Storytelling Landscape

DNA acknowledges that stories do not exist in a socio-cultural vacuum and locates them within a dynamic context which includes the relationship between the storyteller, the listener and the storytelling landscape. Narrating stories is perceived as the first attempt at making life narratable and "re-piecing a shattered self" (Tal, 1996, p.138) or "a broken narrative" (Hyden, 2011). Exploring the storytelling landscape provides a learning opportunity for counselling psychologists about how narrating stories may be a means (or not) for the shattered pieces to be reconstructed.

4.5.1 Research Q. 2: What happens as a result of narrating stories online?

The second research question, used email interviews and asked: *Can you please tell me about the stories you shared online, the responses you received and whether or not you are still sharing stories online?*

DIAGRAM 4.5.1 THE STORYTELLING LANDSCAPE

Q2. What happens as a result of narrating stories online?
1.THE STORY TELLING LANDSCAPE
a) Community of Storytellers

5. HINDSIGHT NARRATIVES
a) Narrative Foreclosure
b) Narrative Unfinalizability

4. PERFORMATIVE ASPECTS OF STORYTELLING
a) Narrative Resistance
b) Narrative Responsibilities

3. DIALOGICAL NARRATIVES
a) Generative

2. RELATIONAL NARRATIVES:
a) Connection
b) Mutual Vulnerability
c) Mutual Empathy
d) Mutual Resilience
e) Mutual Growth
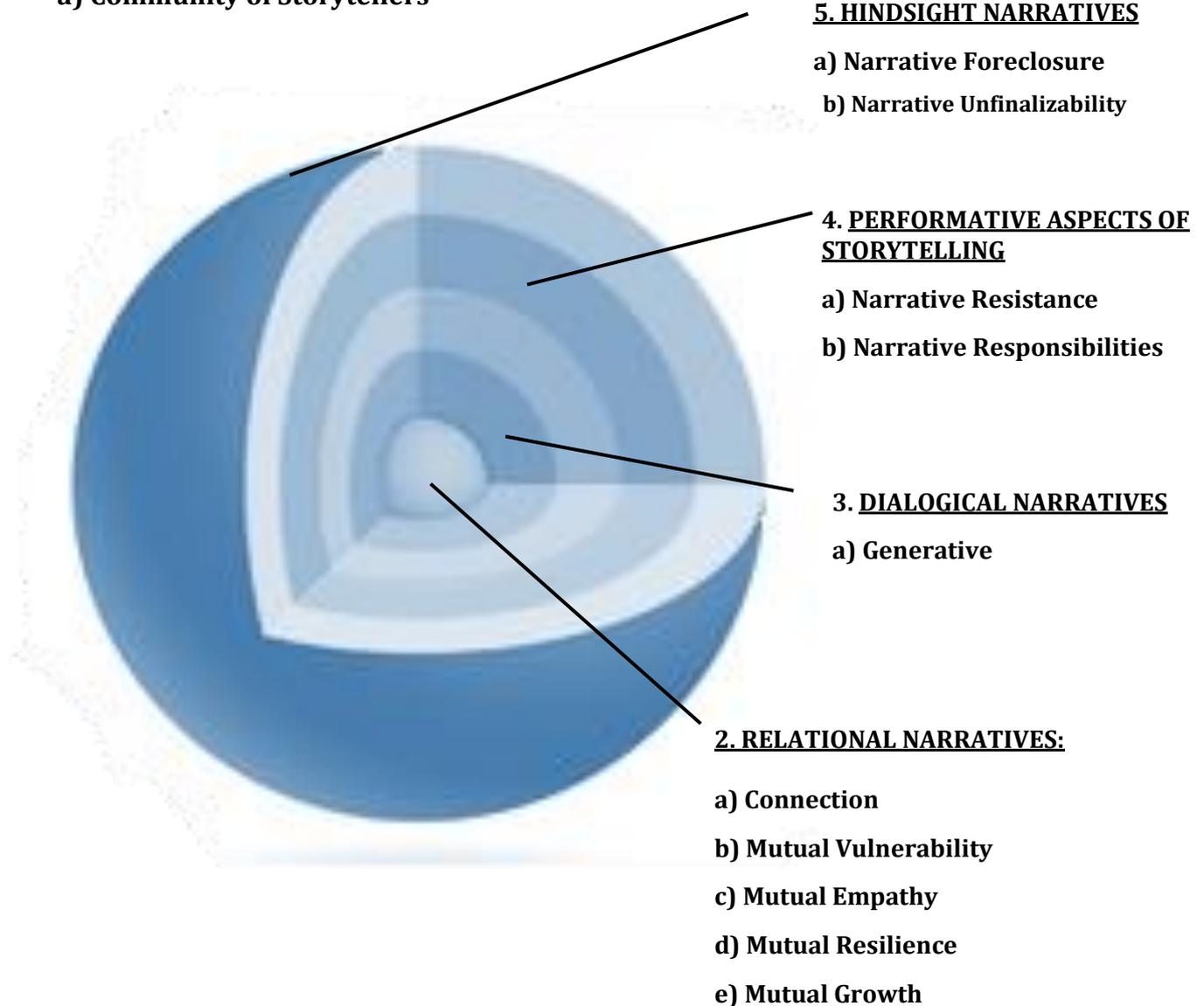
The focus of this question was on the a) storytelling landscape b) performative aspects of storytelling and c) hindsight perspective. The aim was to illuminate the relationship between narrating stories online and the event of narration, that is, the effects of storytelling. The expectation was that exploring the storytelling landscape and gaining insight into hindsight perspectives would illuminate the conditions that cause suffering; the therapeutic nature of storytelling (or not) and the storyteller's available resources. The discussion is structured to systematically address each of the research findings as follows: 1. The storytelling landscape, 2. Relational Narratives, 3. Dialogical Narratives, 4. Performative aspects of storytelling, and 5. Hindsight Narratives.

Even though I chose to address the two research questions separately, they are in fact interrelated and overlap significantly because DNA implicitly seeks to illuminate the relationship between the events being narrated and the event of narration (Frank, 2012). The findings therefore, converge in the storytelling landscape because narrative analysis takes retrospective meaning-making as an additional lens of interpretation (Riessman, 1993). Discussing the two questions separately illuminates both the temporal and hindsight perspectives by shedding light on the complex issue of how stories evolve (or not) over time which is central to our work as counselling psychologists. (See Appendix R Participant Feedback).

4.5.2   Community of Collective Storytellers

Storytellers and listeners come into contact with others "engaged in the process of interpreting themselves" (Lieblich & Josselson, 1995, p. ix). Storytelling is an interactive process that can be transformative. Issues of relationships, relational safety, time and space remain central (Bruner, 2004). With time, GBM caregivers transformed into a community of storytellers and developed a collective identity (Richardson, 1990). As a community of global

storytellers, members engaged in the cathartic sharing of experiences across time, borders, cultures and other boundaries. The process of sharing allowed for normalisation of experiences, validation of subjectivities, belonging, comfort and support from a collective community. Newly diagnosed caregivers received comfort from bereaved caregivers. This in turn provided opportunities for telling and re-telling across time to different caregivers, creating a pathway for reauthoring or reconstruction of stories (White & Epston, 1995). Several distinct characteristics present in the storytelling landscape and salient to counselling psychology practice were *Relational Narratives, Dialogical Narratives, Performative Aspects of Storytelling and Hindsight Narratives.*

4.5.3   Relational Narratives

Understanding of experience is an interactive act that is processed through dialogue over time (Mauthner (2002, p.32). All participants narrated their stories through a "web of intimate" relationships I refer to as *Relational Narratives*. Relational Narratives were stories uniquely dependant on the bond forged between the storyteller(s) and the listener(s). Feminist relational theories take a relational approach to counselling and psychotherapy (Jordan, 1995). A relational perspective advances that connection through mutual vulnerability and mutual empathy is the underlying change ingredient that enables transformation. Disconnection and isolation lead to suffering. The conduits to development, empowerment and growth are connections through relationships and collaborations. Feminist relational theories argue that the pursuit of self-sufficiency *per se* is not desirable and can lead to separation. This blends well with Narrative theories which advance that "stories are not material to be analysed; they are relationships to be entered; each story requires "a different kind of attentiveness and response" (Frank (2000, p. 200). GBM Caregiving stories are borne out of relationships, which are at the centre of caregiver experiences. The concept of relational being as presented in my epistemology

acknowledges that we come into being through mutual recognition of each other, a phenomenon validated by all caregivers (Gergen, 2011). Wiltshire (1998, p.196) suggests the experience of illness further "breaks up the hard-autonomous shell" of individual identity to make way for identity as relational. The concept of relational narratives underpinned by social constructionism views knowledge as co-constructed within relationships (Burr, 2015).

4.5.4 Dialogical Narratives

Your words bring my words into meaning, but without my words your words fall into emptiness (Gergen, 2011, p.6).

Dialogical Narratives referred to the idea that each story received a response or responses, thereby, generating conversations which led to more stories. DNA presumes that each caregiver engaged in internal conversations sometimes characterised by fear and anxiety before they joined the community of storytellers. These internal conversations are referred to as monologues. Monologues are transformed into Dialogical Narratives when GBM caregivers join other storytellers. Dialogical narratives include multiple voices, listening and responding to each other and others. Dialogical narratives are anchored in relationships. The initial dialogue begins a process in which the storyteller is heard and others who respond or simply read their stories are witnesses. Dialogical narratives have the capacity to bring individuals out of isolation. Dialogical narratives have the potential to shift the emotional lives of the participants who became part of a bigger conversation, which is the foundation of the community of storytellers. Stories, thus become generative as they invite the responses of others. Frank (2012) refers to this as the creation of a Dialogic Space. Caregivers initially join the storytelling landscape because they are fearful and isolated. They soon connect with other caregivers who share similar fears. Caregivers learn to listen empathically and respond meaningfully to each other. Meaning then is co-created from the empathic exchanges facilitated by the dialogic space (Weingarten, 1991). Plenty of caregiver stories evidence this

movement from a monologic place of fear, anger and isolation towards a dialogic stance of mutual vulnerability and mutual empathy.

4.6 Performative Aspects of Storytelling

Narratives are performative. Narratives do things. Narratives move people into action. Narratives call on people to respond as well as act (Mattingly, 1998). So far, the research has illuminated story as "a portal into the mind," that is, story contents. Additionally, DNA seeks to illuminate what storytelling does, that is, its performative aspects. In this storytelling landscape, stories bind caregivers emotionally through shared experiences of suffering and healing. Their collective stories mitigate the effects of isolation and alienation. Through collective narratives caregivers are transformed into a community of storytellers (Richardson, 1990). Performative aspects of storytelling were too numerous to elaborate on. I have focussed on two aspects, which appeared to underpin all the stories and are of importance to counselling psychology. These are *Narrative Responsibility and Narrative Resistance.*

4.6.1 Narrative Responsibility

Kinjo & Morioka (2010) define Narrative Responsibility as the storyteller's responsibility to tell, re-tell, and conclude the last chapter of the life narrative of a loved one. When GBM abruptly disrupts family life, caregivers take the responsibility to ensure their loved ones' life story is coherent and meaningful. Narrative responsibility is the driving force behind the need to do something to avert the impending fate of *GBM the destroyer*. Narrative responsibility is at the centre of many moral dilemma narratives because "many health care professionals tend to underestimate (or fail to perceive) how serious family members are about fulfilling their narrative responsibility to complete a loved one's unreasonably terminated life narrative" (Kinjo & Morioka, p.92). Understanding the role of narrative responsibility has the potential to bridge the gap between the moral dilemma narratives that separate health care

practitioners and family members. In particular, moral distress viewed through the prism of narrative responsibility can potentially provide an alternative lens for engaging with Moral Dilemma Narratives.

4.6.2 Narrative Resistance

GBM caregiving stories involved multiple resistances. Being part of a community of storytellers means that caregivers also share their hopes and desires for unique outcomes (a cure) (White & Epston, 1990). This co-construction of unique outcomes further aids the collective act of resistance against the dominant *GBM the destroyer* narrative. This kind of resistance can potentially lead to social action. Through telling and retelling their stories caregivers break the silence and open up the possibility to unique outcomes. Narrative resistance is often resisted by other caregivers who have accepted narrative conformity and are against "false hope." Caregivers who engage in narrative resistance need to overcome both internal and external resistance which come from medical practitioners who have already advised them to *put their affairs in order*. Through collective stories, caregivers begin to resist the idea that events will unfold according to the dominant GBM story and begin to seek unique or preferred outcomes (White & Epston, 1990).

From a narrative perspective, resistance starts when the storyteller begins to tell their story. This is described as taking a stand to make disrupted lives narratable, thereby implying that life is meaningful. Telling stories oblige others to listen and to respond. Resistance also occurs when there are no listeners. Stories are perceived as enactments of resistance by people who take a stand against dominant narratives in their search for unique outcomes (White, 1995). For example, the dominance of The Suffering of Caring core narrative overshadows Woman as Healer. Frank (2012, p.81) argues that through stories caregivers are able to "come to grips with their fears" (Frank, 2012, p.81). Telling stories is the beginning of reclaiming voice and regaining agency.

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4.7 Hindsight Narratives

Hindsight Narratives include post-bereavement stories, which looked backwards to inform the present, sometimes providing new insights and lessons (or not). Hindsight is "the process of looking back over the terrain of the past from the standpoint of the present" (Freeman, 2010, p.4). This process enables storytellers to see things anew (or not) and draw connections possible only in retrospect. This retrospective process is referred to as "demystification" and allows individuals to reflect on the stories they have internalised (Freeman, 2010, p.139).

Holstein & Gubrium (2000, p.116) point out that with hindsight "new narrative resources develop and are reflexively employed both to story selves and to revise expectations." In this respect Sharma's story is markedly different from the other stories. Her story is strongly framed and shaped by the *useless* suffering narrative, and her environment does not provide the resources to challenge it. But, given that "stories revise people's sense of self, and they situate people in groups," (Frank, 2012, p.33) Sharma gains additional resources as part of collective storytelling which is potentially the beginning of reconstruction. In this case, the function of hindsight can be perceived as reconstruction (Freeman, 2010) or restorying (White, 1995). Weingarten refers to this as the process of telling stories from a position of strength. Demystification and reconstruction of the suffering narrative offers a pathway for meaning making.

Psychologists have acknowledged the role of hindsight or 20/20 in learning even though hindsight has sometimes proven to be unreliable (Freeman, 2010). Hindsight, can serve as a profound source of insight, understanding, and self-knowledge. Hindsight is also intimately connected to what Freeman (2010) calls narrative reflection. For caregivers, hindsight becomes as important as *being in the now* and *living in the moment* were during the active caregiving

period. The significance of hindsight in reconstructing meaning cannot be underestimated. Below is Helen's hindsight perspective on humanity.

Finding humanity in the midst of this very tough journey is one of the many, many challenges that brain cancer patients and their loved ones experience. I have learned many things along the way since my son was diagnosed. First and foremost, I learned that humans have the capacity to be compassionate, but for that capacity to be developed and put into action, they have to be trained or stimulated by events in their own lives. Helen

Freeman (2010) argues that human beings often defer virtue and are frequently morally late, meaning that we require the passage of time to appreciate virtue. Hindsight provides opportunities for the correction of previous short sightedness. Hindsight narratives enabled the participants to share stories about what drove them to action, changed their opinion, brought tears to their eyes, bonded with each other and so on. The stories are of interest to counselling psychologists because they illuminate the various pathways GBM caregivers use to find meaning (or not) (White, 1995; Freeman, 2010). For the most part, old stories become hindsight narratives and act as learning tools for new- comers who witness what might shortly become their fate. All GBM caregivers credited other caregivers' hindsight narratives and the relationships they forged with them for providing the support they needed. Below are examples of hindsight perspectives years apart.

2011

Somedays the loss wells up so hard and I just bleed tears. Maybe being able to cry is a sign that I am healing from the loss, but it still feels like a gaping wound. Helen.

2012

I realized I had to make a decision about what I was going to do with the landfill that

had replaced my heart. So, every day and sometimes several times a day, …… I do what I can to re-sculpt all those hard emotions of grief into positive, compassionate actions for others in order to honor the memory of my son and not loose the rest of my self and sanity to this evil disease. But it is a fight. Daily. Hourly at times. Helen

2013

I must have within me a wide and bottomless cauldron of flaming guilt because it is a parent's #1 responsibility to protect a child from all harmful and evil things and I failed. I utterly failed. My son is dead. My enormously strong, otherwise healthy, brilliant, robustly alive son is dead from a stupid, microscopic disease. How can this be? It is so hard to compute. It defies all logic. Helen

2014

Hearing from others that they went to this great doctor at this great hospital and tried that great clinical trial and did all manners of extraordinary things that maybe we didn't try, but they still buried their loved one regardless helps alleviate the torture of guilt I feel. So, it is not so much as what I learn in a fact-based way, but what I learn in an emotional way. Each death, and there are many of them on the forum, teaches me there was nothing I could do. That he was, we were, I was completely helpless against this disease. Helen

2015

I am there for anyone who wants to exchange messages with me; in one case I have been exchanging messages almost daily for about five months now. I

often end up being the first person they turn to with the latest MRI, especially

if the news is bad. If a critical symptom emerges, I give them the

encouragement and focus they need to get on the phone with the doctor,

regardless of the hour of day. I am there for them when they need to decide

whether or not to start hospice, marking the end of the fight. I tell them what to

expect in the journey through hospice, even down to what size sheets to have

on hand, how to prepare baggies with wipes, and what to watch for so that

they are with their loved one in the moment their loved one expires. Of course

it reminds me of my own journey and sometimes I have to walk away from a

message and just cry over what they are going through, but again, if there is

any little thing I can share with them that makes their burden lighter and

makes their loved one's landing a little softer, then the effort is definitely worth

it. Helen.

Narrative hindsight can be useful for counselling psychologists because it is where "self-understanding occurs" (Freeman, 2009, p.4). It is noticeable how Helen shifts between a place with a "gaping wound" into wanting to "do compassionate actions for others" in memory of her son. This metaphor also fits into Frank's (1995) Quest Narrative where something meaningful and transformative occurs along the journey.

4.7.1 Narrative Foreclosure

Narrative hindsight is not without problem. There are many perils involved in looking backward. Hindsight, "far from being a source of consolation, becomes instead a source of guilt and especially shame" (Freeman, 2009, p.76). Narrative foreclosure refers to "the conviction that one's story is effectively over, that no prospect exists for opening up a new

chapter" (Freeman, 2012, p.12). Hindsight is not a panacea for insight, as illustrated by Anna's stories.

2011

I will never understand why this is happening to him - NEVER.

I keep thinking that my private tears of sorrow and rage will

eventually dry up and they just never do - they just never do.

I hate this disease…Anna

2013

Watching the light in the eyes go out of a brilliant human being is the worst experience of my entire life. I still grapple with why this happened – and can find no valid reason for it. I hope at some time in my life I understand why this happened. I do not think I ever will – I just do not understand. I am not religious so all this better place stuff is lost on me and I am left with nothing but questions and emptiness from all this. I am so sorry. Everyday I ask myself why did this happen? I never planned to be alone at 52. Anna

2015

It was two years on XXX of this year. I am sad. I am angry about a lot of things. Sometimes I just sit and stare into space. I cry - a lot and always alone . But mostly I am just numb. My life has moved on; I work, I go out, I travel and I am numb - Totally incredibly numb. This is not an experience that has given me patience or understanding. It is an experience that has made me far less tolerant of BS … Anna

Rosemary's stories (below) illustrate "the conviction that no new experiences, interpretations, and commitments are possible that can substantially change one's life-story

and the meaning of one's life as it is told now" (Bohlmeijer et al., 2011, p.367) meaning that hindsight can be a source of "extraordinary pain" (Freeman, 2009, p,76).

2013

I was unable to do the many hard things. I couldn't crawl in bed with him, turn him, change him or do the many exhausting, caring things for him. Had the roles been reversed he would have done it for me. I will forever be broken. Rosemary

2015

I am almost two years out from the loss of my XXX. Prior to my husband's diagnosis XXX I wound up in the hospital in XXX for XXX months and was diagnosed with XXX. When I was in the hospital, my husband was there every day, fighting my battles, feeding me when I couldn't feed myself. I left confined to a wheelchair where I am today. I could no longer work or drive. He did the paperwork to get me qualified for disability. He took me to therapy, managed the house, paid the bills, bought the groceries and cooked the meals. He was my full-time care giver while holding his full-time job working from home. And then we were hit with his GBM diagnosis … I've always worried that the stress of caring for me contributed to his brain tumor. I think I'll always wonder that. Rosemary

2016

*I am disabled and in a wheelchair and it was just so hard to be with him when he couldn't communicate. But I now regret those feelings….And so I go on. I have managed many obstacles of grief. I read many posts and reply to many, hoping to help others. But in many ways I feel like a fraud because I didn't do what so many spouses did. And for that reason, I feel I'll be forever broken. Rosemary*

4.7.2 Narrative *Unfinalizability*

The focus of DNA is to engage stories in an ongoing dialogue. For this reason, DNA maintains that stories do not end as people continue with their lives. Frank (2012) credits the concept of unfinalizability to Bakhtian's (1984, pp. 58-59) writings about the unfinalized nature of human beings and the belief that: "As long as a person is alive he lives by the fact that he is not yet finalized, that he has not yet uttered his ultimate word…. "What this means is that any story stands to be revised in subsequent stories. From a counselling psychology perspective, this can be seen as having faith in the human capacity to change and adapt to adverse circumstances. The diagram below illustrates the potential performative aspects of storytelling. The unbounded nature of DNA leaves the door open for more stories to come in further highlighting the unfinalizability of DNA. All these interrelated moving parts influence each other making it impossible to claim specific cause and effect, but rather emphasising the unbounded nature of storytelling. The reader is invited to make their own interpretations.

DIAGRAM 4.7.2 UNBOUNDED NARRATIVE POSSIBILITIES
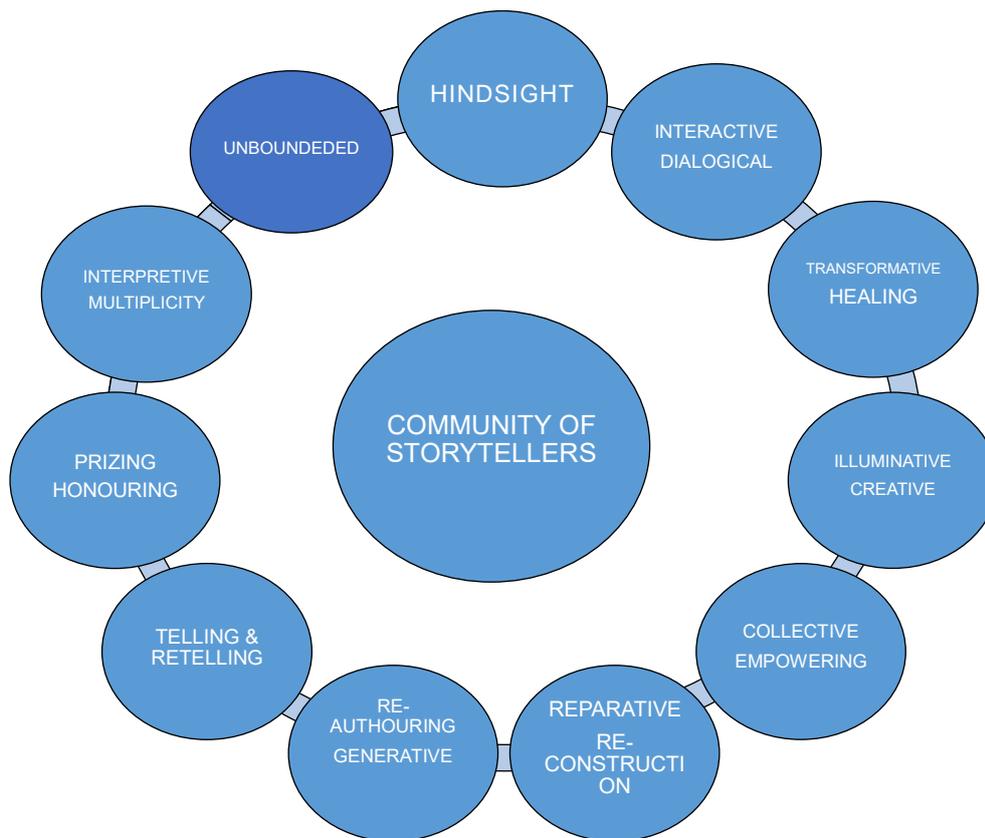
4.8   Implications for Counselling Psychology Research & Practice

This section zeroes in on fundamental differences which emerged between

conceptualisations of caregiving in the literature review and participants' stories. The most

prevalent conceptualisation of caregiving emerging from the literature review was that of a

burden (personal, familial, community, economic) to be addressed by governments and

national policies (DoH, 2016; CarersUK, 2017)). This conceptualisation is based on

biomedical research (neuro-oncology, palliative care, nursing and psychiatry) which has

identified caregiver burden, caregiving demands, impact of caregiving, caregiver burnout and

caregiver stress as the most salient topics (APA, 2016, 2017). In sharp contrast, GBM

caregivers' stories elucidated a more complex, multidimensional conceptualisation of

caregiving. Caregivers described caregiving as an experience which occurred in response to

an emotionally charged and life-threatening emergency event. All participants became

caregivers overnight. There was no learning curve. Even though caregivers did not dispute

that caregiving was difficult, time-consuming and had the potential to drain both mental and

physical energy, including social and financial resources, they decried the dominance of

caregiving as a burden narrative which has led to the monetisation of caregiving, meaning

that caregiving is perceived purely from an economic lens (Kleinman, 2008, 2009; Mahaffy,

2015).

There is argument that caregiving is not an activity that caregivers engage in that is separate

from themselves (Mahaffy, 2015; Kleinman, 2008, 2009). Some common descriptions of

caregiving emerging from GBM caregiver narratives were: spiritual practice, providing "a life-

line to a loved one", "a deep relationship", "a reminder of how fleeting life is", "being loving",

"acts of kindness", "part of daily life", "attuning to the needs of a loved one", "a moral

obligation", "a responsibility", "sacred presence," living in the present", "becoming attuned to

the rhythm of life", "awareness of the exquisite gift of life", and "solidarity with loved ones in

great need (amongst others), all of which require responses such as, witnessing, empathy,

compassion, grace and so on. The question then becomes: *Does this difference in

conceptualisation have any implications for counselling psychology?* From a narrative

perspective, engaging with this query can be framed as problematising the dominant

caregiving as a burden narrative.

4.8.1   Problematizing Current Conceptualisations of Caregiving

These opposing conceptualisations notwithstanding, there was no apparent difference in the

types of support caregivers received. Supportive care interventions were predominantly

guided by the biomedical model. Healthcare practitioners organised their responses which

included multiple instruments of measurement designed around the dominant caregiving as

a burden narrative. This research emphasises that how a phenomenon is conceptualised in

research has a direct impact not only on the findings, but also on practice (Miller, 2005; Frank, 2012). Kleinman (2008, 2009) points out that each diverging conceptualisation represents a valuable part of the picture, but not the whole. It is notable that supportive care interventions based on one part of the picture does not address the whole picture. Kleinman (2008, p.22-23), who is a caregiver to his wife, notes that caregiving is "far more complex, uncertain, and unbounded" than research suggests. Based on the above, this research takes the stand that a reconceptualization of GBM caregiving is necessary if practitioners aim to respond to the whole picture and not just some of its parts.

4.8.2   Reconceptualising GBM caregiving

Participants conceptualised GBM caregiving as a role and practice arising out of an emotional bond based on caring for and about a loved one (Gilligan, 1982), while the literature review described caregiving as a burden. From a narrative perspective, the dominant narrative of caregiving as a burden is recognised as a powerful metaphor with significant influences over research and practice. Lakoff & Johnson (1980), in their seminal publication *Metaphors We Live By* explain the powerful impact metaphors have in our daily lives. For example, all participants shared stories which embedded caregiving in a relationship, making it a relational role and practice (See Section 3.2; Cassell, 1982, 1991; Gergen, 2016). All participants shared stories that encapsulated caregiving as embodied (See Section 3.4.2; Eakin, 1998; Wiltshire, 1998; Bourke, 2014). All participants shared stories that captured caregiving as a moral experience (See Section 3.4.3; Kleinman, 2008, 2009). Most participants (5 out of 7) described caregiving as a spiritual experience and practice (Section 3.5.2; Mahaffy, 2012, 2017).

In view of the above, this research argues that ignoring the relational, moral, embodied and spiritual contexts of caregiving means that some caregivers who do not identify with the dominant caregiver as a burden narrative are denied the care and support they deserve. I

argue that the language and metaphors used by GBM caregivers to narrate their experiences are a guide for service providers which can be employed to define and develop practice. Hence, this research proposes a conceptualisation of GBM caregiving that is aligned with participants' stories, the research findings and concerns raised. This proposal is in keeping with counselling psychology ethos which are underlined by multiple realities.

Counselling psychologists are trained to remain open to various ways of conceptualising client difficulties, the phenomena they present with, how each phenomenon is categorised within theory and recommendations for best practice. In addition, trainees quickly find out that organisational aims and goals are the main drivers in the kinds of services provided and practices adopted (Henton, 2012; O'Hara, 2014). Hence, experiential knowledge provides an additional lens from which counselling psychologists engage with clients. What this means is that counselling psychologists embrace methodological pluralism, remain aware of the societal discourses which impact policies and practice, endeavour to balance all competing interests while acknowledging all the uncertainties and ambiguities that they encounter, both in practice and research (Cooper & McCleod, 2011; Kasket, 2012; Douglas et al., 2016).

Expanding psychological services to reflect the concerns raised in these stories has the potential to bring in from the margins those who do not identify with the dominant caregiving as a burden narrative. Furthermore, a focus on reconceptualising caregiving as a relational, moral, embodied and spiritual role and practice, can potentially lead to alternative services, more choices and increased response-abilities to suffering.

4.8.3   Expanding Counselling Psychology's Response-Abilities to Suffering

According to Frank (2001, p.359), the "task of research is to specify the conditions that cause suffering so that these conditions can be changed to lessen suffering." Like caregiving, suffering is a term which carries with it certain implications for the way we think

about it and respond to it. In psychology, the dominant conceptualisation of suffering is captured in DSM-V (2013) which represents suffering in parts, such as anxiety, depression, trauma, and so on. Hence, counselling psychologists might find it a challenge to engage with suffering as a whole picture, given that the term is scarcely used in practice (Miller, 2005). Relegated to obscurity, the term suffering conjures up images from afar and can evoke uncertainty and discomfort as in the case of Jamie (Smith & Sparkes, 2011). Counselling psychologists who work with clients who identify themselves as suffering are encouraged to explore the metaphors clients use to describe what it means to suffer (Smail & Hagan, 1997; Miller, 2005).

Cassell (1991) argues that addressing the question of what it is to be human and what it is to suffer can provide insights into how suffering is conceptualised, which in turn influences how practitioners respond to suffering. Suffering is a fundamental concern to counselling psychologists because" the complexity and variability of suffering reflects the complexity and variability of human life itself (Malpass & Lickiss, 2012, p.2). One of the challenges of engaging with suffering is that "one's words, no matter how eloquent, will always seem to fall short of what is undergone, to be incapable of meeting the needs of the one who suffers. Sometimes we can do no more than stand as witnesses" (p.3). For it is in human presence and encounter that suffering can be understood as something which we must respond to. Thus, failure to respond to suffering contributes to loss of opportunity to find meaning and face the future. Frank (1995) advances that suffering is a relationship between the storyteller and the listener rather than "an iron cage" around the storyteller (p.199). Significantly for counselling psychology, narrative perspectives do not advocate for replacing the dominant caregiver as a burden narrative (biomedical model), but instead argue for its decentralisation thereby creating space for the multiple narratives which exist both individually and collectively within societies. Working integratively, counselling psychologists can expand their response-abilities towards this group of caregivers.

Expanding response-abilities means remaining open to ideas from clients, other cultures, societies and other disciplines. Central to feminist relational theories is how to engage with suffering, even when it remains silent or silenced (Fivush, 2010; Carillo-Rowe & Malhotra, 2013). Page (2017, p.13) encourages practitioners to "remain open and receptive to what will always resist sense-making." She argues that being open has the potential to "bring certain forms of knowing and unknowing into focus". Admittedly, working with people who are suffering might create uncertainties about how to respond to what is not known, and there are no easy answers to these questions. As counselling psychologists, we do not shy away from discomfort; Instead, continuous dialogue with the unknown, the unsettling, and the unfamiliar has the potential to provide space for the generation of new ways of knowing. For example, caregiving research has continued to report on how caregivers struggle with self-care. Sabo (2014) noted that suggestions made for brain tumour caregivers to practice self-care was often met with resistance. Why? If the self is relational, perhaps the best location to practice self-care is in relation rather than within the individual. Furthermore, if caregiving is an innate gender role, as suggested by several researchers (Carlson, 2001; Taylor, 2000; WHO, 2017; UN, 2017), then perhaps conceptualising caregiving as a burden is not helpful. It is plausible that caregivers feel privileged to carry the burden, thus answering in the affirmative the rhetorical question: Am I my brother's keeper? This concept is succinctly expressed by the title of the iconic song: *He Ain't Heavy, He's My Brother (The Hollies, 1969).*

4.8.4   Perspectives from the Margins: Saying Hullo Again

Suffering GBM caregivers soon become bereaved caregivers. Like suffering, bereavement is a universal human condition. Agreement that grief is a highly individual process, influenced greatly by social and cultural practices has not deterred efforts by mental health researchers from categorising what it means to grieve, and linking it to various mental and physical

health deficits, such as depression, cardiovascular disease, high risk of suicide, and so on (Hefren & Thyer, 2012). Prolonged and complicated grief reactions have been categorised as psychiatric conditions (PCBD) in DSM-V. Guidelines on how to work with bereavement are continually revised (DSM-V, 2013), even as current conceptualisations remain problematic for some populations.

Most conceptualisations of bereavement are based on the understanding that death is the final separation and the living need to let go, to continue with their lives without their loved ones. Bereavement therapy, thus involves helping the client to accept their loss and separation as final. Therapy is influenced by Kubler-Ross's (1991) stages of grief and is focussed on *saying goodbye, letting go and finding closure*. From a narrative therapy perspective, the dominant narrative on bereavement is *Saying Goodbye*. White (1998) proposed the *Saying Hullo Again* metaphor as an alternative to the dominant *Saying Goodbye* narrative. At the centre of White's (1988) *Saying Hullo Again* metaphor is the notion that relationships with deceased loved ones can continue post-bereavement.

Sharma, Anna, Heather, Rosemary, Lilly, Jasmine and Helen all express that the death of their loved ones does not mean that their relationships have also ended.

> *I see his influence reflected back to me through all those he touched. I see his goodness and kindness reflected back to me and this is the balm that continues to give my life hope. Cancer sucks, but life and death are separate from that process. Life and death are about love and connection even when that physical connection is gone. Heather*

Heather's stance is in tandem with this narrative perspective, where the loss of a loved one is not considered final, even though they are not physically present. Bereavement therapy

involves supporting clients to continue having a relationship with their loved ones through letters, stories, memories, dreams, mementos, photographs, shrines, and imagination. These activities are a source of strength, comfort and inspiration as needed (White & Epston,1990, p. 33-34). For example, Jasmine finds her husband's continued presence in her life as a form of guidance and support and is reluctant to let go of this resource. Hers is a clear example where the Saying Goodbye metaphor is not helpful:

> *I was told by someone on Monday that I need to let go of the thought of holding on. I wasn't sure what was meant,… I think it meant I have to let go of the loss. I'm not sure how to do this or what I'm doing that is still holding on. I asked the person who said this for clarification. This was the response "It's about getting to a place of acceptance and knowingness that he's with you and you don't have to do anything. You don't have to wear or carry anything of his. You don't have to grieve. I know XXX is with me.*
> *It's like I have a foot in the past, a hand reaching for the future, and the rest of me is just here, trying to figure out how to move forward. I'm still leaning on the memory of my husband for moral support. Maybe that is the aspect of holding on that I need to let go?*
> *Jasmine, 3+ years post-bereavement*

Counselling psychologists are encouraged to include the concept of *Saying Hullo Again* in their repertoire of responses to GBM caregivers. Expanding the conceptualisation of bereavement to include *Saying Hullo Again* introduces a perspective that is marginalised, but, equally deserving of recognition. White (1995, 1997) suggests a process of *re-membering* through rich stories, which continue to evoke the loved ones' presence and voice as significant and vital today as in the past. Counselling with bereaved caregivers might involve asking them to step back into the suffering in order to evoke healing. Working with bereaved caregivers involves affirming resilience, resourcefulness and the continuation of

life and relationships, rather that separation and finality of death. Narrating stories online is comparable to the development of online memorials, which are currently undergoing increased interest evidencing, that there is space for multiple ways of caring and grieving.

4.8.5   Strengths of the Research

To my understanding, several novel features associated with this research are conspicuous, while others are potential "firsts" in social science research which; a) targeted GBM uniquely as a disease-specific topic in caregiving; b) was conducted by a GBM caregiver as a researcher; c) recruited uniquely GBM caregivers as participants; d) followed GBM caregivers throughout the illness trajectory and post-bereavement; e) utilised online stories narrated by GBM caregivers spanning 2-3+ years as data; f) had continuous communication with participants throughout the research; g) conducted email interviews focussed on a retrospective perspective on the data; h) shared findings of the research with participants and asked for feedback; i) used a combination of participant stories, email communications and feedback as data; j) used Narrative Inquiry as a research methodology; k) integrated DNA and feminist relational theories into the research methodology, and; l) originated from a counselling psychology perspective.

The impact of these "firsts" was the injection of: a) rich, unfettered storied experiences without the influence of the researcher or the complexities of face to face interviews; b) rich textual content, both "in the moment" and retrospective; and, c) an insightful temporal context illuminating how stories emerged and changed over time. Further, the research methodology facilitated the co-construction of findings that are emotive and evocative, allowing for the amplification of participant voices. The findings captured subjective and collective layers of understanding encompassing relational, dialogical, hindsight and performative aspects foregrounded in the therapeutic nature of storytelling (or not) to underscore what causes suffering. In addition, the analysis of stories grounded extensively in text fulfilled the aim of giving voice to the participants. This aspect of retaining whole

authentic stories is uncommon in counselling psychology research, where often participants'
voices remain peripheral to theories, diagnoses and expert interpretations
(Polkinghorne,1995; Frank, 2012; Miller, 2005). Further, carrying participant texts beyond
analysis into the discussion section is an uncommon practice in counselling psychology
research, but which manifested the researcher's continued commitment to "giving voice" in
research. It is my humble submission that, all of the above features, evidence several
aspects of originality in counselling psychology research (Phillips & Pugh, 2010).

4.8.6   Limitations of the Research

Despite careful planning, this research has limitations, some of which have been addressed
(See Section 4.9). Most limitations are inherently linked to general critiques about qualitative
research and narrative inquiry, while others are specifically related to the research question
and design. The research question and its underlying epistemologies limit the type of
knowledge obtainable, beginning with the disease specific nature of the research question,
which means that the findings cannot be generalised to caregivers of other cancers (Willig,
2008). The recruitment of participants online and lack of face to face interviews is
problematised by some researchers, and I acknowledge that face to face interviews would
have produced different findings. Specifically, the lack of non-verbal cues which researchers
rely on to decipher subtle meanings can be considered a disadvantage ((Illingworth, 2000;
2006; Mo & Coulson, 2014). Other factors, such as interviewer style did not apply to the
research as participants had already storied their experiences without any influence from the
researcher.

Some researchers have argued that online recruitment depends significantly on individual
personalities, who are often white and middle class. Im & Chee (2004) found that online
cancer support group users tended to be White, high income, and high education with the
majority of those who participate in research being women. Lieberman (2008) suggested the

under representation of men was due to their anxiety about sharing stories which may have portrayed them as vulnerable. Some researchers pointed out that ethnic minorities were under-represented in comparison to White participants, and that it is difficult to verify the identities of the participants (Fogel et al., 2008). Further, the global nature of the participants means that the findings cannot be generalised to the UK population. Additionally, it is not possible to account for how the varying degrees of healthcare provisions and psychosocial support available impacted caregiver stories or influenced their reasons to participate. However, research also showed that when a topic is complex and multi-layered, increased diversity generated more ideas, broadened the net of exploration and opened up the inquiry to multiple experiences.

Another limitation is that analysis of data did not focus on issues, such as culture, race and socio-economic status. Moreover, the research epistemology and choice of methods follow on from the research question further narrowing down the lenses through which the data is analysed and presented (Denzin & Lincoln, 2003). The findings were discussed through the narrowed lenses of the chosen social constructionist, narrative inquiry and feminist epistemologies.

All of the above elements present potential limitations of the research but the researcher posits that, they did not limit the ability to draw conclusions, gain in-depth knowledge, and address the research questions for various reasons, the main one being the rare nature of GBM. Further, the percentage of GBM caregivers narrating stories online is relatively low, making this a small sample, but good enough statistically in an area where there is scarce research focussed on caregiver stories and voice. I consider that designing the research by use of online stories provided access to a unique population, who would have otherwise remained out of reach and unavailable.

Finally, the amount of data collected was overwhelming. It was not possible to address all the emergent story typologies or themes. Even so, the findings sufficiently addressed the aims of the research questions within the chosen methodology. It is important to note that there is no agreed upon definition of caregiving, which means that any research on caregiving can be critiqued on this basis. Careful consideration was given to ways in which these limitations could be minimised and are addressed in Section 4.9. The findings of this research are therefore limited and *unfinalizable,* which is in keeping with the research epistemology.

4.8.7 Suggestions for Future Research

The story typologies and core narratives discussed in this research warrant further investigation, in particular, Embodied Narratives and Moral Dilemma Narratives, which continue to be a source of distress post-bereavement. Research on Embodied Narratives from a non-pathological position would further strengthen the findings in this research. Further research on Moral Dilemma Narratives would support both healthcare practitioners and GBM caregivers in addressing the numerous ethical issues fraught within GBM treatment and care. Currently, the most trending topics on brain tumour forums are: a) Where is the humanity? and b) How do you make medical decisions? These topics suggest high unmet needs and inequalities in the provision of treatment and care in comparison to other cancers (Arber et al., 2016; Collins, et al., 2016; Phillips et al., 2016). Finally, caregivers continued to find great comfort in sharing their stories online more than 2 years post-bereavement suggesting benefits for storytelling.

Counselling psychology, embedded in the scientist-practitioner model, reflexive researcher model and researcher practitioner model is in a vantage position to lead research on

caregiver stories, including the relational, embodied, moral, and spiritual nature of caregiving.

4.9   A Posteriori Reflexivity

Reflecting on Reflexivity: Reflexivity involves an ongoing self-awareness (Finlay & Gough, 2008) where "research is a process, not just a product" (England, 1994, p. 82). The series of steps and activities taken towards data collection, analysis and interpretation to achieve research completion are all significant. *A posteriori* reflexivity involves engaging with research at the end of the study. This section revisits reflexivity based on the premise that *a posteriori* reflexivity is as significant as *a priori* reflexivity and reflexivity *in situ,* which have been addressed in Section 1.4 and Section 2.7.

I embrace Finlay's (2012) proposal that reflexivity begins the process of separating what belongs to the researcher from what pertains to the researched as discussed in Positionality, Section 2.2. To manage the multiple intersecting selves and the researcher's own propensities and methodological allegiances I was guided by "packaged accounts" (Finlay, 2012, p.16) of reflexivity, (personal, epistemological, methodological). However, reflexivity is "invariably more confusing, complex, multilayered, situated, enactive, emergent, precarious" and messier than traditionally acknowledged (p.16). The categories of reflexivity elaborated on below are interrelated, interactive and sometimes overlap.

4.9.1   Personal reflexivity

The range of activities counselling psychology researchers engage in to ensure personal reflexivity are varied (Etherington, 2004). My supervisor and I discussed numerous issues that could potentially pose challenges in conducting this research. We agreed that these challenges could be mitigated by: a) declaring my stance on the topic, and addressing my

preconceptions and feelings about the topic (see Section 1.4); b) Reflecting on ethical considerations as they arise in the methodology (See Section 2.7.1), and c) in the analysis and interpretation (See Section 3.8); d) Keeping a reflexive journal/diary addressing my expectations and hopes regarding the research aims and findings, and; e) Contemplating and acknowledging how this might affect the research, the participants and the researcher.

The first question arising was how to write about a topic stemming from a profoundly personal experience professionally. My readings on the topic led me to Arthur Frank, whose book *(The Wounded Storyteller,1995),* I found hugely informative. I wrote to him and to my absolute delight he responded providing me with invaluable information. He disclosed he had first written a memoir as a way of resolving any *unfinished business* before writing for academic publication. He recommended I read biographies as they represented the ultimate standards in publication and were invaluable sources of learning. I read three books: *The Iceberg (Coutts, 2012)* and *A death of one's own (Lerner, 1985)* in which both authors narrate the experience of caring for their husbands diagnosed with GBM. In the third book, *Patrimony (Roth, 1991)* the author narrates his experience of accompanying his father "through each fearful stage of his final ordeal" (blurb) with GBM. These readings elucidated the differences between personal and professional writing.

Next, I signed up for a 30-day online seminar titled "Writing Your Grief" encouraging caregivers to narrate their stories. *I wish just one person would let me say how I really feel,* disclosed on participant. From this seminar, I learned the fundamental need for a safe space for expression. Next, I wondered who was writing about illness narratives and what I could learn from them? I signed up for another seminar "Qualitative Writing for Publication" at the Tavistock Clinic, London, and joined a group of researchers whose topics were *close to the heart.* Serendipitously, I met a 27- year old woman who was writing about caring for her twin

who died of cancer. We agreed to read and peer review each other's writings. The rest of the group offered to provide feedback on my initial research proposal, thus acting as a focus group. Confident that I had Arthur Frank's support, a peer reviewer and a focus group I could depend on, I focussed on the issue of balancing personal emotional involvement and professionalism.

Writing about a personal experience as an academic endeavor presented many challenges, the first one being whether or not to tell my story? The prevailing advice from Golden-Biddle & Locke (2007, p.10) was to adopt a stance of distance as academic writing ought to be "unadorned", "disembodied" and "mostly scrubbed of personal involvement". Anteby (2012, p.3) argued that this "taboo on telling our own stories stems in part from an epistemological misunderstanding" involving perceptions on identity. Willig (2008) advices the researcher to *bracket* their own story. Counselling psychologists routinely disclosed their experiences as helpful at various stages of research meaning I could not completely bracket my experience (Etherington, 2004), but rather, reflect on its influence on the research. The issue of whether or not to tell my story was resolved through reflecting on the aims of the research. Foregrounding the research was the desire to give voice to GBM caregivers. Part of my heritage is post-colonial research which raises concerns about the misappropriation of voice in research (Mazrui, 1986; Mutua, 2001), referred to as *imperialistic interpretation* in which the voices of research participants are *colonised* by the researcher. The concern that telling my story might *colonise* the participants' voices led to my decision not to include my story or the contents of my reflexive diary. I still grappled with how to represent the participants and their stories and questioned what my research could add to what was already known. The concern shifted to how I could tell the stories of a vulnerable community in a manner that was not inimical to them; a question embedded in epistemology.

4.9.2 Epistemological Reflexivity

Sections 2.2, 2.3, 2.7 and 3.8 discuss epistemological issues. In Section 1.4, I touched upon how my attitude towards caregiving was influenced by my grandmother. This attitude is best captured by the Swahili saying: *Mutu ni Utu*, which translates to *Man is Humanity.* Towards the end of the research, I elaborate on this philosophy.

At the heart of African philosophy are relationships and community. Personal identity is developed and recognised through interactions with others and an individual's place in the community. This worldview is extant throughout Sub-Saharan Africa as evidenced by literature on *Ubuntu* philosophy (Dutoit, 2014) and captured by the saying "I am because we are, and since we are, therefore I am" (Mbiti, 1970, p. 141). Relationships are central to shaping identity, revealing who we are, and providing opportunities for continued growth. Knowledge is transmitted through relationships - "Who I am is shaped by who I am in relation with" (Kasenene, 1994, p.141). These values and beliefs are not dissimilar to those espoused by narrative theories and feminist relational theories. As an African woman, this is an additional influencing lens in my research.

4.9.3 Methodological Reflexivity

Two salient issues for counselling psychology that I have chosen to address are the research question and *voice*. Willig (2008) proposes reflecting on how the research question was developed and how it has influenced what can be found. My research question was greatly influenced by my readings on illness narratives and email correspondence with Arthur Frank (See Appendix S). Awareness of these challenges led to the open-ended research question I posed and the follow up email interview, which focused on the retrospective aspect of storytelling. The open-ended nature of the research question allowed for multiplicity in the findings, while the email interview allowed further insights into the retrospective and performative aspects of storytelling. I considered direct questioning, though precise, was too narrowly focused and had the potential to produce unidimensional

content in contrast to the contextual richness associated with stories (Tomm, 1987, 1988, 1995).

The issue of *voice* emerged from the literature review which identified two important, but, competing voices, both begging for attention: a) Participant voice and b) Researcher/Practitioner/Organisational voice. Participant voice illuminated the psychosocial experiences of GBM caregivers, elevated their own stories in their own words, revealing emotion and impact, evoking response, advocating, raising awareness and generating more stories which evolve over time. The second voice, Researcher/Practitioner/Organisational voice, is a significant conduit for informing practice, influencing decisions and policy making. It was a challenge to balance both voices in this research. Chase (2005) advices the narrative researcher to distinguish between three voices: a) the *authoritative voice,* as a separate and expert narrator of the storyteller's story; b) the *supportive voice,* as an advocate for the storyteller's voice, which remains central in the text, and; c) the *interactive voice,* which aims to express the mutual influence between the researcher's voice and the narrators' voice, with a focus on the researcher's interpretations and personal experiences. This research adapted a supportive voice with a caregiver-skew, while remaining firmly embedded in counselling psychology values.

4.9.4 Embodied Reflexivity

Narrative inquiry and feminist relational theories support the notion that researchers and participants can be deeply affected by the stories they share. As a bereaved GBM caregiver and researcher, I was aware that the research process had the potential to generate significant emotional issues. I held Cassell's (1991, p.181-183) warning that an embodied experience can create ethical dilemmas, which are "reactive, situational, emotional", and fall short of the standard for scientific research. I reflected on researcher/participant vulnerability

to transference and countertransference. Two contradicting perspectives emerged. Gemignani (2011) argued for embracing and addressing the researcher's emotional responses as an additional rich source of data; while Behar (1996) warned against exploring the complex dynamics of the researcher/researched relationship as potentially increasing vulnerability. I gravitated towards Parker's (2005) stance that addressing the researcher's tensions and dilemmas has the potential to enrich the study, and Etherington's (2004) stance that reflections on the researcher's subjectivity and emotional reactions could be used to interpret the research rapport and the limits or possibilities it offers. I managed my emotional responses by planning and pacing my work. My supervisor, focus group and peer reviewer were most helpful in grounding me at all times. Email exchanges with Arthur Frank were helpful in keeping me on course with the research design.

Embodied reflexivity is also described as non-verbal communication and the lens that "puts under the microscope the wisdom of our embodied felt sense" Finlay (2012, p.7). The focus is on "the language of the body," and the meanings ascribed to bodily senses. In this case, embodied reflexivity concerned my felt-sense as I engaged with the participants' stories. Throughout the research, I experienced tingling sensations in various parts of my body which I wrote about in my reflexive diary and managed with long walks in the woods. This experience led me to appreciate the need for embodied reflexivity in research. Finlay (2005) argues that the researcher's empathy is more than emotional knowing and can be understood as embodied empathy, necessitating the need for *reflexive embodied empathy.* Finlay (2012, p.8) offers that an "awareness of the bodily communication" can lead to a deeper understanding in research. She suggests the use of focusing to interpret the body's responses by asking the question: "What is my feeling and felt sense as I write this now?" I found this practice useful in addressing areas of discomfort and uncertainty.

4.9.5 Conclusion: Unfinalizability of DNA Research

Counselling psychology values a relational approach to problems and challenges, even while engaging with subjective and collective experiences (Strawbridge & Woolfe, 2010). A relational approach acknowledges the client's engagement with others, and with the world (Gergen, 2015; Milton 2010). I put forward that relational, embodied, moral and spiritual care have the potential to produce a paradigm shift in our understanding of caregiving. This suggestion is not antithetical to BPS guidelines for professional practice, which recommend that practitioners consider "all contexts that might affect a client's experience and incorporate it, into the assessment process, formulation and planned intervention" (BPS, 2005, p.7)**.** Research indicates that all therapies are equally effective, if a strong therapeutic bond exists between client and therapist (Norcross, 2010; Wampold & Norcross, 2011). It is against this backdrop of understanding that implications for research and practice were conceptualised and proposals made for integrating narrative therapy and feminist relational theories in our work with GBM caregivers.

Even though research must come to a close, the participants' lives and the researcher's life continue, evidencing the *unfinalizability* of research. For example,

> *Dear Susan,*
>
> *I finally mustered the courage to read your summary and it was as tough to get through as I thought it would be, but it was also beautiful in its way the same way that a poem crystallizes the emotions. It was fascinating, too, to step back and objectively see some of the dynamics that we have each lived and see the similarities in our reactions (e.g., how we all were gripped with silences). Then at the end the thought occurred to me: but what about how this experience changes the trajectory of our lives as we try to find some equilibrium in a wake of grief (that may never end)? I wonder if we are stronger or damaged, or both…… Thank you for your illuminating and deeply compassionate work. It is much needed. Helen*

Helen's question brings forth the *So What Question* in storytelling captured poignantly by Audre Lorde in this poem:

> *What do we want from each other?*
>
> *After we have told our stories*
>
> *Do we want*
>
> *To be healed?*
>
> *Who will make the pain go away?*
>
> *And the past be not so? –*

It is my hope that the research captured both subjective and collective dimensions of storytelling, including their relational, dialogical, performative and hindsight perspectives, with emphasis on "voice" as an authentic representation of multiplicity. Reflecting upon events and experiences, I hope a temporal dimension has emerged, highlighting the fluidity of storied experiences, perhaps demonstrating how caregivers in narrating stories online became part of a transformative community of storytellers. What I have learned from this research is that focussing on how my participants conceptualised caregiving, enabled a deeper understanding about how different conceptualisations of caregiving can result in different interpretations of what it is to give care. Conceptualising caregiving as a relational, moral, embodied, spiritual experience and practice comes close to capturing the complexity of what it means to give care to a loved one in need.

Reading through this thesis, I hope the reader feels that they have gone through an experience with seven incredibly brave and generous women, and not data represented by buzzwords. I hope the reader comes close enough to the stories to reflect on how they might respond to the storytellers. I hope I have represented the storytellers in a compelling and

compassionate manner. I hope the reader, like me, is not just a by-stander, but a witness who is moved to care. I hope the metaphors bring forth images that are evocative enough to enable the sharing of suffering and caring. These are the stories that no one wants to hear. These are the stories that inspired me. I hope they inspire you too. The struggle to find meaning continues, *a luta continua* (Makeba, 1980).

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6. Appendices

Appendix A (3.5.1) Ethical Approval Letter

![City University London logo]

Psychology Research Ethics Committee

School of Social Sciences

City University London

London EC1R 0JD

23rd June 2015

Dear Susan K-Schlachter

Reference: PSYCH (P/F) 14/15 192

Project title: A Narrative Inquiry into online brain tumour stories by bereaved caregivers

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

      (a) Recruit a new category of participants

      (b) Change, or add to, the research method employed

      (c) Collect additional types of data

      (d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee (███████████████), in the event of any of the following:

      (a) Adverse events

      (b) Breaches of confidentiality

      (c) Safeguarding issues relating to children and vulnerable adults

      (d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Karen Hunt	Katy Tapper
Departmental Administrator	Chair
Email: ██████████████	Email: ██████████████

CITY UNIVERSITY LONDON

RESEARCH PARTICIPANTS ARE NEEDED FOR A STUDY ON ONLINE BRAIN TUMOUR STORIES BY BEREAVED CAREGIVERS

- Are you 18 years old and over?
- Are you a bereaved caregiver, male or female?
- Have you previously posted stories online about your experience of caring for your loved one who was diagnosed, treated and died of a brain tumour?
- Would you like to continue writing about your experience for an important research project?
- Are you at least 12 months post-bereavement?

If you answered YES to all of the above questions, you may be eligible for participation in this study. The purpose of this research is to explore the kind of stories bereaved caregivers who have witnessed their loved one diagnosed, treated and died of a brain tumour narrate throughout the illness trajectory. The research is also interested in how these stories change over time. I hope that exploring these stories will lead to an increased understanding of the psychological needs of brain tumour caregivers and their care-recipients. The time required to write the story or stories will be entirely up to you.

My interest in this topic is based on my experience of caring for my husband who died of a brain tumour during which time I posted stories online. I believe bereaved caregivers can play an important role in informing healthcare practitioners about their needs and those of their care-recipients.

My sincerest thank you and gratitude for participating in my study.

For more information about this study, or to find out how to take part, please contact:

Susan K-Schlachter, Researcher

Email: ▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮ , or

Dr. Don Rawson, Research Supervisor

Email: ▮▮▮▮▮▮▮▮▮▮▮▮▮

Appendix C (3.5.1) Participant Information Sheet

Department of Psychology City University London

PARTICIPANT INFORMATION SHEET

A Narrative Inquiry into Online Brain Tumour Stories by Bereaved Caregivers

I would like to invite you to take part in my research study with bereaved caregivers. Before you decide whether you would like to take part, it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. You will be given a copy of this Participant Information Sheet to keep. If there is anything at all that you do not understand, or you would like any further information on, please contact:

<div align="center">

Susan K-Schlachter, Researcher

Email: ██████████████████████████████ , or,

Dr. Don Rawson, Supervisor

Email: ████████████████████

</div>

What is the purpose of the study?

I am interested in gaining an increased understanding of the experiences of bereaved caregivers who have cared for a loved one who was diagnosed, treated and died of a brain tumour and have shared these experiences through online story telling. I believe that exploring your experiences more fully can lead to an increased understanding of the psychological needs of brain tumour caregivers and their care-recipients. The findings of this study will be used to write a doctorate report which may be published and shared with organisations and health care professionals who provide health care services to brain tumour patients and their caregivers.

The main research question is:

What kind of stories do bereaved caregivers who have witnessed their loved one diagnosed, treated and died of a brain tumour narrate throughout the illness trajectory and how do these stories change over time? Other questions of interest are: What kind of forums are used to tell these stories? Who is listening to these stories? Who is not listening to these stories and why? My interest in this topic is based on my experience of caring for my husband who was diagnosed, treated and died of brain tumour during which time I posted stories online.

Why have I been invited?

You have been invited because you have visited the website www.glioblastoma-narratives.org and identified yourself as a bereaved caregiver who has witnessed a loved one diagnosed, treated and died of a brain tumour and posted stories about these experiences online. Following your visit the website, you have expressed interest in participating in this research by providing your contact. This study is open to 10-20 participants, who are male or female, over 18 years old, and, who are at least 12 months post-bereavement.

Do I have to take part?

No. Your participation in this research is completely voluntary, and you may decide to withdraw at any time, even after the study has started, without a reason and without any consequences. Just let us know that you wish to withdraw. It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a Consent Form.

What will happen if I decide to take part?

It will be great if you decide to take part. You will need a computer, email address and internet connection to participate. The following describe the steps to take part:

a) There is a question on the website www.glioblastoma-narratives.org (See research advertisement) which asks whether you are a bereaved caregiver who would like to share their story for research. If you answered yes and meet the research criteria and provided your email address, you will be contacted to discuss the Participant Information Sheet and to provide any further information you may need.

b) Your email details will not be passed on to anyone else other than myself and will only be used to communicate with you about the research.

c) Please note that not all who express an interest to participate will be accepted as the maximum number of participants is 20.

d) You will be asked to sign a Consent Form indicating that your participation is voluntary and that you understand your rights.

e) You will be asked to complete a brief demographic questionnaire about your name, gender, age, occupation, social support and geographic location (country). This information is important and will provide a context for your story.

f) In order to communicate securely and to safeguard confidentiality, you will be asked to open an account with SecureSafe, one of the most secure online storage tools for confidential files currently available. There is a link on our website showing you how to do this. It is a free service and you will not incur any costs.

g) You will then be asked two things; one, to write a story about your experience of caring for your loved one who was diagnosed with a brain tumour from the time of diagnosis and throughout the illness; two, to give permission for the use stories/posts/blogs that you have previously posted online.

h) There will be no face to face meeting unless requested by you and then it will be via Skype (in which case you will need to have a Skype account) or Telephone. You will not incur any Skype or Telephone charges.

i) It is up to you how much time you take to write your story/stories. There is no minimum length.

j) It is expected that the study will be completed in March 2016

What are the possible disadvantages of taking part?

Some people find that thinking, talking or writing about their story may be upsetting. Please ensure that you are not alone and can seek support from family and friends. If, however, you do get upset and need further support, please refer to the attached list of free online bereavement support services (also available on the website) which you may find useful.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time without an explanation or penalty. You do not have to take part in this study if you do not want to.

What are the possible benefits of taking part?

I believe that there are significant benefits to doing research with bereaved caregivers as they are best positioned to provide information that can be valuable for understanding, planning, caring and supporting brain tumour patients and their caregivers. Even though researchers have conducted important research with bereaved caregivers for conditions such as Alzheimer's and Dementia, there is not enough research about brain tumours. Brain Tumour is an uncommon condition which has both oncological (side effects from radiation and chemotherapy) and neurological (side effects from brain injury/damage) symptoms suggesting that different conditions require different responses. This study provides an opportunity to talk about your experiences, potentially leading to an increased understanding of the unique needs of brain tumour patients and their caregivers. I hope that increased understanding will lead to increased support for brain tumour patients and their caregivers. I also hope that you will find it beneficial to write your story. Writing stories is known to offer opportunities for reflection and insight. Most people who write stories about their experiences of suffering have revealed that they found it beneficial. As a bereaved caregiver myself, I hope our stories will benefit others who are going through the experience of caring for a loved one diagnosed with a brain tumour.

Will my taking part in the study be kept confidential?

All stories will be collected and stored in accordance with the UK Data Protection Act 1998. All information collected about you, as part of this research, including the demographic questionnaire and your stories will be kept strictly confidential. To ensure anonymity and confidentiality for you and any other people mentioned by you in your story, all identifying information will be anonymized (this means that your information will be stored in a way that it cannot be linked directly to you). The information will be disguised by codes known only to the researcher and any identifying information removed and held on an encrypted memory stick and a password protected computer accessed by the researcher only. My responsibility for maintaining confidentiality will not include stories that you have previously posted and are freely available online even though I will anonymize these stories as well. There are other limits of confidentiality.

What are other limits to confidentiality?

Other limits to confidentiality can involve a situation arising where I might need to act to ensure access to help or support for your protection or someone else identified by you. These situations can involve abuse or neglect or serious physical or mental health problems. In case of such a situation, I would have a duty to act. What this means is that I would first discuss the issue with you and encourage you to seek help. I would also discuss the issue with my supervisor and seek further guidance. I will, however, not tell anyone else what you tell me unless I think you or someone else might get hurt. If so, I will talk to you first and agree on the best thing to do.

How will the records be kept secure?

Data security includes collecting, handling, processing, storing and destruction of data, which will be safeguarded according to the UK Data Protection Act 1998. The information collected will be stored securely and safely using SecureSafe, one of the most secure virtual digital safes available online currently. SecureSafe is a virtual digital safe with an encrypted server requiring a valid login and password. Each participant will have their own SecureSafe account with a valid login and password. SecureSafe will be used to transmit the stories you write and only I, the principle researcher, will be able to access the digital data stored on this server. Data printed out for the purposes of analysis will be kept in an encrypted memory stick, which will be locked

in the principle researcher's safe. Only the researcher will be able to access the hard copy data in this cabinet. The British Psychological Society recommends that data be retained for a maximum period of 5 years, after which it will be disposed of securely according to City University rules for disposal of data.

What will happen when the research study ends?

When the research ends your story will be part of a report. You will be offered the opportunity to see this report before it is finalised. This report will form part of my doctoral thesis in counselling psychology, which may result in a publication in an academic journal or other publication. As already discussed, your story and your name will be kept separately so that no one will be able to link your story to any identifying information you have provided. If you wish to receive a copy of the research, please let me know where I can send it. This report and the key findings will also be made available on the City University Research website.

Expenses and Payments

There will be no monetary compensation for participating other than my sincere appreciation for your story and your time.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone +44120 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee quoting the name of the project which is:

A Narrative Inquiry into online brain tumour stories by Bereaved Caregivers

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: ██████████████████████

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London *[insert which committee here]* Research Ethics Committee, [*insert ethics approval code here*].

Further information and contact details are as follows:

The Research Team, Susan K-Schlachter, Researcher, Email: ██████████████
██████████████████████ Dr. Don Rawson, Research Supervisor, Email: ██████████████

Thank you for taking the time to read this Participation Information Sheet.

Appendix D (3.5.1) Informed Consent Form

Department of Psychology City University London

A Narrative Inquiry into Online Brain Tumour Stories by Bereaved Caregivers

Ethics approval code: [*Insert code here*]

Please initial box

CONSENT FORM

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve:: • Completing a demographic questionnaire • Writing a story • Opening a free account with SecureSafe to protect my confidentiality • Allowing the use of posts/blogs/stories that I have previously posted online	
2.	I can confirm that: • I am over 18 years old • I have witnessed and provided care for a loved one who was diagnosed, treated and died of a brain tumour • I have previously posted stories online about my experience of caring for a loved one who was diagnosed, treated and died of a brain tumour • I am at least 12 months post-bereavement	
3.	This information will be held and processed for the purpose of writing a research study and: • I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. • The identifiable data will not be shared with any other organisation. • I understand that I will be given a transcript of data concerning me for my approval before it is included in the write-up of the research.	
4.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
5.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out	

	in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
6.	I agree to take part in the above study.	

_____   _____   _____

Name of Participant   Signature   Date

_____   _____   _____

Name of Researcher   Signature   Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Appendix E (3.5.1) Email Interview

EMAIL INTERVIEW RESPONSES

Please be as elaborate and descriptive as possible. There is no right or wrong answer, just write what you feel like writing.

Statement: Sometime after your loved one was diagnosed with a brain tumour, you joined an online brain tumour forum.

Looking back on the stories you shared online – Can you please tell me about the stories, the responses you received, and whether or not, you are still sharing stories online?

SHARMA

I had read about avastine being given to GBM patients on the forum so I went and spoke to the oncologist , he knew about it and prescribed irreoitican and avastin infusions every 10 days. He also tendered an apology from the neuro surgeon to me.. I read on this forum the single most important thing , be kind, that is what I would like to repeat, be kind . All empathy comes from kindness.still showing empathy to the patients who are looking to them for solutions and putting their lives in their hands is imperative. 2; we are all mortal and running scared from death will not make us immortal . the person who is facing this disease needs his friends and relatives more than ever, be there for them .
I am still a member , I don't post neither do I respond but I still read the posts, I am not ready to cut off from this community yet, I don't respond because I don't know what I can say that will make some one feel better and I see the same situation and same questions repeated again and again, it is heart breaking to read these posts …. so many human beings hurting. Maybe given some more time I would be able to help someone with my experiences.I think some where along the lines of this battle field it did become two battle fields, I didn't tell my husband what I thought or felt and soon it didn't matter because I felt he couldn't process information as given, as decline became more evident my priorities were also being questioned and adjusted to by myself, strange thing is that I felt oddly detached from the reality yet totally focused. Nothing could have prepared me for my husbands passing as I am sure that after looking after our loved ones for months or years, we still could not imagine what was coming, we just keep making room for the changes and keep going, yes I do believe given a choice I would have chosen an easier death for my husband, this disease is like being handed a death sentence and waiting for it to be executed. This disease is total annihilation from word go, and I watched helplessly as it ate into my husband bit by bit, watching him lose his faculties was the hardest thing for me , from not being able to walk after biopsy to not being able to form sentences , from not being able to write to not being able to read ...or speak, being confined to wheel chair to hospital bed... for me protecting my husband, s feelings and dignity was paramount, nothing else mattered at that time for me. Only a person who has seen a degenerative disease up close and has been a care giver can understand what it is like, give it all one has got , fight on in the face of such hopeless and difficult situation, and when you have no hope given and becomes increasingly apparent what lies ahead ,this disease is relentless , it does not give you a respite anywhere, it requires adjusting to very fast changes in mental and physical abilities , sometimes in days and sometimes in a matter of hours, it is a huge burden that the care giver carries . Which is impossible to bear without the selfless and deep love I have seen in all the care givers, what compels you to do that, in my case I felt just as protective about my husband and felt the same tender love that I felt when I had my children .Hello Susan, I hope my email finds you well ,First of all i want to thank you for all your previous emails. I tried editing the recent form

Appendix F (3.5.1) Demographic Questionnaire

DEMOGRAPHIC QUESTIONS

Q.1 Age

18-24 years old ☐   55-64 years old ☐
25-34 years old ☐   65-74 years old ☐
35-44 years old ☐   75 years and over ☐
45-54 years old ☐

Q.2 Gender

Male ☐
Female ☐
Other ☐

Q.3 Geographical Location

North America ☐   South America ☐
Europe ☐   UK ☐
Africa ☐   Asia   ☐
Middle East ☐   Australia/New Zealand ☐

Q.4 Employment Status

Employed full-time ☐   Student ☐
Employed part-time ☐   Unemployed ☐
Self-employed ☐   Retired ☐
Home-maker ☐   Other ☐

Q.5 Education

High School ☐   Master's degree ☐
College ☐   Professional degree ☐
Bachelor's Degree ☐   Doctorate degree ☐
Master's Degree ☐

Q.6 Family and Social Support

Alone ☐
Children ☐
Other ☐

Appendix G (3.5.1) Amendment to Recruitment

CITY UNIVERSITY LONDON

Psychology Department Research Ethics Committee

Project Amendments/Modifications
Request for Extension

For use in the case of all research previously approved by City University London Psychology Department Research Ethics Committee.

Was the original application reviewed by light touch?
If yes, please send this form to the individual who reviewed the original application. Once they have approved the amendment and signed the form, it should be emailed to psychology.ethics@city.ac.uk

Was the original application reviewed at a full committee meeting?
If yes, please email this form to psychology.ethics@city.ac.uk. It will be reviewed by the committee chair.

Note that you only have to respond to the sections relevant to you.

Details of Principal Investigator and Study	
Name	Susan K-Schlachter
Email	▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮
Title of study	A Narrative Inquiry into online brain tumour stories by bereaved caregivers
REC reference number	PSYCH(P/F) 14/15 192

Study Duration	
Start Date	23 June 2015 (Date of ethics approval)
End Date	30 September 2016

Project Amendments / Modifications

Type of modification/s (tick as appropriate)

Research procedure/protocol (including research instruments) Recruitment method	X
Participation group	
Information Sheet/s	
Consent form/s	
Other recruitment documents	
Sponsorship/collaborations	
Principal investigator/supervisor	
Extension to approval needed (extensions are given for one year)	

Other	

Details of modification (give details of each of the amendments requested, state where the changes have been made and attach all amended and new documentation)

HOW WILL PARTICIPANTS BE RECRUITED?
In addition to recruitment of participants via my website, I would add

snowballing technique and online advertising to recruit more participants. Snowballing technique is a method whereby participants with whom contact has already been made are asked to use their social networks to refer the researcher to other people who could potentially participate in the study. Bereaved caregivers often belong to other groups where they seek support and can therefore be a rich source for recruitment. I propose to gently ask participants whether they would be willing to pass on the research advertisement flyer and/or information about the study to other potential participants. These potential participants would be requested to contact me, the researcher if they are interested.

Online advertising has become a common method for recruiting participants and websites such as www.findparticipants.com and www.callforparticipants.com exist and I plan to place my research advertisement flyer asking potential participants to get in touch with me, the researcher if they are interested.

The same care provided participants who are recruited via my website www.glioblastoma-narratives.org would be provided to them. Through an initial presentation of the participant information sheet I would ensure that the potential participants are in a position to give informed consent.

Justify why the amendment/extension is needed (including the period of extension being requested)

Brain tumour is a rare condition. Bereaved caregivers of brain tumour patients who meet all the recruitment conditions of the study are a small group and it is my belief that the recruitment method should employ multiple methods in order to have the best possible chance of recruiting sufficient numbers for the study.

The amendment is needed in order to maximise all avenues available for recruiting this minority population.

Period of extension requested

Other information (provide any other information which you believe should be taken into account during ethical review of the proposed changes)

Change in the study team

Staff member

Title, Name & Staff Number	Post	Dept & School	Phone	Email	Date and type of CRB disclosure*

Student

Name & Student Number	Course / Year	Dept & School	Date and type of CRB disclosure*

External co-investigator/s

Title & Name	Post	Institution	Phone	Email	Date and type of CRB disclosure*

Declaration (to be signed by the Principal Investigator)

☐ I certify that to the best of my knowledge the information given above, together with any accompanying information, is complete and correct and I take full responsibility for it.

Principal Investigator(s) (student and supervisor if student project)	Susan K-Schlachter Dr. Don Rawson, Supervisor	*Susan K-Schlachter*
Date	09/10/2015	

Reviewer signature To be completed upon FINAL approval of the amendment.		
	Signature (Please type name)	**Date**
Reviewer	**Katy Tapper**	**12th October 2015**

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Department of Psychology City University London

A Narrative Inquiry into Online Brain Tumour Stories by Bereaved Caregivers

DEBRIEF INFORMATION

Thank you for taking part in this study! Now that it's finished I would like to explain the reason why I undertook this research. My interest in this research was triggered by my own experience of caring for my husband who was diagnosed, treated and died of a brain tumour. During his illness, I used online support groups, but found it difficult to talk about my experience face to face. Many other caregivers disclosed that they also did not use psychological services. Being a trainee counselling psychologist, I wondered why this was so. In addition, the experience of caring for my husband revealed just how much the healthcare system relies on caregivers. I believe that bereaved caregivers have acquired significant experiential knowledge that can be helpful to brain tumour patients, their caregivers and healthcare professionals.

Through your stories, I hope to develop an enhanced understanding that can identify the kind of psychological resources are needed by brain tumour patients and their caregivers. I also hope to gain insight into both the individual and collective impact of telling brain tumour stories online. This study is part of my doctorate studies in counselling psychology.

The following resources may be useful should you find that you need to talk about the experience of participating in this research.

AMERICAN BRAIN TUMOUR ASSOCIATION ABTA
Provides support for patients, families, friends and caregivers of brain tumour patients. Their CareLine is staffed by licensed professionals if you would like to talk
info@abta.org
www.abta.org
CareLine 800 886 2282

BRAIN TUMOUR ACTION
Provides support and counselling for brain tumour patients and their families. Their helpline is open 24 hours a day and staffed by trained counsellors.
www.braintumouraction.org.uk
HelpLine 0131 466 3116

BRAIN TUMOUR CHARITY

Provides professional and compassionate support for brain tumour patients and their families.
support@thebraintumourcharity.org
HelpLine 0808 800 0004

BRAIN TRUST
Provides support to brain tumour patients and their families.
HelpLine 01983 29405
Email hello@braintrust.org.uk
HelpLine 01983 29405

I hope you found the study interesting. If you have any other questions please do not hesitate to contact me or my supervisor as follows:

Researcher: Susan K-Schlachter
Email: █████████████████████████████

Supervisor: Dr. Don Rawson
Email: ████████████████████

Ethics approval code: *[Insert ethics approval code here.]*

Thank you for taking part in this research.

PSYCHOLOGICAL RESOURCES

AMERICAN BRAIN TUMOUR ASSOCIATION ABTA

Provides support for patients, families, friends and caregivers of brain tumour patients. Their CareLine is staffed by licensed professionals if you would like to talk

info@abta.org

www.abta.org

CareLine +800 886 2282

BRAIN TUMOUR ACTION

Provides support and counselling for brain tumour patients and their families. Their helpline is open 24 hours a day and staffed by trained counsellors.

www.braintumouraction.org.uk

HelpLine +131 466 3116

BRAIN TUMOUR CHARITY

Provides professional and compassionate support for brain tumour patients and their families.

support@thebraintumourcharity.org

HelpLine +808 800 0004

BRAIN TRUST

Provides support to brain tumour patients and their families.

HelpLine 01983 29405

Email hello@braintrust.org.uk

HelpLine +1983 29405

Appendix J (3.5.1) Amendment Number of Participants

Psychology Department Research Ethics Committee

Project Amendments/Modifications
Request for Extension

For use in the case of all research previously approved by City University London Psychology Department Research Ethics Committee.

Was the original application reviewed by light touch?
If yes, please send this form to the individual who reviewed the original application. Once they have approved the amendment and signed the form, it should be emailed to psychology.ethics@city.ac.uk

Was the original application reviewed at a full committee meeting?
If yes, please email this form to psychology.ethics@city.ac.uk. It will be reviewed by the committee chair.

Note that you only have to respond to the sections relevant to you.

Details of Principal Investigator and Study	

Name	Susan K-Schlachter
Email	Susan.Kinyany-Schlachter.1@city.ac.uk
Title of study	A Narrative Inquiry into online brain tumour stories by bereaved caregivers
REC reference number	PSYCH(P/F) 14/15 192

Study Duration	

Start Date	23 June 2015 (Date of ethics approval)
End Date	30 September 2016

Project Amendments / Modifications	

Type of modification/s (tick as appropriate)

Research procedure/protocol (including research instruments) Recruitment method	X
Participation group	
Information Sheet/s	
Consent form/s	
Other recruitment documents	
Sponsorship/collaborations	
Principal investigator/supervisor	
Extension to approval needed (extensions are given for one year)	
Other	

Details of modification (give details of each of the amendments requested, state where the changes have been made and attach all amended and new documentation)

HOW WILL PARTICIPANTS BE RECRUITED?
In addition to recruitment of participants via my website, I would add
snowballing technique and online advertising to recruit more participants.
Snowballing technique is a method whereby participants with whom contact
has already been made are asked to use their social networks to refer the
researcher to other people who could potentially participate in the study.
Bereaved caregivers often belong to other groups where they seek support
and can therefore be a rich source for recruitment. I propose to gently ask
participants whether they would be willing to pass on the research
advertisement flyer and/or information about the study to other potential
participants. These potential participants would be requested to contact me,
the researcher if they are interested.

Online advertising has become a common method for recruiting participants
and websites such as www.findparticipants.com and
www.callforparticipants.com exist and I plan to place my research
advertisement flyer asking potential participants to get in touch with me, the
researcher if they are interested.

The same care provided participants who are recruited via my website
www.glioblastoma-narratives.org would be provided to them. Through an
initial presentation of the participant information sheet I would ensure that
the potential participants are in a position to give informed consent.

Justify why the amendment/extension is needed (including the period of extension being requested)

Brain tumour is a rare condition. Bereaved caregivers of brain tumour patients who meet all the recruitment conditions of the study are a small group and it is my belief that the recruitment method should employ multiple methods in order to have the best possible chance of recruiting sufficient numbers for the study.

The amendment is needed in order to maximise all avenues available for recruiting this minority population.

Period of extension requested

Other information (provide any other information which you believe should be taken into account during ethical review of the proposed changes)

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Change in the study team

Staff member

Title, Name & Staff Number	Post	Dept & School	Phone	Email	Date and type of CRB disclosure*

Student

Name & Student Number	Course / Year	Dept & School	Date and type of CRB disclosure*

External co-investigator/s

Title & Name	Post	Institution	Phone	Email	Date and type of CRB disclosure*

Declaration (to be signed by the Principal Investigator)

☐ I certify that to the best of my knowledge the information given above, together with any accompanying information, is complete and correct and I take full responsibility for it.

Principal Investigator(s) (student and supervisor if student project)	Susan K-Schlachter Dr. Don Rawson, Supervisor	*Susan K-Schlachter*
Date	09/10/2015	

Reviewer signature To be completed upon FINAL approval of the amendment.		
	Signature (Please type name)	**Date**
Reviewer	**Katy Tapper**	**12th October 2015**

Appendix K (4.4.1) Excerpt Sharma's Story & Email interview

Sharma's Story continue to love him. Wonderful daughter to care so deeply and give so effortlessly warmest regards and prayers My husband passed away on xxxxxxxxx yet when my husband passed away I didn't post anything…..nothing……no announcement I am silenced and I have read so many heart breaking posts ....seems like an echo, and you are absolutely right that it seems like they could have been written by myself and so many others probably feel the same.I learnt more from the members of this forum then the doctors themselves, infact I learnt every thing here, about treatments to care giving"…..I read on this forum the single most important thing , be kind, that is what I would like to repeat, be kind . All empathy comes from kindness. ; …..we are all mortal and running scared from death will not make us immortal . the person who is facing this disease needs his friends and relatives more than ever, be there for them ."Hi …… , thank you for your reply . since xxxx i had been reading all posts here and have learned so much , i cried with every wounded soul who lost a loved one but never posted anything ...... why didnt i do that earlier, i dont know,....i knew i will find the understanding and support that i needed badly right here, but i just didnt...Hi , Thank you for your reply , I am so very sorry that your father is going through this , yes it is a very difficult road that we all have to walk along with the people so very special to us.......i have read your other post , you are a very caring daughter and i am sure your father knows that and loves you for standing by him ....Hi , Thank you and God bless you for having such a generous heart , i am so very sorry and can only imagine how hard it must be to see your childrento go through this , you are truly brave ... thank you for searching for visiting nurses facility..I dont have any family here and his only brother lives in another city and to be honest he is not bothered so it is just me , I can hospitalize him but that means i will be living in the hospital as his attendant and paying quite a large amount per day , what does help is that in my country you can find domestic live in help so atleast i dont have to cook or clean .....I feel so alone as if he is already gone from my life , he has been my rock. Thank you again for your kindness.loads

Appendix L (4.2.2) Excerpt Anna's Story & Email interview

Anna's story procedures. I know this first hand as I nearly had to dismantle the office of xxxxxx dentist with my bare hands when they were just about to start an unnecessary root canal when I stepped out of the office to run to the bank - he did not get that it was SUPER dangerous because he had just had an avastin infusion - and the dentist had no idea what avastin was, what it did and why on earth it would matter if he was gonna do a root canal - since he (the dentist) would not nick xxxxx mouth. I stopped the procedure before it got started by DEMANDING that the dentist put in writing an absolute guarantee that he would not under any circumstances nick xxxxxx's mouth. Guess what, he would not do it, said unfortunately there was no way he could do that. He further went on to tell me I was paranoid - literally said that - I proceeded to advise him bluntly to go perform a carnal act on himself and we left. It was not pretty! But I was right and I had the designated health care surrogate form that said I could do that!! xxxxx did have X-rays that day - radiation never even crossed my mind.xxxxxx was MAD, but when I called his neuroncologist I was told I had done the right thing. Make your own decisions but do them with guidance from your medical team.I am sorry. This disease is a brutal beast. Be extra kind to yourself. I am sorry - there is nothing more I can say. This disease is brutal and unforginving. Know that you are much stronger than you think.Lots of love to you my sister - because after what you have been through though I do not know you, we are sisters. Nine Months ago today xxxxxx succumbed to the Monster - Glioblastoma. He survived 17 months to the day from the date of his debulking surgery. He was in two clinical tirals - Celldex - a vaccine trial targeting EGFRViii Positive tumors - through xxxxxxxxxx - all indiciations were that he was receiving

the vaccine. Every time he got the injection the injection site swelled, turned bright red and his head began to hurt really badly. After five doses he was forced to drop out due to brain swelling and progression. We were tremendously disappointed to say the least. Avastin/and something they were testing that is used for renal cell cancer - so bizarre when he was sick my memory was spot on and I could remember everything - now not so much- anyway he was randomized to the Avastin arm only - so he just got avastin anyway. Once he had progression on that he was dropped from that tiral as well, but did continue on Avastin. He was admitted to the hospital in earlyxxxxxx because in a matter of hours he almost completely lost use of his left side - he spent three days in Neuro-Intensive care and was discharged to Hospice care at home and a week later moved to inpatient hospice care. His pain was not managable at home since the meds that were needed to keep him pain free (which I do not believe he ever was fully) - at least in the state of FL - can only be administered in a hospital/clinical setting.

Fast forward...things I have learned - as the caregiver you call the shots and to h#!! with what non-caregivers think - they are not there - they do not know - they do not get a say - their vote does not count!!!! Foods for the brain cancer patient - WHATEVER they want - provided the dcos say it is ok for them to eat - unless and until there can be a definitive study done that shows organic, green, clean, whatever other buzz words are out there, really make a difference - the h#!! with it, Brain cancer is terminal the patient should NOT have to eat carboard!Try to live - yes the person you love has been handed a horrible diagnosis, but try

Appendix M (4.2.3) Excerpt Heather's Story & Email Interview

Heather's story My husband developed these shivering fits sporadically. Initially, when he got them, they would go away after a few minutes. After several weeks of this, they turned out to be a sign of an infection that ultimately turned out to be meningitis. Turns out his immune system was strong enough to fight it off a short period of time, but ultimately he developed meningitis five times. He went on IV antibiotics, but each time he went off, meningitis would return with the onset of a shivering fit!He was on hospice for the last four months of his life, and as so many have said prior, it was both a relief and heartbreaking at the end. I also experienced that death is a holy process, even as it is extremely difficult, and that weaning my husband at the end of all the toxicity of chemicals used in his treatment made him seem more at peace. Hospice also provided plenty of narcotics, anti anxieties...He diedXXXXXXXXXMy husband is at home in hospice, has a right parietal lobe tumor diagnosed inXXXXXX. We have been through multiple treatment rounds. The tumor is now unresponsive to treatment, and is now in the motor strip. His current symptoms include left hemineglect, left sided paralysis, some word slurring, fatigue and sleeping a lot, some incontinence, some falls. He walks with assistance (gait belt), and cannot use a walker because of the left sided paralysis. He also has swallowing issues, and aspirates regularly when eating or drinking. Lately, he runs low grade fevers in the night. He has some headaches mostly at night. He can't sleep because of the severe gastritis. He also can't urinate even though on flomax. I assume the tumor is causing some urinary inhibition. He does not want to take narcotics for the pain, because he fears constipation but will take acetimenophen and diazepam .(Valium). Of course, there has been some cognition changes, mostly impulsivity, but they have not been the most difficult symptoms, as he seems to be fairly unaware of those cognition changes. Last spring he had 5 recurrent cases of meningitis (psuedomones) and spent months in the hospital, and it really started the continuous downward spiral. He is now on 3x per day IV antibiotics.XXXXXis much more comfortable with the ambiguity then I am, perhaps because as caretaker, I feel the weight of his care fall on my shoulders. Keeping him safe feels like no small task. For a long time, I felt like our backgrounds were a blessing. He was a XXXXXXXXXXXand I am an XXXXXXXX. At first, when XXXXXwas in active treatment, I felt our knowledge of medicine and research was a blessing because it helped us to find relevant research. Now I struggle because my knowledge can't help us, and we must live in the ambiguity of the diagnosis. Thanks so much for your words of

Appendix N (4.2.4) Excerpt Jasmine's Story & Email Interview

Argh..tough choice, and I know regardless of what I decide in the end, I will have no regrets, as it will be the best decision given the facts and emotions at the time, and that's the best anyone can do.My husbands quality of life is more important then keeping on fighting a losing battle which is robbing him of everything: memory, sight, mobility, muscles, taste, continence, etc. It is a terrible disease.there are days here and there where he has a resurge of energy and can hold a conversation.His biggest fear when he found out he had a tumour was to be bed ridden, "useless" and a burden. He is bed ridden. He is not useless to me or his kids, and he is not a burden either though I have to do everything for him, but I know he does not want to live this way. We haven't stopped treatment yet (he is on avastin), but I do wonder if we should as prolonging this current life for him is not living for him Yes, I am glad that I still have him, but he is no longer the same man he was …. More of a shell, with an occasional spark of life in him.'m working from home when I can and the company I work for has been very supportive. Going on unpaid leave is not a good option as it affects your medical insurance coverage, and if your insurance covers temodal and avastin, you want to keep it! These drugs are really expensive! There is no cure. So why are we going through all these treatments whose side effects are just as bad or worse as the disease?" Found out in xxxx when we went to see the neuro opthomologist that he had developed cataracts in his right eye, which is apparently a potential side effect of the dexamethasone. He can have laser eye surgery to correct it, but because of waiting times, his appointment is not until

Great post. We did our wills and power of attorney as soon as my husband was diagnosed last year. It was he who wanted this done ASAP, and I am glad he did as it gave us both some peace of mind. It is also good to do these before side effects of treatments and tumour set in.He is now bedridden, and too weak for another avastin treatment. I am looking after him at home, but have a nurse visit frequently, personal support workers three times a day coming in to help me with his basic care. He has been put on oxygen last week as his levels have been dropping. Seems to have helped a bit, but not much. I am still debating with myself whether it is better to stay home, or try to move in to a hospice home. I like our privacy and comfort at home, but maybe having constant help would be better? I think he prefers it here. It is such a horrible disease, to rob them of so much and make them dependents like babies. He is exactly how he was most afraid to become. As much as I want him here with me, I know he wants to move on, as he is no longer 'living', he just is. I am doing the best I can to make his days as comfortable as I can. He sleeps most of the time, which is a blessing for him.Yes, I still have hope. I am glad there are many on here who have success with conventional and alternative treatments. But I hope people respect wishes of those with the tumour, and do not force them into various treatments. It is their life, and they should be able to choose what they want for themselves, even if it is not what we want. And we should accept and make peace with each decision. Life

Appendix O (4.2.5) Excerpt Rosemary's Story & Email interview

The last 3 months were spent at home, bed bound and unable to communicate. …., I chose to have him at home because visiting him would have been too difficult. I had hospice care for him in the morning and hired private duty nurse for late afternoon. ….. The good days are when he can say good morning. The bad are when he can say nothing. I just wish I knew if he is really in there. He would be so upset to know all he's going through…is inability to communicate was the absolute hardest. I wanted to talk with him but he was not able to respond to me. the brain tumour website when he was diagnosed and shared many of his feelings with other members. I wish I had better news.. I wish he'd been on a chemo with the avastin, but he wasn't. We had to put him on paliative care and he passed away about 3 months later. I know avastin is helpful for some and I'm happy for them but it's definitely not a cure all. Good luck on your journey.Mostly she told her storyMaybe avastin works for some

people but it certainly didn't work for him and I'll always feel guilty that I wanted him on it, I pray your experience, whatever you decide, is betterMy husband was not allowed to drive from diagnosis to the completion of his radiation treatments. He had no seizures while he was able to drive, but if I remember correctly, you could not drive for at least 6 months following a seizure. Unfortunately, yes, she could die from another problem other than GBM. We all could. The question is, what caused the blood clots? Was this a side effect from medication or an unrelated problem? I think you are right that we may become so concerned over GBM problems that we may overlook something else. Try to see if the doctor knows why she had the blood clots. A UTI is very common, especially if she is not very mobile. Is she bed or wheelchair bound? If so, can they give her something like bactrim to try and prevent future UTIs? reassuringPlease don't feel you are being paranoid. It sounds like you are being a good daughter and caregiver. We must stay vigilant and it sounds like you are doing so. I know you've had a couple of rough weeks, but hopefully things will calm down again soon. Thinking of you and your mom and hoping for the best.I do not recommend avastin alone. I lost my husband 2 1/2 years ago. Upon recurrence, they put him on avastin. After only 1 treatment, his tumor blew up and we had no options left. Avastin may have had nothing to do with his death, but I do not trust it. know this is a scary diagnosis for your dad and your family. I lost my husband 2 1/2 years ago, just before XXXXXXXXX, to GBM. Fortunately, there are more treatments out there, and I would advise you to investigate them. Also, there are molecular studies that can be done to see the likelihood of the tumor being genetic. They may have to still have the tumor to do this test, but it might give you peace of mind.Is your father at a teaching hospital with a good brain tumor center? If not, I would recommend he move to one. They are likely to be aware of new treatments. I know a GBM dx is scary, but it is a reminder that we all should take every chance to share our love with those around us. Be positive with him, ensure he is being positive and when he is able, do things he may have wanted to do but has put off. The statistics are miserable, but there are survivors and I hope your father becomes one. Please feel free to use this site as a sounding board. That's what we are here for. We will all be thinking good thoughts for your father and your family.I wish you weren't having to go through this. It is so hard to answer your questions because you have so much information you don't know. I lost my husband to GBM 2 1/2 years ago, and it is a tough road. I wish you hadn't been right too.

Appendix P (4.2.6) Excerpt Lilly's Story & Email interview

Lilly's story. . my husband's surgeon has a license to write the prescription, that's where we got the prescription for medical marijuana. My husband uses a vaporizer so he does not actually smoke it. As far as being prayed over . . . . when my husband was diagnosed, I knew immediately I needed to reconnect with the Holy Spirit and people who are solid in their relationship with the Holy Spirit. I attended a Life in the Spirit Seminar and I went to charismatic prayer meetings and I was a proxy for my husband, since he was not well enough to go anywhere in the beginning. I read books about REAL faith healing to see how it works. I read Frances McNutt, s. And then I prayed over my husband.I did what the books said. To pray over my husband that the Holy Spirit would bring the root cause(s) of this illness to the surface for healing. I brought him to healing masses where I knew for a fact that the priest was a charismatic priest who was baptized in the Holy Spirit. This is our experience . . . . I was lead to the ketogenic diet in a dream given to me by God. I was lead to cannabis by a "word of knowledge" (that means Holy Spirit). And believe me, I was the last person on earth to consider marijuana as a solution to ANYTHING. I was a firm NON-believer in medical marijuana.
nd today I continue my studies and involvement to charismatic prayer. I was prayed over this weekend by two people, very strong in the Lord who used the Unbound prayer model (see Unbound, Neal Lozano for more information).

I hope that helps. When I read what GBM was at the time of the dx, I knew this was a job for the big guns of healing or I needed some radical faith to be shown how to walk through this. Either way a massive spiritual upheaval was necessary, and that's just what we both got. - so sorry to hear this. I too enjoyed his posts. He will surely be missed. Love, peace and comfort to you and your familyI am so very sorry to hear this. Your husband was so blessed to have you in the good times and in the terrible times of GBM. Although we've never met, I send you love and wishes for comfort and peace. God bless you, your family and everyone on this website. God help us all.

This article was very helpful for my husband to read. It validated for him, how and why he feels different XXXXX months post-op. It is very technical in some parts, but it may help to understand what actually is happening in the healing process after a craniotomy. My husband (the patient) found it yesterday. He feels that this aspect of the healing is not addressed by the docs and the patients are left to fend for themselves too much with this.My husband started ketogenic diet in had surgery, radiation, temodar). He has had 7 good MRIs. He was extremely strict on the diet from . He is doing quite well.This is such tough stuff. No one can imagine what we go through and what our loved ones go through with this terrible disease. But we have each other to lean on. My husband was "messed up" mentally for awhile post-op. It took him an hour to figure out how to use the coffee maker, once he was well enough to look for the coffee maker. The radiation and temodar took away appetite and caused lots of "taste perversion" - which is when things really taste different. We had to take it ONE DAY AT A TIME - at best. And many days it was 1 hour at time. He felt that he was not able to really think because of the temodar, could not remember much. So his big task was to simply relax and let the meds take their course. His Onc wanted him on Temodar for 1-2 years. And my husband was very agreeable to do whatever the Onc suggested. My husband

Appendix Q (4.2.7) Excerpt Helen's Story & Email interview

Helen's story

precious time. CCNU has a reputation for being more effective in younger persons. Because it is not all that effective (i.e., is not typically used as a primary treatment), in jurisdictions that mandate that a patient be off all treatment before getting into hospice, some hospices are able to consider this a palliative and will cover it /allow it in conjunction with their services. But on the larger, more important issue - my heart is broken for you and your family and I will keep all of you in my prayers for strength and solace and peace as you go through the last and deeply poignant steps in this journey. information on Hospice I am heartbroken for you and will continue to pray for you, your DIL and all your family as you face this next phase of this journey. Here is some advice:. If your loved one is suffering in any way, breathing hard, not drinking or eating, running a fever or experiencing any other symptoms, tell hospice right away and request their assistance to manage the symptom.

If you are unable to move or properly clean or feed your loved one, tell hospice and request their assistance and/or equipment. Take no chances that your loved one might fall or be dropped or hurt or that you might be hurt. If you don't like your lead nurse, say something to hospice about changing him/her out with another. No medals are available for being long-suffering or more discontented than you otherwise need to be during this highly critical time. Especially during weekends and holidays, hospice can get overwhelmed so if you aren't getting the help you think you need, pester. Be nice, but pester. Call at any time of the day or night, but best time to call and alert them to a priority need is early in the morning before shift change (usually 7am). If you have competent family or a close friend helping you, get them to call hospice for what you need. Keep hospice phone numbers nearby and easy to locate. Know the name of your assigned nurse's head nurse or team lead just in case you need to escalate a requirement. Do not be shy about your real concerns. Hospice can provide all the

equipment you will need, for instance a hospital like bed which is essential for lower/raising your loved one so that you can best care for them. That hospital like bed requires an extra-long twin fitted sheet that no one really has. Make sure you have or get several (4 to 6) twin flat sheets. You can tuck these. You'll need several to be able to keep your loved one in clean linens. Don't be surprised if you do several laundry loads a day If you need a wheelchair, toilet with handles, lifting device or any other equipment, do not hesitate to ask hospice. Be careful to ask before you need them. A brain cancer patient can degrade very rapidly and you'll need to equipment to be able to properly care for your loved one. For ease of clothing your loved one, use soft, cotton t-shirts. If you slit the back of the t-shirt from the bottom to the top of the neckline, you'll have a shirt you can easily slip on and off to keep your loved one covered and clean. Keep a good, reliable thermometer handy and take your loved one's temperature regularly. If you notice any fever spikes beyond 100.4 (Fahrenheit) [or whatever the medical team tells you the magic number is], call hospice immediately who will probably suggest you treat with acetaminophen (aka Tylenol). Track temperature carefully. The higher the fever and the more constant that fever (absent some underlying reason like an infection) may be indicative of how close your loved one is

Appendix R (3.5.6) Lilly's Email Feedback

Email 1

Susan,

Just read it . . . . I IMMEDIATELY burst out crying, I'm sure everyone does who

contributed. It was like a cold smack in the face when I saw the reference right at the start to

"the beast". I'll never forget the first time I saw someone call it that in the XXXXXX I got

such a chill. Yes, it is a beast.

My heart broke to read how others loved ones took such a horrible decline. XXXXXX was

fast and furious - one day independent, the next flat on his back.

And the "have to do something" reference. That is trauma, that is what living in the war zone

is.

You've done a great job with this. It is very validating to read it, and I am awed by what we

caregivers have been through. (and I do not use the word awe or awesome as it is used

today by so many).

Is it ok for my XXXXX to read? They may not want to for the obvious reasons. I know you don't want an apology for it taking me so long to read, I knew it would be heavy, but I want to apologize anyway.

I found a journal of XXXXXX's a few weeks back. He wrote it before diagnosis when he did not understand what was happening. I can not read it yet which is very unlike me. Normally I'd be so curious, so nosy even, but I am (as I'm sure you are) a different person. Forever changed by this and learning to get to know the new (and sometimes very foreign) me.

All the best to you with this - I won't say good luc* (won't even type it). I'll say <u>good courage</u> - I like that better. I don't like the L word anymore, I need the C word. Much love to you - please stay in touch about this and THANK YOU for asking me to participate. (Email feedback from Lilly).

Email 2

Thank you Susan.

I just read it. So many emotions and memories flooded back. Though painful, it was also comforting to remember that I have been through a lot and it is okay for me to still be affected by it. And also to remember that those around me cannot comprehend what may be going on inside me, only those who have lived it can come close to relating.

I think you've captured a lot of great findings and made some interesting synthesis (or is the appropriate word analysis?) of the information. and I look forward to seeing the end result. :). I really hope it will help others in the future. May I share this preliminary summary with my psychotherapist? I haven't seen him in a few months, but he was interested in the project when I had mentioned it to him.

I was told by someone on Monday that I need to let go of the thought of holding on. I wasn't sure what was meant, but after much musing Tuesday night, I think it meant I have to let go

of the loss. I'm not sure how to do this or what I'm doing that is still holding on. I asked the person who said this for clarification. This was the response "It's about getting to a place of acceptance and knowingness that he's with you and you don't have to do anything. You don't have to wear or carry anything of his. You don't have to grieve. "

I know XXXX is with me. It's like I have a foot in the past, a hand reaching for the future, and the rest of me is just here, trying to figure out how to move forward. I've met new people, tried new things, and am "living" more (not just being). I've grown a lot, have become much more aware, and have learned to be more in the moment with people which has made new connections/conversations more meaningful. I'm at the point where I want to quit my job and try something new (though I don't know what yet), move to a smaller place by a lake or ocean (I don't know where yet), and through this, I'm still leaning on the memory of my husband for moral support. Maybe that is the aspect of holding on that I need to let go? I'm just thinking by writing, I'm not expecting an answer :).

Have a great weekend Susan. Wishing you much love, Jasmine

Email 3

Dear Susan,

I finally mustered the courage to read your summary and it was as tough to get through as I thought it would be, but it was also beautiful in its way the same way that a poem crystallizes the emotions. It was fascinating, too, to step back and objectively see some of the dynamics that we have each lived and see the similarities in our reactions (e.g., how we all were gripped with silences).

Then at the end the thought occurred to me: but what about how this experience changes the trajectory of our lives as we try to find some equilibrium in a wake of grief (that may never end)? I wonder if we are stronger or damaged, or both. Perhaps that is outside the scope of this study, but understanding the aftermath would perhaps be helpful to caregivers

as we try to make sense of our tragedies and rebuild our lives. Thank you for your

illuminating and deeply compassionate work. It is much needed. Helen

Appendix S (3.6.1) Email Communication with Professor Arthur Frank

On 2015-02-08, at 7:14 AM, Susan Schlachter

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Dear Dr. Frank,

My name is Susan and I am a doctorate student at City University London in Counselling Psychology.

The reason why I am writing to you is that my research topic is based on your work.

I plan to collect stories from 8 co-researchers who have already posted stories online and invite them (including myself) to re-author their stories. I will then use your Dialogical Narrative Analysis described in your book "Letting stories breathe" to analyse the stories. My thinking is that perhaps this research can in some way contribute to useful support for caregivers of brain tumour patients. I am also wondering who is best placed to listen to these stories.

I would be keen to hear about your opinion and any advice you can give me. I have not received much support from my teachers who think the topic "is too close to home" and therefore not objective research. My reply is that who else can do this research if not me who has the experience of being embedded and embodied in it?

I can imagine that you are a very busy person. Nevertheless it would mean a lot to me to hear from you.

With my very best wishes,

Susan

Susan K-Schlachter
Skype: ▬▬▬▬▬▬▬▬▬▬
Cell: ▬▬▬▬▬▬▬▬▬

to me

Dear Susan,

Sorry for the delay. Or actually not. You raise some complex issues, best not replied to in haste. Foremost, my condolences on your husband's death. When I edited the "Case Stories" series for the (now defunct) journal Second Opinion, the first story was by a man who had that same tumour. He died a couple of years later and for a while I kept in touch with his wife, whom I had met. It's a sad illness, taking people way too young. I'm sorry. I'm particularly interested in your observation that you find it easier to use an online forum than f2f support. That is a topic well worth exploring. I think the design you describe provides a much-needed structure. Students of mine who have studied online support groups have gotten lost in the boundary-less, constantly expanding nature of the online world. Can I ask, are these 8 "co-researchers" people whom you can, at some point, interview f2f? I ask more from practical than theoretical reasons. I can't give a theorised rationale for f2f foundations to online research, but in practice, I'm convinced it has a better chance of producing a finished dissertation. Dialogical narrative analysis can, as you realize, take multiple forms, so I'll leave that for now. At some point I'd be happy to hear about what you plan to do specifically. At this stage, it's probably best left as a variety of possibilities. That brings me to your last issue. I have some sympathy for your teachers' comment about the dangers of work that is too close to home. When I began writing about my own experiences of illness, my situation differed from yours in at least two respects. One is that I began with a personal memoir that was not submitted to academic scrutiny; that resulted in At the Will of the Body (1991, still chugging along in print). Thus, I already had that non-academic outlet for what I wanted/needed to express as my own unfinished business from being ill. Second, I was already in early/mid career, and I maintained a complementary academic publishing track (sociology of the body, and some contemporary theory articles) while I was developing my illness writing. The eventual style of The Wounded Storyteller had about five years of writing and publishing behind it, before I began that manuscript. In other words, I practiced.Please do keep in touch. I'll look forward to hearing about your progress and eventually seeing your work.

best wishes,
Arthur Frank

Appendix T (3.4) Excerpt Ethical Decision-Making and Internet research

EXCERPT FROM:

Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)

AUTHORS Annette Markham, Umea University, Sweden & Loyola University, Chicago Elizabeth Buchanan, University of Wisconsin-Stout, USA

Key guiding principles

We find the following principles to be fundamental to an ethical approach to internet research:

1. The greater the vulnerability of the community / author / participant, the greater the obligation of the researcher to protect the community / author / participant.

2. Because 'harm' is defined contextually, ethical principles are more likely to be understood inductively rather than applied universally. That is, rather than one-size-fits-all pronouncements, ethical decision-making is best approached through the application of practical judgment attentive to the specific context (what Aristotle identified as phronesis.

3. Because all digital information at some point involves individual persons, consideration of principles related to research on human subjects may be necessary even if it is not immediately apparent how and where persons are involved in the research data.

4. When making ethical decisions, researchers must balance the rights of subjects (as authors, as research participants, as people) with the social benefits of research and researchers' rights to conduct research. In different contexts, the rights of subjects may outweigh the benefits of research.

5. Ethical Decision-Making and Internet Research: Recommendations from the AOIR Ethics Committee Approved by the Ethics Working Committee, 08/2012. Endorsed by the AOIR Executive Committee, 09/2012. Approved by the AOIR general membership, 12/2012. This work is licensed under a Creative Commons Attribution 4.0 International License. Ethical issues may arise and need to be addressed during all steps of the research process, from planning, research conduct, publication, and dissemination. Ethical decision-making is a deliberative process, and researchers should consult as many people and resources as possible in this process, including fellow researchers, people participating in or familiar with contexts/sites being studied, research review boards, ethics guidelines, published scholarship (within one's discipline but also in other disciplines), and, where applicable, legal precedent.

Part 2: Case Study

In Limbo: An Integrative Case Study

The Professional Practice Component of this thesis has been

removed for confidentiality purposes.

It can be consulted by Psychology researchers on application at

the Library of City, University of London.

Part 3: Publishable Paper

Location of Self