# From Personal to Professional:

# An Autoethnographic Study of my Experience with Breast Cancer

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### **Candidate Declaration**

I, Lucinda Theresa Johns, declare that this thesis entitled: From Personal to Professional: An Autoethnographic Study of My Experience with Breast Cancer represents my own work and is submitted to fulfil the requirements of the degree of Doctor of Philosophy at the University of KwaZulu-Natal, Howard College Campus, Durban. The contribution of any supervisors and others to the research and to the thesis was consistent with normal supervisory practice. I confirm that no part of this thesis has been submitted for publication in advance of its submission for examination. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma.

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#### **Abstract**

My breast cancer experience facilitated the exploration of my intersectional identities within an autoethnographic framework. I contextually reflected on my personal and professional identities within the interactional lens of silence and vulnerability. The qualitative methodology of autoethnography allowed me to use autobiographical self-reflective data collection that included self-narrative, poetry, photographs, presentation, intersecting academic and community spaces. The data collection informed the analytical intersecting chapters that reflect the research question and the associated three objectives: (1) to explore the transformative nuances of my breast cancer in relation to my intersecting identities, (2) examine how my profession as an academic and psychologist had an influence on meaningmaking of my illness and healing and (3) investigate the contextual contributions of interconnectivity within communities. The concluding chapter reasserts the intersecting matrix of my identities as I navigated through my breast cancer experience. This elaborate autoethnographic process ultimately contributes to existing knowledge and the national narrative of breast cancer within the South African context.

Key Terms: Autoethnography; Breast Cancer; Identities; Intersectional Identities;

Intersectionality; Invisibility; Journaling; Mastectomy; Poetry; Psychology; Self-

Narratives; Silence; Spirituality; Transformational Healing; Visibility; Vulnerability.

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# **Chapter One**

## **Landscaping My Breast Cancer Experience**

This introductory chapter provides the relevant background to my lived experiences as a professional woman of colour who was diagnosed with breast cancer at 32 years of age. A key aspect I explore is around the complexities of my "Coloured" identity and the history of this categorisation, especially within a South African context. I present my views of how my breast cancer experience facilitated the journey into self and the understanding of my intersecting identities. To present a coherent study, I prioritised the organic evolution of the chapters but was cognisant not to distract from the essential content required in a PhD thesis. It therefore became apparent that a literature review did not need to appear discretely as a chapter on its own; instead, it is embedded across all chapters, inclusive of this chapter. My decision was supported by Tuura's (2012) autoethnographic PhD study, which did not include a distinct literature review chapter. I therefore contextually framed pertinent international, African, and South African research and literature on breast cancer and the illness experience. Thereafter, I provide an explanation of how I navigated the diverse opportunities and challenges to locate my study within an autoethnographic framework. Subsequently, I present my justification for adopting autoethnography as an appropriate methodological orientation to meet the objectives of my study. I then outline the significance of the study, followed by the research question and objectives of the study. The chapter concludes with the structure of the thesis.

### **My Breast Cancer Story**

At the age of 32, I detected a painless lump and discharge from my left breast when conducting my routine self-breast examination that necessitated a visit to my General Practitioner. A sample of the discharge fluid was taken and the results were found negative for cancer. A few weeks later, during my annual gynaecological visit, I briefly mentioned the discharge and was immediately referred to a specialist surgeon who requested a similar sample of the discharge. Once again, the results indicated no cancer cells. An ultrasound was then suggested and no abnormal tissue was detected. Subsequently, a Doppler ultrasound was scheduled to detect abnormal blood flow and to verify the reason for the discharge. It was during this examination that a radiologist suggested a mammogram. The mammogram was conducted and the results were duly forwarded to my surgeon who scheduled surgery for a lumpectomy.

A week later, while hospitalised and during the pre-surgery procedure, my surgeon requested a second opinion from an oncologist. The male hospital resident oncologist after reviewing my scans suggested a mastectomy. My reaction to his recommendation was one of confusion and disbelief. My surgeon recognised my discomfort and doubt. He held my hand and suggested continuing with the lumpectomy that I was initially scheduled for on that day. Post-surgery of my lumpectomy, my surgeon informed me that the results of the frozen sections indicated Ductal-Carcinoma in-Situ (DCIS) and therefore I required a mastectomy. Upon verification of the diagnosis, I requested to be discharged and spent a few days at my parent's home. It was during this stay that I asked my mother to take photographs of the surgery. Two days after the first surgery, the mastectomy was scheduled and completed on 06 September 2004. After two days, I requested a discharge and thereafter had my medical

records transferred to another oncology centre where my chosen oncologist was a resident.

This was an exercise in prioritising self-care and self-advocacy. Once again, I had photographs taken to record my mastectomy experience.

During my initial visit to my oncologist, it was suggested that I undergo counselling. Evidently, my oncologist recognised the value of allied health disciplines as integral for holistic patient care, which as a psychologist I appreciated. The medical treatment included hormone therapy and Tamoxifen was prescribed. Chemotherapy was not necessary. During this phase, I was confronted with a myriad of questions and although I read-up extensively on my diagnosis and treatment options, dialoguing with former patients of my oncologist afforded me a more intricate understanding that facilitated my decision-making on appropriate treatment. Psychologically, I began to interrogate my thoughts and feelings, yet within this processing phase I decided only to share with my closest supporters.

On 13 October 2004, my 33<sup>rd</sup> birthday, a radiation planning session was scheduled. I invited my mother and a friend to accompany me and to share in a celebratory birthday lunch thereafter. For a period of five weeks, I attended all radiation sessions on my own in the morning and resumed work for about two to three hours each day. This structured routine provided comfort, as I was able to connect with a few colleagues and have some time alone in my office away from home. I also required Zoladex that was an injectable hormone treatment. During this phase of treatment, I invited my mother to accompany me to one of the trimonthly sessions that unfortunately proved to be too emotionally challenging for her. It was after her reaction of anxiety and discomfort that I decided to continue attending treatment on my own.

During my treatment, I became more introspective and self-reflective and captured most of my thoughts in my journal. Moreover, I commenced with an extensive research of different treatment modalities and the effects of prescription drugs. Despite being informed to continue with Tamoxifen for five years, after a discussion with my oncologist, I elected to discontinue the prescription eighteen months into my treatment. The most pertinent reasons that informed my decision were the side effects and ultimately me assuming ownership of my holistic health.

One of the most vexing developmental aspects was identity and the labelling of self as a breast cancer patient during the trajectory of my journey. When my treatment concluded, I reflected on the following questions: Am I a breast cancer survivor? Am I comfortable with this label? Am I a woman who has had breast cancer? Will this label always belong to me? Do I describe myself as cancer-free or in remission? Similarly, Rees (2018, p. 316) in her study acknowledged her respondents' posing similar questions as they "did not fit neatly into the categories of 'healthy' or 'ill', 'cancer-free' or 'cancer patient'". Equally important were the questions generated during my treatment which I explore in the analytical chapters.

Like Lorde (1997), I viewed the intersectionality of my identities to include the emotional, psychological, physical, and socio-cultural aspects. Moreover, the words of Holman Jones (2018) resonated with me:

Valuing intersectional identities, and the particularities and uncertainties of experience asks us to attend to how we are connected through our efforts to mark time, map relational geographies, and name identities (p. 9).

When I started questioning my identity and mapping my relational spaces and connections, it raised other questions such as: How will breast cancer influence my future personal and professional relationships? As a psychologist and academic, how will breast cancer shape my professional practice? These questions are addressed and elaborated upon in the analytical chapters below. The questions of my identity are inextricably linked to my social and cultural experience: Am I a 'Coloured' woman? What does 'Coloured' mean to me? These questions are linked to my culture and 'Coloured' identity that I believe needs to be contextualised.

# Contextualising Complexity the Intersecting Self: Connecting Culture and the Coloured Identity

The definition of 'Coloured' has been historically troubled. Anderson (2009, p. 45) expands on the variedness of the term 'Coloured' and suggests that it is "heterogeneous and intricately intertwined with the social location". Holtzman (2018) contributes to the debate on the definition of colouredness and specifically declares it a "fallacious racial category that does not exist as an authentic construct" (p. 528). He further suggests that it "should cease to be used as a defining term because of its derogatory and defamatory colonial and apartheid connotations". According to Erasmus (2001, p. 24), it is fraught with "entanglements with whiteness, Africanness, East Indianness in the process of creating new cultural forms, practices and identities which do not have to be coherent and/or complete". I often reflected on this and my own sense of belonging. I wondered if this inherent sense of entanglement had benefits or created blurred boundaries such as class disparities, politics of the deferring colour of colouredness and the accessibility to educational opportunities. Pertinent to

Erasmus's statement, the different facets of entanglements create multiple and often contradictory lived experiences.

When I reflect on such entanglements, my identity as 'other Coloured' captured on my birth certificate, further confused me as a child. I remember engaging with my parents, Rosemary and Aubrey Johns, about their own identities. It was revealed that my mother was classified a 'Cape Coloured', yet not born in Cape Town, a predominantly 'Coloured' community. My father however was classified a 'St Helena Coloured'. Nevertheless, both were born in Durban, KwaZulu-Natal, where they continue to reside. The history of the categorisation of 'Coloured' and its historical development is summarised by Martin (2000) where he acknowledges the list of the subgroups, "Cape Coloured, Malay, Griqua, Chinese, Indians, other Asians, other Coloureds" (p. 105). Initially, these categorisations created some level of unsettlement of my own identity as I identified first as South African and hence the racial category became secondary.

Isaacs-Martin (2014, p. 55) is of the opinion that two thoughts in South Africa dominate the debate: First, "the Coloured population does not possess an ethnic identity". Second, in post-apartheid, "the group does not embrace the collective national identity". I conceded and accepted the complexity and racial contestation in South Africa that I had to contextually navigate around throughout my life. Erasmus (2001) also acknowledges the complexities of 'Colouredness' and writes extensively on re-imaging Coloured identities in post-apartheid South Africa. He draws attention to the powerful emotional burdens of the Coloured identity that include, "feelings of anger, guilt, betrayal, shame, pain, and humiliation" (p. 26). Shame is also acknowledged by Adhikari (2006, p. 468) as a concept of "attached to racial hybridity". During my childhood, I became acutely aware of my racial

classification as 'other Coloured' and the value of being fair-skinned as compared to someone who had a darker skin tone. This often became a contested issue especially with one of my cousins who felt alienated and confused during her childhood years because of her darker skin tone. This identity sensitively brought with it a level of uncertainty, invisibility, and unsettledness, resulting in my voice as a child often being silenced in some spaces and contextually questioning where I could exercise my right to be vocal. In addition, in some spaces, being a minority, I was often judged for asserting thoughts that were not popular with the majority.

Historically in South Africa, the Group Areas Act No. 41 of 1950 segregated individuals demarcated for a designated population group into specific geographic areas. While the Western Cape (WC) was designated a 'Coloured' homeland, prime farming land, and urban areas were nevertheless reserved for European-Whites. Coloured people also populated other provinces of South Africa, such as KwaZulu-Natal (KZN), where I am currently a resident. In terms of the Group Areas Act, the geographical areas of Wentworth, Sydenham, Greenwood Park, Newlands East, and Red Hill were each identified as predominately for Coloured settlement. Coloureds in KZN are noted by Anderson (2009, p. 45) as, "the specific cultural context of Coloured determines and defines certain character traits and behaviours, and the way in which space and identity are mutually constitutive provides a backdrop for understanding the distinctiveness". Extensive research was conducted both in the WC and KZN. In Wentworth, studies conducted by Chari (2009), Desai (2018), Palmer (2015) and Palmer (2016) sought to explore the various complexities and distinctives pertaining to the Coloured community.

In Wentworth, where I resided until the age of 30, an added complexity was captured by Chari (2009) who suggests it seems to be "different from other places, it's Coloureds different from other populations, and its migrant workers different from other South African migrants" (p.529). The difference related to geography, in other words, spatial and structural location. Wentworth is described as a residential-industrial area located in the South Durban industrial basin. It is a community that co-exists with industries that intersperse residential spaces. This co-existence has often been contested, particularly by environmentalists. Chari (2009) and Desai (2018) have also questioned how oil refineries in the community have impacted on the health, social space, and quality of life of its residents. It was within this community that I witnessed activism and advocacy that facilitated the development of my own political and social awareness.

Desai (2018, p. 379) has aptly observed that the "coloureds are an overlooked minority in post-apartheid South Africa". This is a thought that often resonates with me, particularly as I interact in different spaces. Post-apartheid, an experience of in-between-ness has often been expressed by Coloured people who felt "caught between the assertiveness of black African empowerment and white minority privilege" (Desai, 2018, p. 378). I have often felt a similar sense of in-between-ness when asserting my rights as a South African citizen, while simultaneously being aware of the boundaries that constrained me, all of which ultimately will influence my future.

A related factor is that of educational space. During the apartheid era, as documented by Anderson (2009), the education space of disadvantaged communities was riddled with challenges of inequity and inaccessibility. The educational spaces in Wentworth that I inhabited as a child were similarly constrained. Despite these circumstances, my

commitment was supported by my parents as I strived for upward mobility when I contemplated tertiary education and my career options. As with Makhanya's (2016) autoethnographic reflections of her own mother's value for education, my parents taught me to value learning spaces.

Even during my adolescence, living in a volatile community of Wentworth and witnessing protests and boycotts frequently caused me to reflect and engage with my father on his own political views on social justice and activism. These often-lengthy discussions contributed to my own comfortableness on how to respectfully engage with authority. My mother's focus was on gender activism, specifically from her lived experiences, inculcating within me an analogous ethos early in my adolescent years. As an only child, I appreciated her constant engagement of promoting a gender lens to my thoughts, which ultimately shaped my future choices. I often witnessed the interactions between both my parents on not being confined to stereotypical gender normative roles, which in retrospect contributed substantially to my future development as a woman of colour as I interacted with my intersecting identities. One of these became my diagnosis of breast cancer. In addition, I am indebted to my parents for inculcating within me a community-consciousness as a child, which became integral to all my community activity.

# **Breast Cancer: Facilitating the Intersecting of My Identities**

Encountering physical obstacles on life's many diverse journeys gives cancer patients a wonderful way to think of cancer not just as the end point of life, but as just another obstacle that is temporarily blocking one's plans and goals in life and that can be dealt

with and overcome to continue living (i.e. continue life's journey) (Gibbs & Franks, 2002, p. 155).

Much like Gibbs and Franks (2002), I initially viewed breast cancer as an interruption in my life's journey. Upon deeper introspection and reflection, I realised the value of the breast cancer journey could not be underestimated. In a similar way, Reissman (2008, p 55) acknowledged the value of the reflective process and conceded that chronic illness can lead to a "cognitive reorganisation-meaning-making" process. Breast cancer became that catalyst to evaluate my life which is not construed as merely "mindless triumphalism" which DeShazer (2016, p. 123) emphasised.

My individual experience was noted in a series of books compiled and edited by the C-Sisters and relevant medical professionals entitled, *A Resource Guide for Breast Cancer in KwaZulu-Natal* (2010), *A Resource Guide for Breast Cancer in South Africa* (2011), and the isiZulu version, *Umhlahlandlela mayelana nomdlavuza webele KwaZulu-Natali* (2011) which are further elaborated upon in chapter five. The mandate of the C-Sisters was "to provide up-to-date information and personal tips for breast cancer patients and survivors, and to create networks outside of the traditional structures for dealing with cancer and its farreaching effects" (de la Rouvière et al., 2010, About C-Sisters, para 2). This series of books included personal stories that capture diverse pathways and experiences at different stages of the breast cancer journey.

The study by Clarke et al. (2016, p. 396) suggests that, "relationships formed out of mutual experiences of understanding" positively contributes to emotional expression and mental health. It could be argued that the group is a therapeutic space to safely share one's vulnerabilities, hurt, healing, and empathy. In addition, I was exposed to various key

stakeholders such as medical and other healthcare professionals, carers, communities, and women diagnosed with breast cancer who recognised the mutual benefits of sharing personal stories and relevant information. The logistics of compiling the books afforded me an insightful opportunity of my subjective contribution to the breast cancer communities.

During this period, there was a paucity of information and comprehensive engagement. In contradistinction, the present day offers electronic media with instantaneous sites of medical information, health, and psychological support that make breast cancer far more visible.

Furthermore, the books became a forum to facilitate support through the shared stories of marginalised women in their different contexts and thereby a catalyst in the engagement with those living beyond the borders of KZN. My personal contribution to the C-Sister's books was my own personal story that led to my interest in exploring my intersecting identities through my healing journey.

### **Lucinda's Story: My Healing Journey**

At 32-years-of-age, a diagnosis of breast cancer challenged me to reflect on my purpose in life. The night before the scheduled mastectomy of my left breast, I asked my mother to take a few photographs of me. I needed to graphically document my physical changes to say goodbye to a part of me and begin the journey of acceptance. My personal and professional insight into coping with trauma played a major role in managing and understanding my emotional reactions during surgery, radiation, and adjuvant treatment.

Emotional chaos and confusion were part of the process of reframing, redefining, and accepting the painful and pleasant parts of who I am. There are a few personal issues that still need to be addressed and this is all right. Perfection can be an overrated illusion. It is the scars and the imperfect nuances that can add meaning and value to life. There are

moments when I look at my own reflection in the mirror and think: "everything is as it should be".

Your first relationship is with YOURSELF and you have the privilege to experience YOURSELF with others. Take good care of you (Johns, 2010, p. 55).

This extract is evidence of how my reflection of my illness became the route towards my PhD and specifically to autoethnography that I discuss later in this chapter. In accord with Foster et al. (2005. p. 4), I initially questioned that, "it had not even occurred to me to explore something as personal as my own experience" for my PhD. My extensive reading particularly on breast cancer from a global and local context contributed to my decision to definitively pursue my experiences as a PhD study. Beyond breast cancer literature, I duly engaged with literature specifically from a lived experience and autoethnographic perspective. The section that follows presents this body of research.

### Framing Breast Cancer: Reviewing the Illness and Pertinent Scholarly Research

I was cognisant that there exists exhaustive literature on cancer generally and on breast cancer specifically. It became evident that in the lived experience of medico-psychosocial factors there exists limited personal, self-reflective research on cancer, more specifically breast cancer. I chose therefore to only include those pertinent and relatable aspects that have direct application to the objectives of this study. These references and others are included throughout the thesis. This section is devoted to some essential international, African, and South African literature. The predominant themes presented focus on a systematic review of women's lived experiences of breast cancer, the interactional complexities of the illness, and women's experiences of dating after breast cancer.

# Relevant International Studies on Breast Cancer

Statistically, breast cancer is the most common cancer in women worldwide. The GLOBOCAN database captures the incidence, mortality, and prevalence of 36 cancers in 185 countries (Bray et al., 2018; The Global Cancer Observatory, 2019a). For 2018, the world statistic for both sexes depicts 2 088 849 (12.3%) of newly diagnosed cases of breast cancer with the number of deaths reported as 626 679 (6.6%). Much of the research has been confined to systematic reviews that offer a comprehensive evaluation of breast cancer. Amongst others, these include the most recent studies as discussed below.

Smit et al. (2019) conducted a systematic review of qualitative research internationally, which was inclusive of South Africa, where the study emphasises women's lived experiences and stories of breast cancer across the illness trajectory. Interestingly, personal narrative and autoethnographic studies were included due to the "richness of textual narrative" even though these studies were perceived as "less rigorous' in nature" (p. 234). Campbell-Enns and Woodgate (2017, p. 1719) rightfully acknowledge the "need for original qualitative psychosocial research focusing on Asian, Central and South America, and African populations". These authors systematically reviewed 24 qualitative studies of women with breast cancer diagnosis and offered a concise summary of psychosocial interventions across the lifespan of women with breast cancer.

A systematic review by Yoo et al. (2014) on breast cancer and coping amongst North American women of colour concluded that they preferred religious and spiritual coping strategies. Furthermore, they emphasise the lack of understanding by healthcare professionals of the socio-cultural context of their patients. All three systematic reviews capture the complexity and scientific rigour of autoethnography, as well as the psychosocial

and cultural factors of the breast cancer experience and spirituality. These are further cited more comprehensively in the appropriate chapters that follow.

Froude et al. (2017) explored the breast cancer illness experience of women diagnosed between 18-39 years-of-age and acknowledged the significant influence the stage of development has on the breast cancer experience. The findings highlighted a few complexities women had to negotiate in terms of work commitments, financial responsibilities, interpersonal relationships, social and medical support, physical changes, and psychological reactions along the illness trajectory. Reflectively, these consequential concerns also shaped my illness experience as I navigated around my financial status, work commitment and who occupied my personal space.

Shaw et al. (2016) explored an interesting component of relationships that recognised the limited number of studies that investigate women's experiences of dating after breast cancer. Their study identified seven themes: "the decision to consider dating; ability and desire to enter into a new romantic relationship; cancer-related disclosure; intimacy and sexuality; body image and dating; changing values in relationships; and learning to trust a new partner" (Shaw et al., 2016, p. 323). These seven themes again became reflective of my own intersecting identities, both personally and professionally. My own dating experience following my diagnosis is pertinent here. Interestingly, Freidus (2017) also considered the partner perspective in her article entitled, "Experiences of men who commit to romantic relationships with younger breast cancer survivors: A qualitative study". The article offers the perspective of the male partner in the breast cancer experience. My relationship with my partner of ten years commenced post-diagnosis. He is a practising veterinarian of approximately twenty-six years standing and a former Director of the Biomedical Resource

Unit at the University of KwaZulu-Natal (UKZN). With his permission, using autoethnographic reflection, I share our intersectional experience.

### Studies on Breast Cancer Experiences in Africa

Pertinent research conducted in Africa adds a nuanced perspective to the breast cancer experience. Breast cancer in Africa, "remains the leading cause of death amongst women in Africa" (Cumber et al., 2017, p. 35) after that of cervical cancer (Trimble, 2017).

Alarmingly, Mohammed and Harford (2014) have shown a lack of relevant breast cancer research in Africa. While international research focused contextually on local health and research priorities, most African studies reviewed concentrated mainly on: (1) management of breast cancer in Africa; (2) knowledge, medical experience, and attitudes, and (3) contextual socio-cultural factors. These clearly reflect the African focus.

An overview of health systems and health administrative resources for cancer care in Africa by Stefan (2015, p. 32) found that a "massive undersupply of cancer care services exists on the continent". The lack of relevant resources, including, oncology centres, palliative care, oncology surgeons, availability of radiography and chemotherapy, access to knowledge about breast cancer and financial support was of concern. Maree and Mulonda (2015, p. 28) reported that women present with advanced stages of the illness because, "women lacked knowledge of breast cancer". They nevertheless found that the participants blamed themselves for allowing the breast cancer to progress to an advanced stage. Akuoko et al. (2017) reviewed contributory factors to the delay in presentation and diagnosis and revealed the lack of knowledge about early detection management, poor understanding of breast cancer process and treatment, as well as other socio-cultural factors. Other researchers have validated the concern of delayed diagnosis and treatment such as Brinton et al. (2017),

Trimble (2017) and Tetteh (2017) which has contributed to the high rates of mortality in sub-Saharan Africa (SSA). As an advocate for early detection, I too continue to support such a contention, particularly as a South African.

Evidently, even Stefan's (2015) overview of control resources to improve the prevention and management of malignant disease on the African continent, recognised different facets of support, together with a higher concentration on the medical model. However, what is abundantly evident is the absence of the lived experiences of patients and their reflective accounts of the breast cancer journey. The patient is a focal part of the medical team and should always distinctively have a voice, something that I recognise from my own experience. Within the holistic healthcare system, the personal reflections and experiences of patients cannot be underutilised or underdetermined.

An associated aspect according to Adeloye et al. (2018) is the paucity of data, the inconsistency of collating data and the statistical quality provided by existing cancer registries in Africa is problematic. Studies conducted by Cumber et al. (2017) and Vanderpuyeet et al. (2017) note a lack of cancer registries in SSA countries, hence the burden of the disease remains unquantified. A systemic review by Adeloye et al. (2018) estimating the incidence of breast cancer in Africa, suggests there is an increase of breast cancer. However, the "inconsistency in data collection" and "paucity of data" are of concern (Adeloye et al., 2018, p. 1). If left unattended, it will be impossible to elicit an accurate profile of breast cancer in a specific country, which in turn will have serious implications for the prevention and treatment of malignant disease. This theme is emphasised in several other African studies on breast cancer.

Another significant factor is that of age. As countries in Africa are home to some of the world's youngest populations, the presentation of breast cancer would be "undeniably younger" (Mohammed & Harford, 2014, p. e1001721). Interestingly, Tetteh (2017) notes the average age in which breast cancer is diagnosed in SSA is ten years younger than that of Western countries. Supporting this contention, the retrospective analysis of medical records of women 35 years-of-age and younger by Darwish et al. (2017, p. 1) found breast cancer to be "aggressive at the time of diagnosis". I too was diagnosed with breast cancer at the age of 32 years. However, the study by Kentelhardt and Frie (2016, p. e875) called to attention the ongoing debate as to "whether the advanced stages are due to a unique aggressive biology of the disease or a delay in presentation". In seeking to understand the biology of the disease process in younger women, the study by Darwish et al. (2017) recommended that further studies contribute to the medical management of breast cancer for younger women. The study also noted the need for breast cancer education and screening campaigns to address the limited awareness of the illness. Added to this is the financial burden of surgery as compared to other forms of treatment, which is also acknowledged by Tetteh (2017). The pervasive thoughts that emanate from these researchers have had implications on my own engagement in awareness campaigns in different spaces that I detail in chapters three, four and five of this study.

According to Tetteh (2017, p. 319), sociocultural assumptions shape the "management of women's health including breast cancer in SSA". Despite the endeavours in breast cancer treatment in West African countries such as Ghana, for scholars such as Tetteh (2017, p. 330), "it does not reflect women's experiences of the disease". I am cognisant of this deficit in Africa that exists in knowledge building and scholarship specifically on breast

cancer and the lived experience of women to address women's global health. Tetteh (2017) acknowledges that in SSA, breast cancer is not viewed as a medical disease only, but also within the socio-cultural context, which includes the "prevailing practices of cultural censoring, norming and policing of the female body" (p. 317). This finding is also evident within the South African context that is further explored in my study.

## South African Studies on Breast Cancer Experiences

The South African statistical landscape depicts the profile of cancer and breast cancer in the country. Among the reported cases of cancer in South Africa, the GLOBOCAN 2018 Factsheet for South Africa (The Global Cancer Observatory, 2019b) recorded a total of 107 467 for both sexes and all ages, of which 14 097 (13.1%) were breast cancer. Clearly, as Joffe et al. (2018); Rayne et al. (2018) and Trupe et al. (2017) can concur, breast cancer in South Africa has become a significant public health crisis. Moodley et al. (2018, p. 1) describe it as the "commonest cancer". Accordingly, in 2017, the South African Department of Health (2017) published its five-year strategic policy document, *National cancer strategic framework for South Africa 2017-2022*, to guide regional breast cancer development. Presently, Rayne et al. (2019) maintain that "there is no screening programme in South Africa, and access to reliable high-quality breast cancer care is geographically varied, with cancer centres concentrated in only the most developed metropolitan centres" (p. 182).

The South African National Cancer Registry (NCR) is a division of the National Health Laboratory Service in South Africa. The NCR is a body that, "collates and analyses cancer cases diagnosed in pathology laboratories (both public and private) nationwide and reports annual cancer incidence rates stratified by sex, age and population groups" (National Cancer Registry, Cancer Statistics, para. 1). According to the NCR, *Cancer in South Africa* 

2014 Full Report, there is an estimated risk of 1 in 27 South African women being diagnosed with the illness. Beyond 2014, the NCR has encountered difficulties in updating the statistics. In past years, submitting data was voluntary; however, due to new compulsory reporting and documenting legislation by the Department of Health (2017) "issuing of regulation 380 of the National Health Act of 2003 in 2011", health care facilities and pathology laboratories are compelled to submit information (South African National Department of Health, 2017, p. 7). The accuracy of the statistics for South Africa may be underestimated as the results are based on pathology reports rather than population reports. Accordingly, Venter et al. (2012) have acknowledged a three-year gap in collating and publishing the statistics. In addition, the South African National Department of Health, National cancer strategic framework for South Africa 2017–2022 (2017, p. 10) notes the NCR report is "largely under-reported due to a lack of population-based data/registry" and is "currently not up to date". The South African National Health Minister released this updated policy in 2017, outlining the Government's commitment in the "implementation of interdependent strategies" as follows: "(i) increasing early recognition of breast cancer, (ii) treating breast cancer more effectively, and (iii) providing timely treatment and palliative care for invasive cancer" (South African National Department of Health, 2017, p. 4). The most recent and available demographical profile as captured in terms of race by the Cancer Association of South Africa (CANSA) published on 13 March 2020 revealed statistics for 2014 as follows: Asian (465); Black (3225), Coloured (1169) and White (3370). These statistics substantiate and are reflective of the intersecting socio-cultural, economic concerns detailed by the National Department of Health. The section that follows focuses on the intersecting contextual identities of South African women's reflective experiences.

An invaluable South African cultural perspective is offered by Lourens (2013) who conducted a study in the Eastern Cape Province. The study explored three Xhosa patients' breast cancer lived experience and noted that "cultural beliefs influence patients' perceptions of health and illness" (Lourens, 2013, p. 103). The participants perceived cancer, "as a curse and an illness of the White population" (p. 113). This in turn highlighted the cultural belief that illness is a punishment from the ancestors and therefore requires cultural intervention by traditional healers to perform certain rituals to appease the ancestors. Another significant factor was the language disparity between patient and practitioner, which influenced the communication especially of medical terminology. Another relevant aspect was the emotional distress attached to the breast cancer experience, which seems to have been neglected in other African studies. This study reemphasised the importance of emotionality as women navigate through their breast cancer journey.

Additionally, a comprehensive study by Edwards and Greeff (2018) explored the emotional challenges of cancer experiences in South Africa. The study adopted an action research photovoice methodology and captured the experiences of 316 participants which included cancer patients and family members as well as oncology support and medical staff. The study findings revealed amongst others the need to include psychosocial oncology services in the country. It further suggested best practice standards of care, patient empowerment and the prioritising of training and support for oncology staff within the healthcare environment. Venter et al. (2012) in their study of cancer survivorship and management in the South African context observed there were few specialists who exclusively focused on psycho-oncology in assessing patient needs and psychological care. This aspect is elaborated further in the analytic chapters of this study.

A study conducted regionally in KZN, the province of my residence, revealed that women with breast cancer often presented in advanced stages specifically in rural areas (Čačala & Gilart, 2017). The study concluded that such patients often had minimal access to healthcare resources and services such as awareness and promoting an understanding of breast cancer. They further recommended the introduction of pictorial information at local clinics. The burgeoning disparity between the private-public healthcare sectors for most of the South African population was noted by Venter et al. (2012) and Dickens et al. (2016). Early intervention was a concomitant aspect supported by Cumber et al. (2017), who also noted that in SSA, most cancers were only detected in advanced stages. I was thus keenly aware that breast cancer was not synonymous with death. Early detection of Ductal Carcinoma in situ (DCIS) was undoubtedly advantageous to me and clearly, allowed for appropriate medical intervention.

Another recent regional study conducted by Moodley et al. (2018, p. 7) was among the first in the country to quantify time intervals and "associated factors between symptom detection and breast cancer treatment". This cross-sectional study of 213 women was conducted from May 2015 and May 2016 at a tertiary hospital in the WC and identified intervention targets in improving diagnosis timeframes. Contextually, they recommended the following:

Address women's limited knowledge of breast cancer risk factors and symptoms; promote breast awareness; target older women; address denial; encourage prompt help-seeking behaviour and educate women not to wait for a lump to get bigger or be painful before seeking care (Moodley et al. 2018, p. 10).

This study reflects the interactional dynamics that exist in the South African context particularly around awareness of how soon detection occurs and treatment ensues which is not peculiar to South Africa and which has also been cited in other associated African studies. Venter et al. (2012, p. 461) also acknowledges the "racially-based lack of access to adequate medical care" in South Africa and further notes the rural and urban disparities that exist in the cancer care continuum.

An innovative, yet underutilised research modality in breast cancer is that of autoethnography (Richards, 2008). This form of qualitative research with its focus on self-reflection and writing became particularly useful for my PhD thesis. As Frank (2000, p. 135) acknowledges, exploring illness through autobiographical work becomes a "privileged means of repair". Research conducted globally stresses the importance of early detection and its consequences in the lived experiences of women. In SSA and South Africa, as developing world countries, qualitative research particularly emphasises the contextual socio-cultural and economic challenges for women with breast cancer to navigate around.

# **Contextualising the Choice of Autoethnography**

The meaning of autoethnography may differ amongst researchers and theorists alike, "having grown out of various disciplines" (Chang, 2008, p. 48). The "divergent evolution" (Chang, 2008, p. 48) is also reflective of autoethnographers varying emphasis, "on the research process (graphy), on culture (ethno), and on self (auto)" (Ellis & Bochner, 2000, p. 740). Munro (2011) elaborates on this and specifically identifies the, "'I' that refers to the 'designer', the ethno alludes to the 'design practice' that is the reflective process and the 'graphy' presents the documentation of 'raw data' to support 'evidence of new knowledge'" (p. 156).

On the other hand, Chang (2008) holds that autoethnography can be "ethnographic in its methodological orientation, cultural in its interpretative orientation and autobiographical in its content orientation" (p. 48). In addition, Sealy (2012, p. 38) explains the research process where, "the researcher shares personal stories that relate to the broader cultural context". Furthermore, Pace (2012) emphasises that autoethnography allows the researcher to "reflexively explore their personal experiences and their interaction with others as a way of achieving wider cultural, political or social understanding" (p. 2). Notably, several authors such as Bishop and Shepherd (2011); Bochner (2014), Chang (2008); Cunningham and Carmichael (2018); Ellis and Bochner (1996), Ellis and Adams (2014), have written extensively on the importance of reflexivity and reflective practice within an autoethnographic research.

Given the above descriptions of autoethnography, initially, I was confronted by numerous questions on the accessibility of an autoethnographic PhD in the psychological academic community. One of the pertinent questions raised was the appropriateness of disclosure regarding my breast cancer story, especially as a psychologist. I acknowledged the comment by Adams et al. (2015) that "doing autoethnography can create personal and professional risks and vulnerabilities" (p. 63), I was conscious of the blurring of the boundaries that had the potential to make me susceptible professionally and uncomfortable to write and to read and constantly be aware of any ethical implications. For Ngunjiri et al. (2010) "vulnerability is part of what makes reading autoethnographic works so compelling, as researchers expose their pains, hurt, loss, grief, heartbreaks, and other emotions" (p. 8). By choosing to share vulnerable stories, autoethnographers expose themselves to criticisms with the aim to acknowledge the "vulnerabilities, questions, injustices, silencing, and shame

that others might endure" (Adams et al., 2015, p. 39). I was reminded of the statement by Ellis (1999, p. 675) that "if you're not willing to become a vulnerable observer, then maybe you ought to reconsider doing autoethnography". I was willing to become vulnerable and reveal personal parts of my life's journey. I was also aware of committing to the credibility of the process to ensure "consistent, honest and transparent reflection" (Mulqueeny & Taylor, 2019, p. 1). The concept of self-disclosure and vulnerability, I interrogate in the analytical chapters that follow, keeping in mind Frambach's (2015) concerns of balancing vulnerability and narcissism.

As a young woman of colour, I was initially challenged to redefine my intersecting personal and professional identities as I navigated through the unchartered landscape of my illness. Prior to the diagnosis, I innately possessed a profound curiosity in exploring my inner self towards expanding my self-awareness that incrementally influenced my professional identity. The selective filtering of knowledge in and between the professional and personal identities was self-motivated and became a habitual and inseparable process of learning. This multi-dynamic and intersectional process amplified the wounded-healer identity within the professional space and hence demonstrated that the private can become the professional. I recognised the breast cancer journey for many other individuals was a unique and deeply personal experience. It was in acknowledging the uniqueness of my own experiences that I began contemplating how my own breast cancer experiences could productively contribute to a PhD study.

By acknowledging my training as a psychologist, my exposure within a multidisciplinary context in mental health and mental illness necessitated reflective practices as being integral to developing professional competency. Such a perspective of questioning, analysing, interpreting, and predicting facilitated a deeper comprehensive understanding of the human condition where transformative healing became an indelible developmental component of my professional practice. Despite possessing considerable professional knowledge about the illness trajectory, my breast cancer experience had a deeply profound influence on my sense of self and self-reflection. Reflectively, I began to have an appreciation of my breast cancer because it troubled and unsettled my thoughts and challenged my beliefs around wellness and well-being.

### The Embeddedness of Reflexivity and Reflection

Central to the autoethnography practice is reflexivity and reflection that were core components that inhabited my differing identities. Muncey (2010, p. 46) defines reflexivity as "the awareness of being aware" while Adams et al. (2015, p. 29) advocate that it is the "turning back on our experiences, identities, and relationships in order to consider how they influence our present work". In this study, reflexivity facilitated the reflective research process as I recognised my intersecting identities which became a "natural consequence of the process" (Cunningham & Carmichael, 2018, p. 56) and like Grant (2010, p. 581) suggests becomes "embeddedness in cultures and cultural symbols". This inward-outward self-exploration process allowed for a deeper holistic meaning of my breast cancer experiences. In agreement, I embraced this process as I made some of my reflections develop into an academic activity (Forber-Pratt, 2015; LaBoskey, 2005).

The value of autoethnographic research practice involves constant questioning while seeking to satisfy my reflective stance, a process which Chang (2008) refers to as "chronicling the past through questions". This translated into several initial reflective

acknowledgements as a researcher-practitioner including amongst others the following pertinent questions:

What do I need to remember? What can I learn from this trauma? What do I do with the information gathered? Who do I speak to? Who do I trust to share with? How would I use personal photographs of my breast cancer in an acceptable manner not only within the PhD endeavour, but generally? How have my personal poems and journal entries together with my visual narratives of my breast cancer experience influenced my reflections on subjectivity and embodied experiences? How are the professional associations that I belong to (e.g. Health Professions Council of South Africa (HPCSA), the Psychological Society of South Africa (PsySSA) actively promote reflection as a research-practitioner? How does my foundational teaching inform my counselling space as I maximise on the researcher-practitioner space? To what extent has my spirituality been infused in my intersecting identities of a psychologist and personal spaces? What role has silence, invisibility/visibility, and vulnerability played in navigating my breast cancer journey? How has my socio-cultural positionality shaped my breast cancer experience? Will my study add to the present academic published works? What new knowledge will my study bring to the academic, professional and cancer community?

These questions assisted in guided the research process by integrating pertinent literature into my autobiographical story and thereby present a comprehensive study. More importantly, these questions promoted a deeper engagement with the literature on breast cancer and the autoethnography research perspective.

### **Autoethnography and Breast Cancer Studies**

There exists a paucity of research dedicated to the researcher being researched, specifically utilising autoethnography within breast cancer studies. Prior to embarking on this study, I extensively reviewed pertinent health policies, guidelines for autoethnography, thesis, and academic studies that cohered the illness component within the autoethnography framework. Ellis (1999) and Ellis and Bochner (2000) promoted the use of autoethnography to explore the breast cancer experience, which further provided the support and justification for adopting autoethnography as an appropriate methodology for this study. This process is popularised in the South African context by a recent study by Mulqueeny and Taylor (2019) who explored the insider/outsider positionality and navigating the process of challenging silence as an HIV+ researcher working in KZN. The study recognised multiple intersecting identities and reflectively examined views on silence, visibility, invisibility, vulnerability, and stigma as these influence the lived illness experience. For me, these aspects resonated with my own methodological and developmental process and synergised with the reflective space, albeit within the HIV environment.

In addition, other South African studies that have considered the meaning making process as significant to the experience of breast cancer. Van der Wiel's ethnographic study (2013a and 2013b) is one of a few that focuses on breast cancer experience in South Africa. Van der Wiel (2013a) adopted an ethnographic approach of participant-observation and interviewed 10 women attending the Helen Joseph Government Hospital in Auckland Park, Johannesburg for breast cancer treatment. The findings contradicted local and global studies on women's perception of mastectomy as distressing due to having only one breast. The study provided invaluable insights into participants' emphasis on survival and a healthy body

rather than conforming to the gendered appearance of having two breasts by undergoing breast reconstructive surgery. This study was particularly pertinent to my own experience of the normativity of a mastectomy and breast reconstruction.

The academic literature about breast cancer in South Africa predominately focuses on medical and scientific procedures and treatment. The research that investigates the social and cultural dynamics of the disease mainly adopts quantitative approaches and are "mostly written by medical professionals" (van der Wiel, 2013b, p. 14). As such, the experience of breast cancer remains "relatively under-researched" (van der Wiel, 2013a, p. 55) particularly in South Africa. In addition, there is limited emphasis on self-reflective scholarly work that explores the breast cancer experience.

Sealy (2012) in her article entitled, "Autoethnography: Reflective journaling and meditation to cope with life-threatening breast cancer", utilised autoethnography to facilitate the development of her understanding of unresolved emotional concerns related to treatment and recovery and to define her breast cancer journey through the use of reflective journaling and meditation. Sealy revealed the significance of acknowledging past unresolved hurts that can be "triggered when encountering a serious illness" (Sealy, 2012, p. 41). Sealy claims that reflective journaling and meditation as complementary practices notably influenced her understanding of suffering and healing. In my process of autoethnographic writing, healing became a prominent feature and was not seen as the "further fracturing" that Greenhalgh (2017, p. 14) has described.

Siméus's (2016) doctoral thesis, "My dance with cancer: An autoethnographic exploration of the journey", explored her identities as a Haitian, marital and family therapist, dancer and choreographer who sought individual therapy to gain a deeper understanding of

her breast cancer experience. In addition, her thesis draws attention to the cultural biases of mental health within the Haitian community. As a therapist, I recognise that when clients share their lived experiences, they often subscribe meanings within the counselling room to those experiences that facilitate reflexivity and reflection for self-development. Siméus also believed that individual therapy would be beneficial to her personal development as a therapist and woman of colour diagnosed with cancer. Unlike Siméus (2016), I did not engage in individual therapy following my diagnosis. I did however participate in experiential therapeutic learning spaces that afforded me the opportunity to share my breast cancer story and to explore the thoughts, feelings, and reactions within a supportive professional space.

Writing as a doctor and social scientist, Greenhalgh (2017) has utilised autoethnography to examine her breast cancer experience. She acknowledges the dominant discourse concentrating on "receiving bad news, fear and uncertainty, coming to terms with a bleak prognosis, coping with disfigurement and compromised sexuality and living with terminal illness" (Greenhalgh, 2017, p. 1-2). Furthermore, she anchored her study within "medical evidence-narratives" (2017, p. 2). My study was cognisant of her criticism of breast cancer narratives particularly in demanding legitimacy in research. However, I chose to focus specifically on my social scientist perspective of my lived experiences and was most comfortable to write from this lens while defocusing on the medicalisation of cancer research. As with Greenhalgh (2017, p. 5), I wished to capture my "experience as data and subject it to a research gaze".

In line with the autoethnography tradition and as supported by Wood (2016, p. 130), I provided layered accounts of my breast cancer experience by using personal narratives,

journals, photographs, poems, presentations, newspaper articles, emails, personal communication, and feedback notes. Like Greenhalgh (2017, p. 5), I organised "my materials into something that could be called a dataset" and considered the emotional labour of this process as data. In a similar way, Rosenberg (2016) expressed her struggles with managing emotions during her self-study process. The multiple data sources allowed for all possible understandings of my breast cancer experience that facilitated self-dialogue, self-exploration, and self-reflection. The inward-outward self-searching process as described by Mitchell (2016) was significant in identifying themes and reflective insights. As expressed by Ellis and Bochner (2006) and Ellis and Adams (2014) my study used methodological tools and pertinent research literature to innovatively analyse my breast cancer experience so as to avoid the "traps of sentimentality and 'pinkwashing'" (Greenhalgh, 2017, p. 14) often used by breast cancer-related charities in their cause marketing, as well as by for-profit institutions touting their purported philanthropic and corporate social responsibility goals and objectives.

I am cognisant of Bankert-Countryman's (2013, p. viii) acknowledgement that usually academic writers confine themselves to "neat gridlines" which are specified by institutions of higher learning. My study does not subscribe to such gridlines or to the traditional structure of a PhD thesis. My commitment to autoethnography required reflexivity and a kaleidoscope of creativity and "digging deep" (Scott, 2014, p. 69). Like Collins (2017, p. 219), I adopted autoethnography "to break from the traditional ways that research is conducted". An early dialogue by Ellis and Bochner (1996), examined universities evaluative requirements that made it problematic to present alternative forms of knowledge. Furthermore, Tomaselli (2015) articulated his own experience of resistance within academia when he argued for a change of present structure and reiterated that whatever the format, it should not digress from

the essential content that is contained in the "design, genre, style, appearance" (p. 69). In other words, alternative formats for an academic thesis that may not fit the traditional structure. In addition, Ellis and Adams (2014) reflected on such a digression from the normative structure and particularly how literature reviews are considered for inclusion in an innovative manner.

Another essential argument to consider is the purpose of the literature review. Bruce (1994) identified six categories of students' experience of literature reviews. These were as follows: (1) list, (2) search, (3) survey, (4) vehicle of learning, (5) research facilitators, and (6) report. The finding indicated that students recognised the direct interaction of literature reviews as a vehicle of learning and facilitation. These features complement my own experience of using literature to learn, facilitate and support my understandings.

Furthermore, as Chang (2008, p. 110) warns, it is important to "keep your review in appropriate proportions" as it is "one of the many data collection strategies". This advice was something I took especial care to follow. Archbald (2011) and Fong (2017) have both recognised an evolving diversification of benefits, particularly when a PhD study meets its necessary academic requirement and is found useful for professional specialisation and/or work outside of academia by potentially offering further access to multiple and diverse audiences. Considering these arguments, I ensured that the content would not be compromised by adhering to the fundamental principles and philosophy of a research PhD.

# Significance of the Study

To address the perceived research gap, this study adopted a qualitative self-reflective approach to explore my breast cancer illness experience. As Frank (1997, p. xii) has emphasised, individuals who are ill "need to become storytellers in order to recover the

voices that illness and its treatment often take away". In the 1980s, this concept was further exemplified by Audre Lorde who eloquently reflected in her writings her identity as a black, lesbian, feminist mother and poet with breast cancer. Often, women diagnosed with breast cancer are often silent and isolated because of the psychosocial and cultural perceptions of the illness. Lorde was determined to educate other women by communicating her lived experiences and thereby conscientise others. This was an objective that I too wanted to achieve in this PhD study. When I first proposed making my breast cancer experiences the focus for a PhD thesis, my parents, family, and critical friends were initially equally concerned, but progressively came to accept that it would ultimately prove spiritually fulfilling for me. By framing my breast cancer experience within an autoethnographic methodology, my intention was to provide a unique contribution to the field of research in breast cancer narratives and to address the limited qualitative self-reflective research.

According to Rayne et al. (2018) there exists a "considerable lack of understanding and research as to the extent by which South African patients' psychosocial or socioeconomic influences" are explored (p 807). In their systematic review on coping of breast cancer women of colour, Yoo et al. (2014) suggest the need for further studies that are cognisant of the socio-cultural context. My study acknowledges this paucity of psychosocial knowledge and places emphasis on the intersectionality of my personal and professional identity as I experienced breast cancer. Furthermore, by adopting autoethnography as my chosen research method, it afforded me greater internalisation of my intersecting realities. Whereas conducted research often includes, for example, an external sample of either breast cancer survivors, healthcare providers or family members, this work seeks to internalise my experiences and thereby make me the subject of the study.

Personal self-reflective studies, like those of Sealy (2012); Siméus (2016) and van der Wiel (2013a, 2013b) gave me the necessary reassurance to share my voice in writing an autoethnographic PhD study. I appreciated my positionality as a patient becoming a researcher. Furthermore, it provided me the opportunity of integrating my experiences in such a way that I could rewrite my story for the purpose of self and others beyond the academic community. In their reflections on embracing autoethnography as a research method within academia, Forber-Pratt (2015), Golding and Foley (2017) and Stirling (2016), each acknowledge its contributory value and transformative nature. These variables have played a fundamental role in my experience of breast cancer as a young woman of colour in South Africa. To reiterate, Charon (2006) in her practice of narrative medicine, acknowledges that illness motivates one to "recognise the self" (p. 87) by interrogating one's existence. Adams et al. (2011) also maintains that the experience of cancer "facilitates a new sense of self to emerge" (p. 855). I came to accept that I am suitably positioned to interrogate through my identities how breast cancer facilitated such a sense of self that was inextricably interwoven with socio-cultural responsiveness.

Brown and de Jong (2018, p. 38) further validate how a study can add to a body of research where conclusions are derived solely from one's lived experience of breast cancer. The cautionary word proffered by Bochner (2014) of "attributing too much significance to academic literature and not my own personal experience" (p. 14), was always uppermost in my mind. This ambiguity required interrogating on several levels from different perspectives. Even my theoretical imagination was brought into focus until I safely arrived at a comfortable intellectual space to engage as I attempted to take personal experience and evolve it into a scholarly piece of work. Moreover, I wanted to ensure that my research

presented my own values of inclusivity and honouring differences, something which Wood (2016) has also recognised. Interrogating my own illustration of how the personal and professional interact further afforded me coherence of my interconnecting self. Such coherence is also pivotal in understanding oneself which Bochner (2014) accepts is an achievement, and not a given (p. 287). The recognition of the constant contradictions that prevail was critically reflected upon to expand my own comfort zones, for what I trusted would be a significant new body of knowledge.

In reference to mainstream psychology, Demuth (2015) argues that "distinguishing between the researcher and the researched world can't hold any longer" (p. 127) as it will fail to appreciate the uniqueness of lived experiences. Another salient observation is the therapist-researcher divide which Bager-Charleson and Kasap (2017, p. 190) acknowledge as "a gap between therapeutic practice and research", specifically within the autoethnographic space. The example of counselling psychologists Kracen and Baird (2017) is of importance in this regard, where they reflect on the use of autoethnography as a methodology to explore their influence as researchers. Methodologically, Buckley (2015, p.2) reassuringly comments that autoethnography "can provide valuable new insights and make a unique contribution to psychology" inspired confidence in me to pursue this form of research.

Most importantly, I became cognisant of the "paucity of counselling psychology literature which explores the experience of people coming from a mixed cultural background" (Egeli, 2017, p. 5), a diverse position that I could identify with contextually. By analysing my personal experience and development, the emergences of meaningful insights could inform the journey of other women with breast cancer. This self-reflective process may be construed as being self-indulgent. However, I use my intersecting positionality to make what

I trust will be a valuable contribution to scholarship as well as a deeper understanding of how professional knowledge and socio-cultural influences the illness experience of breast cancer.

I was thus acutely aware that the research process should be firmly focused on the research questions of the study.

### **Research Question and Objectives**

As noted by Doh and Pompper (2015, p. 610), when it comes to breast cancer, individuals have "varying lived experiences steeped in their intersecting social identity dimensions of age, culture, ethnicity/race, physical ability, socioeconomic status, nation, sexual orientation, religion/spirituality, and more". This ultimately informed my research question that focused on my own lived realities, which accommodates the intersecting of the personal and professional self-expression of my breast cancer experience.

The research question that guided the study was as follows:

### How did I contextually experience breast cancer through an intersectional lens?

The objectives of this research study were as follows:

- To explore my breast cancer experience in relation to the intersectionality of personal and professional identities.
- 2. To explore the influence of my professional knowledge and practice on my breast cancer experience.
- 3. To contextualise interconnectivity within the community of care.

#### **Structure of the Thesis**

## Chapter One

This introductory chapter contextualises my study by providing relevant information and a summary of the understanding of breast cancer and the autoethnographic research process, as well as to establish credibility for my study.

#### Chapter Two

This chapter provides a justification for adopting autoethnography as a methodology and research method and its utility in exploring my breast cancer experiences. The chapter goes on to explore the theoretical history of autoethnography as well as my developmental journey coming to autoethnography. Given the intricacies of the autoethnographic process, there have been concerns surrounding the suitability of the methodology and criticism related to academic rigour that I also explore in this chapter.

# Chapter Three

This is the first of my three analytical chapters. In this chapter, I present the intersectional aspects that contributed to my personal lived experience prior to and post my breast cancer diagnosis. I go on to present my cultural and racial identities within a South Africa context. Moreover, while I acknowledge the interruptive nuances of breast cancer, I show how it became a catalyst for self-exploration.

# Chapter Four

This chapter is devoted to my intersecting professional identities. In brief, the chapter presents my professional development and teaching ethos within higher education. The chapter also creatively explores the tensions associated with silence, voice, and vulnerability within an academic context.

# Chapter Five

This chapter explores the interconnectivity of my personal and professional identities within diverse professional communities. The chapter seeks to validate my commitment to advocacy, enhancing cultural awareness, connection and having reflective dialogues in diverse settings. Using autoethnographic tools, alternative interpretations, and views of self and other are contextually presented.

### Chapter Six

This chapter offers a synergised conclusive commentary on the breast cancer experience framed within the autoethnographic perspective. In true autoethnographic design, the chapter concludes with a poem capturing the interrelatedness of self and other when exploring personal lived experiences.

### **Chapter Two**

### A Methodological Design and Process: Autoethnography

To address my research questions related to exploring my intersectional identities as I navigated my breast cancer experience, I adopted a qualitative approach, specifically autoethnography. The core elements of autoethnography are introduced and explored in chapter one. Structurally, this chapter adopts a normative style to best capture the relevant methodological content without digressing from the core principles of autoethnography. Emphasis is placed on the process of autoethnography design and method in relation to the research questions. I explore the sites reflectively that facilitated the development of my understanding of autoethnography as a methodology. As a reflective process, this affords an understanding of my intersecting identities which reflect my own feelings, thoughts, actions, beliefs, and insights. The critiques of autoethnography are also addressed. Methods of data collection are thereafter presented. The method of analysis is justified for inclusion and presented as it relates to the analytical chapters. The ethical considerations are thereafter presented. The chapter concludes with the limitations of the study.

Initially, I was cognisant of my own methodological immaturity; however, as I navigated the research process of autoethnography as a methodology and method, I gained in confidence. Chapman-Clarke (2016, p. 10) observed the common phrase of researchers as "coming to" autoethnography "as a research genre, methodology and method". What constantly framed and guided my thinking through the autoethnographic design and research process was "the question of so-what?" which Mitchell (2016, p. 181) acknowledges as common across the various forms of autoethnographic practices, such as critical, performance, visual and collaborative.

Illness can be an isolating experience, and as Frank (1997) has argued, there is a "need of ill people to tell their stories, in order to construct new maps and new perceptions of their relationships to the world" (p. 3). By engaging in writing a PhD thesis, it gradually became a form of catharsis and healing as I interrogated my own areas of discomfort. This autoethnographic form of writing which integrates and draws connections with the ethnographic aspects (i.e. gazing outwards at world/others) and the autobiographical (i.e. gazing inward at self) (Schwandt, 2007) allowed for the discomfort to be confronted.

Mitchell (2016) also captures this inward-outward lens in her chapter entitled, "Autoethnography as a wide-angle lens on looking (inwards and outwards): What difference can this make to our teaching?" which additionally provided a methodological parameter within the transformative journey. Furthermore, there was a synergy with Chang's (2008, p. 137) description of data collection and interpretation strategies as a process in which, "you zoom in on the details of your life and zoom out to the broader context".

Couture et al. (2012) acknowledge the intersectional identities and the reflexive accounts that both shape and re-define the insider/outside experience. Indeed, the inward gaze offered me opportunities to bring attention to vulnerabilities which are core components of autoethnography, namely, to question silence and the in/visibility of illness. In other words, to unmask the interlocking layers of my personal and professional intersecting identities purposively and confidently and thereby expose myself by outwardly expressing the discovered and reflective insights within a scholarly task. Adams et al. (2015, p. 36) further supports my motivation by offering four main reasons for utilising autoethnography as a research methodology:

1. To critique, make contributions to, and/or extend existing research and theory;

- 2. To embrace vulnerability to understand emotions and improve social life;
- 3. To disrupt taboos, break silences, and reclaim lost and disregarded voices;
- 4. To make research accessible to multiple audiences.

All the above synergised with my own reasons for considering this methodology. Firstly, was my intention to contribute to the research within the breast cancer community as I deeply reflected on my own experience. Methodologically, in examining and reflecting on my breast cancer experience, it is my hope that this study will add to the existing research knowledge contextually within the South African academic environment. It has been widely noted that in psychology, "on the whole, been slow to incorporate newer theoretical constructs into its practice and research" (Frazier, 2012, p. 381). Complementary to this notion is that of Kracen and Baird (2017) and Wall (2008), whose reflections on the philosophy of psychology have been consistent with the methodological practice of autoethnography. Secondly, my vulnerability post breast cancer was examined and reflected which extended my engagement within breast cancer communities and professional spaces. Thirdly, breast cancer interrupted my life journey at it was this interruption that afforded me the opportunity to disrupt personal, cultural, and social beliefs around breast cancer. By sharing my story in various contexts, I confronted and facilitated conversations on the traditional norms and understandings of breast cancer. Furthermore, the breaking of the silences occurred not only in my writing but also in sharing intimate experiences in various forums, including the exposure of my vulnerability through photographs, journal entries, newspaper articles, personal communications, presentations and poems which are analysed in chapters three, four and five of this study. Lastly, this study seeks to add to the existing knowledge in the illness community within a methodological qualitative space. The

publication of a resource guides another example of the benefit of collaborating with others outside of the academic space, such as medical professionals, communities and women diagnosed with breast cancer. This further promoted accessibility within the cancer community. Other sites of sharing are discussed in this chapter and are acknowledged in the analytical chapters which follow.

## The Process of Research Design

I progressively accepted that autoethnography as a research design and process is never neatly linear or sequential. Munro (2011, p. 160) acknowledged that unlike traditional research, "the approach taken by most designers is haphazard and non-linear". Furthermore, as Bochner (2014, p. 23) alludes, "life is messy, riddled with gaps, contradictions, and discontinuities" which I accepted in my breast cancer experience. I was therefore careful to accommodate within the design process the inevitable "messiness of a creative life" (Kamanos Gamelin, 2005, p 189) as I navigated "through painful, confusing, and uncertain experiences" (Adams et al., 2015, p. 44). For Bochner and Ellis (2006, p. 111), autoethnography "shows people in the process of figuring out what to do, how to live and what their struggles mean". Being consciously aware of these considerations, my focus was on how I presented sources of data in a coherent and scholarly manner that would afford a system of presenting data as evidence for analysis and interpretation.

As described in chapter one, in order to gain insight into the context and meaning of lived experiences, an autoethnographic research design is both reflexive and reflective in practice (Bochner, 2014; Chang, 2008; Ellis & Adams, 2014; Mitchell, 2016; Munro, 2011, Pace, 2012). Similarly, for Gray (2017, p. 181) reflexivity is "important across all stages of the research process" which is evident in my study. Objectively, Skeggs (2002, p. 367)

notes: "that some forms of reflexivity are reproductive, repetitious and reinforce existing power relations, while others may be challenging and disruptive". My perspective was the latter, which afforded me a level of interrogation that reflectively allowed for the disruption of the traditional research process. I was keenly aware that my positionality as an academic/psychologist could possibly reproduce or support the social and cultural views by writing my personal narrative. Yet, in the true tradition of the autoethnographic process, "it enhances cultural understanding of self and others" (Chang, 2008, p. 52) and may not merely reproduce or support social and cultural views. Adams et al. (2015) and Costley et al. (2010) also maintain that it extends beyond self-understanding and intersecting identities to that of theoretical, methodological, and practical implications.

To support my decision to utilise autoethnography, I found the article by Doloriert and Sambrook (2011, p. 608) particularly consoling as it aimed at "redressing the dominance of the traditional thesis/dissertation and the traditional student" by empowering "students and supervisors to take risks" to produce autoethnographic thesis/dissertations. For Doloriet and Sambrook, it was important to recognise an autoethnographic thesis/dissertation, "as a genuine and valid way of contributing to knowledge creation" (2011, p. 608), as it clearly creates its own space in the research community. Scholars such as Belbase et al. (2008), Ellis and Bochner (2000), Ellis and Adams (2014), McIlveen (2008) and Méndez (2013) acknowledge the ambiguity of autoethnography, yet reassert its contribution to existing knowledge. I accept Chang's (2008) perspective of methodological modification:

The flexibility of research design should not be misconstrued as a lack of diligence or indecisiveness in planning. Rather, this research design gives you freedom to modify

your plan as needed so that the most insightful understanding of complex human experiences can be gained with few presumptions and an open mind (p. 67).

These cited articles incrementally provided the confidence to embark on such an innovative methodology as I ultimately accepted that "I only knew that it filled a gaping hole evident in so many academic texts" (Kamanos Gamelin, 2005, p 184-185). This became a maturing commitment as I commenced on this scholarly journey. While I identified that autoethnography and psychology are both reflective in their practice (Klemple, 2015; Rosa, 2015), it became apparent that there was negligible autoethnography research in the discipline psychology. Like Ellis and Adam (2014), I questioned the reasons for psychology's hesitance in using autoethnography. As a reflective practice, psychology according to Ellis and Adams (2014, p. 256) "would seem like a good methodological fit" as it promotes the development of cross-cultural sensitivity and possesses "self-transformative potential" (Chang, 2008, p. 54). However, as Gray (2017) observes, while a few psychologists have attempted reflexive research methodologies, "most have not been as successful at challenging their traditional disciplinary boundaries as scholars" (p. 182).

As Custer (2014), Ellis (2004), Hayes and Fulton (2015), Kracen and Baird (2017) and Kumari (2017) acknowledge, autoethnography has a therapeutic value not only for the writer, but also for the reader within the knowledge space. In supporting this contention, Ellis (1999, 2006) further suggests that autoethnography can be an evocative and therapeutic instrument – something my vulnerable self had to be constantly aware of, so that I could write from my truth. Similar to my own positionality as a researcher and teacher, Siddique (2011, p. 310) reflects on the "in-between-ness" of autoethnographic work with that of psychotherapy, as both are reflexive practices which she argues influenced her "career

decision to train as a psychotherapist". For me, the practice of psychology was not only a catalyst that precipitated my present teaching skills, but also helped me engage with students and promote self-reflective methods. In addition, it seemed logical that I considered autoethnography as an appropriate research methodology.

The comparative nature of the research process with counselling and therapy is what captured and sustained my interest. Likewise, for Egeli (2017), the "choice of methodology was in part a reaction to the binary thinking I was experiencing in the counselling literature" (p. 6). A fitting example is that of Evans (2016), who as a writer, researcher, and therapist explored the intersectionality of her identities which offered the space of not knowing and meaning-making. Clearly, autoethnography as a reflexive process not only recognises the value to explore the unknown, but also to interrogate and transcend boundaries of existing understandings of experiences. My constant inquisitiveness was to explore what I "have not yet comprehended and tolerate that space of 'unknowing' or 'non-certainty'" (Evans, 2016, p. 44) in the spaces of therapy and/or research to contribute towards the meaning-making process.

### The Intersecting Identities: Self as Researcher-Participant

In autoethnography, the researcher occupies a dual role as both researcher and participant. The added comfort was Pathak (2010, p. 2), who proffered that, "as an autoethnographer, my story is unique because it is mine; it is a lived experience, and also because I have the academic training to examine it critically". In similar fashion to that of Pathak (2010), I persistently reflected on how my academic experience and psychological knowledge positioned me uniquely to write and many times rewrite my story, to add coherence. Grant (2010) thus affirms that social science researchers often pay little attention

to the "knowledge and expertise they alone possess" (p. 577) when designing a research project.

Researchers such as Berry (2013), Adams et al. (2015) and Ngunjiri et al. (2010), have indicated that autoethnography as a methodology best captures the experience of self and allows the researcher-participant to engage with the socio-cultural context. Prosser (2013) thus describes the researcher as, "the instigator, designer, collector, interpreter, and producer in the research process" (p. 186). Additionally, I was reminded by Adams at al. (2015, p. 48) that the process, "requires us to do the simple, yet deeply reflective work of starting where we are". I embraced this cyclical reflective process as I contemplated which aspects would coherently contribute to the analytical framework of my thesis.

For Rosa (2015, p. 19), such "apparent circularity" is a core element to reflexivity in psychology and has occasionally been criticised when it, "fails to pay attention to the details of how psychologists turn their own lived experiences into the scientific records". This criticism professionally provided me with confidence to continue my PhD study, with myself as the focus. I was cognisant of the historically reflexive practice as an indelible process in psychology (Klemple, 2015) and within this reflective space, the vulnerable self is embedded in the process.

In addition to the above, I became acutely aware that vulnerability was embedded in the research process, which can inspire "methodological innovation" (Arditti, 2015, p. 1570). I accepted the declaration of Ellis (1999, p. 672), that an "honest autoethnographic exploration generates a lot of fears and self-doubts-and emotional pain". I confronted the complexities even as a vulnerable academic (Bhattacharya, 2016) to reflect upon my own intersecting identities and "apparent vulnerability" (Foster et al., 2005, p. 7) in using self as

the subject of my study. Like Kamanos Gamelin (2005, p. 184), I experienced a "sense of responsibility, fear and vulnerability" in presenting my experiences realistically, accurately, and scholastically. I gradually accepted that vulnerability will be a core element throughout the entire writing process and committed to the credibility of the process to ensure "consistent, honest and transparent reflection" (Mulqueeny & Taylor, 2019, p. 1). Vulnerability and accountability to self is an inextricable part of the authorship process. As explained by emerald and Carpenter (2015, p. 746), "emotional vulnerability can be confronting and uncomfortable to write and to read", yet it was essential to seeking deeper meaning and understanding of my breast cancer experience in relation to my intersectional identities.

I conceded that within this process, the emergence of emotional discomfort in revealing my personal experiences had to be interrogated, "as unflattering as they may be" (Adams et al., 2015, p. 40). In addition, I acknowledged the comment by Adams et al. (2015) that, "doing autoethnography can create personal and professional risks and vulnerabilities" (p. 63). Even though the emphasis of vulnerability and accountability to self is part of the authorship experience, I was cognisant of the blurring of the boundaries that had the potential to make me susceptible both personally and professionally. I read extensively to justify the various reasons to address my discomfort and vulnerabilities and often found answers from authors like Adams et al. (2015); Ellis (2004), Bochner (2014); emerald and Carpenter (2015) and Siddique (2011) who extensively explored vulnerability and conclusively accepted it as a risk within autoethnographic research.

As a psychologist, I understand the value of the therapeutic process of telling, retelling life experience, exploring the self, and developing personal insight into one's existence. It is widely accepted that the different intersecting systems that co-exist contextually inclusive of cultural, social, community, political beliefs, and spiritual practices present themselves developmentally in sessions. This therapeutic space affords the exploration of the emotional, cognitive, and behavioural aspects towards psychological and transformative growth. Reflexivity in my practice materialises practically (Klemple, 2015; Rosa, 2015) since it demonstrates the interactive and dynamic process of client/patient and myself as we mutually arrive at an evolving sense of identity and reality.

As a lecturer, I "offer a way for students to process their own reflexivity and play with the tension between definition, practice and knowledge" (Faulkner et al., 2016, p. 199). I often experientially explore ways of learning beyond the prescriptive manner and as with Scott (2014, p. 85), I "consider ways to improve" within the learning and teaching space. However, as Warren (2011) points out, applying reflexivity activities has the potential to create an environment that affords the space for students to be vulnerable. Being cognisant of this possibility, concerns around confidentiality and privacy were discussed. Ultimately, the point was to have my students creatively, yet unconsciously, enjoy their learning (Scott, 2014, p. 85). Others such as Berry (2013), also demonstrate how reflexivity is a practice of mindfulness as students can identify their own identities, relationships, and positionalities.

Within academia, there exists a shared belief that as academics/researchers, we need as Tomaselli (2015, p. 69) suggests, "to take conceptual and methodological risks. I therefore accepted the fact that within risk-taking there exists the potential to unsettle normative ways of thinking".

### The (Un)Settling of the Research Process

In her interdisciplinary exploratory work of intersectional ideas, histories, and practices, May (2015, p. 65) promotes "unsettling dominant ways of thinking" which facilitated my acceptance of the methodological process. Within the process of qualitative research and writing of the self, Gannon (2018, p. 21) recognises how the practice of autoethnographic work can be construed as "troubling". As a result, the various intersecting contexts, and spaces I occupied framed my experiences and stories as an only child, a woman of colour in South Africa, a psychologist, a lecturer, and a scholar who experienced breast cancer. In addition, these spaces provide a "public face to autoethnographic work" (Mitchell, 2016, p. 186) which frames this study. Like Evans (2016, p. 45), I recognised the research value of exploring the intersectional and relational aspects of the personal and professional as it presents with "transformative possibilities". It is within such a presentation of possibilities that I was able to critically explore and examine my narratives around breast cancer within and from a scholarly voice and space.

In the past, the "personal-reflexive voice was marginalised" (Gray, 2017), being restricted to "safe places for voice" such as the "appendices, footnotes, prefaces, acknowledgements, introductions, and afterwards" (p. 182). In contrast, autoethnography foregrounds my voice which according to Sparkes (2000, p. 22) challenges the "accepted views about silent authorship". My silences gradually gained momentum as I introspected the value of my own voice as I sought to contribute to knowledge production. Through my exploration and writing, I challenged the silent authorship and reaffirmed the significance of the intersectionality of personal and professional experiences that add voice to existing knowledge. This process often subjected me to self-scrutiny and critical examination to

unmask my multi-layered identities, meanings, and socio-cultural aspects (Couture et al., 2012). Such was my obvious positionality that it allowed for shifting positions and inward/outward exploration "without losing face" (Mitchell, 2016, p. 183) by "opening up the private-public to vulnerability and risk-taking" (Pillay et al., 2016, p. 5). Yet again, this draws to attention the concern of revealing the unbecoming and unattractive parts of self as discussed by Adams et al. (2015).

Early in the process, I was overwhelmed and uncomfortable in determining what constituted the data. Like Eisner (1997), I reflected on "alternative forms of data representation", as well as "the variety of ways through which our experience is coded" (p. 7). It was my exposure to different spaces and the variety of evidence that created opportunities to interrogate such uncomfortableness. These developmental spaces contributed to my acceptance of the process.

**Intersecting Spaces: The Exploration of Autoethnography as a Methodology** 

Supervision: My Reflective Experience

Trahar (2013) reflected on supervision as an academic process to encourage creativity and reflexivity, yet recognised the tension within academia as to "what constitutes 'sound' academic practice" (p. 369). This reflective question facilitated robust dialogue with my PhD supervisors over several hours. We debated, explored, and interrogated the perceived messiness of autoethnographic work, including "decisions about voice, writing with and through theory, and issues of narrative fidelity and relational ethics" (Adams et al., 2015, p. 69). Because I selected a non-traditional approach, a concern I share with Forber-Pratt (2015) concerns the negotiation policies and procedures of the department. Like Egeli

(2017), we identified that autoethnography is a less familiar methodological process. We reviewed the literature on lived experiences and autoethnography and how it can be coherently presented as a methodological process.

In 2013, another supervisory space included the PhD cohort programme located in the College of Humanities, UKZN. The ethos that framed the cohort sessions was that of critical reflection and interrogation to enhance learning and create confidence within an eclectic research community on a preferred methodology. My experience of the cohort, like Trahar (2013, p. 369) positioned me as "vulnerable and susceptible to criticisms of self-indulgence". Such a space required me to develop my own confidence as I communicated my preference to consider autoethnography, which was an unpopular research method in academia. This collaborative sharing assisted in maturing my methodological arguments, a perspective shared by other researchers such as Foster et al. (2005), O'Neil (2018), and Pithouse-Morgan et al. (2016). The collaborative space brought into focus the paucity of knowledge that exists on lived experiences, particularly in academic spaces and the South African context. The cohort model facilitated learning from the group of supervisors and between students themselves that ultimately improved the quality and refinement of my own PhD study as it progressed.

Another space of exposure in 2015 was the collaborative Transformative Educational Studies (TES) project at UKZN, an inter-institutional, trans-disciplinary project that addresses complexities of conducting work across disciplines in South Africa's higher education institutions. This space offered diversity on self-study scholarship that welcomed developing innovative context-based methodological approaches (Pithouse-Morgan et al., 2014). According to Golding and Foley (2017, p. 398), "telling our stories and hearing other

people's stories and about 'where they have been' is actually good for all of us". This sharing was meaningful for me as it brought into focus the educational value and the potential for self-study research. It also facilitated in the recognition of the complexities and the tension in utilising autoethnography as a methodology. My presentation to the TES members, dated 07 August 2015, reflectively facilitated the interrogating of the methodological processes on self-study in comparison to the traditional methodologies. This supportive experience organically allowed for the embracing of self-study as a PhD. The feedback received from the team acknowledged my vulnerability and further provided contextual insight into how such vulnerability, visibility, and silence shaped lived experiences. This space became yet another productive "support network" (Wood, 2016, p. 129) within the university in affirming my resolve to self-study. Beyond the university, another site of engagement and exploration was the 22<sup>nd</sup> South African Psychology Congress, held in Johannesburg, 20-23 September 2016 under the auspices of the Psychological Society of South Africa (PsySSA).

# The Psychological Society of South Africa Congress (PsySSA): Shattering My Silence

The 22<sup>nd</sup> South African Psychology Congress, held in 2016 focused on critical engagement with the theme "conversations on psychology's response/ability to individual, professional, and societal challenges" (Psychological Society of South Africa, 2016, p. 1) was an appropriate professional space to present my PhD work in progress. The poster I presented was titled, "Shattering silence: Diverse methodology to facilitate voice in the process of writing an autoethnographic study on the experience of breast cancer". The objective of the presentation was to invite constructive comments within this research-academic-psychology space. It also created the opportunity to dialogue around self-reflective

studies, methodological tensions, and professional identity. More specifically, the intersectionality of psychologist/researcher/participant/academic was purposefully explored. The different professional dynamics and ethics around such a position were examined. In addition, it facilitated a conversation with congress attendances on the acceptability to become researched. Like Gibson (2012, p. 294), I understood the "passionate convictions and uncertain discomfort" for a psychologist to self-disclose. Another space to explore such discomfort was my conversations with my critical friends.

#### Reflecting on Critical Friends Facilitating Critical Conversations

While I developed my insights into and confidence about autoethnography through the above sites, like Rosenberg (2016, p. 46), I used critical friends as a "sounding board" to explore the research process reflectively and critically within a supportive space. These critical friends included PhD candidates, psychologist, and researchers. Storey and Wang (2017) define a critical friend as "a detached outsider who assists through asking challenging and uncomfortable questioning, provides another viewpoint, and facilitates reappraisal" (p.107). For Storey and Reardon (2016, p. 16), incorporating critical friends becomes an "evolutionary step" in constructing a PhD study. Programmes such as TES therefore create a mutual learning environment that is collaborative in exploring research and practice problems, offering a space to reflectively interrogate and evaluate responses. My critical friends thus became "interlocutors" (Greenhalgh, 2017), by providing that space for justification of the methodology and assisting in maturing my thoughts, often after long debates on the academic character and "PhD-ness" (p. 12) of my endeavour. I valued the support and encouragement of my critical friends as I moved beyond the comfort zones of

normative methodologies and consequently allowed for collective learning (Pithouse-Morgan et al., 2012; Pithouse-Morgan et al., 2017).

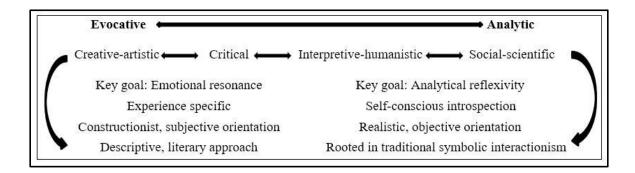
I acknowledge the interconnectedness of the contextual spaces discussed above as contributing to my methodological maturity and reflexivity. Further analysis of these spaces is provided in chapters three, four and five of this study, as they played a significant role in my learning, thereby deepening my knowledge and application of autoethnographic principles.

## **Autoethnography Approaches Range from Evocative to Analytic**

According to Le Roux (2017), autoethnography has four orientations: "social-scientific autoethnography (likened to analytic autoethnography); interpretive humanistic; critical and creative-artistic – the latter two being akin to evocative autoethnography" (p. 199). Figure 2.1 encapsulates the distinction in autoethnography, being categorised by the continuum between the evocative and the analytical.

Figure 2.1.

A continuum of autoethnographic research adapted from Le Roux (2017, p. 0198)



With reference to this continuum, the debate between the evocative and analytic autoethnography schools of thoughts range from having a "narrative, emotional, therapeutic,

and self-focused", to that of a "theoretical, analytical, and scholarly, with a more traditional understanding of self as connected to a particular ethnographic context rather than the focus of it" (Stahlke Wall, 2016, p. 2). The primary objective along this continuum is "to document personal experience" (Le Roux, 2017, p. 199). As Stahlke Wall (2016, p. 3) has noted, there are autoethnographic studies "that fall at all points along" the continuum. This blurring of the lines as acknowledged by Stahlke Wall (2016) certainly occurs in my study where clear distinctions could not be made. Stahlke Wall (2016, p. 7) thus advocates for "a moderate autoethnography" to provide a balanced view, "that captures the meanings and events of one life in an ethical way but also in a way that moves collective thinking forward". In utilising this continuum, I identified with commencing evocatively and progressively, utilising an analytical reflexive focus to address my objective of the study.

Unsurprisingly, autoethnography has been challenged because the approach does not always fit with the conventional assumptions of research methodologies and academic writing and thus "remains a contested methodology" (Guzik, 2013, p. 268). Furthermore, according to Golding and Foley (2017, p. 387), autoethnography has become "more robust and relevant" as a method to explore lived experiences. Having said this, it is not without its criticism as it "is by no means universally accepted in academic circles" because of methodological pitfalls (Hayes & Fulton, 2015, p. 12-13). Researchers such as Adams et al. (2015); Ellis et al. (2011); Ellis and Adams (2014); Frambach (2015), Guzik (2013); Golding and Foley (2017); Le Roux (2017), Tullis (2013) and Stahlke Wall (2016) have deliberated on such methodological challenges.

# A Critique of Autoethnography

Chang (2008) who has published extensively on autoethnography, promotes a contextual cultural analysis and interpretation that is relational to this study. Her book, *Autoethnography as Method*, acknowledges the existence of five pitfalls that I was cognisant of throughout the research process. These were as follows:

(1) excessive focus on self in isolation of others; (2) overemphasis on narration rather than analysis and cultural interpretation; (3) exclusive reliance on personal memory and recalling as a data source; (4) negligence of ethical standards regarding others in self-narratives; and (5) inappropriate application of the label 'autoethnography' (Chang, 2008, p. 54).

In the sub-sections that follow, I will present five criticisms of these perceived pitfalls, as well as offer supporting arguments from those of other researchers.

### Autoethnography has been criticised for being Narcissistic and Self-indulgent

When I became cognisant of my work being criticised for being narcissistic and self-indulgent, I sought the continual guidance of Wood (2016, p. 129) so that it did not become a "self-congratulatory story". This led me to deliberately adopt the "intersubjective validation and scrutiny" (Doyle, 2016, p. 149) of my critical friends and supervisors, as well as the inclusion of analysing the different autoethnographic data that contributed to my breast cancer experience.

Arguably, I was aware that "writing that crosses personal and professional life spaces goes further than auto-biography" (Denshire, 2014, p. 833) as it includes the writer's "life as

the researched within wider social and cultural contexts" (Liamputtong, 2007, p. 167). Further justification is found in the argument of Hayes and Fulton (2015) that the self is a social construct and therefore focusing on the self considers the intersecting socio-cultural context. Similarly, the perspective of Reed-Danahay (2017) that, "autoethnography as lying at the intersection of insider and outsider perspectives, rather than setting up a dualism that privileges the insider account" (p. 145). For these reasons, Ellis and Bochner (1996) and Ellis and Adams (2014) contend that the concern of self-indulgence is unjustifiable. To address the concern of self-indulgence, Stahlke Wall (2016) recommends that researchers demonstrate analytical insight and connect personal experience to that of the socio-cultural context with the aim of advancing knowledge. For this reason, Stahlke Wall's (2016) concern framed my motivation for the study. Furthermore, researchers such as Le Roux (2017), Mitchell and Weber (2005), Tullis (2013), Valentim (2017) and Wall (2008) examine the legitimacy of self-study with reference to quality, guidelines, and method. I was also guided in my PhD study by Méndez (2013, p. 282) who asserts that a researcher has the "right to tell their truth as experienced without waiting for others to express what they really want to be known and understood".

### Limited Focus on Analysis and Cultural Interpretation

Being cognisant of this criticism, my study is framed within a socio-cultural context and is similarly analysed. As Pace (2012, p. 3) contends, autoethnography "does not privilege traditional analysis and generalisation". Other researchers such as Chang (2008) and Le Roux (2017) support such an argument. To address the concerns of the analytical techniques used, Ellis (1999, 2004), Chang (2008), Hayes and Fulton (2015) and Stahlke Wall (2016) suggest there are analytical strategies employed to interpret and make sense of

experiences that do not digress from the research purpose. In addition, I was acutely aware that there should not be an "underdeveloped cultural analysis and interpretation" (Chang, 2008, p. 55) to my study.

#### Data Sources Reliance on Personal Memory

It is accepted that the process of remembering is fallible. To address this controversy of "memories are fragmentary" Muncey (2005, p. 69) adopted a multifaceted method which I have also incorporated in the study of complementary internal and external data sources. Such multiple sources created triangulation (e.g. personal narratives, data, critical friends, and significant others) to ensure "accuracy and validity" (Chang, 2008, p. 55). Accordingly, Duncan (2004, p. 31) supports the use of multiple sources to ensure "scholarly and justifiable interpretations". By utilising the suggestion of Ellis and Adams (2014), I was able to capture in the analytical chapters the experience of memory, which at different times creates another level of meaning and reflexivity. Another contentious aspect articulated by Ellis and Adams (2014) relates to personal narratives as data sources, which "often are the most controversial form, especially if the stories do not include more traditional academic analysis or are not situated among relevant scholarly literature" (p. 267). These concerns have been expansively addressed within autoethnographic socio-cultural analysis supported by pertinent literature.

### Practising the Ethical Principle of Inclusion of Others and Confidentiality

Undoubtedly, personal narratives are inclusive of others and are influenced by others, which suggests ethical consideration of permission for participation and disclosure of identity. I was cognisant of Ellis (2007) concerns and therefore duly discussed the relevant inclusion of others into my study and gained permission and consensus of the final draft

where they have been specifically included. Full authorship was consensually agreed upon as this was perceived as a PhD enterprise and they would be duly acknowledged. Other relational ethical aspects are presented below and are covered in the analytical chapters.

### The Complexity and Confusion of Defining Autoethnography

Chang (2008) describes the list of labels that have been used to indicate autoethnographic perspective as creating confusion in the exact labelling of the terminology. Such terminological clarity was addressed in my study by the definitional methodological parameters chosen. In addition, it distinguishes this method from ethnography, autobiography, biography, and memoirs. It has also been acknowledged by Ellis et al. (2011), Ellis and Adams (2014), Hayes and Fulton (2015), Le Roux (2017), Méndez (2013) and Stahlke Wall (2016) that autoethnography is positioned across various disciplines which are eclectic in nature and there has been no "exclusive license" (Chang, 2008, p. 56) for this term in any particular discipline. Hayes and Fulton (2015) thus extend the understanding of interdisciplinary practice by positioning it as a:

Methodological tool which permits a critical understanding for professionals from a whole array of working contexts and environments to illuminate a critical view of their own selves, and to bring a degree of intellectual objectivity into what can then become a shared interdisciplinary perspective (p. 12-13).

In acknowledging the methodological limitations of autoethnography, I became cognisant of maintaining reasonable scholastic objectivity in my choice of utilising this methodology. Considering the complexities of my intersecting identities, this approach provided the necessary guidance and framework without digressing from the objectives of my

study. I also recognised that this methodology informed the choice of data collection and the multiple benefits of different forms of data.

### **Autobiographical Self-Reflective Data Collection**

Autoethnography considers "personal experiences" as "primary data" (Chang, 2008, p. 49). Chang (2008) goes on to suggest that relevant literature can be consulted for various reasons to collect information on the "sociocultural, "physical, political, and historical" context of your life" (p. 110). Guided therefore by the objectives of the study, the context of my intersecting identities contributed to the knowledge that would be shared in a public domain.

Initially, I document memories and experiences related to my breast cancer journey in a chronological order that was determined by the objectives of my study. This memory work was not the only source of legitimate information to capture the dynamic unfolding of my lived experience. I searched for other significant sources such as written narratives, journals, poems, photographs, cards, emails, newspaper articles, presentations, brief notes, medical records, and feedback related to those memories. Like Grossi's (2007, p. 75) experience, I found compiling the autobiographical data a "lengthy process" as these documents were stored in various places, spanning some 15 years (2004-2019) of content. During the accumulation of these sources, reflectively, other memories emerged which once again broadened my search for further pertinent data. Even though this reflexive process was essential to the autoethnographic process, as with Frambach (2015, p. 957), the "meticulous documentation of the choices made" ensured the credibility of my research.

Clearly, there were gaps in remembering the sequence of exact events and associated feelings which my significant family members and critical friends assisted to recall and validate, a procedure which Chang (2008) recommends. Often hours were spent reminiscing, sharing, and authenticating some of my memories that initially seemed vague. The inclusion of significant others was one way to address the concern of the trustworthiness and credibility of my personal narratives particularly when I navigated the research process in terms of evidence collection, selection and critical reflection. Moreover, their role became as witnesses to my research process that further facilitated reflection. Despite these discussions occasionally being sensitive and vulnerable, it contributed ultimately to an insightful and deep reflection that enabled me to reclaim and capture lost memories and voice. The multiple perspectives provided new possible ways of knowing, while allowing me to be authentic, honest, and critically reflective.

In debating what should be included in the selection for this academic exercise, I was often aware that any such choice required to aptly communicate my experience which added to the analytical frame of the thesis. I was cognisant of the "dynamic relationship among data collection, management, and analysis" (Chang, 2008, p. 121). As I contemplated the selection of data, there were invariable "tensions in researching inwards" (Mitchell, 2016, p. 176). The intellectual and emotional tensions, as well as contentious aspects related to revealing personal information, initiated discussion with my critical friends on selecting appropriate evidence that synergised with my research questions. This emotional labour as described by Nutov and Hazzan (2011, p. 20) is "the effort a person invests in expressing or coping with his or her emotions so as to achieve objectives pertaining to his or her work" which I accepted as an inherent part of my developmental and research process.

My decision of inclusion was always substantiated by a definitive rationale and this decision trail is presented coherently and systematically in the study. I selected personal narratives, personal journals, photographs, poems, presentations, newspaper articles, emails, personal communication and feedback notes, which Wood (2016, p. 130) supports for analysis. Each item provided the scaffolding of meaning and interpretation of my lived breast cancer experience. This reflective process was an intimate connection to the self. The data presented in this study, while limited, nevertheless contributed significantly to deepening the understanding of my intersectional identities within the context and recognising the value of the inward and outward analytical lens in self-study. I was also guided by the recommendations of Chang (2008, p. 121) on "trimming some and expanding others".

Hereunder, I detail the choice for each ethnographic data as it offers coherence and guides interpretations in my analysis chapters.

#### Self-Narrative

Admittedly, there is an increased use of various forms of narratives in research, especially in the field of psychology (Haden & Hoffman, 2013). Such forms as an autobiography, diary, journal, letters, memoirs, and personal essays. Like Chang (2008) I believed my "personal stories can mix well with scholarship" (p. 9) for analytical exploration of self and intersecting identities. As a result, I presented specific journal entries, personal communications, and emails.

Hayman et al. (2012) acknowledges journaling as an acceptable and valid data collection method. LaBoskey (2005); Ortlipp (2008), Richards (2016) and Sealy (2012) effectively use journaling to reflectively document memories, thoughts, and insights about their experiences, all of which resonated with me. My habit of journaling was established

prior to my diagnosis and continued throughout my PhD work. Like Sealy (2012, p. 39), the process of writing a reflective journal "contributed to cognitive insights" and I found the process reduced my emotional turmoil as I made sense of the anger, anxiety, doubt, and confusion induced by the diagnosis. The participants in Williams and Jeanetta (2016) study, in exploring the lived experiences of breast cancer survivors revealed that journaling provided comfort to them. In addition, as a psychologist, therapeutic modalities inclusive of journaling, letter writing or diaries are considered effective tools within a transformative learning space that can be mutually beneficial.

#### **Poetry**

Poetry can encapsulate feelings, thoughts, and life events, and arguably a better way of presenting qualitative data (Liamputtong 2007). For Faulkner et al. (2016, p. 207) poetry "gets to the essence of qualitative methodology" by creating the transformational space to understand human experiences. Furman (2014) also recommends poetry within the transformational space and acknowledges it as an autoethnographic task beyond the "literary use of poetry" (p. 208). Equally important, the study by Chisanga et al. (2014) entitled "Enacting reflexivity through poetic inquiry", emphasised the reflective process of crafting poems and in the creation of knowledge. In relation to this reflexive process, the confidence and vulnerability of the poet/writer during the crafting of the poem was also important. Similarly, Faulkner et al. (2016, p. 207) identified poetry as a reflexive practice "that requires a naked intimacy and a level of honesty", features which were initially unsettling for me.

With specific reference to how researchers used poetry, Furman (2006) describes two forms. Firstly, where data is collected and poems created to represent the data. Secondly, where poetry is "not solely as a means of data representation but as a tool that gives shape to

the research design as a whole" (Furman, 2006, p. 562). These two forms of poetry were evident within the supervisory space of this study. These specifically emerged from my individual supervision sessions and facilitated group creative writing exercises. Poetry became "the vehicle" to reflect relational and shared realities that shaped my experience, thereby enabling me to explore and understand my personal experiences (Butler-Kisber, 2005, p. 95). The poetic expressions emerged from narratives exercises related to memories of a lived or preferred experience, which in and of itself is a process of inquiry. The initial aim of the poems was not for research, but rather to facilitate self-exploration and were only later selected as autoethnographic data for this study. Moreover, they depict the intersecting space that I occupied.

### **Photographs**

According to Bays et al. (2018), photographs provide valuable evidence and are useful in probing into the past and triggering memories. Photographs allow for the contextualisation of the experience in a single frame and to reflect from a position of looking at them later. In addition, Cartwright (1998, p. 117) describes photography as "alternative texts" to facilitate thinking "about the ways in which issues such as race, age and beauty are key aspects in the experience of breast cancer". This observation I found supportive of my decision to incorporate my personal photographs in my study. Furthermore, Grossi (2007) and Mitchell (2016) confirm the complementary aspects of visual methodology and autoethnography. For these reasons, I believed the intersecting of my visual and narrative processes of inquiry would ultimately contribute to comprehensively detailing my breast cancer experience. It was also my belief that such layering would promote the scientific methodological rigour required to sufficiently support the analysis.

## Presentations: Intersecting Academic and Community Spaces

For Richards (2016, p. 168) presentations assist in the process of self-searching, self-reflection and developing critical insights as "each allowed and disallowed different ways of seeing and expressing". I specifically selected a few presentations, some of which were only photographic, whereas others included both photographs and text. Two forums of engagement were decided upon for inclusion in this study, namely academic and community spaces. These two depict my engagement and feedback that contributed to my process of the creative synergy of my experiences.

## Textual artefacts: Newspaper Articles and Emails

According to Chang (2008, p. 107), official and textual artefacts are an invaluable source of information that can "shape and control the social context of your life". The textual artefacts used were authored by others, including newspaper articles from *The Daily News*, *UKZNdaba* and emails which authenticated the chronological experience and assisted in exploring my personal and professional developmental stages. Only accessible documentation from those who gave their consent was included in the study.

The above forms of data collection concisely contributed to the analytical chapters of the study. It also demonstrated the inextricable relational process of data collection and analysis.

## **Data Analysis**

As discussed above, autoethnography is not a traditional method of research. Ellis and Bochner (2000) and Pace (2012) thus suggest that a traditional method of analysis to

guide the process is not required. In this study, I used different analytical methods at various stages of my writing. Drawing on works by Ellis and Adams (2014), Stahlke Wall (2016), Chang (2008), Hayes and Fulton (2015) and Le Roux (2017) I analysed my experiences reflectively and reflexively by utilising an intersectionality lens of the personal and professional. The approach allowed for critically exploration and interrogation of my past experiences to gather "knowledge from the past and not necessarily knowledge about the past" as cited by Bochner (2007, p. 203). The process of uncovering insights of the past and rediscovering myself was an empowering, yet vulnerable experience. Contextually, I present myself in the study "as an object of description, analysis, and/or interpretation" (Chang, 2008, p. 35).

While the developmental stages of my experience were depicted thematically applicable, they were sometimes fragmented in the analytical chapters. Indeed, as Chang (2008, p.69) suggests, while it may not be "rigidly sequential", there is a possibility to "mix and match strategies of data collection, analysis and interpretation". Ultimately, I found this the most appropriate manner methodologically to coherently meet my research goals.

Chang (2008) proposes ten strategies to analyse and interpret data. Although I did not utilise them all, they nevertheless guided the process to coherently synergise with the aims of the study. Interestingly, I identified that these strategies potentially overlap with psychology practice. Consequently, the ten strategies proposed by Chang (2008, p. 131) elicited the following results:

# Search for Recurring Topics

This process assisted in identifying, recognising, and categorising data into significant recurring themes that did not regress from the key objectives of the study.

## Look for Cultural Themes

The foundational thematic elements that seem to recur within my breast cancer experience are analysed within the intersectional analytical chapters of this study.

## **Identify Exceptional Occurrences**

Life-changing illness facilitated engagement beyond myself and contributed to my confidence to explore breast cancer as a PhD study. The process of such occurrence contributed to the transformative and reflective ethos that prevailed.

## Analyse Inclusion and Omission

This intersectional process allowed for deeper reflection and justification to include or omit sources of data. For example, the exclusion of my intimate relational space prior to my breast cancer diagnosis was not considered. Instead, I concentrated on my personal relationship with my current partner after the diagnosis. Within the professional space, heretofore I was guided by the objectives of the study which to a large extent determined the data to be included for further analysis. This process of interrogation also determined the data that was finally omitted for utility in the study.

#### Connect the Present with the Past

This procedure provided an essential procedural process to explore how my past experiences have shaped and contributed to the clarity of my present intersecting identity.

## Analyse Relationships between Self and Others

This strategy necessitated a process of interrogation and reflection of my connectivity and relational dynamics with significant others. In my study, it included my family, partner, critical friends, and communities. Some issues of familiarity and unfamiliarity also emerged during this process.

### Compare Cases

This process facilitated my understanding of self as I reflectively compared myself to others who shared similar intersecting personal and professional communities, such as breast cancer, academic and cultural spaces. This comparison was also beneficial as I explored existing literature to determine differences and commonalities.

## Contextualise Broadly

This procedure required me to look beyond self with the intention to contextually explain and interpret my personal and professional intersecting identities that I occupied.

## Compare with Social Science Constructs

As a psychologist trained in the discipline of the human services profession, the intersectionality of my position within a multicultural community was reasserted during my transformative breast cancer journey. Appropriate literature provided justification and

support for the various analytical themes. Beyond comparison, the similarities between psychology and autoethnography became increasingly evident.

## Framing in Theories

As detailed in chapter one and the present chapter, the relevance of autoethnography as a theoretical lens that framed my study and clarified the choices of data collection and the associated autobiographical data was confirmed. The above strategies and processes thus informed my analytical chapters, both relationally and developmentally.

#### **Ethical Considerations**

This subsection is devoted to all the ethical considerations I contemplated as I navigated within my intersecting identities. Such a process facilitated my continuous commitment to maintain an ethical perspective. I was guided by the conclusion of Ellis (2007, p. 26) that "autoethnography itself is an ethical practice", a statement that constantly directed my study. Ethical approval for this study was granted by the Humanities and Social Science Research Ethics Committee (HSSREC), UKZN College of Humanities, dated 14 July 2016, Protocol Number: HSS/1035/016D.

I was initially confronted by a fundamental and vexing question: How does being an ethical being promote ethical practice? I was cognisant of Adams (2008, p. 177) who declared that, "if narratives are tools and if the crafting and sharing of stories involve morals" then it is of value to explore the importance of being ethical. In addition, Bishop and Shepherd (2011) maintain that ethical reflexivity requires a thoughtful evaluation of risk and benefits in sharing stories as stories relate to self and others. I deliberately debated this risk-benefit concept in the study. The acquisition of knowledge through the exploration of self-

narrative included co-construction of meaning – for example, the poems generated by Professor Sliep and myself, supervision with Dr Richards or my parents as part of the reflective team in producing the poster for PsySSA Congress in September 2016. Such coconstruction generated meaning making that contributed to the key objectives of the study, within the confines of ethical research. As such, recognising the principles of doing no harm, privacy, and confidentiality constantly allowed me to be reflective of ethical practice (Adams, 2008; Bishop & Shepherd, 2011; Ellis & Bochner, 2006). In addition, my intersecting identity as a psychologist and a registered member of the Health Professions Council of South Africa (HPCSA) require that I subscribe to certain ethical stipulations as a practitionerresearcher. I became acutely aware within my interactional spaces that I could not transgress and ethical stipulations (Edwards, 2014; Ellis & Adams, 2014). It afforded me the opportunity to recommit to professional practice as I positioned myself within the intersecting spaces. Priority was afforded to the process of ethical reflexivity and self-reflection as discussed by Bishop and Shepherd (2011); Faulkner et al. (2016) and McDonald (2013) in telling my story. More importantly, as Gingras (2008, p. 2) has asserted, "personal writing is an ethical act, one that requires implicit trust in the self and the reader".

It is acceptable that normative ethical consideration as implicated in autoethnography were deliberated upon and hence all contact persons contained in this study were approached for their inclusion and only upon mutual agreement were they subsequently included. A process suggested by Chang (2008) particularly when disclosures of identities become evident. The acknowledging of those significant others as located in the study inadvertently "let voices of others tell your story" (Chang, 2008, p. 68), which is especially evident in the analysis chapters. In addition, this ethical process was informed by the relational ethics of

including other voices such as family and significant others as suggested by Ellis (2007) and Tullis (2013). Greenhalgh (2017), Méndez (2013), and Tarantino (2016) also reinforce the necessity of such a step. In support, Chatham-Carpenter (2010) also alludes to ethics when incorporating others into the study. In addition, she questions the potential harm that may occur for the researcher/autoethnographer. Like Chang (2008, p.69), the suggestion is made that others included in the study are both "visible or invisible participants". To further engage with those participants who provided their consent for the utilisation of any data or information that was related by, or shared with them, were afforded the opportunity to read and comment on the accuracy of the description. Moreover, as a psychologist and researcher, Chapman-Clarke (2016) also endorses the importance of relational ethics in self-reflective research.

I was cognisant that some evidence was already in the public domain and did not warrant a decision of its inclusion or exclusion for the study. However, when considering much more sensitive and vulnerable aspects, the process I followed consisted not only of identifying, debating, and deliberating with my critical reflective friends on such sections, but was also guided by the research objectives (Chang, 2008). Eventually, what finally was included as evidence or data was my decision, entirely motivated by my level of comfort for disclosure as a researcher. This process was authenticated within the autoethnographic tradition by scholars such as Chatham-Carpenter (2010) and Faulkner et al. (2016). Any email communication and those who appeared in group photographs were specifically contacted for their permission and only once consent was received were included.

As Wood (2016, p 130) has emphasised, the autoethnographic approach allowed him to place himself "as the object of critique" which Greenhalgh (2017) also successfully

achieved in her study. However, I contemplated the question: How do I legitimately maintain research scientific rigour, as I am the object to be explored? This was a concern also noted by McIlveen (2008) when using self-narrative and art-based approaches. Ellis and Adams (2014), Forber-Pratt (2015), Gray (2017), Le Roux (2017), and Nowell, Norris, White and Moules (2017) interrogated the trustworthiness and methodological strategies applied to demonstrate scientific rigour. Similarly, Greenhalgh (2017) also employed four criteria to ensure the legitimacy of her autoethnographic study of breast cancer. Le Roux (2017, p. 203) also acknowledges the impracticability of developing "an all-inclusive list of criteria" given the "diverse orientations". Instead, she proposed five criteria based on apparent common practices among autoethnographers, namely, subjectivity, self-reflexivity, resonance, credibility, and contribution (Le Roux, 2017, p. 204). My study was cognisant of these all-inclusive criteria as I committed to writing my PhD thesis.

## **Limitations of the Study**

Any study has its limitations and this present work is no exception. The study was guided by the research objectives and therefore limited to my breast cancer experience in relation to my intersecting personal and professional identities. The personal accounts and experiences are subjective and therefore, make no claim whatsoever to be representative of professional women of colour who have experienced breast cancer.

One of the criticisms of autoethnography is its reliance on personal memories, a characteristic that was deliberated upon earlier. Retrospectively, by retelling and repeating my past experiences in memory (Buckley, 2015), I was able to discover new meaningful ways of knowing and exploring the transformative self. Firstly, this process generated such a volume of memories that I had to restrict my data selection in accordance with the stated

objectives of the study. Secondly, I was aware that recalling and re-accessing information about past experiences may not be the same as the real events, a dynamic which Muncey (2005) alludes to in her article. To address these concerns, my critical friends guided the process and the use of various data sources to layer the meaning of my breast cancer experiences. Thirdly, while I recognised the potential implications my narratives may have on a vulnerable reader, I was guided by the judgement of Méndez (2013, p. 284), that the aim of autoethnography was to "recreate the researcher's experience in a reflexive way, aiming at making a connection to the reader". I envisaged such a connection that will encourage the reader to critically reflect on her/his own lived experiences. Finally, I was aware the data captures experiences in a specific context at a point in time and attempting to present these important experiences on a chronological timeline was not always possible. Hence, their appearance within the intersecting analytical chapters was deemed appropriate.

More importantly, the data selected meaningfully relates to the objective of my study as it ultimately contributes to knowledge. My primary focus was that of the analytical process of my breast cancer experience, rather than egocentricity or evocative presentation. Ellis and Bochner (2000, p. 745) thus state that autoethnography as a narrative, "is always about a story about the past and not the past itself". I was firmly focused on this statement as I wrote my analytical chapters.

#### **Conclusion**

In summary, within this chapter I have sought to demonstrate how autoethnography as a methodological tool was "indivisibly integrated" (Scott, 2014, p. 70) within my PhD process. In addition, the process of exploring and "figuring" (Bochner & Ellis, 2006, p. 111) the messiness of my breast cancer experience was to ultimately make meaning of my

intersectional experiences. Like Siddique (2011), as a researcher-practitioner, I believe there are merits in adopting autoethnography as a methodology as it complements my own practice. The data selected and validated for inclusion thus informed the intersecting analysis chapters which follow. Encouraged by Komatsu (2017, p. 15), I explored "the meaning of the unseen" by using the data I selected and delving into the invisible and the unknown to interrogate the assumption of self, other and world. In the words of Siddique (2011, p. 315), this approach allowed me, "to move out of the comfort of the therapists' chair to be in the thick of it".

## **Chapter Three**

## **Contextualising my Intersecting Subjective Identities**

The following three chapters are devoted to thematically analyse my intersecting identities. In this first of these three analytical chapters, I focus on my personal identities. Chapter four will relate to my professional identities, with chapter five analysing the contextualising interconnectivity within the community of caring. Despite these three analytical chapters being inextricably linked, to satisfy the objectives of the study, they appear as discretely presented components within the thesis, with each thematically framed and informed by autoethnography and interconnectivity. As established in the methodology chapter, the analytical and interpretive meanings of my experience are situated within and between the intersecting identities as depicted in the chapters that follow. Such intersectionality is acknowledged by Shin et al. (2017), who suggests that it reflects a "much more radical and transformative potential than when it is used only as a prop for supporting the contention that people are multiple things at the same time" (p 459). It also allows for critical examination of the perceived rigid boundaries assigned to the identities that I will identify and navigate. The chapter contextualises my identities as an only child, residing in Wentworth, the background to my breast cancer diagnosis, and the interconnectivity within community and spiritual spaces.

My commitment to innovatively explore different modalities of my healing often resonated with my levels of comfortability. Indeed, such a process offered me a certain level of coherence to expose myself to different sites that would facilitate my healing journey, including my concentric circles of healing and care, my journaling, reflective poetry, and photographic evidence. These experiences further affirmed my philosophical practice

perspectives when interacting even in the therapeutic space to facilitate healing in others. As I noted in chapter one, Siméus (2016) chose individual therapy in her pathway to healing. I however chose a different route, by considering different modalities that contributed to the coherence and accuracy of situating my breast cancer experience. This chapter supports my autoethnographic contextual breast cancer journey using poetry, identifying photographs that chronicled my experience, selected extracts from my journals and personal communication with others depicting the exploration of the transformative self. This process of reflection allowed for the invisible to become visible within my PhD journey. Considering Komatsu (2017, p. 26) encouragement for researchers to "rethink psychological studies to consider how the tension of visible  $\Leftrightarrow$  invisible works in each person's meaning making and actions", the use of autoethnography not only provided deeper meaning into my identities of self, but also exposed the tensions of in/visibility.

## Residing in Wentworth, Durban

The community of Wentworth, Durban, located on the east coast of KZN, was historically demarcated for people identified as Coloured. Invariably, Wentworth came with its associated stigmas, discrimination, and stereotypes, especially within the South African historical context. I was cognisant of being Coloured and the associated racial overtones that existed. Like Erasmus (2001), at the age of 17, I too felt the anger and humiliation of being Coloured, when a White woman at a high school career fair informed me that purely in terms of my race, I would not be accepted to study at the high school because it excludes all other races, except white-Europeans. My initial response was silence and my politeness did not allow me to respond, yet I was tortured by her words. Moreover, the culture of silence in the Coloured community informed my choice not to confront. As Holtzman (2018) has rightfully

argued, the culture of silence and invisibility was a pervasive experience within the Coloured community. Reflecting upon my own experience, such invisibility, and silence progressed into visibility and voice not only in terms of my personal space, but also in my profession.

As I engaged in different forums, I began to gain the confidence to become more visible and vocal.

Words such as "gangsterism, violence, teen pregnancy, and dirty" described communities such as those of Wentworth (Palmer, 2015, p. 200). Popular stereotypes were "being drunkards or fierce fighters" (Palmer, 2015, p. 13) as "weekends in Wentworth signified hard-drinking, aggressive behaviour, fighting and sexual promiscuity" (Palmer, 2015, p. 137), all of which supported the racial stereotypes of the Coloured community. Interrogating such categorisations often occupied my thoughts back then and reflecting on how I sustained and maintained these categorisations was a constant preoccupation. According to Desai (2018, p. 371), residents recognised the "violence that accompanies gang life and drug peddling", where they saw Wentworth, "as *their [sic]* space, a coloured place", as I noted in the introductory chapter.

Figure 3.1 portrays me with an alcoholic drink in my hand, which depicts the racial stereotype. Interestingly, I selected this photograph taken during my 30<sup>th</sup> birthday party, to show that the image may have unintentionally perpetuated this racial stereotype. Like that Boylorn (2017, p. 9), there was an awareness, "to embrace stereotypes as well as to challenge them". In the words of Holman Jones (2018, p.4), it is a "critique of culture through the lens of the self". Yet, by unmasking my free-spirited persona, I potentially reinforced the misperception and mischaracterisation of Coloured women from Wentworth. In other words, I was able to unsettle the habits of being in a Coloured community (Svensson, 2017) as I

embraced the context of cultural change around my own comfortability. It is these intersecting stereotypes rooted in race, gender, and class that became so pervasive within the history of South Africa, that were purposively intended to categorise individuals (Thompson, 2017) and by which I was constantly confronted from within my own community.

Figure 3.1.

My Surprise 30<sup>th</sup> Birthday Party, My Aunt's Home, Wentworth, Durban, 13 October 2001



## The Position of the Only Child

Being the only child to my parents, Rosemary and Aubrey Johns, meant I experienced more focused and attentive parenting with resources and valuable time alone, factors that Pickhardt (2008) and Sorensen (2008) have both acknowledged. My extended family often

reflected on the negative social and emotional stereotypes of being an only child since my parents were the only couple with one child. The typical stereotypes of being spoilt by my parents, being lonely, not learning to share and not experiencing sibling rivalry, were narratives I became accustomed to. Initially, these stereotypes generate some level of discomfort as I became acutely aware that as the only child there were associated privileges. Nonetheless, having an extended family meant constant interaction and socialisation that arguably shaped my social interactions and informed my personal relationships within other conversational spaces. Furthermore, any lack of siblings was not to my detriment as it allowed me quality time with myself to reflect (Pickhardt, 2013), which afforded me the awareness and witnessing my sense of self. I had the privilege to socialise when I preferred to do so. Moreover, having the benefit of reflective time and socialising with my extended family also facilitated the space for me to pursue activities even if it unsettled me to continue to explore myself. Salient examples as a teenager include learning to play the piano that was an activity not common in my community and enlisting in a dance school, which was predominately White during that era. Both activities exposed me to different degrees of discomfort. In hindsight, such exposures created opportunities for me to gain confidence, a sense of independence and responsibility. It also focused on me acknowledging my sense of vulnerability.

As a young adult, another example was my parent's insistence that I take the role of master of ceremonies for most of the family functions. Although I engaged in these activities, at the end of the day I retreated into my room and spent a substantial amount of time reading, journaling, writing poetry or listening to music. My parents inculcated in me a healthy balance, by recognising my independence and valuing age-appropriate dependency.

Such an example of demonstrating my independence and negotiating with my parents occurred at the age of 11, when I elected to remain home alone while they attended a function and have a neighbour check in on me.

Reflecting positively on being an only child, was also acknowledged by Sorensen (2008, p. 166) who claimed that, "only-children are high achievers, successful, independent and mature". Much later, as I engaged in a relationship, I found the statement by Pickhardt (2008, p. 62) particularly validating, that "any partner to whom they commit must accept this solitary streak as an ingrained characteristic". This quality I found in a partner who was also an only child. He respectfully appreciates our quality time apart. It is during these periods that we individualistically engage in activities that we appreciate in our own private spaces.

The bond and closeness with my cousins served as my primary relational support. Referred to by Pickhardt (2013) as surrogate siblings, they facilitated my sense of connectedness, as well as experience of dependence and independence. Moreover, my parents promoted spending quality time on self to reflect on actions and inactions. My extended family relations are typified by beliefs of integrity, support, and loyalty. They established social, cultural, familial cohesiveness and relational interactions, all of which are noted by Edwards and Greeff (2018). My cousins often organised celebratory occasions, often demonstrating their support by acknowledging my endeavours and celebrating my accomplishments as I embodied the person with possibilities. One such occasion, is captured in Figure 3.1.

Within the extended family, I was the only person who attained a Master's degree.

This unsettled the traditional way of knowing within a Coloured community, a feature which Anderson (2009) freely acknowledges. Generally, it is understood that most Coloured people

in my community do not pursue postgraduate degrees. My ambition, which clearly deviated from the stereotypical norm, was self-motivated. Interestingly, during the 1970s and 1980s under apartheid, a racialised employment hierarchy privileged Coloured men to "dominate the welding, boiler-making and semi-skilled and skilled jobs in the building trade" (Desai, 2018, p. 375). Nevertheless, the practice of marginalising men, both professionally and politically, was evident in the workplace. My childhood memories reassert my constant challenging nature where I chose to enrol at a high school in a non-traditional technical course that was predominately intended for males. Thereafter, I challenged the boundary of engaging post-school in at an institution for predominantly White students and subsequently registered for a diploma course in mechanical engineering. This qualification was also primarily populated by White males and I was the sole woman and only student of a different race in the class. I identified my positionality as I intersected across the complex and different systems of "classism, sexism, racism" which Harris and Patton (2018, p. 10) acknowledges as the contextual experiences of people of colour. As Palmer (2015) has shown, students in a Coloured community were encouraged to pursue a profession that provided "them the skills to find jobs and solve problems" (p. 200) such as that of an artisan or skilled worker. By consciously engaging and inhabiting such a "complex positionality" of being in an educational environment that was traditionally confined to males is also acknowledged by May (2015, p 37). My 'othering' created extreme discomfort and after much contemplation, I de-registered from the diploma course in mechanical engineering in 1990. Thereafter, while exploring other possibilities, I engaged in part-time employment and volunteered at an old age facility.

My inclination to work with people became more pronounced as I engaged in various other employment experiences. Pursuing psychology therefore became the logical choice. Again, my Coloured normative script was challenged by not following any stereotypical forms that would normally support my own levels of comfort. It is within the academic space I began to explore and acknowledge my present script to demonstrate, "cultural humility and competence" (Sewell, 2017, p. 113). Palmer (2015, p 200) defends Coloured people who study the "softer arts and sciences" and who typically come from more financially stable families. Despite the financial burden, I was afforded the opportunity to make my own decision and choose psychology as a career path. Psychology was the cornerstone of the helping profession and solving problems as Palmer (2015) notes was the notion of the Coloured identity. Both my parents prioritised education and constantly reinforced the benefits of higher education and promoted the pursuit of a PhD qualification after my breast cancer diagnosis.

At the age of 29, I moved out of my family home and rented an apartment much to the astonishment of my extended family, since it was not considered normative and acceptable to do so. When I was 32, I purchased my own apartment in Sydenham, a Coloured community located west of central Durban. However, the apartment complex I occupied was home to a diverse, multi-cultural, and multi-religious group of homeowners. As an only child, the commonly held perception was that continuing to reside with my parents was sensible, comfortable, and financially practical. Moreover, there was potential to reinforce the stereotype of a young, Coloured, single, educated woman, who was childless and living alone (Boylorn, 2017) and in my case with feral cats. My parents were extremely supportive as I demonstrated my independence and self-reliance.

## **An Interruption: Breast Cancer Diagnosis**

Introspectively, the interruption of my ideal life progression challenged my sociocultural script at both the personal and professional level. Breast cancer was not scripted into
my ideal life story, yet it became a catalyst for personal and professional engagement with
difficult discourses in relation to breast cancer experiences. In truth, the diagnosis initially
angered me by requiring me to confront the unknown. Based on the findings of the study by
Adams et al. (2011), young women's breast cancer experiences revealed a common theme of
"being different and 'out of sync'" as breast cancer "under the age of 45 disrupts a normal
life-course" (p. 854). For the young women and myself, concerns such as reproduction, body
image, sexual relationships and fear of recurrence unsettled and disrupted the social and
cultural prescribed beliefs of a normal life trajectory.

Journaling was one method I used as a facilitative method to process the emotional and physical experience which Sealy, (2012), van der Wiel (2013a), Hayman et al. (2012) and Williams and Jeanetta (2014) found to be a beneficial practice. I was grateful for the reflective space to interrogate how to reframe this experience and visualise myself transformed by cancer. Journaling allowed me to negotiate my inner thoughts, emotions and "my need for advocacy" (Bhattacharya, 2016, p. 316). I reflected on the concept of the wounded healer and the salient meaning it now occupied in my lived experience.

The understanding of my psychological health was equally prioritised. In my silent moments, I reflected on my healthcare experience, especially my hospitalisation and the priority of patient-centred care particularly from some members of the medical team. A journal entry, dated 25 April 2005, captures the sense of silence prior to my surgery on 06 September 2004:

The voices of doubt and confusion silenced by my vulnerability and honesty. I found my strength. Now I am ready for the wide local excision and frozen section to verify my diagnosis. My breast would never be the same again.

Most importantly, I valued the truth of my diagnosis and treatment process to facilitate my understanding of how breast cancer influenced my emotional and physical healing. It was during my journaling that I tacitly embraced the associated emotions of anger, anxiety, and vulnerability. I also recognised that the breast cancer diagnosis unsettled my perception of health and through the journal process I embraced the unknown and noncertainty.

Apart from this, I reflected with a sense of disappointment on a medical professional's lack of sensitivity and thoughtfulness. A similar lack of interpersonal skills was also noted in the study by Lekhuleni and Mothiba (2013). Another essential aspect noted by Edwards and Greeff (2018) was that patients tend to be "submissive to medical authority" and there were "few opportunities for patient-inputs" (p. 1416). With reference to the SSA context, Tetteh (2017) captures the lack of patient-centeredness in the healthcare system and that health decisions are often made without consultation with the patient. These factors directly or indirectly contribute to the detriment of the doctor-patient relationship and a reduction in the quality of life. In support of this assessment, the findings of Kugbey et al. (2018) suggest that the improvement in quality of life of women with breast cancer was probably related to patient involvement in the decision-making process. Providing patients with treatment and healthcare options, combined with effective communication tends to improve the doctor-patient relationship. Due to my unpleasant experience, I elected to choose an oncologist that prioritised my voice and afforded me the opportunity to converse around my social-cultural

anxieties, medical procedures, and side effects. My oncologist understood these tensions that existed within a doctor-patient relationship. Hence, our mutually shared philosophy of patient-centeredness and managing comfortability and compatibility informed my final decision to appoint her as my oncologist.

I recalled my oncologist's words that the breast cancer was, "God's way to say stop and pay attention" (personal communication, September 2004), a sentiment I readily accepted from my own spiritual space. By her sharing such compassion and empathy, she acknowledged my vulnerability as a patient and the experience reasserted a level of confidence in my healing journey. In their study, Lynn et al. (2014, p. 1713) found women of colour identified the use of religion and spiritual practices, "to accept their diagnosis, gain comfort and inspiration, and actively cope". This conclusion both authenticated and confirmed my experience. I was particularly reminded of Condit's (2016) article entitled, "Catholic social teaching: Precepts for healthcare reform", which addressed the social teachings of "human dignity, common good, solidarity, and subsidiarity" (p. 370). Specifically, I recalled the relevance of my own intersecting realities of being a psychologist raised within a Roman Catholic community and now as a patient having to encounter the healthcare system. I was acutely aware I was not my diagnosis, but a person on either side of the healthcare system whose dignity always had to be maintained. Another supportive space was my concentric family circle of care who afforded the articulation of my understanding of my unpleasant medical experience.

A journal entry, dated 25 April 2005, demonstrates the interrogation of my inner existential qualities with the focus upon my definition of self:

I was not the psychologist but a woman diagnosed with breast cancer and had a mastectomy. Simple. I hear the words I needed to hear so desperately with no sugar-coated-half-truths, but with unthreatened vulnerability and honesty.

Vulnerability became integral to my healing. In an article by Shildrick entitled, "Becoming vulnerable: Contagious encounters and the ethics of risk", the author proposes to reframe vulnerability not as weakness "but as the very possibility of becoming" (2000, p. 215), a perspective which resonates well with that of Brown (2012). In other words, the feeling of vulnerability experienced during illness can foster resilience and personal growth. From the findings of their study, Tiedtke et al. (2012) concluded it was important for professionals to consider the "feeling of vulnerability of breast cancer survivors" (p. 11). In my study, I explore the interconnection between vulnerability and resilience which is pivotal to my breast cancer experience. Hence, as a professional who experienced breast cancer, there is a need to acknowledge both my professional and personal expressions of vulnerability and resilience.

Another noticeable aspect is the realisation that I prioritised others needs over my own and post-diagnosis readjusted my boundaries to be reflective of prioritising my own personal space. The creation of these relational boundaries incrementally offered healthier and better-quality relationships. These qualities of honesty, hope and resilience particularly arose during my periods of vulnerability, where I interacted authentically about my own comfortability. I thus asserted my own identity, resolutely deciding not to be subscribed to any stereotypical views on breast cancer. This eventually became a sustained pathway towards my healing. The process also meant the unsettling and flexing of my personal and professional identities, which was a reflective narrative describing the experiences before and

after my surgeries captured on 24 April 2005. This was a deeply subjective rant on self and other expectations of my reaction to the breast cancer diagnosis. As a young Coloured South African female psychologist, I had a new inescapable, unavoidable illness identity to contend with (Froude et al., 2017), the identity of a breast cancer patient. With this new emerging identity and the intersecting of womanhood, age, race, culture, and psychological knowledge, I witnessed a dynamic interplay that was reflected in a journal entry, dated 24 April 2005:

The space to be a woman and not a psychologist blurs into grey, because the ingrained voices of psychological theory escaped the confines of the psychologist box to articulated rational judgment. To fuel this impression, the obscure voice of a non-significant member reminds me that I am a psychologist therefore, 'I should know these things!' Meaning, I should be able to handle the situation with great ease and no stress what so ever. The luxury of being irrational, emotional, and uncertain is characteristics not displayed by a professional, educated individual. In this case, a psychologist. The dual relationship of 'a woman with breast cancer and-psychologist' was generally inconceivable especially in the profession I am in which expects healing of others.

From this journal entry, the socio-cultural constructions of my identities as a woman and psychologist, were emphasised and interrogated for the functionality they provided situationally within the continuum of autoethnography. As a woman and psychologist, my reaction to the new identity was observed and assumed by others to be an easy, seamless transition of acceptance and understanding. This privileged positionality of a psychologist was perceived to be rational, logical, sensible, decisive, knowledgeable and an expert on human thoughts, emotions, and behaviour. My experience was not a taken-for-granted

phenomenon; instead, it dictated that I embrace a myriad of emotions (Bager-Charleson & Kasap, 2017; Buckley, 2015; Chapman-Clarke, 2016), each of which complemented my training as a psychologist. The interrogation of my thoughts tormented me since it was fuelled with anger and disappointment that I was diagnosed with breast cancer. From the journal entry cited above, the interrogation of my intersecting identities called into question my professional persona and how such professionalism does not prioritise vulnerability. The diagnosis of my breast cancer thus positioned me as a patient to understand my physical illness. This was a reflective encounter, which resonated well with my own clinical practice as a psychologist as I occupied the space of reflective healing.

I believed my body betrayed me despite my healthy lifestyle and my new identity felt imposed, much like that of Greenhalgh (2017). By narrating my autobiographical experience, this process become a privileged space for healing to occur. My journal entries and photographs capture the essence of these sentiments. In addition, the various forums with which I engaged and interacted, was undoubtedly a privileged space to occupy. The reconnection to my body initially was facilitated through the engagement of dance, yoga, and tai chi. Thereafter, it seemed logical for me to enlist in two dance schools, i.e. Latin American and belly dancing. Reflectively, it became apparent that I reconnected with my adolescent activities of dance and exercise as a form of healing.

The final duality of accepting the woman-psychologist identities emanated from several hours of tortured thought. It is within this duality that I questioned how do I heal others when I need healing myself. I questioned who should facilitate this healing, since I usually facilitate healing in others. In response, I realised my emotions were expressed in isolation until I gained the confidence to be more visual and engage with the public. Often, I

used my reflection and contemplation of the varied emotions in the different spaces I occupied to address this duality. The expectation of false bravado again was interrogated, as I did not hesitate to digress from normativity on my levels of comfort as I questioned stereotypical notions of personal and professional spaces. The blurring of these evocative perspectives once again welcomed and solidified the continuum of uncertainty, especially as I questioned myself in the research process. This was explored comprehensively in the previous chapter.

#### **Breast Cancer: An Embodied Experience**

Evidently, there is an absence of the body in research. Researchers such as Longhurst et al. (2008); Roth and Lawless (2002); Samudra (2008) and Waples (2014) acknowledge the significance of embodied experiences in "understanding human life" (Carless & Douglas, 2016, p. 48). The body is viewed as the place of illness (Kielhofner & Mallinson, 1997) and the place of knowledge (Knoblauch, 2012). The literature suggests it is difficult to separate the body and mind as these are closely intertwined in producing embodied cognition (Häfner, 2013). In addition, phenomenologists have challenged the artificial body-mind disconnection and encouraged further inquiry within different disciplines, for example, clinical practice in psychiatry and psychotherapy (Crawford, 2010). New insights of the interconnectivity of body and mind have been generated by some studies that promote further investigation of this "intimate and inseparable" relationship (Crawford, 2010, p.703). I conceded that this inextricable link existed as I contemplated my own breast cancer experience.

Within the medical process, I exercised my decision-making as a patient. It allowed me to not only assert agency over my own body, but also to detoxify and incorporate a healthier lifestyle to holistic care (Brown & de Jong, 2018; Coetzee et al., 2019). Like

Gibson et al. (2015, p. 132) I remained "vigilant for recurrence". I asserted myself through a wounded body with the goal of seeking wellness and meaning. For Waples (2014), this process of embodied experiences and knowledge was essential to redefining my self-presentation which further illustrated the body-mind synergy.

Reflecting on Spence's (1995, p. 213) experience of a failed dialogue between herself and her surgeon and on her "not knowing how to have a dialogue", I specifically reflected on prioritising my comfort levels and determined the referring oncologist was someone I resonated with. As noted by Lourens (2013), in the South African context, the "sociopolitical history has conditioned people to be polite and submissive, especially toward educated and authoritative people" (p. 116). This situation creates invisibility and lack of voice of the patient which is an aspect I witnessed in my childhood, where any form of authority was supposed to be revered. By questioning such authority, it was presumed one was being disrespectful of her/his expertise. Hence, I chose a female oncologist of colour who immediately synergised with my own priority of giving voice to the patient. She did not view me as a passive health consumer as a recipient of medical attention who consented to any suggestion she made. Within the doctor-patient relationship, she often allowed my voice on being the authority of my body to be expressed. Her medical expertise thereafter complemented my own analysis and this allowed her to focus on the best treatment plan. Our consultation was typified by the discussion on both the limitations and benefits of her treatment suggestions. My experience with my oncologist was holistic, as she constantly focused on my contextual lived realities and employed the perspective of viewing my breast cancer in the context of my intersecting identities.

## My Vulnerable Breasts: The Site and Sight of Transformative Healing.

According to Williams (2012, 2012, p. 7), the breast was viewed for many years "as a wonderful adornment-like the peacock's tail-designed to attract the opposite sex". Yalom (1997) also elaborates on the multiplicity of meanings with respect to breasts:

From outside, the breast represents another reality, and one that varies in the eyes of each beholder. Babies see food. Men see sex. Doctors see disease. Business sees dollar signs. Religious authorities transform breasts into spiritual symbols, whereas politicians appropriate them for nationalistic ends. Psychoanalysts place them at the centre of the unconscious, as if they were unchanging monoliths. The multiplicity of meanings suggests the breast's privileged place in the human imagination (p. 275).

The first line had relational prominence for me as I isolated an incident that occurred after my mastectomy, when a relative ("eyes of the beholder") stated in jest, "your partner will only have one breast to play with" (S. D. Singh, personal communication, 04 May 2018). His interpretations communicated stereotypical sexual overtones that suggested the pleasure of the other. My immediate response was as follows: Is this man questioning the loss of my femininity as the breast is stereotypically viewed as the site of sexuality. My reflective response was to acknowledge the dominant ideology on the politics of the body as I navigated and contemplated thoughts of loss, vulnerability, sexuality, and femininity as it constituted my holistic self. This feeling was also confirmed by Sun et al. (2018, p. 377), that "the loss of the breast is related to the women sense of self, identify, femininity, and sexuality", a conclusion also supported by Fallbjörk et al. (2012) and Manderson and Stirling (2007).

In addition to the above experience, the breasts represent different interpretations for those that intersected with my reality. The medical professional, my oncologist, viewed it as a disease to be managed (Froude et al., 2017), which is also discussed in the study by Brown and de Jong (2018). The legitimacy of the medical dominant discourse that is recognised and supported by its scientific status has been influential in shaping women's illness experiences. My health perspective was to reconstruct my identity positively (Gibson et al., 2015) being cognisant of my own context.

In their review of sociocultural factors in the African context, Akuoko et al. (2017), found that women "make health a low priority" (p. 11), a finding which Tetteh (2017) also confirms. Furthermore, their study revealed African women experience stigma and poor self-esteem that invariably delayed them acquiring healthcare assistance. My experience was evidently different as I prioritised my health and sought medical assistance immediately. Moreover, there was little stigma or feelings of poor self-esteem particularly from my self-reflective perspective. The priority on self-care was inculcated in me as a child and progressively within my profession. These medical challenges presented the opportunity to gain trust and confidence in my own decision-making, always within a reflective and real space. A significant concern often confronting women with breast cancer is breast reconstruction. Often in SSA, the high cost of breast reconstruction surgery is a significantly determining factor (Tetteh, 2017) after a mastectomy. Another associated issue to consider is the profit margin for cosmetic surgeons. To address this in SA, the Helen Joseph Breast Care Clinic (HJBCC) offers breast cancer surgery to women at little to no cost (van der Wiel, 2013a). The concept of breast reconstruction I explore more in-depth later in the chapter.

## **Debating the Inclusion of Photographs**

As detailed in chapter one, I requested my mother to take photographs which she readily conceded to do, but questioned the purpose and future use of these photographs of my lumpectomy and mastectomy. Her feelings were justified as DeShazer (2016, p. 119) notes, that photographs of women with breast cancer may evoke "ambivalence or controversy". In particular, she was concerned how the consumers of these photographs, amongst others, who possibly have breast cancer themselves, would be able to visualise the illness and the scarring. Moreover, from her social-cultural perspective, these photographs would break the "cultural silence" (DeShazer, 2016, p.120) and deviate from the normative Coloured cultural script. In response to my mother's legitimate query, I agreed to block my face and/or surgical wound. Subsequently, when my breast cancer experience matured into a PhD study, I revisited these pictures with my parents and my partner. The photographs of both post-surgeries were shared with my partner with no pressure and our discussion revolved around body image, femininity and sexuality, and a mature sense of comfortability prevailed.

Moreover, my partner's sense of humour was facilitative during these discussions.

My mother's apprehension reiterated the vulnerability and visibility of the photographs selected and its utility in the PhD study. In particular, she remarked, "you have to cover up, you can't be exposed like this, you did say you will cut your face out later" (R. T. Johns, personal communication, 06 May 2018). In response, my mother and I had one of many lengthy discussions about the merits of her perceptions as a parent, particularly as a mother. Clearly, I appreciated her maternal thoughts about exposure and her suggestion on how best to pictorially represent my healing journey. As much as she reminded me that in one of the initial discussions, I had suggested that I would block out my face, we

progressively reached a level of consensus to retain the photographs for the PhD study. Mitchell (2017) also debated such visual displays. Particularly, as it draws attention to power dynamics and the ethics surrounding such graphic representation of my illness. I nevertheless maintained that these photographs were a powerful and influential method of depicting by different identities. These photographs aptly captured post-surgery and it coherently substantiates my confidence which was a salient aspect that my father articulated as, "courage, determination and will power to get through it, and you did not ask why me why me" (A. W. Johns, personal communication, 06 May 2018). My father's reflections focused on my levels of optimism and not being labelled a victim. He recognised that I was practically and realistically focused on solutions towards my healing.

Often in discussions with both my parents, my father also acknowledged my mother's inherent maternal unease about the visibility and exposure within the public domain. My father, however, reaffirmed my courage and determination and had no anxieties about exposure in the public, which from his perspective as both a parent and male seemed harmless. Yet, my mother within her gendered perspective was mindful of such exposure and visibility and the associated vulnerability, especially from my cultural and religious community.

Since my culture dictates that women's bodily parts should not be exposed, as exposing women's bodies communicates disrespect not only to self but also to the family and community, who will ultimately view it as digressing from the normativity of the representation of women and femininity. My community values conservativeness and decorum and celebrates womanhood to fit an idea of gentility and femininity. Likewise, this

ethos was reiterated within family spaces that promoted and instilled this conservative decorum and space, and in which I belonged for a substantial part of my life.

Being cognisant of the socio-cultural-religious connotation, when I contemplated the endeavour of a PhD thesis, I reflectively accepted that I would be publicly sharing my vulnerable self. Doh and Pompper (2015) acknowledge that not everyone would publicly want to share information about the female breast. As noted earlier by Palmer (2015 p. 137), "sexual promiscuity" was often used to describe the Coloured community, a stereotype we were all acutely aware of. When exploring this aspect from my own perspective, the female breast was not objectified, but was rather viewed as a site of illness requiring immediate medical intervention. When I contemplated the photographs and their utility, it ultimately added to my own interpretation of wholeness and the possibility towards redefining my intersecting identities.

As noted earlier by Mitchell (2016) and Schwandt (2007), the process of autoethnography involves the movement of inward-outward exploration. Complementary to this practice, Swinton et al. (2011, p. 640) from a spiritual context, refers to "inwards, outwards and upwards", as a process that validates my inextricable link of mind, body and spirit that coherently added to my personhood. The additional concept of "upwards" suggests for me a more spiritual engagement with the Higher Power, i.e. God. I thus considered the sharing of the photographs not as embarrassing or shaming, but rather as capturing the essence of my "upwards" spiritual engagement and contemplative self in my healing journey. My parents acknowledged this spiritual component that was pivotal to my healing journey, in their poem to me five years later. This journey was indicative of my vulnerability as a spiritual being.

My mother recalled my assertion of independence and courage by embracing my medical treatment without any further physical support, for example, my attending radiation, and other medical intervention independently. She continued her support by preparing nutritious meals, inquiring of my post-treatment of my experience, and constantly accessing new information prevalent in the breast cancer community. The latter became a point of discussion between my parents and myself.

In response to the study by Shaw et al. (2016) on women's dating experiences after breast cancer that captured reports of poor body image and self-esteem, I too reflected on my own sense of poor body image and self-esteem. The fluctuation in my weight also created differing levels of physical discomfort. On one occasion, the reactions of a male friend about my weight gain startled me as he remembered my physique prior to my breast cancer diagnosis. A concomitant issue was my confidence and self-esteem in contemplating reentering the dating space. I meaningfully engaged with the dating space, commencing first by socialising with friends and progressing to occasional speed dating. Thereafter, a mutual friend introduced me to my present partner who is of a different ethnicity, religion and is 13 years my senior. Our mutually shared interests were community engagement, social advocacy, academic space, and passion for animals, a wicked sense of humour and respect for individuality. I initiated the discussion of my breast cancer and his pragmatic response was informed by his own medical knowledge. He did not view the mastectomy as a deterrent in pursuing the relationship and expressed unconditional acceptance of the role cancer played in our relationship. Also, his mature perspective facilitated authenticity in the relationship and prioritised the value of individuality. He describes me as "a person that I see as natural not unnecessarily made up" (S. D. Singh, personal communication, 04 May 2018). This level of authenticity was not only acceptable in our relationship, but was further validated when he viewed the post-surgery photographs for the first time.

Like my parents, my partner also reflectively articulated thoughts of exposure and vulnerability within a broader domain and questioned logically the form of presentation: "Do they allow the person's face to be exposed, or do you block the face out?" This question was a legitimate ethical concern, as he is a member of the Biomedical Research Ethics Committee (BREC) at UKZN. Again, my agency was demonstrated in my response when I affirmed: "It is my face. My image" (L. T. Johns, personal communication, 04 May 2018). After hours of discussion, it was mutually accepted and confirmed that the photographs allowed ownership of my breast cancer experiences. His decision left no room for doubt: "This is your story. You are writing your story" (S. D. Singh, personal communication, 04 May 2018). The sense of ownership once again being mine without editing any of the processes validated my internal script of connectivity and care. Moreover, he assisted in realigning my commitment to research ethics on authenticating my own voice and remaining true to the tradition of autoethnography, which Kumari (2017, p. 84) identifies as maintaining an "idiosyncratic voice". He identified with the duality of my voice as a researcher with breast cancer, since he too had recently completed a PhD and could readily identify with the writing process. His support resonated with the study by Shaw et al. (2016, p 326) that participants' partners were "calm, supportive, encouraging and accepting". The deliberations with my parents and partner facilitated the choice of the photograph in Figure 3.2.

## Visualising the Scar

By including the photograph, I knowingly lend credibility to making visible my breast cancer which similar Waples (2014) identifies as what is depicted and what remains invisible

which contributed to my breast cancer textually. The paradox is also acknowledged by DeShazer (2016) on how photographic narratives depict vulnerability yet demonstrate strength. During the taking of this photograph, my mother and I at first dialogued through the initial anxiety and apprehension of capturing my loss photographically. The dialogue gave rise to humour. In their exploration of the lived experiences of breast cancer survivors from diagnosis, treatment and beyond, Williams and Jeanetta (2016) found that humour was used as a means of coping with the seriousness of the breast cancer process. Hence, this photograph captures the interchange of my private experience becoming a public engagement.

Figure 3.2.

Photograph taken by my Mother, Post-Surgery, Wentworth, Durban, 16 September 2004



The photograph captures my "visual breast cancer narratives" (DeShazer, 2016, p. 119) of loss and triumph, of illness and health. It embodies the memorialising of the surgery experience (Doh & Pompper, 2015). This photograph is one that troubled and unsettled my sense of self when speaking about my post-mastectomy body. My mastectomy visually presented a bodily transformation and like participants in Manderson and Stirling's (2007) study, I initially experienced my scar as "confronting" (p. 87). I recall hiding the "unfeminine surgical drains, infusion devices" (Doh & Pompper (2015, p. 600) under the pyjama shirt. My smile and the covered surgical scar can be viewed as ambiguous. The smile expressed my cordiality and sociability, while the scar presented loss as well as opportunities for personal growth. Over time, I accepted that my body had to relearn "how to move and feel" (Doh & Pompper, 2015, p. 600) as I navigated my healing process.

My confrontation of my breast cancer did not isolate me as I engaged openly with family and friends to make sense of the experience. On one occasion, I offered to share my scarring with a friend, which was not received positively. On another, a family member questioned my reasons for not showing her my scar. During these conversations, it was their discomfort that I needed to facilitate to accommodate the myths surrounding a mastectomy. It was in these spaces that I recognised my discomfort about having a mastectomy and my confusion as to who I could safely share the visual experience with. The process of constant communication with family and friends about my private experience becoming public facilitated my comfortability in accepting the healing discourse around my body being less fragile, feminine, and redefined.

Coincidently, my partner has a scar from his heart surgery and very often, our common scarring became focal to our healthy debate about body image and disfigurement.

In the study by Freidus (2017), men also reported not being bothered by scars. Our candidness and honesty contributed to the success of our relationship to date. Our relationship is often typified by humour and assistance and the need for privacy and silence is mutually agreed upon. This finds resonance with the study conducted by Shaw et al. (2016), which also focused on such traits within a relationship. Humour is a significant aspect of our relationship, where often the playfulness and light-heartedness further connected us to each other. Shaw et al. (2016) also acknowledged such playfulness in their study. Reflectively, the strength of our relationship has often rested upon our deferring perspectives and our mutual capability that are often complementary. Such strength was also acknowledged by Freidus (2017). In addition, his focus on rehabilitation was a priority. Moreover, our relationship from different perspectives often focused on vulnerabilities and how foundationally we have a shared vision. Our respective professions focused on healing space and prioritising communication both verbally and non-verbally.

As my confidence grew beyond my immediate family, my invitation to view the scar extended to three female work colleagues and friends who visited in October 2004. This spontaneous invitation unsettled on several levels not only my colleagues, but upon reflection even myself. Interestingly, although all my colleagues who visited on that occasion were females, their immediate response was a respectful polite "no" with no further reference made to the physicality. I was respectful of their response. My perspective was of quiet acceptance of their own comfortability, which did not require further interrogation. This experience reminded me that in the act of listening there was an "obligation toward another human being" (Charon, 2006).

Post-visit, I continued to reflect on my own motivations to reveal the scar. Initially, I experienced feelings of guilt and regret as I may have placed my friends in an uncomfortable position. I questioned if I possibly offended them or violated a boundary of our friendship. Exploring these emotions more deeply, I found helpful as I recognised the effects on my choices and the importance of feeling responsible for my actions. This reflective experience facilitated my progressive confidence in accepting the scar as my 'new' body allowed. Moreover, I conceded that the invitation to discuss and view the scar represented the beginning of my comfortability, confidence, and willingness to expose a part of me to significant others. Once again, Manderson and Stirling's (2007, p. 88) concept of "sight/site" emerged. I felt comfortable to refer to the mastectomy scar instead of the popular reference to my breast/s or my mastectomy. The scar provided the space for dialogical interaction with self and others. Evidently, for me, womanhood, self-image, and sexuality did not depend on possessing two breasts only. The scar for me was construed as a temporary feature that will potentially heal in time. I progressively and contextually redefined what beauty and femininity meant to me, which is also shared by DeShazer (2016).

The breast also became a site of humour as I reflected on one incident in the gym. A journal entry dated 10 October 2006 captures my jocular interpretation:

Training when one breast moves to the rhythm of the music, while the 'other' remains fixed, false, and fake.

I reflected on stories shared by the C-Sisters of their touches of humour related to the use of a prosthesis. One shared her story of the prosthesis floating in the pool and swimming to retrieve it, while the other narrated the occasion of forgetting her prosthesis on the

passenger seat while she shopped and only became aware of its absence when she returned to her car. Reflecting on these humorous incidences, it often allows breast cancer to be understood within evolving and transformative contexts.

For two years, I preferred not to use an external prosthesis, but rather employed scarves, socks, and a makeshift cotton wool breast in my bra so that I did not have to contend with the weight of a prosthesis. I found ways to create a look of breast symmetry. Personally, this process allowed me to explore my lived understanding of a body with one breast. I recall still wearing strapping tops for six months after my surgery. The creative use of the neck scarf became a common feature of my daily attire and ascetically the draping provided an illusion of breast symmetry. Within the professional space that reasserted and prescribed the expectation of etiquette, attire, and presentation, I deliberately prioritised my own comfortability and adjusting to my changing bodily shape. I did not subscribe to any normative perspective on how I should represent myself professionally. To illustrate, prior to breast cancer, make-up was not an essential feature of my attire, which continued post-breast cancer to the present. Generations of women in my family, including that of my mother, often asserted a preference for being natural in appearance. I reflected this was one feature that my partner declared his appreciation for. However, when occasions so dictate, I am comfortable to wear make-up. The photographs in my photoshoots capture such occasions. As such, reasserting my individuality and prioritising the quality of my engagement within these spaces such as workshops, conferences, and seminars became the new norm for me. This was also my perspective that prevailed in my practice.

As with Lorde (1980), I initially rejected wearing an external prosthesis when it was suggested to me post-surgery. As explained by Fallbjörk et al. (2013, p. 343), "wearing an

external prosthesis in everyday life can camouflage the cancer wound physically and, to some extent, also psychologically". While it created an outward appearance of breast symmetry, the feelings of emotional and physical discomfort were nonetheless covered by an external object with a promise of normalcy. However, my choice not to wear an external prosthesis was challenged when exercising at the gym or in yoga class. Even though I wore tank tops and sports bras in the hope that my creative inserts would not move or fall out, there were a few hilarious moments during my workouts. I accepted the external prosthesis and mastectomy bra as practical and suitable for my lifestyle, which as van der Weil (2013) notes, is an alternative to breast reconstruction. Despite being cognisant of not maintaining a heteronormative cultural script, I did so for my own comfortability. Within those first two years I debated how such an appendage would create a difference around my identity as a woman and to what extent I would be emotionally comfortable wearing one. Unlike Tetteh (2017, p. 320) who thinks that women's attempt to normalise their experiences using a prosthesis is due to "cultural expectations of the feminine body to be double-breasted to be considered beautiful", my decision was determined by my comfort and confidence.

Another option for breast symmetry was that of reconstruction. I did not consider reconstruction surgery, as I did not view my transformed identity as requiring an additional appendage. Instead, I devoted my energies to the psychological ramifications of my new identity as it intersected with the various spaces I occupied. Scholars such as Adams et al. (2011); Doh and Pompper (2015); Fallbjörk et al. (2013); Tetteh (2017), and van der Weil (2013) have debated the various merits of breast reconstruction.

The cultural and social lens I belonged to dictated that women should be respectfully covered. The societal stereotypical perspective of covering and uncovering came to a focal

point after breast cancer that spoke to my comfortability to unlearn what I had learned beforehand as a young woman. To promote respectability within my Coloured culture, the internal narrative inculcated as a young woman was to be covered up and to expose as little of your physical self. I unlearned this after breast cancer by confronting normative stereotypes when I engaged in photoshoots that emphasised my femininity.

## The Lens of the Photoshoot Amplifies the Nuances of My Intersecting Identities

Approximately six months after Figure 3.2 was captured, I was invited to participate in a professional photoshoot as captured in Figure 3.3., dated 26 May 2005. This was my first experience of a professional photo shoot and I was advised to bring attire that I was most comfortable wearing. My perspective was to view this engagement as an adventure and to capture my journey in a professional way. In hindsight, it did generate a little anxiety for me. Similarly, to other young women diagnosed with breast cancer, I also viewed my "mastectomised body as a deviation from a normative female body" (Adams et al., 2011, p. 855). Within this intimate space, my nonconforming body changed by surgery and radiation socially engaged with the photographer to explore my "appearance as a bodily experience" [sic] (Ucok, 2005, p. 292). What became apparent from the photograph taken by my mother compared to that of the professional photograph was the orchestrated space with direction from the photographer. Like the experience with my mother, it was also initially anxiety provoking and uncomfortable having a professional photographer engage with me in this space. My internal dialogue explored reasons for my initial anxiety and after acknowledging this, I then meaningfully engaged with the photographer. The dialogue facilitated a deeper connection between the camera lens and myself. These photographs framed moments of expression in time.

Upon reflection, the experience afforded me the opportunity to confidently embrace the new embodied self and to translate the narrative of confidence visually. Furthermore, it captured the feminine self through a lens within my transformative journey. The first photoshoot emphasised my contemplative self as I navigated through the multiple identities that informed and framed my own internal scripts of femininity and sexuality.

Figure 3.3.

Umgeni Business Park, Durban, 26 May 2005



To extend my level of confidence, a second photo shoot took place on 09 February 2007. Instead of capturing breast cancer as tragic, its purpose was to employ the notion of artistic licence to incorporate humour and playfulness. This experience offered a nuanced visual version of my femininity as compared to the image in Figure 3.3. It re-emphasised my journey of illness to wellness and gave voice to my intersecting identities.

In Figure 3.4., my connection progressively became more directive with the camera lens and communicated my evolving self. The photo shoot itself was initially intended for my parents and myself and not to be shared beyond my concentric circle of care. Its inclusion in this PhD study was justified contextually to visually capture the different levels of my confidence. It added to my reflections on the developmental and transformative phases of my illness. The anonymity of the photographer reinforced my confidence and courage with the invisibility and visibility of the illness to be effectively captured.

The photographs reflected the calm acceptance of the vulnerable self and the confidence to visualise such vulnerabilities. As recognised and acknowledged by Teunissen et al. (2015, p. 303), "vulnerability and dependency of patients are factors to take into account in health policy discourse, professional health practice and patient involvement" and provided a "counter story" (p. 288) which I demonstrated through my choices. Similarly, Gibson et al. (2015) concluded that women who position themselves as empowered and in control of their own health could make sense of their cancer experience. Clearly, giving visibility to my own internal script reaffirmed my self-confidence and brought to fruition some of my anxiety and heteronormative cultural script of exposure of the body, beauty, and femininity. Davis and Warren-Findlow (2012, p. 312) have suggested that such a reframing provides "a sense of control over" the body, which is depicted in Figure 3.4. The hat and hand, symbolic of self-nurturance and reflectively related to my internal dialogue of nurturance. Evidently, these photoshoots were examples of self-experimentation that motivated reflexivity (Corti et al., 2015).

**Figure 3.4.**Photograph taken by a professional photographer, Umhlanga Rocks, Durban, 09 February 2007



Figure 3.4 is one representation of my acceptance of my beauty and the female form as it represents the construction of the self, post-surgery. In addition, I became more acquainted with body activism and the re-definition of beauty, especially as "public breast cancer culture" developed (DeShazer, 2016, p. 122). It added to the existing breast cancer narrative that was sometimes more textual than visual and posed pertinent questions of

mainstream femininity and beauty. Furthermore, this photograph challenges the dominant representation of Coloured cultural identities. This is particularly true of women who have not been the representational focus of breast cancer in mainstream media, especially when representation is depicted in the South African landscape that is both complex and diverse. In the breast cancer post-operative community, the pertinent questions that I reflected upon concerned whose bodies are being represented, as well as the 'how and why', especially as it contributes to the national dialogue on breast cancer.

### **Extending Textual Meaning-making**

One contemplative aspect was the emotional meanderings related to redefining and acceptance of my 'new' ill body as I compared both photoshoots and their objectives. The concept of my illness as transformative became as an additional category that needed to be acknowledged and demystified. I illustrated this in my journal on 10 October 2006 by expressing the truth of the new body-self change. Clearly, the weight of the written word encapsulated the initial response to an altered body image and acknowledging the loss of the left breast.

But I have no left breast. This visual representation of 'me' is now distorted and altered by breast cancer.

From the above journal entry, the initial social-cultural script questions self as an image of womanhood and perfection amply dictated to by hegemonic society. This journal entry allowed confrontation of residual anger and disappointment for not being considered normatively physically perfect. The initial awareness of the acknowledgement of loss, hopelessness and helplessness as phases captured in the process of mourning was especially

evident. The associated grieving of the loss and the distortion of the altered physicality moved me towards a different identity. Yet, there was a hint of the transformation of self as I did not belong to the dominant discourse as a woman and did not reproduce such constructions (Gibson et al., 2015).

My altered body and illness sparked the dialogue within self to focus more intensely at what was vital in my life and reprioritised my notions of a healthy self. Inclusive of the healthy self was the change in my dietary patterns. I elected to follow a healthy diet that was not substantially different from my pre-breast cancer routine. I specifically followed a vegetarian diet. This adjustment in my dietary patterns synergised with my commitment to focus more deliberately on my health and well-being, unlike the participants of Lekhuleni and Mothiba's (2013) study, who found such adjustment restricting and challenging especially with the consumption of their favourite foods. The adjustment, however, was peculiar to my experience, as my extended family had to make the necessary changes and include alternative vegetarian cuisine. Socialising with food is a significant component of my family interrelations.

There was logically internal conflict of anxiety, sadness and yet the knowing and acceptability that this was merely a phase towards transformation. This was reflected concisely in an interview and subsequent article, "I choose not to" by Lindsay Ord in *The Daily News* published 30 September 2008, where I acknowledged the defining and redefining of the transformative self through the gendered lens of women's health and the

<sup>1</sup> See Appendix A.

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popular narrative that surrounded breast cancer. This paragraph concisely summarises my intersecting identities post-breast cancer. Evidently, the subtleties of my self-confidence became prominent in acceptance. Ord (2008) captured my words:

I am defined by many things: I'm a psychology lecturer at the University of KwaZulu-Natal, I'm a woman with a wonderful family and wide circle of friends, I do yoga and tai chi – and I happen to have just one breast.

To further support my position of redefining self, the article captured my thoughts on the loss of a breast. This media also afforded me the opportunity to assertively express my rights over my own body and validate my choices that may have digressed from normative thought and allowed self-determination not to consider breast reconstruction at that point.

Ord (2008) quoted me saying the following:

I didn't want to go through the drawn-out and painful process of a reconstruction. I felt it would be better to learn to accept the loss of a breast.

The concept of reconstruction was a re-definitional statement. It referred to the recreation of a breast and to present womanhood and personhood in an anatomically correct and acceptable manner (Gibson et al., 2015). The study on women by van der Wiel (2013a, p. 59) revealed that, "only a small group (one-fifth) spoke enthusiastically about having breast reconstruction or were determined to have this surgery". Another essential finding was that participants between the ages of 35 and 61, "rejected breast reconstruction" (van der Wiel (2013a, p. 60). For me, reconstruction is related to the reconstruction of self and the deconstruction of the perception of womanhood. Hence, the "reconstruction of one's self and life rather than her breasts" which Ucok (2007, p. 77) concisely captured was reflective of my

own thoughts. Another essential point emphasised by Tetteh (2017, p.320) was the "cultural expectation of South African women who have had a mastectomy to have breast reconstruction surgery to hide the defect and to restore wholeness to the body". However, Ehlers (2018) questioned the promise to reclaim wholeness through the process of breast reconstruction. In support of this, Shildrick (2000) argues that breast cancer brings with the experience a bodily dissonance that challenges the perception of a seamless body. In Ord's (2008) article, I reflectively focused on the evolution of the self by saying:

The loss of a breast has meant the loss of my old self and a creation of a new self and the lessons I have learned have been invaluable. I wouldn't have it any other way.

I began to reflect on the multiplicity of perspectives of the female breast. Are they owned by the artist, media, or fashion-makers in our culture to take advantage of the female breast and dictate their shape and contour? Pornographers exhibit women's breasts for financial profit like that of cosmetic surgeons and therefore claim possession of them, which Yalom (1997) captures in the text, *History of the Breasts*. My interpretation is that these body parts belong to me despite the change of appearance that may no longer fit societal stereotypical interpretations. My singular reasserted thought is that I will continue to appreciate my present body. It is within this reassurance that I accept responsibility for the self which furthered my understanding on how to "(re)create a unified mind and body" (Ucok, 2005, p.291). Tschetter also authenticated such thoughts (1998, p. 134) in her poem:

The breasts are gone

But I am

Whole

Disfigurement

## Need not include my soul.

These thoughts resonated throughout my reflective journal entry dated 10 October 2006. It further acknowledged my spiritual journey of loss, acceptance, and reconfiguration of the embodied self. It seemed to me that post-mastectomy, there was an appreciation of my mind, body, and spirit to be allowed to follow their own progression to healing. This development journey I believe was an intersectional one.

# My Hair: Extending the Socio-cultural Lens

The significance of the Figures 3.1., 3.2., 3.3 and 3.4 sequentially illustrated the change in physical appearance, mostly my short hair, which communicated my comfortability in my own body nine months prior to my diagnosis. Prior to my first surgery, I decided to cut my hair short and close to my scalp in anticipation of the potential loss of hair.

A chapter by Upshaw (2017) entitled, "My body knows things", uses an analogy of braids as an illustration of her intersecting Afrocentric identities as a "twist under/over, under/over, under/over" (p. 56) braiding process. This synergises with the autoethnography process as I contemplated the writing of the PhD, which strengthened the strands of my breast cancer narratives. Reading her work prompted a memory of a story of my childhood often recited within my extended family. The story of my maternal grandmother plaiting my hair. This strand of memory was cited by my cousin who labelled them as 'phuthu plaits'. Phuthu is a traditional South African food made from maize meal; historically an African cuisine, it is eaten by most racial and cultural groups. The plaiting was construed as confirming to cultural dictates on how Coloured young girls should present their hair. Like Norwood (2018, p. 72) who writes from an African-American perspective, her thoughts resonated with mine when she suggested, "from straight to tightly coiled hair reflects a racialised hierarchy".

Such a hierarchy is evident, even in the South African context. As an adult, the prescription of having one's hair straightened was more culturally acceptable. Like Upshaw (2017), plaiting also reflected the stereotypical cultural expectations of Coloured women and maintaining a presentation style of neatness. Such Coloured assimilation was consistent with "distancing from Africanness, whether it be in the value placed on fair skin and straight hair, the prizing of white ancestors", which was often reasserted within my community (Adhikari, 2006, p. 479).

Post-breast cancer, I chose to experiment with different styles and embraced the most comfortable, which from me is of naturalised hair which remains unpopular and less fashionable. Moreover, my choice not to colour my hair prevails to the present day. The photographs selected illustrate the diversity of my hairstyles. Beyond the politics that surround hair, other intersecting areas emerged as I peeled some "deep seeded layers" (Sewell, 2017, p. 113). The potential loss of my hair, if I had chemotherapy, was not a concern as prior to my diagnoses I had already reached a healthy perspective on the politics of hair. The level of visibility and invisibility through the process nevertheless became evident.

According to Hofmann (2004), the female breast is visible, symbolises femininity and has social and cultural significance. Various treatment methods such as surgery, hormone therapy, and chemotherapy may result in visible signs of illness. Women employ various methods to creatively conceal the loss or partial loss of a breast, such as using an external breast prosthesis or undergoing reconstructive breast surgery. This in turn renders the illness invisible. This is also applicable to hair loss, including the wearing wigs or scarves to

conceal the side effects of the treatment. This process aids it by facilitating others comfortability and normalising illness.

I navigated around facilitating my own comfortability and discomfort of significant others. My internal dialogue around my levels of discomfort was not shared prematurely until my own confidence increased. It was acceptable that when it comes to the invisibility and visibility of the breast cancer journey, disclosure has accompanying risks such as rejection, stigma, and the inability to control the reaction of others. For me, the visibility of breast cancer was further evidenced in the various spaces I occupied. Moreover, by exploring my breast cancer experience in a PhD study, it became yet another way to courageously be visible.

Beyond the physical, I reflectively questioned relevant questions of my own sense of self. A significant aspect of this was the interconnectivity of my religion and spirituality which Barnett (2016) sees as "important aspects of diversity" (p. 6).

## The Intersecting of Religion and Spirituality

I have come to accept that religion and spirituality remain inextricably linked. For the purposes of this study, religion has been defined as "adherence to the beliefs and practices of an organised church or religious institution" (Shafranke & Malony, 1990, p. 72). As Standard et al. (2000) have argued, the challenge with defining "spirituality is its connection to religion" (p. 205). Spirituality has been defined as having an "innate capacity and tendency to move towards knowledge, love, meaning, hope, transcendence, connectedness and compassion" (Fukuyama & Sevig, 1999, p. 5). Pargament (2013b) describes it as a "searching process that can shift and change over the lifespan", further qualifying his

understanding by labelling it as a "process of discovery of the sacred" (p. 274). Such meaning making became focal to my spiritual evolutionary process as I explored my breast cancer journey.

I particularly identify with the study of Schreiber and Edward (2015) who explored the influence of breast cancer diagnosis on the experience of religion and spirituality for women. Their study concluded that having a belief in God contributed to the processing of experiences and making sense of behavioural changes. Similarly, a South African study by Coetzee et al., (2019) explored the breast cancer diagnosis and treatment experiences of those that had access to primary healthcare. Their study found the presence of three significant themes, namely, "reactions to diagnosis experience; the role of religion in illness sensemaking, coping, and acceptance; and the importance of a sense of agency in the face of illness" (p. 8). These three themes are also emphasised in my study. Earlier therefore, I reflected on my diagnosis and treatment experiences and the development of my own agency as it related to socio-cultural dynamics and breast cancer.

Undeniably, my initial spiritual interest and its subsequent evolution was embedded within the Roman Catholic religion. Having been raised within a predominately-Christian family, the social and moral teachings of the church concerning "protecting human life and dignity and promoting social justice" (Eick & Ryan, 2014, p. 29) became an inherent part of my own persona. These values substantially shaped the foundational aspects of my spiritual evolution and became infused with my multiple identities.

The profound interconnectivity of moral and ethical codes of religious, spiritual, and professional which Barnett (2016) highlights, reflectively contributed to giving meaning to my breast cancer journey. For example, respect and dignity of clients and other

professionals; rights and responsibilities; dealing with the vulnerability of others and nurturing communities by sharing my breast cancer experience, respecting the dignity and rights of others, as well as acknowledging my responsibilities as a person and professional. As with Sperry (2011), I acknowledge the incompatibilities that existed between psychology and the Roman Catholic worldview and reflectively navigated around each to offer a coherent coexistence of religion, spirituality, and psychology. According to Puchalski (2012, p. 49), spirituality has been "recognised as a critical factor in the health and well-being of patients". Likewise, the American Psychological Association (APA) have acknowledged the prominence of religion and spirituality as being part of the diverse human experience (McMinn & Hathaway, 2009).

# The Space of Spirituality in Psychology

As acknowledged by Brown and de Jong (2018) in their *Cancer Storytelling: A Study of Well-being Expressions Made by Patients*, there is a mutual correlation between spirituality and well-being. Despite this recognition, mental health providers may appear to be indifferent to spirituality as a supportive resource (Edwards, 2013; Hatala, 2013; Shafranske, 2016). Diversity within the psychological practice is nevertheless acknowledged by Plante (2014, p. 288) who declared that, "when it comes to multiculturalism as it relates to religious diversity, too often psychology professionals are relatively silent and perhaps uninterested". The reason for the silence may relate to perceptions of religion and spirituality, as well as the diversity in defining the concepts as discussed above. In addition, there is a lack of consensus in defining religiousness and spirituality. Piedmont (2014, p. 265) considers this to be problematic, for "without a clear definition of what it is being examined, the scientific process cannot create a cumulative body of knowledge capable of

moving the field forward". In response to such a criticism, Symonds et al. (2011) explain that spirituality assists in the realisation of one's life purpose and the overall meaning of life. In other words, spirituality can be a transformative experience (Pargament, 2013b). This explanation resonated with me and suited my purpose as I searched for meaning and "yearning for the sacred (i.e. spirituality)" (Pargament, 2013a, p. 398) which developed and transformed as my breast cancer experience unfolded. The transformative experience became an unsettling and challenging process as I surrendered old ways of thinking to allow new understandings to emerge.

As Edwards (2013, p. 536) has suggested, counsellors "need knowledge, experience, insight and expertise in their own cultural background and in those of other individuals, families and communities". My family members and friends from diverse cultures became collaborators in the exploration of the spiritual self and contributed to deepening my understanding of my spiritual being. Furthermore, the insights into my cultural background offered me a unique critical lens to reflect on the diverse dynamics of multiculturalism. Reportedly, Swinton et al. (2011, p. 643) have stated that, "relational consciousness is experienced when one realises one's interconnectivity with others, with God (for the believer) and with the world". Through interacting with my eclectic circle of family and friends, the discovery and development of my spirituality emerged within the safety of reverent and respectful sharing. A key concept of sharing was the concomitant aspect of providing assistance. Occasionally, I experienced the paradox of help which Coyne et al. (2012) capture, the request for which was always respectfully received. For me, personal retreats of self-care from family and friends were used to explore the unknown and what were at times unsettling feelings.

A vexing question I reflected upon often related to how professional training adequately prepares psychologists to explore more meaningfully with clients from a multicultural and religious context. Jafari (2016) offers the opinion that within professional training, religious knowledge was often embedded in other areas of learning. I further questioned whether such training was adequate. Plante (2014, p. 289) addresses what is often a contentious issue, when he states that, "much has been written and reported on psychologists' ambivalent and too often conflictual relationship with religion over the years". The complexities of multiculturalism and the multiplicity of religious traditions provide a diverse range of understandings and responses. Vieten et al. (2013 p.129) pose the dichotomy that, "religious and spiritual issues are not discussed in psychotherapy, nor are they included in assessment and treatment planning". Edwards (2013) adds to this critique, by stating that the mental health professional needs to be "sufficiently developed in the universal culture of humanity and relatively free from personal trauma in order to be able to provide an authentic culture of care" (p. 535). Acknowledging this assessment, I purposefully exposed myself to interfaith experiences which moved me beyond my own religious training which Purnell and Anderson (2009, p. 176) acknowledge that, "spirituality should have beneficial psychological adjustments effects regardless of religious affiliation". In the same way, Edwards (2013) conclusively promotes intersecting identities as an essential feature of holistic psychology through "its recognition of spirituality and its importance of its ongoing practice for personal, communal, and cosmic transformation" (p. 536).

## Key Collaborators in my Spiritual Journey: Capturing My Circle of Healing

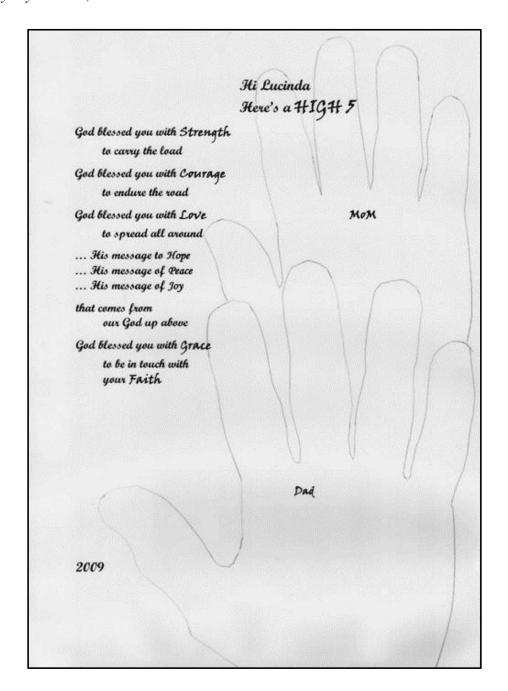
A poem written by my parents, dated 09 October 2009, to celebrate my fifth year of remission sought to acknowledge the presence of God's within my healing process. The

symbolism of their hands communicated nurturance, support, and compassionate care, with which they both held me throughout my journey of healing. The poem further strove to reflect their validation, admiration, and their faith in a higher power whose intervention and guidance they believed supplied their own strength and courage. Notably, prayer was a central part of our existence as a family (Coetzee et al., 2019; Fronde et al., 2017).

A further essential aspect of this poem was the creativity and novel approach it uncovers in celebrating such a significant milestone. In this, I acknowledge that my inner creativity and innovative practice is clearly rooted in that of my family. My father learned to paint and draw in his younger days and my mother enjoyed sewing, knitting, and crochet work. From a young age, both my parents instilled in me a love for art and craftwork and encouraged me to develop my skills in their pursuit.

Figure 3.5.

Poem by My Parents, dated 09 October 2009



As identified by Adam (2014), Blumenfeld (2011), and Bracegirdle (2011), the writing of poetry facilitates healing and personal growth following a traumatic experience. Similarly, McCartney (2018) illustrates how poetry is supportive of reflexive engagement within the helping profession. As a professional woman of colour who experienced breast

cancer, poetry as a literary and creative practice was comfortably situated in and between these identities. It is my firm belief that the practice of poetry facilitated "self-awareness, self-insight, and personal accountability" (McCartney, 2018, p. 138). The pantoum poem that follows, dated 01 July 2015, and transcribed during a supervisory session, succinctly captures the evolution of my spiritual self and healing journey.

Majestic power to stand tall

Leaves that fall are not terrified

Let go and nourish the earth

Knowing. Being. Becoming.

Leaves that fall are not terrified

Circles of healing are in the tree trunk

Knowing. Being. Becoming.

Grounded tree reaching the blue sky

Circles of healing are in the tree trunk

Melodies in a sacred space

Grounded tree reaching the blue sky

The healing is within

Melodies in a sacred space

Let go and nourish the earth

The healing is within

Majestic power to stand tall

This poem illustrates my quest for meaning by exploring the deeper existential questions of my life purpose. The poem reflects my desire to be grounded and rooted in respectable life values and is reflective of "being, becoming and/or interbeing" as noted by Edwards (2013, p 532). Furthermore, it demonstrates the value of my religion and spiritual awareness as it, "also represents an important way of making sense of and coping with the demands of the illness" (Welgemoed & van Staden, 2014, p 140).

Symbolically, the transforming tree sheds its leaves. This represents change, loss, and death, whereby space is left for re-birth and re-growth. The ability to accept such transformative and visible losses led me to explore self-meaning which could be shared with others. My desire to constantly expand and develop my understandings was illustrated by a concentric circle of actions and inactions. This invariably extended to my interactions with others. I was open to redefining of self, which was reflective in the poem: "Leaves that fall are not terrified, let go and nourish the earth". Edwards et al. (2013) also noted the contemplative self.

My personal connection with breast cancer provided the opportunity to engage with and connect to communities outside of self. In other words, it allowed me space, "to reach out and connect with someone or something beyond one's self" (Swinton et al., 2011, p. 643). Generosity was a component of the spiritual self, which required sharing both personally and professionally. As a wounded healer, my deeply intimate inner exploration to transform my life placed me in a unique position to shape the lives of others contextually. The recognition of self and others' interconnectedness through illness or trauma created a community of sharing, compassion, empathy, trust, and support. Furthermore, "Melodies in a sacred space" reflected my reactiveness to others within the diversity of spaces. Occupying such

diverse contexts, the professional self analytically and curiously facilitated the emergence of nuanced reflections. In addition, the respectful acceptance and exploration of diverse voices, the melodies of others thoughts and emotions, once again illustrated the interweaving of individual knowledge into the fabric of collective awareness. Consequently, these spaces represented a communal connection of an individual facing the human experience of illness.

The "Circles of healing" marked my growth and transformative healing and illustrates the value of surrounding myself with individuals with a common interest. My friends and family, unlike the experience of Greenhalgh (2017), provided honest and critical comment, despite being cognisant of my vulnerability. Such responses furthered the healing within, by unsettling and challenging my internal dialogue and to be bravely honest. To support the transformative healing, I often practiced mindfulness as it promoted being awareness of the present moment in which feelings, thoughts and bodily sensations are acknowledged and accepted. Tate et al. (2018, p. 1) supports this practice of mindfulness and describes it as an "effective intervention to help people adjust to living with and beyond cancer".

#### **Am I a Breast Cancer Survivor?**

My discomfort with the label of breast cancer survivor prompted me to ask the question: Am I a breast cancer survivor? A qualitative study by Smith et al. (2016) examined the complexity of survivorship as an identity. The authors noted survivorship was, "one piece of a multifaceted, somewhat fluid construction of self that is highly likely to change over time" (Smith et al., 2016, p. 464). Such a perspective synergised with me, as I believed the sense of self is adaptable across the lifespan. Similarly, Berry et al. (2019, p. 11) findings suggest the term was problematic and if a label was required people can, "choose the one that is most empowering and reflective of their experience". Like most participants, who "did not

want to be called breast cancer 'survivors' or 'warriors' (Williams & Jeanetta, 2014, p. 640), I reflected on the utility of the concepts. More importantly, my wish was to "maintain and expand my identity as a scholar, not a survivor" (Davis & Warren-Findlow, 2012, p. 311). I concede that the label of a survivor is one aspect of my identity and not the focal point. In other words, my identity is not primarily identified by the illness. As I write this, I define myself as a woman who has experienced breast cancer. However, over time and with new and differing experiences, I may re-define this identity.

#### Conclusion

In this chapter I have sought to contextualise my intersecting personal identities. I commenced with describing my breast cancer diagnosis story which I believe provided the essential aspects of my experience. These aspects are further reflected upon in the analytical chapters which follow. Within this chapter I also elaborated on the complexities of my Coloured identity and the challenges of living in the Coloured community of Wentworth. In addition, I explored my position and understanding as an only child and the complexities of being a racially-mixed family. Thereafter, I examined how a diagnosis of breast cancer interrupted my perception of self, health, and relationships – particularly, doctor-patient relationships and the tensions experienced by both the doctor and patient. These interactional spaces brought into focus the value of vulnerability and reflexivity as I progressed on my transformative healing journey. Equally important was my spiritual practice as I wrestled with the complexities of the illness journey. One such complexity was the breast cancer survivor identity expressed in this chapter. In the unmasking of my personal identities, I was cognisant of my intersectional professional identities which are identified and explored in the chapter which follows.

### **Chapter Four**

### **Interconnectivity Continued: Exploring my Professional Identities**

The aim of this chapter is to explore my intersectional identities as an academic and psychologist. In addition, it offers a comprehensive understanding of my breast cancer experiences at various stages of my professional development that is key to the research question of the study. In this chapter, I contextualise my pedagogical orientation and academic development as a lecturer and supervisor. In relation to this theme, I examine the benefits of continual training to extend my pedagogical skills and inform my professional practice. Thereafter, I reflect on my challenges related to vulnerability and voice within an academic setting and how I grew in confidence to expose my vulnerability and share my voice. Next, I present reflections of my postgraduate supervisory experiences and recognise the value of this multicultural context offered to me as a supervisor and supervisee. I draw on the various sites of professional learning to illustrate the maturing of the PhD process. I conclude by exploring the nuances of silence and how it challenged and facilitated my professional practice.

## **Locating my Pedagogical Practice and Academic Development**

As I entered academia in 1999, I questioned my competence and suitability for the traditional portfolio of an academic as it created some uneasiness and discomfort. A similar experience was noted by Bochner (2014), and Bhattacharya (2016), both of whom examined their levels of comfortability coming into an academic space. At the time, I was one of two Coloured colleagues in the psychology department which initiated reflections on my capability and capacity to occupy this space as a young Coloured female academic. During

my 16-year tenure at the university, I progressively gained in confidence and experience as an academic and psychologist. It was within this environment that my interrelationships between the personal, lived educational experiences and wider social-cultural contexts were explored and deepened (Pillay et al., 2016).

As a lecturer, my pedagogical orientation was committed to creatively inspire students to learn and ultimately understand psychological concepts, theory, and therapeutic contexts. I often contemplated the benefits of including artistic methods which Burge et al. (2016, p. 735) admitted, "can lead to fresh insights and new knowledge". The artist methods encouraged critical deliberation and allowed students to witness theory articulating into practice. As discussed by Collins (2017), Demuth (2015), and Meskin and van Walt (2014), creative approaches may be viewed as unsettling the traditional methods of teaching and research. This unsettling compelled me to "think deeply, about my motivations, my vision, and my paradigms and allowed me to find ways to pursue my goals while living in harmony with my fellow academics" (Woods, 2016, p.130). I thus attempted to establish a balance between the "bureaucratic requisites" (Valentim, 2017, p. 176) and my deep passion for constantly refining my teaching and learning engagement with students.

I was acquainted with the perspective of Cunningham and Carmichael (2018) to "reflect on how the academic structure, systems, and processes were an inhibitor to finding my voice" (p. 56). Although higher education is an environment that supports divergent and novel practices that contribute to knowledge development, there are contentious areas of systemic contradictions that exist. While I acknowledge and respect the operational systems employed, over time I learned how to navigate around these contradictions. Finding my voice meant honouring the academic enterprise, while not deviating from connecting with my

students and discovering how to meet their learning needs. In this, I found Mudaly (2015, p. 42) autoethnographic reflections on the professional identity encouraging as she acknowledged her "obligation to students to teach for meaningful change" and explored difficulties in transcending academic boundaries.

I believed academic spaces to be fertile ground in which to "deploy strong critical reflection" (Graham, 2017, p. viii). In hindsight, such reflective thinking was fostered as a family practice. Within the academic space, reflexivity was identified and actively promoted as a skill and the cornerstone of psychology (Klemple, 2015; Rosa, 2015) and autoethnography (Ellis & Bochner, 2000; Hayes & Fulton, 2015; McIlveen, 2008). As I have demonstrated, embedded in the process of my teaching was a reflexive approach of "digging deep" (Scott, 2014, p. 69) to improve my active engagement with theoretical constructs and the curriculum. Topics such as mental health, psychological theory, socio-cultural concerns, ethical conduct, and legal issues were often presented creatively to promote "pedagogical thoughtfulness and wakefulness" (Belbase et al., 2008, p. 94). Likewise, Wood (2014, p. 127) validates the methodological soundness of critical debate as it allows for rearticulation and reassessing understandings in a teaching and learning space. I aimed to create a conducive learning and teaching environment, and like Warren (2011), ensure my students experienced the lecture room as a less dangerous and guarded space.

With my students, I constantly considered how to remove barriers to learning and instead promote, "profound and lasting learning, allowing it to contribute to one's own development, and that of others" (Meyiwa et al., 2014, p. 114). Like Bochner (2014), I believed my students continued to shape and influence me. In the same way, I was aware of how I continued to influence my students. These reflections on my academic experience also

extended to questions related to demonstrating reflexive practice in the lecture room.

Questions such as:

- 1. What courses allowed me to reflect and re-assert my practice?
- 2. What is it in the curriculum that allows for and promoted reflectivity and creativity?
- 3. How did the academic experience become an unending expedition?

These questions assisted in framing the overlapping between the personal and professional and motivated me to expand my skills and competencies. I was conversant with the vision and mission of the university to be student-centred and identified with the philosophy and psychology of person-centeredness. In the same way, Wood (2016) acknowledged the interrelatedness of student-centred and person-centred approaches. My commitment to student-centeredness also allowed for one-on-one consultations and mentorship. While often forfeiting my available time, I nevertheless believed it was a good investment in creating scholarship and an opportunity for the student to experience "reflection in action" (Graham, 2017, 34). Mentoring, as explained by Makhanya (2016, p. 93), "is not just about supporting students academically, but about inculcating and shaping values". Likewise, Cummins (2017, p. 170) explored the "power of care in education" and noted, "Teachers should care for their students, but they should also work to teach their students how to care" (p. 164). With these key aspects in mind, my aim was to ensure my students felt comfortable in their exploration of the complexities of humanity.

While the feedback received from my students was often overwhelming, it was nevertheless motivating and encouraging. The evaluative component of my teaching and learning practice solidified how students appreciated the intense level of engagement.

Undoubtedly, the feedback became a catalyst to explore my teaching methodology. I interrogated the complexities and utility of using creative pedagogy for the diverse psychology modules that I taught. In fact, Meskin and van Der Walt (2014, p. 56) recognised this creative process as negotiating "the tensions and struggles" within a reflective practice.

As a lecturer, such reflective practice also required self-evaluation and critique of my own actions and inactions. Like Holman Jones (2018), I believed it was important to be aware of my own cultural identities, struggles, memories, biases, prejudices and reflect on how these may influence the learning space. This process invariably facilitated and encouraged the development of my self-confidence as a lecturer and academic. I was constantly cognisant of Eisner's (1997, p 9) warning of "not substituting novelty and cleverness for substance". Overall, students appreciated the variety of teaching modalities as these afforded deeper interaction and engagement not only with content, but with their own comfort of digressing from conventional teaching methods. My aim was to maximise learning for my students.

Like Mudaly's (2015) experience as a new academic, there was no mentor appointed to nurture me as a novice academic. Nonetheless, I learned my craft from a few supportive staff members who were willing to guide and support me. Mostly, I learned from observing other academics and researched teaching techniques that facilitated the development of my own unique style. My experience as a lecturer positioned me to mentor a few novice academics as they developed their own lecturing style. In this mentorship role, like Wood (2016, p. 127), I regularly, "shared articles and other resources electronically, did critical reading" and supported without judging to create a "humanising space" for growth. This

supportive interaction and learning environment with both staff and student synergised with my role as an academic and psychologist.

### **Extending my Pedagogical Skills**

To expand my own learning, I registered for the University Education and Induction Programme (UEIP) in 2014 and 2015. Of the four modules, two were devoted to research supervision, teaching, and learning. Both these modules expected a reflective account of my engagement with my postgraduate students and undergraduate teaching. The group exercises afforded collegial contribution to best practice to improve teaching and learning as explained by Belbase et al. (2008), Berry and Hodges (2015), Burge (2016), Faulkner et al. (2016), Pithouse-Morgan et al. (2016) and Samaras (2011). In a group discussion, I shared the benefits of using creative teaching tools such as movies, poetry, music and ice breakers to facilitate students understanding of psychological disorders. An example I presented was where students are required to select a character from a movie and discuss the symptoms and challenges of diagnosing a psychological disorder. Another example was having students listen to different genres of music and for them to track their emotions while listening. The assessments attached to these two modules focused on pivotal areas of teaching and learning. Also, these assessments resonated with me as I valued the inquiry of self within this context. Equally important, like Mudaly (2015) and Weber (2014), I began questioning my teaching, research, and evaluation practices. Some of the pertinent questions captured by Weber (2014), included: "What am I really doing/teaching? How does my teaching affect others? How might I improve what I do? How might I view things differently? How can I make a difference to others?" (p. 8). These questions furthered my exploration of my teaching philosophy. Complementary to this process, like Wood (2016, p. 129) "I have learned to

follow my own vision and let others follow theirs" on the idea of quality education. This conviction gave me the confidence to explore and develop my vision of learning and teaching. This also allowed me to respect other pedagogical approaches that colleagues were teaching.

### Academic Environment: The Practice of Vulnerability and Voice

When my surgery was scheduled for 06 September 2004, I considered whether it was necessary to discuss such a personal event and duly planned around my academic responsibilities and renegotiated my academic requirements (Froude et al., 2017). I reflectively glanced inwardly and outwardly of the merits of self-disclosure. After careful deliberation, I thought it courteous to inform my students of my two-week absence and to discuss the contingency plan. I was comfortable to inform the students about my surgery in a manner that I felt self-protected (Cantham-Carpenter, 2010; Bolton, 2006; Knowles, 2014).

I settled on what I needed to reveal and for what specific purpose. This process questioned my level of vulnerability and awareness of my own power and how I use it.

Admittedly, "the power imbalance inherent in teacher-student relationships" (Cummins, 2017, p. 168) can evoke feelings of vulnerability, trust, and openness for both my students and myself. Valentim (2017) also questions the influence of power within academic spaces and tensions related to the disparity. Of equal importance from a South African perspective, Knowles (2014, p. 89) expresses concern regarding the "oppressive pedagogies" and advocates for self-study as an effective research process for self-transformation as a teacher. My personal experience sensitised me to the concerns around power and privilege, as well as the effectiveness of self-reflection and reflexive practice. Within an academic space, I

believed by demonstrating my vulnerability, I cared for my students and felt comforted to know that I too was cared for.

There were varying degrees of responses from my students. While some were surprised, others became anxious and distressed, questioning how my absence would influence my academic responsibilities. One such example came from an ex-student, who sent an email, dated 26 February 2019, on her reflections on disclosing my breast cancer diagnosis. Her permission was sought to use extracts from her reflective feedback and she duly consented. The student described herself as a mature student who was 33 years old at the time of my diagnosis (A. Sewsunker, personal communication, 26 February 2019). She continued by saying:

The morning she told the class about her diagnosis, we sat in the lecture room dumbfounded. After the class, a few of us discussed her strong personality to deal with things in her stride.

We spoke to her and in her kindness; she explained the diagnosis, prognosis, and surgical procedure/s. We were further blown away by her tenacity to survive.

Reflected in the extracts are varying intersectional aspects of my identities from the perspective of the student. It also captured her vulnerability and voice as a student who at the time was one year older than me. I envisaged my self-disclosure as a significant life event where I mindfully reveal personal and professional aspects of myself. The intersecting of my identities and the relational dynamics was an unexpected challenge for me as well as for my students. After my disclosure, students shared their anxieties, uncertainties, support, and well

wishes, for which I was grateful. Moreover, the student recognised my personal strength, courage, kindness, and care as an indelible part of managing my healing process.

For Cummins (2017, p.163), "caring in pedagogical spaces" requires reflexive exploration of power dynamics as it shapes "how and whom we care for". Within the pedagogical space, I reflected on how emotionality and positionality influence my relationship with students. More importantly, my desire was to illustrate self-awareness, management of emotions, vulnerability, and reflective empathy, which Leigh and Bailey (2013) acknowledge as important aspects of psychology practice. The students witnessed how emotions are accommodated and adaptive situationally and contextually. The size of the class promoted deeper engagement, and despite being cognisant of my role as lecturer, I did not digress from the academic focus and task, allowing my students the opportunity to process the experience.

As counselling psychologists committed to the practice of autoethnography as a qualitative research method, Kracen and Baird (2017, p. 162) describe how the process encouraged them to "speak with authenticity about our experiences". I was keenly aware that such a skill is vital to the therapeutic relationship. Reflectively, my authentic sharing illustrated theory into practice that is often contested within an academic space (Kracen & Baird (2017). The aim was to encourage my students to devote time to develop self-awareness and self-regulation, as these processes will have a crucial effect within the psychologist-patient therapeutic space.

Beyond my students, I recall a staff meeting being scheduled to discuss the management of my lecturing responsibilities while I underwent medical treatment. I was grateful for the level of collegiality and support, as this facilitated my healing process.

Obviously, during radiation, my energy levels dictated the intensity of student and staff interactions. This, however, did not digress from the quality of engagement with my students. I encouraged alternative forms of communication such as emails and consulted only on specific days to ensure not to compromise my health. However, the one task I felt obliged to continue while undergoing radiation treatment was the marking of examination papers. Evidently, my intersecting identities as a psychologist, lecturer, examiner, and patient became more pronounced during this period.

### **Reflections: Postgraduate Supervisory Engagement**

Within this learning and teaching space, research was an integral component of the academic space. Postgraduate supervision afforded innovativeness as a supervisor to develop students' proficiency in research and therapeutic practice. Here again, the basic tenets of autoethnography became apparent within the supervisory space. In her study, Trahar (2013) reflects on the usefulness of autoethnography within the supervisory practice, which I found to be reassuring and affirming. Of equal importance was the creation of a conducive and supportive supervisory environment that had mutual benefits.

The student cohort I supervised for research and clinical practice were eclectic and comprised of diverse socio-cultural backgrounds. I was cognisant of this diversity and its significance within supervisory engagements. Like Trahar (2013, p. 370), I recognised the "ethnocentricity in my own practice". Being mindful of this diversity, I adapted and accommodated to meet the student's needs and did not hesitate to digress from the normative supervisory structure. Moreover, I did not hesitate to digress from any popular research and therapy methodology, especially with those paradigms that were substantially different from mine. In addition, I had little hesitation in declaring to the students if I was unfamiliar with a

research methodology or therapeutic practice. I duly capacitated myself to supervise an unpopular modality if I thought it suitable for their study or professional practice.

In addition, I often interrogated the utilisation of any Western theoretical concepts and its utility within my own supervisory space. Such a perspective is the focus of critical communication pedagogy which Cooks (2010, p. 295) describes as "a space of self-reflectivity and critique in one's teaching and research". This ethos has typified my engagement in this diverse academic space and has afforded me an "aesthetic experience" (Pillay et al., 2016, p. 5-6).

The ethos that guided the supervisory space was reflexivity and self-reflection as the students navigated the research process or through their own professional identity and practice. As has been previously noted, researchers such as Cooks (2010); Faulkner et al. (2016), Leigh and Bailey (2013), Pillay et al. (2016) and Shin et al. (2017), all emphasise reflection as an essential practice. In relation to clinical supervision, I like that Kracen and Baird (2017) questioned my influence as an academic and counselling psychologist. In view of demonstrating reflective practice, students evaluated their supervisory experience. As discussed above, the feedback acknowledged my ability to be supportive, encouraging, approachable and challenged them to consider other perspectives. I gladly appreciated such salient, evaluative comments, as they facilitated my development as a supervisor.

## My Identity as a Psychologist

During my formal training as a psychologist, I deemed it necessary to engage in personal therapy. The reason was to engage reflectively with aspects of self that I was unable to explore outside of the therapy room. Within the therapeutic space, I witnessed clinical

techniques in practice as I explored and navigated through my personal challenges. In addition, I observed how reflective learning, teaching, research, and practice informed one another within the healing space. I found personal therapy created a greater awareness of the client's position and developed my empathic understandings of potential client difficulties that was recognised by researchers such as Kumari (2017) and Wilson et al. (2015). In my opinion, personal therapy was a facilitative mechanism to refine my awareness of clinical practice, something which Malikiosi-Loizios (2013) has also validated. The required personal therapy was paved with challenges, yet it provided the necessary support during my first year of study. This process I viewed as an essential foundational phase that enhanced my learning and developed an understanding of my identity as a psychologist.

In addition to personal therapy, the Department of Psychology funded group therapy for training student psychologists in which I participated. The process offered novice student psychologists the experiential exposure to psychological concepts, especially in terms of group dynamics. The personal experience of self-disclosure, building connection, developing trust, enhancing self-confidence and self-insight, and understanding of relational ethical conduct, conflict resolution, and boundary setting within a safe therapeutic space deepened my awareness and knowledge. I found the experience to be beneficial in enhancing my understanding of group dynamics and facilitative skills, some of which I incorporated into my lecturing and presentation style.

As a psychologist and academic, I "strive to be self-reflective and aware" (Kracen & Baird, 2017, p. 165). Together with Leigh & Bailey (2013), I accept this as a true reflection of a core professional competency, both in therapy and training. To enhance my self-reflective practices, I selected training workshops that included experiential learning such as

Gestalt therapy, Narrative Therapy, Emotionally-Focused Therapy for Couples, Solution-Focused Therapy and Family Constellations. In addition, I expanded my skills repertoire to include: Cognitive-Behavioural Therapy, Emotional-Focused Therapy, Time-Limited Dynamic Psychotherapy, and Brain Working Recursive Therapy. Besides the transferability of my therapeutic skills within a therapy setting, I found the various training workshops as a facilitative space to interrogate my internal dialogue about my breast cancer experience. I believe these approaches have significantly contributed to my practice and development as a reflective psychologist and academic.

The utility of these therapies often became evident within the therapeutic environment. In addition to adhering to the key therapeutic principles of a modality, another significant focus of my therapeutic engagement was for clients to recognise the personal-cultural connection and to allow clients to gain a contextual understanding of self. In this way, it invited clients to witness the intersectionality of their own identities across various contexts. I found this psychological practice overlapped with the autoethnography process I have previously emphasised. Once again, it was reaffirming of my converging practice as a psychologist, academic, and researcher.

The guiding ethos of my practice was cognisant of the core clinical skills such as congruence, unconditional positive regard, warmth, genuineness, and empathy (Clarke et al., 2016; Kumari, 2017). Notably, Lekhuleni and Mothiba (2013) promote empathy and compassion when engaging with a diagnosis of cancer. Complementary to this, my specific focus was to innovate around client's needs that encompasses various theories and therapies in which I have been trained. Of equal importance, I attended peer supervision to ensure the quality and relevance of my practice. My ability to be able to choose across various theories

and theoretical underpinnings thereby prioritises client's therapeutic agendas, where the focus is often on developing life skills and reflective insights within their own situational realities.

Ultimately, it helped them to independently relate to life's challenges that they may encounter.

In embracing the words of Graham (2017, p. 31), I "shaped my professional commitment to protecting people from harm", to be accountable and responsible in my practice. Other researchers such as Clarke et al. (2018), Kracen and Baird (2017) and Pretorius (2012) have emphasised the importance of ethical professional practice. Specifically, in relation to the therapeutic process, clients consented to the use of modalities such as music, art, poetry, journals, photographs, view relevant visual material and read specific authors to facilitate their reflective process. Adopting a creative practice granted clients the permission to creatively engage with emotional pain and to witness their healing and self-transformative journeys.

An unexpected email from a client captured their reflective experiences of therapy. Permission was granted to include pertinent aspects of the email. To maintain privacy and confidentiality, the name of the correspondent is excluded.

I would like to say that I really really appreciate your perceptive, and gentle, analysis and reflection. Along with your intellect, and sense of humour, has made the sessions so fruitful and rewarding. It has done our relationship a world of good (Anonymous, personal communication, 13 December 2018).

The above extract illustrates my sustained philosophy of engagement with my clients to maximise the therapeutic space. Moreover, my academic learnings influence my practice

as a psychologist. Innate intuition guided, engaged, and supported mindfulness to self. In addition, my commitment to artistry was infused in my therapeutic space that facilitated play, imagination, subjectivity, and constantly focusing on the voice of the client. Often, when I receive similar feedback as that above, I consciously turn my gaze inward and engage in my own internal talk that constantly influences my practice (Graham, 2017).

### Navigating through the Continuum of the PhD Process

Another site for extending my own learnings was the PhD cohort supervision programme that focused substantially on methodological coherence. The PhD cohort supervision model used at UKZN and inherited from the former University of Durban-Westville, was cited by Berry and Hodges (2015, p. 92), where they "highlight the need for the programme to cultivate academic maturity and student autonomy in the post-proposal defence stage". For me, it is within this critical nurturing space that justification and validation were often required to support the selected methodological perspective. Moreover, this conducive, yet vigorous learning environment afforded a team of experts to reflect on my PhD, respectfully interrogate, and conclusively facilitate growth within the research journey. The monthly robust debates on the merits of choosing such a methodology as autoethnography often expected me to justify myself within the team. This process assisted in refining my own thoughts before I could commit to writing. In addition, within this reflective space, research coherence was instilled and shaped into the form I finally matured when defending my thesis. My commitment to ensuring that I did not decisively separate my own self from my academic endeavours further added to the coherence of my PhD experience. Bochner (2014) also acknowledged this level of interrogation of personal and academic practice.

The participatory approach permitted critical conversations and welcomed self-reflective stories and experiences as it assisted in making immediate scholarly connections to the research and to my own life (Alejano-Steele et al., 2011). The extension of such a space further solidified and contextually promoted narratives as a valuable source of experiential knowledge. Moreover, the supervisory relationship extended the notion of "engaging in stories and a way of understanding experiences that may otherwise be inaudible" (Thomas-Maclean, 2004, p. 1656). In addition, the cascading and transferring of skills were also evident. Related to the autoethnographic process, the supervisory space allowed me the mutual benefits of entering these painful spaces while courageously exploring this emerging model within my own scholarly methodological repertoire.

## Supervisory Space: The Facilitative Mechanism to (Re)claim Voice

As this PhD study evolved, I became intensely aware of the enmeshed identity as a research supervisor and PhD supervisee. The dual roles were distinctly apparent within the academic space and acknowledged as establishing beneficial boundaries. Admittedly, the scholarly supervisory space fostered and nurtured my own academic curiosity, while refining and reframing my methodological understanding of self-reflective research. As an academic and psychologist, I also found that autoethnography "lends itself for use in professional development practices" (O'Neil, 2018, p. 483).

I was encouraged to seek clarity in my own supervision in terms of the research process and purpose. It was within these supervisory spaces that I critically reflected on finding my voice and recognised the obligatory responsibility to expose myself which Forber-Pratt (2015, p. 1) depicts as:

It's voluntarily standing up naked in front of your peers, colleagues, family, and the academy, which is a very bold decision!

Complementary to this characterisation, Custer (2014, p. 4) also affirms:

The exposition is at first cold, calloused, and terrifying, but by keeping our eyes open, the courage of being naked and vulnerable begins to heal our gashes.

Such vulnerability furthered my writing which was aided by the supportive and reassuring responses from my supervisors which ultimately promoted personal and scholarly transformation. During the process, Professor Yvonne Sliep creatively encapsulated a supervision session related to embodied knowledge, silence, vulnerability, and invisibility, which she expressed in a poem, dated 26 February 2015.

silencing C
has not helped me
soft-spoken by nature
my voice now
disappeared completely
closed mouthed
i went about
acting "normal"
which helped
others enormously
i cultivated my silence
like C cultivated in me
considered my responses

respectful and well-bred

my manners

did not serve me well

while C

continues to spread

effortlessly

not serving others well

Her poem concisely and aptly challenged the anxiety and apprehension I felt in producing an autoethnographic study. The poem conveyed my considerate, well-mannered, and polite disposition, duly informed by my family, socio-cultural and religious context. Her supervisory focus was constantly trained to ensure that I did not digress from my commitment to the modality of autoethnography.

Dr Roselee Richards work on autoethnography and her articulation of this methodology in her PhD was particularly helpful in shaping my own confidence. She availed herself constantly to offer specific assistance on the methodological challenges that I often reflected on and fittingly offered associated readings to expand my understanding. Her own experience of illness offered a perspective that was deeply personal and rooted within a PhD which became a constant reference when I encountered feelings of vulnerability or of being overwhelmed. Many of my incomplete and sometimes errant thoughts were due to my being a neophyte in autoethnography. However, these inadequacies were often embraced by her, leaving me confident to pursue them more deeply. Accordingly, the joint wisdom and guidance provided by Professor Sliep as Supervisor, and Dr Richards as Co-Supervisor, became a valuable source of inspiration within such a collaborative supervisory.

I was acutely aware of the tension between the silent (re)searcher and vulnerable voice. In fact, the analytical intersectional lens highlighted the intimate choreography of silence and voice in both my professional and personal spaces. During the supervision process, I became acutely aware that I was "placing my experience at the centre of analysis" (Nowakowski, 2016a, p. 899), to explore my vulnerability, silence, resilience, and growing confidence.

Professor Sliep's poem emphasised silence as unwittingly promoting the belief that censorship was a protective practice for me. While I was naturally a generous person, her interpretation was that my silence was sabotaging and ironically not allowing any sharing. Upon reflection, the silence was partly attributed to contemplating using autoethnography as a methodology to frame my breast cancer experience. I questioned my comfortability of sharing personal breast cancer experiences within an academic environment. Professor Sliep subsequently facilitated not only with poems, but also with music to effectively address my silence. The silence then became pivotal to me sharing progressively in the different spaces that I occupied. According to Charmaz (2002, p. 306):

Stories of and silences about sickness hold promise for exploring narrative meaning, temporal duration and sequence, and reconstruction of self after loss.

The promise for me was in experiencing silencing and being aware of the silences within my stories. The words "silence of presence" (Denham-Vaughan & Edmond, 2010, p. 8) resonated with me, describing as it did my being fully in the moment. I did not identify myself as a victim of the illness and of silence as I recognised the value of these aspects as I

progressively grew in awareness of my experiences. It was within the tensions of victimhood/survivorship, silence, and voice that I developed a deeper knowing of self.

The poem challenged me to recount my cancer story of pain, confusion, anger, and chaos. This poem metaphorically provoked me to question, "acting normal" and to embrace the process of unsettling the dominant discourses and self-descriptions. I questioned, "What was my normal?" "Was I preoccupied with others comfortability and not my own?" To effectively address this multifaceted concept of normal, it demanded a reflective interrogation of silence, vulnerability, visibility, and embodied knowledge. I resonated with Kamanos Gamelin's (2005) description of "feeling very vulnerable, naked to the reader's eyes" (p. 184), where being exposed and vulnerable to others, I would not only gain a more comprehensive understanding of what my normal was, but possibly even redefine it. Accordingly, the poem witnessed the nuances of breast cancer and was pivotal to an inward-outward exploration of self and brought into focus the tensions of being vulnerable, silent, and reflective.

Constructing my poem in response to that of Professor Sliep enabled me to accept and embrace my silences, vulnerabilities, and socio-cultural dynamics related to breast cancer.

The poem thoughtfully captures the innumerable questions that I subsequently encountered when reading her poem. Dated 26 February 2015, it both reflects and respects my empowering voice, while acknowledging that my stories can be influential to others.

within the body I reside

within the body the answers

for my life will arise

through a mouth once silenced by c

a well-mannered voice will roar
saying 'see me'
silence have no fear
you had a part
and it is clear
cultural embarrassment
what was your intent
time to embrace
give meaning to the meant
now i will speak to I
a reflective conversation
stories to share
to tell
serving others
and me well

While my poem mistook my body as the site of illness, it nevertheless acknowledged that the voice of "I" was not to be ignored. Like Upshaw (2017), my body had a story to tell and it was the "site of knowledge" (Ellingson, 2006, p. 301). Through the process of introspection and curiosity, I was willing to dig deep into parts of me that I was initially afraid to venture. Admittedly, breast cancer was the catalyst for deepening my self-awareness and reflectively exploring my understanding of my intersecting identities.

Moreover, the poem captures the synergic properties of both the body and the mind. Another essential argument from Ellingson (2006, p. 301) was that "qualitative health research is virtually bodiless" and reflected on the "disembodied" researchers. She went on to argue that by "framing the body as self rather than mind-body split" (p 306), it allows an individual to

make sense of their unique experiences and circumstances. As therapists, Bager-Charleson and Kasap (2017, p. 190) were keen to explore their "relational, emotional or embodied response during the data analysis stage" of their research. They specifically addressed the issue of emotional entanglement in research because there was limited research in this area. Moreover, they addressed the embodied reflexivity that mirrored my own research experience reflected in the poem. Consequently, by examining the embodied self in autobiographical work, it provided the confidence I required when writing this PhD study.

A few of the noteworthy qualities I received from my immediate family, as well as those inculcated from my cultural and religious context, included kindness, graciousness, responsibility, and respect. This is captured in my poem as "a well-mannered voice" who is self-sacrificing. Initially, my family members silenced the culture of cancer as well. My courteousness was also identified in my academic spaces about Professor Sliep's poem. As an outsider witness, she brought to my attention how I was perceived within the department. This insight further challenged me to redefine myself by demonstrating my self-confidence, placing personal boundaries, and acknowledging the power of my voice. The lines, "now i will speak to I" "a reflective conversation" capture the inner dialogue reflecting an expansion of self (i - I). Like Zapata-Sepúlveda (2012, p. 643), my attempt was, "to free and recover my I" that had been silenced, obscured, and rendered vulnerable.

In my experience, I found people were afraid to mention the word 'cancer' and would rather use the capital letter 'C' to camouflage the seriousness of the illness and the fear associated with it. As a member of the C-Sisters, the use of the capital letter 'C' as a euphemism for the illness, 'Cancer' is often debated and reinterpreted by group members.

Adjectives such as caring, compassionate, and courageous are used to substantiate the

uniqueness of our sisterhood of professional women. This group comprises not only of those diagnosed with breast cancer, but includes carers and those working professionally with people with breast cancer. The vision and mission of the group is to share and extend our experiences and knowledge to other communities. I recognised the value of co-constructed meanings that developed from my critical engagement from supervision sessions, discussions with other academics, and the C-Sisters, which Ricci (2003, p. 591) acknowledges "together, or separately, we can create meaning". An example in support of this claim is the co-creation of meaning demonstrated in the production of poems by Professor Sliep and myself as detailed above.

My poem infers the selfless care and support of significant others which strengthened and encouraged me. The support was construed as both "affective and instrumental" (Froude et al., 2017, p. 1500) to my transformative healing. By receiving such emotional support, I was able to endure my own emotional entanglement. Also, by maintaining my sense of humour, I was provided with a healthy means of managing my emotional pain. A significant finding by Davis and Warren-Findlow (2012) reveals that humour is often a missing coping mechanism among those facing challenges such as breast cancer.

Support has multifarious meanings across different spaces, which Coyne et al. (2012, p. 129) describe as "being supported and supporting". I found, supporting respectfully did not create unwarranted stress for me. However, following my cancer diagnosis, my father became hypertensive, a condition that became a source of anxiety and angst for me. The historical role I had occupied in my family was to provide support, rather than being supported; following my diagnosis, I witnessed a noticeable reversal in my role. During the initial stage of my treatment, my family collectively supported one another and offered their

assistance to me when it was required. They respectfully assisted when requested to do so, which set the tone for authentic communication between us (Coyne et al., 2012). Like Denham-Vaughan and Edmond (2010), I believed the "sharing of presence, uninterrupted by words" (p. 7) is connected silence.

# **Extending the Nuances of Silence**

Silence is a prominent feature in therapeutic practice (Denham-Vaughan & Edmond, 2010). As Ladany et al. (2004, p.80) have emphasised, silence can, "convey empathy, facilitate reflection, challenge the client to take responsibility, facilitate the expression of feelings, or take time for themselves to think of what to say". Within a therapeutic space, these degrees of expression are essential for transformative healing. Silence can be related to a shared understanding with no need for expression (Fivush, 2010). Moreover, silence transcends the therapeutic space and features in other modalities such as meditation, yoga, and tai chi. I found such practices useful post-breast cancer as they complemented both my emotional and physical healing.

As noted in the poems above, there are other interpretations of silence, such as signifying the loss of power and self (Fivush, 2010). Related to this is self-silence, that "creates a loss of identity and an inability to effectively express oneself in relationships, which sometimes leads to disempowerment and hopelessness" (Clark (2014, p. 1). Professor Sliep's poem witnessed my silence particularly within academic relationships. In hindsight, at the time I felt a need to preserve relationships, to take care of others, and to silence my own fears during the initial phase of my treatment. More importantly, I experienced a loss of an identity related to my health and was in the process of accepting a new normal and identity as a young academic woman with breast cancer.

A quote from Audre Lorde, *The Cancer Journals* (1980) facilitated my introspection around silence. She wrote:

My silences had not protected me. Your silence will not protect you. But for every real word spoken, for every attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all believed, bridging our differences.

The relevance of this quote from Lorde (1980) illustrates how silence can be obstructive in the process when confronted with breast cancer. By interrogating the perceived diverse differences in women's experiences, meanings can be generated that may transverse those differences and provide deeper insight into the breast cancer experience. As Charmaz (2002, p. 303) explained, "stories and silences are emergent" within historical, social, and cultural contexts. For me, my breast stories and silences permeated different spheres of my life in diverse ways. In my academic life, the experienced voice of an effective lecturer living through a defective body concealed the voice of grief and transformation. In my personal life, my protective stance was to purposefully select what to share about my personal distress to parents and family members. Being willing to dig deeply into self, I accepted that self-protection of self and others is not necessary. I embraced the belief that breaking the silences and sharing personal narratives can positively influence the psychological and physical well-being of self and others.

### Conclusion

In this chapter, I have presented the progressive development of my intersecting professional identities and how the exploratory process of my various identities facilitated my

understanding of my breast cancer experience. I supported my reflective insights with data from emails and poetry that facilitated the deepening of my understanding and self-awareness. The data incrementally illustrated the building of my confidence in navigating around silence, vulnerability, and voice as a psychologist, academic, and researcher. In psychology practice, I was accustomed to and comfortable with self-reflective practices. Moreover, I recognised that the interweaving of my psychology and academic identities offered the reflective distance and professional knowledge in sharing my personal vulnerabilities and accomplishments. I also acknowledged how my innovative and creative teaching and supervisory methods were of benefit in facilitating students' personal and professional insights. This pedagogical ethos is what I prescribed to upon my entry to academia and felt validated in my student engagement. Using autoethnography as a reflective tool further supported the shift in self-awareness as I took ownership and responsibility for sharing my story.

The chapter that follows analytically focuses on my interconnectivity with community engagements.

## **Chapter Five**

## **Extending my Interconnectivity: Multiple Identities-Multiple Realities**

The aim of this final analytical chapter is to explore my commitment to community engagements and connectivity within diverse community contexts. Following my diagnosis, I was invited to several independent forums, both academic and professional spaces, to share my breast cancer experiences. This chapter examines and illustrates with examples the benefits and complexities of cancer conversations, my experiences of breast cancer awareness campaigns, and reflections on sharing in multicultural settings. The chapter is divided into two main sections. The first section reflects on my participation in breast cancer awareness walks, expanding my cultural understanding of cancer, media engagements, and demonstrating my advocacy. The second section examines my presentations specifically within the academic community and highlights the multidimensional aspects of my breast cancer journey.

# **Ongoing Dialogue of Connectivity with Communities**

With respect to the South African context, I support the argument of Nowakowski (2016b) that there is value in moving beyond academic work into community engagement. However, there were competing academic demands of teaching, research, and administration that I needed to navigate. In this, Pithouse-Morgan et al. (2016) have explored the burden of attempting to achieve these academic demands while developing a scholarly research portfolio. I could relate as a young academic to this experience. Notwithstanding, these community and academic engagements facilitated my confidence and comfortability in presenting my story, all of which I found self-rewarding.

Often, I was invited to present in interchangeable public-private spaces as I "embraced the in-betweenness of change" (Pillay et al., 2016, p. 6). To illustrate my intersecting identities beyond the academic setting, I selected the following community engagements: The Reaching Out Sisters, C-Sisters, Al Ansaar Breast Cancer Support Group, PinkDrive, The Narrative Foundation, The Durban Passion Play, and The Sedibeng Book Club. For my presentations within the academic community, I included the following: Women in Leadership and Leverage (WILL), Excavating Bodies, Together Against Cancer (TAC), Student Counselling Centre, The PsySSA Congress. Legitimately, these community engagements facilitated in deepening my understanding of who I am, my connections with others, and the relational benefits of sharing within unique diverse spaces.

Another motivating aspect was that of Holman Jones (2005, p. 766), as I began to question, "what is the relationship between knower and known, how do we share what we know and with what effect?" Some of the time, those who invited me to make a presentation had a personal and/or professional relationship with me. However, most of my talks were to people I had no personal relationship with or connection to. I thus shared my personal stories with strangers, inviting them into my stories and allowing them to witness my vulnerability. Despite this, I often recognised and validated our communal connections within the presentation space. These community engagements not only facilitated reflective dialogues, but also prompted constructive feedback from the participants. I appreciated these forms of connectivity for redefining and reclaiming my breast cancer experiences.

## Reinterpretation of the Experience of Breast Cancer Awareness Walks

The Reaching Out Sisters from St. Anne's Roman Catholic Church, located in my community of Sydenham, requested my participation in the *Breast Cancer Awareness Walk* 

on 25 October 2009, which I appreciatively accepted. I believed the walk reasserted a sense of community and the value of connection and symbolised a community of caring and compassion. I described the experience as a pilgrimage of solidarity, in which my family and friends gladly participated to celebrate my five years in remission. It was within this space that my family members reflectively shared and reinterpreted the nuances of my breast cancer experience. They acknowledged the qualities I possessed that resonated with others, including my independence, resilience, supportive nature, determination, and kindness. They also shared concerns about my need to be courteous and the stubborn trait that renders me silent. Such sharing presented an opportunity for the re-editing of my personal and breast cancer narratives, which became complementary to the autoethnography framework.

A spiritual communal space such as the *Breast Cancer Awareness Walk* was also beneficial in coping with the multifaceted aspects of the illness (Lynn et al., 2014). Cancer is often seen as a crisis affecting the body, mind, and spirit, along with relationships and lifestyle. It seemed to me that the walk was a representation of the interconnectivity of these identified aspects. Moreover, I was acutely aware that a presentation of illness could be "problematic in social context because it violates notions of acceptable identities and behaviours" (Nowakowski, 2016b, p. 1621). In my post-walk talk, I reflected on these various contexts and focused on my level of adaptability, recognition of my comfort around my identities, and interaction with the world. I also acknowledged my spirituality as a springboard to expand and deepen my connectedness with self and others.

# A Space that Enhanced My Cultural Intersecting of Self and Others within the Cancer Community

The dynamic extension of the circle of healing and sharing materialised in three publications (as referenced in chapter one above). The first provincial edition by the C-Sisters entitled, *The Resource Guide for Breast Cancer in KwaZulu-Natal*, was published in 2010. The book launch was reported in a local newspaper, dated 11 November 2010.<sup>2</sup> It was my participation in St. Anne's Roman Catholic Church, *Breast Cancer Awareness Walk*, which contributed financially to the printing costs,<sup>3</sup> while other sponsors included Novartis Oncology and Keal Property Management.

The diversity of the group experience of co-creating an informational text was both cathartic and liberating. Within the group environment, I reflected on the diversity of co-writers as their contributions within the interconnectedness of the cancer community. This DeShazer (2016) captures as a visible link to women who have experienced breast cancer to share from their eclectic racial and socio-cultural identities. Being the only woman of colour in the editorial group, there were no racial undertones present; instead, a sense of purpose and collegiality prevailed throughout. Our constructive debates and diversity of opinions often led to hours of deliberation on suitable information for inclusion in the publication. I was able to maintain my singular voice and appreciated the challenging discussions that afforded me the space for expanding my own capabilities and knowledge.

<sup>2</sup> See Appendix B.

<sup>&</sup>lt;sup>3</sup> See Appendix C.

Figure 5.1.

The C-Sisters at the Book Launch, Coastlands Musgrave Hotel and Convention Centre,

Durban, 04 November 2010



With the success of this publication, a subsequent request by Novartis, one of the sponsors, necessitated a second national edition. While this invitation created the space to evaluate the effectiveness of the first provincial edition, it also afforded the inclusion of more topical information. A pertinent gap on breast cancer and sexuality was identified and hence an invitation was extended to a psychologist whose expertise was on breast cancer and sexuality. Her contribution included patients' stories that highlighted several normative stereotypical views that were mooted during our editorial commentary. In particular, the concern for censorship, the intimacy of breast cancer, sexuality and the side effects of offending readers were strongly debated features. Being cognisant of the diversity of the editorial team, we negotiated around the objectives of this edition and to speak directly to the

lived experiences that are often unspeakable, invisible and inaudible – an important aspect acknowledged by Holtzman (2018), Komatsu (2017), Lorde (1980), Sparkes (2000), and Valentim (2017). In addition, my own perspective validated, substantiated, and promoted the inclusion of my intersecting identities. It became evident that silence and invisibility are powerful mechanisms that often prevent the maximum engagement of women's identities. When renegotiating new identities after breast cancer, we conceded as an editorial team it would be counterproductive not to include such pertinent aspects of body image and sexuality. We therefore facilitated the extension of the narrative that the second edition published in 2011, entitled, *The Resource Guide to Breast Cancer in South African*, addresses (Ness et al., 2011). This endeavour also transgressed academic boundaries that enhanced my experience of writing for an intersectional audience.

As an academic in the editorial team, I became keenly aware of the publish or perish culture that has been debated by scholars across various disciplines (Callaghan, 2016; van Dalen & Henkens, 2012). I was also mindful of the comment by Weber (2014), that "studies sink quietly without a ripple" (p. 9) or have maximum impact on those that are vulnerable. Evidently, publication output has become a standard measure for scholarly credentialing and promotion. Like Mudaly (2015), I realised "how deeply academic publications (and the authors thereof) were valued" (p. 40). While Callaghan (2016) examined the influence such academic demand has had on family life, Storbacka (2014) questioned the integrity and relevance of published research. These were points, which I constantly questioned, since my intention was to always maximise the benefits of any academic endeavour and thereby extend those experiences which implicate themselves in the lived realities of the community.

Similarly, Lattier (2016) has argued that knowledge generation can be specialised and/or

inaccessible to those in the public domain. This publication was yet another indication of the successful integration of ethnographic constructs, which holistically contribute to existing knowledge. Moreover, it demonstrated group cohesion and respect for unique methodologies, which ensured that the book was not purely an academic text. This increased the accessibility of the publication to a wider audience, beyond that of the academic community, something that also concerned Lattier (2016), Akuoko et al. (2017), Maree and Mulonda (2015), and Stefan (2015) in their research findings. I also recognised the value of writing for a non-academic audience, to reach a far wider, more diverse readership. As I engaged with members of the C-Sisters, this became an important guiding philosophy. The argument that the production of knowledge and the privileging of writing became driven by how many people we can influence by sharing our stories. Moreover, Wood (2014) also recognised how collaboration with internal and external stakeholders can promote transformation within and beyond an academic institution. Like Wood (2014), I was able to commit to the agenda of not only producing knowledge for academic purposes, but to reach a wider, more diverse audience, a notion which finds resonance with Bochner (2014) and Ellis (2004).

Another dimension of this initiative extended to translating the first edition into isiZulu. This important initiative further maximised its readership. Campesino et al. (2012) acknowledged a further dimension of examining the stigma and discrimination within the breast cancer community. The involvement and voice of the community were also acknowledged by The Narrative Foundation who generously offered to translate the text, together with the assistance of the Community Health Workers (CHWs) in Inanda, KZN who all belonged to the black community. Published in 2011, the book was entitled,

*Umhlahlandlela mayelana nomdlavuza webele KwaZulu-Natali*. This collaborative effort facilitated and promoted community sensitisation of breast cancer, which is supported by Cumber et al. (2017). In addition, the book offered multiple benefits as the CHWs extended themselves to not only share its contents with one another, but to also engage with others in their community to expand breast cancer knowledge and awareness.

It was in the context of the initial meeting with the women CWHs based in Inanda that I shared the visuals of my breast cancer, which included my scarring and external prosthesis. This first intimate visualised experience in a public forum once again validated the evolution of my silence to sharing. Reflectively, such an experience facilitated my confidence in including a photograph as noted in chapter three. My surgery was more than "flesh healing over physical wounds" (Doh & Pompper, 2015, p. 605), as it offered alternative positive meanings in a shared breast cancer space. Furthermore, I received comments by the women, noting that despite my breast cancer diagnosis, I was healthy in appearance and did not take on a typically sick role. In addition, they recognised how I readily negotiated socially stigmatised identities that both Berry and Hodges (2015) and Boylorn and Orbe (2013) identified. They also commented on my courage to share intimate aspects of my scarred body, debating from their own socio-cultural position the anxiety of sharing a scarred body. As Doh and Pompper (2015, p. 597) have observed, scar tissue damage is viewed as "un-gaze-worthy" and so needs to be concealed and disguised. Although I was aware that the "challenges I have weathered have aged my body" (Nowakowski, 2016b, p 1621), I acknowledged this as a process of my personal and physical transformation.

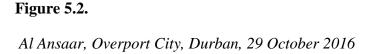
As I extended my advocacy role beyond the visibility of the female body, such an environment created an interrogatory space to develop which allowed for navigating the complexities of the breast cancer trajectory. As has been noted in chapter one, this further challenged the cultural value attached to the female breast and the influence of stereotypical societal understandings perpetuated around the breast and acknowledged by Edwards and Greeff (2018); Lourens (2013) and Venter et al. (2012). Likewise, Tetteh (2017) has acknowledged the socio-cultural realities that maximise the ethos of engagement with women with breast cancer in Ghana. The ethos of engagement was never to silence the voice of the individual women. It was to hear their specific challenges within the breast cancer community. My perspective of inclusion, which in turn was guided by my socio-cultural identity, thus informed my respectful community engagement. Moreover, I was cognisant of the various dynamics of accessibility and the realities of the public health services in KZN.

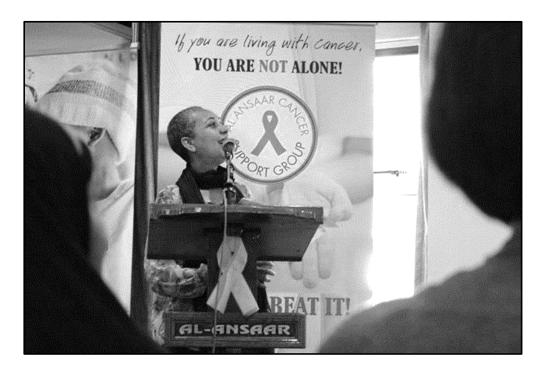
### Extending Empathic Listenership

A promotional opportunity for the first edition book was an invitation by Radio Al Ansaar to interact with their listenership about coping with breast cancer. Like Charon (2006, p. 66), I believe the act of listening is to "recognise what the teller is revealing about the self" and to be empathic in my listening and response. In so doing, this honours the illness stories of the listeners. I later shared my journey with the pre-established Al Ansaar Breast Cancer Support Group. These engagements extended from 2011 to 2015. My intersecting positionality cohered well within multiple religious contexts that reasserted and broadened the dialogue within the religious/spiritual community. The target audience was predominately-Muslim women who situated and extended their own comfort within the Islamic faith and scriptures and which became a salient aspect of their engagement. In

facilitating these dialogues, which addressed the concepts of suffering and illness, the bodily response was consolidated by acknowledging a higher purpose. It also solidifies the humanness that transcends individual differences and promotes connectivity and oneness. Without a doubt this led to a "deepening appreciation for the ultimate uniqueness and complexity of any life as lived and narrated." (Berry & Patti, 2015, p. 267).

Within the Al Ansaar Breast Cancer Support Group, another modality of engagement inadvertently facilitated a discussion on differing ideas about the body, illness, healing and on sharing with confidence about an illness that knows no boundaries. The C-Sisters group was invited to another Al Ansaar event where I was asked to share my experiences. This event was captured in the photograph depicted in Figure 5.2. This space offered a reflective opportunity of my 15-year long breast cancer journey that spoke to my different levels of dis/comfort through my intersecting identities. Vacillating between these two emotions became the focus of many of the questions within my healing trajectory. My responses were framed from my intersecting identities as a psychologist with breast cancer. An additional benefit from occupying this transformative space promoted self-activism and self-advocacy which Bond et al. (2010) cites as a priority in self-care particularly related to breast cancer, a position which resonated with my perspective and healthcare priorities.





## Extending Awareness, Activism and Advocacy

A further effort to extend my community engagement and activism, dated 23 May 2011 was to promote breast cancer awareness and screening in Inanda, KZN. This event is depicted in Figure 5.3. A study by Williams and Jeanetta (2014) exploring the meaning of breast cancer survivorship found participants had a "shared focused on advocacy and foundation creation" (p. 637). The collaborative initiative with the C-Sisters, Al Ansaar and PinkDrive created the opportunity to extend the circle of care (Williams & Jeanetta, 2014) as well as demonstrate agency (Coetzee et al., 2019). Froude et al. (2017) also acknowledge the benefit of such collaboration and networking, reaching beyond urban areas to that of rural communities. The primary purpose of PinkDrive is "to contribute meaningfully towards

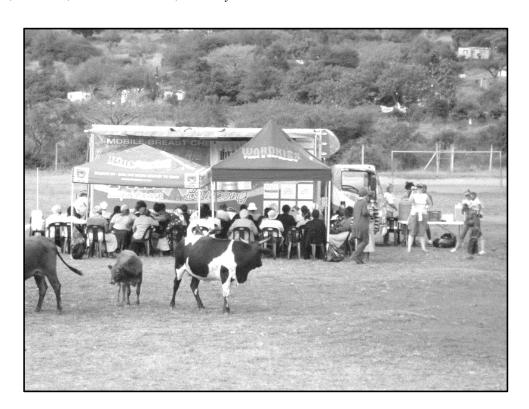
preventing as many people as it can, from succumbing to breast, cervical, prostate and testicular cancer" (PinkDrive, n.d.). One of its priorities is to focus on accessing healthcare in deprived communities and not to digress from "survivorship and hope" (AbiGhannam et al., 2018, p. 462). As noted in chapter one, South African studies on breast cancer conducted by Trupe et al. (2017) and Joffe et al. (2018); Rayne et al. (2017) have collectively cited it as being the most common cancer for South African women, a statistical pattern which is replicated globally. As Wadler et al. (2011, p.2) asserts, women in South Africa have limited "access to information and screening" and thus suggests that "disparities along racial lines" are among some of the challenges experienced, a position which Čačala and Gilart (2017) and Trupe et al. (2017) also share. Smit et al. (2019) recognise the importance of the sociocultural context as it contributes to the meaning attached to the body and its changes. In addition, as Čačala and Gilart (2017, p. 497) suggest, in rural South Africa, "pictorial information about breast cancer needs to be introduced", a stance which PinkDrive also emphasise.

In their study, Campesino et al. (2012) explore racial, ethnic, and healthcare discrimination in cancer care, even though these are complex issues. I was aware that the disparities in healthcare delivery require extensive attention particularly in the South African context. Accordingly, in terms of my community engagement, I was acutely aware of the diversity of South African society and appropriately adjusted my contributions to meet their differing needs. I agreed with the findings of Trupe et al. (2017) that validated the feasibility of training nonphysicians "for use of breast ultrasound in limited-resource settings" (p. 505). PinkDrive also fully supports the initiative to promote breast self-examination as an initial step prior to engaging a professional healthcare facility. Women prioritising self-care thus

became focal in this space as they occupied several identities. Contextually in rural South Africa, women navigate multiple roles, for example, caregiver, financial provider, mother, and wife which relegates self-care to a lower priority. Reflectively, my position of privilege provided an engaging opportunity as I learned from the realities of rural women and afforded them the vocality of their own challenges, reiterating the truth that breast cancer does not discriminate.

Figure 5.3.

Inanda, Durban, KwaZulu-Natal, 23 May 2011



Within the activism space, there has been substantial controversy around pink ribbon initiatives which I am acquainted with. For example, Doh and Pompper (2015) suggest that numerous foundations have been accused of "pink washing" [sic] as many marketing campaigns strategically use these initiatives to promote their products. Likewise, Greehalgh (2017) was cognisant of the emotional reactiveness and sentimentality linked to the pink

ribbon initiatives and thus ensured that her research did not reflect such. Furthermore, "The SCAR Project" Facebook page has been used "as a forum for criticising inauthenticity of the pink ribbon imagery used in breast cancer campaign" (Doh & Pompper, 2015, p. 606). Similarly, Sulik (2011) asserts that, "pink ribbon paraphernalia saturate shopping malls, billboards, magazines, television, and other entertainment venues" (p. 4). While being aware of this assertion, my objective has been to honour the initial objectives of the pink ribbon initiative and not allow it to devolve into a marketing strategy that digresses from its original purpose of promoting awareness and prevention.

Another interactional catalytic space was my participation in The Durban Passion Play. This religious play, performed by Durban Catholic Players' Guild in association with the Playhouse Company, was staged in 2011 and 2015. These opportunities further demonstrated the capacity of compassion and performative experience. Meskin and van der Walt (2014) reflexively explored the intersectional merits of self-study, art-based and theatre research using autoethnographic tools. They discovered how "performance before and audience" (Meskin & van der Walt, 2014, p. 55) allows for reflective awareness and interrogation of one's subjective understanding. In addition, Holman Jones (2018) reflected on the transforming of self and others through the creative arts as well as the emotional vulnerability to perform.

An article in *Sun News*, dated 08 April 2011, captured my story of breast cancer within the context of my spiritual journey and participation in the Durban Passion Play.<sup>4</sup> The

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<sup>&</sup>lt;sup>4</sup> See Appendix D.

cast included members diagnosed with breast cancer or other forms of cancer. While some members have since died, the remaining cast members continue to be committed to the ethos of divinity in humanity. The Durban Passion Play is family-orientated, even expanding across generations ("The Durban Passion Play", 2015). Within this multi-faceted context, the boundary of healing and hope beyond religious space was reflective on how religion and spirituality cohere, a factor which Froude et al. (2017) have recognised. It became evident to me that cancer created connectivity within a performative space. This connectivity facilitated activism and advocacy. Such interfaith and multicultural contexts offered the differing influential dynamics such as gender, race, ethnicity, culture, and age to intersect. I respectfully acknowledged how such engagements deepened my own spirituality.

### Activism Commemorated on Women's Day

I participated by invitation from the Sedibeng Book Club to present at the Women's Day celebration on 09 August 2012. My presentation focused on principles of healing which Edwards (2013, p534) defines as the process "to restore to harmonious balance, to heal, to make whole, to transform from illness to health". My engagement offered reflectively how my interesting identities cohered towards restoration and healing.

The Sedibeng Book Club consisted of ten professional Coloured women who were residents of Wentworth, Durban, KZN. They challenged the stereotypical view of Coloured women from Wentworth and exemplified the importance of education, social connection, support, sharing, the value of reading and community outreach. They valued art-based and creative activities such as the use of poetry and writing exercises at the event to explore the personal stories. These methods used at the event demonstrated the benefits of reflexivity within a communal space, which I identified with and recognised as an autoethnographic

process. I believe the communal space was a transformative experience as it had the capacity to influence the overall well-being of the attendees. I willingly participated in a communal meditative exercise that facilitated further curiosity and digging deep into self. The practice of meditation was supported by Sealy (2012) as discussed in chapter one. More importantly, mediation and reflection continue to be my family practice and its value in my life as a psychologist is undoubted.

## **Professional Concurrent Connectivity**

The following are selected presentations, which capture and explore my reflective experience within professional communities. It is evident that such exposure in diverse university spaces facilitated introspection on my own positionality. It is within these open-interactions that my subjectivity was emphasised by Fernandes et al. (2006) and the ownership of my experience became more comfortable. Although the study by Fernandes et al. (2006) focused on familial breast cancer, eating disorders, and infertility, it found the meaning of personal suffering is to be "discovered, discerned, and experienced" (p. 872). These presentations allowed for discovery and reflection as I searched for meaning within my own breast cancer experience.

### Addressing Women in Leadership and Leverage (WILL)

It is within this academic community that I was invited by Women in Leadership and Leverage (WILL). The WILL is a committee comprised of female academics from the College of Health Sciences, UKZN. In this space, I innovatively presented a series of photographs that captured my transformative breast cancer journey. Such a visual methodology was also acknowledged by Makhanya (2016, p. 87) as "visual artefacts" as

these deepened my analytical reflections and became more meaningful to me. Moreover, Scott (2014, p. 69) acknowledges these as "visual indicators of my value". It was also an opportunity to ask myself "how is this sharing adding value to others?" This self-questioning gained in momentum as it afforded me the strength to resolve and to contemplate how my PhD study will add value to a scholarly research community.

Figure 5.4.

WILL Presentation, UKZN, 14 November 2013



Initially, I contemplated the issue of vulnerability within this community. However, I reminded myself of Graham's (2017) words, "that to be vulnerable is to be strong, enlightened, determined, and possibly motivated to change what may be making one unguarded" (p. 121). Engaging about my breast cancer within this academic community demonstrated the ability to transgress personal and professional boundaries respectfully. Furthermore, this space became a catalyst for my interest in autoethnography within a scholarly community. Moreover, it brought to fruition how lived experiences and visual

methodology are located within academia without destabilising any normative methods of teaching and learning.

### Reflecting on the Anthropological Seminar

Another occasion that allowed for purposeful reflection of these merging identities was when I was invited to present at a postgraduate anthropology seminar on "Cancer Journey: Long Walk to Freedom". I was requested to contribute to the seminar under the theme, "Excavating the Body", hosted on 26 February 2015. Like the *WILL* presentation, to capture my experiences I elected to present my journey chronologically with photographs and an associated narrative. In contrast, the "Excavating the Body" presentation permitted deeper exploration as I shared my ill- versus well-embodied experience. Specifically, I concentrated on autoethnography as a methodology to unpack my breast cancer lived experience. The discussion that pursued generated debate on the methodological appropriateness of autoethnography and the mechanism to capitalise on the basic tenets of choice. The resultant debates echoed the concerns addressed by researchers such as Adams et al. (2015), Guzik (2013), Le Roux (2017) and Stahlke Wall (2016).

Having an exclusive audience of postgraduate students moved me to further broaden my horizons on my methodological orientation because some were intrigued by how personal experience can become an academic endeavour. It demystified them how a research paradigm can coherently guide a personal experience and establish how intersectionality can articulate itself. This experience extended the scholarship of the benefits of autoethnography which also led to an engaged discussion with established researchers who participated in the seminar.

In preparing for the presentation, I was aware of the messy and often chaotic nature of my illness story. My aim was to share the messy and not place "emphasis on stories which are culturally preferred" (Thomas-MacLean, 2004, p. 1654). Generally, the cultural response to chaotic stories is one of discomfort and unease. However, my audience were psychologists who were well-acquainted with feelings of discomfort and unease. Furthermore, as Thomas-MacLean (2004, p. 1653) has argued, "the chaos narratives are also recognised as opportunities for healing, which Frank (1997, p.109) supportively noted the "need to honour chaos stories is both moral and clinical". The chaos certainly emerged in my own story-telling and was my opportunity for meaning-making and healing. It was through the lens of intersectionality that my chaotic story was given coherent meaning. Once again, I found myself forging my own path into the messiness of researching self.

Additionally, this seminar permitted me to address the concerns of the absent body in research as expressed by Roth and Lawless (2002), Samudra (2008), Longhurst et al. (2008). Häfner (2013) qualified this concern, emphasising the difficulty in separating the body and mind as these are closely intertwined in producing embodied cognition. With specific reference to developing reflective practice, Leigh and Bailey (2013, p 168) insist it was essential to engage with the body with the aim "to achieve greater embodied awareness". This description aptly captures how my embodied experience with breast cancer facilitated my deeply reflective thought process. As the UKZN campus newspaper *Ndaba Online*, <sup>5</sup> reported:

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<sup>&</sup>lt;sup>5</sup> See: https://www.ukzn.ac.za/media-publications-reports/ukzn-ndabaonline/

Ms Lucinda Johns shared her powerful and poignant story about being diagnosed with breast cancer at the age of 32 and her decade long 'walk' through remission. Her story depicts her grace and courage in the face of shattering news (Mungroo, 2015, p. 3).

Reflectively, this experience created further confidence around my methodology. In this academic space, the worrier of cancer took transformative steps to become the Warrior who had the "grace and courage" to share. The label of breast cancer survivor was a catalyst to identify my compassionate courage to share the messiness of my experience, to unsettle the perception of a perfect female body and to explore the ill/well body and self. In my presentation, I did not maintain the identity of survivorship as it is "complicated" (Smith et al. 2016, p. 462) and difficult to articulate (Williams & Jeanetta, 2014) as validated in chapter one. The fluidity of such a label allowed me to embrace the changing stages and progression of my self-concept.

### The Reflection of a Student Participant

A postgraduate student in attendance at the seminar provided the following observation which is captured by Mungroo (2015, p. 3), illustrating the transformative nature of the illness narratives:

It was enlightening and somewhat of a cathartic experience, rather emotional too. To hear first-hand accounts of how women have survived cancer, was inspiring and made me reflect on my experiences of losing someone with cancer. It also made me realise that life really is too short and I shouldn't be afraid of letting go once in a while and being free and enjoying myself.

Receiving feedback solidified for me the significance of sharing my cancer story. Similar to the experience of Boylorn (2017) when sharing her autoethnographic story on the way her life was shaped by the interconnectedness of race, gender and class, she acknowledged the audiences' appreciation "for allowing them access to an experience they were unfamiliar with, for trusting them with my truth" (p. 8). The extract highlights the witnessing and validation of my cancer story. Of equal importance, is how my story encouraged the student to reflect on the fragility of life and the enjoyment of living without fear even for a moment.

Like Cummins (2017), I believe feedback and engagement with the audience required me to be authentic and vulnerable. As Custer (2014) cautioned, that the autoethnographic process requires the researcher "to face their own pain, oftentimes they are exposed to the pain and anguish of other people who have experienced similar circumstances" (p. 1). This was evident in the numerous forums and platforms from which I shared my voice and experiences. However, within this academic space, I believe my professional practice and insight facilitated my engagement with the diverse audience allowing me to maintain healthy personal and professional boundaries.

As with Knowles (2014), I believe receiving constructive feedback is fundamental, especially towards a transformative agenda in academia. I prioritised students' feedback as essential to my own development as an academic. Moreover, I was unafraid to engage with the critique of the students, very much like that of Wood (2016). Such critique allows for reflective learning between "personal histories and the developing professional self" (Graham, 2017, p. 89). These intersecting identities defined my developmental journey, which I felt safe to share in an authentic way within this intimate academic space.

## A Reflective Email from a Panellist

One of the panellists that I shared the podium with at the seminar was Dr Barbara Boswell. She subsequently emailed me the following observations:

As researchers, we entered into our respective fields as embodied beings. The trauma that shape our bodies leave their imprint on our psyches and physicality yet we hardly ever address the meanings of embodiment in our life's as scholars. This is especially important for women scholars, especially black women academics, for whom self-care and love can be so foreign as to be framed as subversive (B. Boswell, personal communication, 05 March 2015).

Dr B. Boswell rightfully raises the connotation of the intersectionality of race, gender, and class that authors such as Couture et al. (2012), Grant (2010), Palmer (2016), and Mitchell (2016) have explored in various contexts. Upon further reflection, I realised that the concept of self-care that she notes is often ignored and relegated to a lower order of priority especially by women. For women with breast cancer, there are competing priorities beyond the medical necessities which I have identified. In addition, I was cognisant of the limited engagement in academia on embodied knowledge of research into self, especially from an autoethnography perspective. The rethinking of my subjectivity, which Boswell recognised as a novel paradigm of thinking was especially helpful, where "self-care and self-love, practices are actively disregarded by academic way of life" (B. Boswell, personal communication, 05 March 2015). My presentation reflectively focused on the interconnectivity of my academic self as it interacted with my breast cancer experience.

Using my photographs, the associated narratives summarised pivotal aspects of the transformation of myself.

Within academia, the interactive tension that is extant between silence and voice is undeniably apparent. This is acknowledged by Valentim (2017) who comments on how external entities are analysed but not self as situated within the university. By courageously sharing my experiences in different forums, silence and voice emerged as allies for transformative change. Subsequently, self-disclosure made me visible and identifiable within my academic space. With this visibility came concomitant feelings of vulnerability and openness which I accepted. I realised that the vulnerability of sharing was not as weakness, "but as the very possibility of becoming" (Shildrick, 2000, p. 2015). As to process, this offered consolation and solace in knowing I am more than the label of a breast cancer survivor. Such "academic becoming" is also acknowledged by Pillay et al. (2016, p. 5) who further recognised the "inside-outside" (p. 6) of the academic environment.

According to Sharma et al. (2009, p.1642), embodied knowledge and experience should not be limited to the participants of qualitative health research, but ought to include the "practice and experiences of the embodied researcher". The idea of being an embodied researcher provided me with a unique yet valuable position to critically reflect and gain insight into the transforming nature of the illness. I was the subject of experience and acknowledged that the self has a history and a story of illness and well-being. For Pearson (2010, p. 345), being, knowing and experience are central concepts in developing a sense of self and its multifarious identities. In her autoethnographic study, she explored her "multiple identities as a hard of hearing, middle-class, female, Korean adoptee" (Pearson, 2010, p. 342) using intersectionality to conceptualise as well as deepen her understanding of oppression.

The study resonated with me given my personal experiences of oppression. Similarly, Longhurst et al. (2008) accepts that "being and knowing cannot be easily separated" (p. 208). My poem dated 01 July 2015 in this chapter reasserted this intersectionality as an embodied researcher with multiple identities as a young, middle-class woman of colour who has experienced breast cancer.

During my presentation, I acknowledged my vulnerability as it fostered resilience and personal growth. To support this assertion, the findings of the study by Tiedtke et al. (2012) conclude that it was important for professionals to consider the "feeling of vulnerability of breast cancer survivors" (p. 11). A key focal area of my presentation was to acknowledge that vulnerability is an embodied process and that is not to be considered as a split between body and mind (Fernandes et al., 2006, p. 854). This relational connection between vulnerability and resilience is pivotal and is acknowledged even in my professional practice. Furthermore, the presentation, experience, and feedback, contributed to my repertoire of professional skills (Shin et al., 2017).

## Engaging with the student university community

A student body at UKZN, Together Against Cancer (TAC), extended an invitation for me to share my breast cancer experience. The health forum dated 14 April 2015 concentrated on the value of prevention and the dis/ease of the body which supports the position of Fernandes et al. (2006) with respect to embodied knowledge. I enthusiastically accepted the invitation as the objective was an attempt at normalising breast cancer and to reflectively reframe body identity and body image. With their transition into young adulthood, students prioritise body image, physical appearance, and sexuality. These identities are arguably both pertinent and central to women with breast cancer.

Being part of the health forum presentation, I shared my vulnerability with confidence through a visual presentation of a woman of colour who had breast cancer in a public academic space. The presentation emphasised the applicability and relevance of my intersectional, personal, and professional identities. The insider binary for me as (1) a lecturer, academic and professional and (2) a woman of colour who had breast cancer further illustrated the significance of my multivocality. This perspective of "being both" allows the audience to benefit from the insider perspective (Frambach, 2015, p. 956). Once again, I acknowledged the essence of autoethnography as I explored the vulnerable self that looks inwards, zooms backwards and forwards (Pearson, 2010, p. 344). Student participants could identify with me as a lecturer and meaningful insights from my personal story served as a catalyst to self-reflect holistically on their own health. Equally important, my impromptu dance demonstrated comfortableness to reveal my entertaining and humorous nature. I believed my brief performance facilitated a meaningful and significant connection with the audience. Researchers such as Holman Jones (2018), Leveen (2019), Mitchell and Weber (2005) and Spry (2001) have considered how the autoethnographic process as a performance through artistic methods requires reflexive practice. It is this practice that leads to self being transformed.

Fernandes et al. (2006, p. 891) has concluded that "suffering remains a personal issue", thereby endorsing my willingness to publicly share and participate in the community of healthcare awareness, advocacy, and activism. Such an opportunity evoked empathy and connectivity (Egeli, 2017, p. 12) which I reflectively acknowledge within the larger university community. Once again, I recognised the inextricable link between empathy, reflexivity, and vulnerability (Berry & Hodges, 2015) which is the focus of autoethnography.

Figure 5.5.

Together Against Cancer, University of KwaZulu-Natal, Howard College Campus, Durban, 14 April 2015.



# Extending Conversational Spaces: UKZN Psychologists

An invitation was extended from the UKZN Student Counselling Centre to participate with five female psychologists of colour on my breast cancer experience dated, 27 May 2015. This occasion initially evoked ambivalence, anxiety, and hesitancy (Frambach, 2015) as I would be engaging with a discipline-specific audience of colleagues. My journal entry, dated 17 May 2015 captures my preparatory reflective questions:

Was I to speak from a professional psychologist view with a hint of personal? Or can I be personal but reflect on the psychological concepts in relation to self?

I ultimately conceded that the intersectional identities of my lived realities were the best focus for my engagement. For my presentation, I once again shared my photographs which

portrayed a changing body and a transforming self. The photographic timeline reflected significant moments captured. My narrative offered me within this space, "a way to grapple with the temporal movement of life" (Russell & Babrow, 2011, p. 240). Analogous to Stirling (2016, p. 27), I explored my grief through "time travel experience" which she describes as "the conscious transportation of self through memory" (p. 26). The recollection of memories related to my intersecting identities associated experiences on silence, vulnerability, and visibility. The divergence and convergence of my identities became even more apparent as the "interplay between inner and outer dialogue" became evident (Pillay et al., 2016, p. 8) to both myself and the participants. In addition, I portrayed my emerging skilfulness as a researcher of self and maturity of thought as I shared the messy contours of cancer and research. The messiness through "reflexive tales" (Collins, 2017, p. 218) brought out the lived experiences of my socio-cultural context and the re-experienced memories with a nuanced intersectional lens.

This presentation facilitated a deeper discussion on personal voice and prominence in practice (Wood, 2016). It was acknowledged by participants that psychologists are generally hesitant to reveal and share personal emotional difficulties in public spaces. According to MacCormack, 2001, p. 1), "there is a general but unspoken code of silence that tends to prevent them from publicly voicing such feelings, much less write about and publish them". I thus illustrated my own experiences of publishing and sharing in public forums as a mechanism to "create space for dialogue" (Denshire, 2014, p. 845). Introspectively, the presentation allowed for further exploration and interrogation of the (de)value of silence, vulnerability, and visibility within a space of psychological awareness. The emphasis was on my courage to break my silence and my willingness to take a risk to be vulnerable within a

professional space. A significant observation from a participant was the unsaid or omission in my story about my transforming body and sexuality. I accepted sexuality as a significant aspect which is located within my intersecting identities and was not the focus of the facilitated conversation. More importantly, it is within this space that I was able to discuss the value of mindfulness and spirituality within the healing trajectory.

We reflected as psychologists on our training and professional development. As trainee psychologists, we were subjected to "scrutiny and reflexive examination in supervisory contexts" (MacCormack, 2001, p. 1) which was viewed as a beneficial process in developing greater self-awareness, empathic understanding, and professional growth.

Undeniably, continuous small peer supervision groups provide the confidential, dialogical space to learn and deepen the "learning curve that changed all future experiences and the reflection process" (Monck, 2017, p. 134). This reflective process contributed to my "personal growth as it becomes part of a system of checks and balances, of praxis, as my experiences inform my theories, and my theories inform my style of practice" (Constantino, 2017, p. 128). In addition, as mental health practitioners, we reasserted our professional responsibility to continually develop knowledge and skills. We affirmed that attending accredited Continuing Professional Development (CPD) workshops and courses ensured that psychologists were upskilled, responsible and competent.

Their professional knowledge and reflective insights provided an enterprising opportunity to explore my experience from the various theoretical and psychological lens. In hindsight, it granted me the opportunity to interrogate my intersectional PhD objectives more deeply as the professional audience became outsider witnesses and a reflecting team to my story. This inward-looking opportunity afforded the space to recognise my evolving identity,

describing the ambiguities and complexities of class, ethnicity, cultural consciousness, family background and social environment, also acknowledged by Boylorn and Orbe (2013), Kracen and Baird (2017), May (2015), and Mitchell (2016).

Extending Interaction with the Professional Body: 22<sup>nd</sup> South African Psychology Congress (20-23 September 2016)

For the 2016 PsySSA Congress, "Diversity in Practice", I was invited to participate in the theme. My poster entitled, "Breaking my Silence" presented an innovative methodology of autoethnography and contained photographs and poems of my breast cancer journey. Here again, my intersecting identities of researcher and psychologist and a woman with breast cancer was aptly communicated. A key aspect of this experience included breaking my academic silence (Zapata-Sepúlveda, 2012) and my silences around breast cancer.

The PsySSA Congress allowed for the vulnerability of myself to be experienced (Frambach, 2015, p. 956). In addition, interacting and dialoguing with other presenters validated an intersectional perspective of my experience and demonstrated how it offered coherent understanding. Moreover, it demonstrated how theory elegantly translated into practice and how my colleagues benefitted from the "insider perspective" (Frambach, 2015, p. 956). Their responses acknowledged the value of self-reflective work and the healing process related to such an exercise.<sup>6</sup>

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<sup>&</sup>lt;sup>6</sup> See Appendix E.

#### **Conclusion**

A characteristic feature of autoethnographic practice is the understanding that, "the knower, the known, and the unknown connect at a deep level of knowing" (Davis & Warren-Findlow, 2012, p. 292). This was a feature that I embraced in the reconstruction and reinterpretation of the personal and professional self as I engaged with diverse communities. In addition, by giving voice to my personal breast cancer experience and cultural context, I disrupted the personal and professional divide by moving in and between both positions. I consciously selected data that revealed the complexities of the in-between-ness I found myself in. The community engagements facilitated personal and professional inquiry and encouraged me to recognise my transforming self and performative healing. By using community engagements, I became visible and comfortable in sharing my vulnerabilities through voice or visual narratives. Moreover, these community activities provided opportunities to enhance a cultural awareness of cancer, recognise the value of advocacy, and promote reflective dialogues with fellow academics, researchers, and community members. I believe these diverse interactional spaces contributed to the meaning-making process and provided insights into the value of community practice.

The concluding chapter which follows provides a comprehensive reflection of the intersecting identities of my breast cancer journey.

## **Chapter Six: Conclusion**

## Reasserting the Matrix of My Intersecting Identities

My study has focused on how my breast cancer experience facilitated the exploration of my intersecting personal and professional identities. Framed by autoethnography, it was reaffirming to reflectively unravel my identities to deeply explore my 15-year breast cancer journey. As identified by several authors such as Gannon (2018), Holman Jones (2018), Mitchell (2016) and Pillay et al. (2016), autoethnography offered a creative and reflective process to maximise the understanding of my breast cancer experience through an analytical and scholarly lens.

While privileging one way of knowing can be both restrictive and limiting, there is room and benefits for other ways of knowing, such as in the use of autoethnography. As I addressed the objectives of my study, there was an acknowledgement that I "seldom ever occupy one position" (Mitchell, 2016, p.183). Furthermore, there were "multiple sites of knowing" (May, 2015, p. 9). Considering my multiple positions, it can be concluded that these ultimately contributed to existing knowledge, particularly with respect to the national narrative of breast cancer within the South African environment. My study demonstrates how my intersectional identities articulated themselves contextually as I reflectively engaged with my breast cancer experiences. Hence, this chapter offers intersecting conclusions that include the benefits of autoethnography, the advantages of exploring my intersectional identities, reflexivity, reflection in practice, and community engagement, after which I conclude the study with a reflexive poem.

The research question that guided the study was as follows:

# How did I contextually experience breast cancer through an intersectional lens?

The focus of the study had the following three specific objectives:

- To explore my breast cancer experience in relation to the intersectionality of personal and professional identities;
- 2. To explore the influence of my professional knowledge and practice on my breast cancer experience;
- 3. To contextualise interconnectivity within the community of care.

# **Intersecting Conclusions**

My intersecting identities informed the matrix of intersecting conclusions which I present below. As previously stated, the inextricable link between these differing identities cannot be understood in isolation from one another and hence contributes to the messiness of the matrix. I thus chose to present the three analytical chapters separately to afford deeper interrogation. These chapters allowed me to gently lean into my discomfort of ambivalence and ambiguity as I navigated the landscape of my experiences and intersecting identities. Furthermore, the process allowed for unsettling dominant discourses of breast cancer, self, and others. This section offers an intersecting conclusion that does not digress from the objectives of the study.

### The Benefits of Autoethnography to Appropriately Frame the Research Process

As Bochner (2014) suggests, autoethnography is one way to make ourselves the object of research which emphasises our lived experiences. When embarking on this PhD study, my desire was to adopt an approach that allowed for the intersecting of research with my lived experience. By contextually exploring my breast cancer experiences in relation to my intersecting identities, the transformational learning and healing process was translated into academic knowledge. Some theorists, notably Arditti (2015), Chang (2008), Custer (2014) and Gülerce (2010) have expressed the self-transformative value of autoethnographic studies. Another essential point of autoethnographic writing is making a connection with the reader aimed at facilitating reflective thinking about personal experiences and to be motivated to transform the self. A consequence of such academic sharing of personal experiences can be influential in generating collective understanding and knowledge.

Like other autoethnographers such as Adams et al. (2015), Bochner (2014) and Kamanos Gamelin, (2005), the exploration of my lived experiences was messy. I identified with the description of Gannon (2018, p. 25) that, "auto-ethnographical writing might be discontinuous, fragmented, sparse, elliptical". Navigating the messiness was a critical and necessary journey throughout the research process. My progressive confidence in the methodological process and the attributes of my work, I believed empowered me to articulate my messiness coherently and intimately in an accessible way. After much debate, I decided to thematically reflect on the transformational nuances of my intersectional identities.

In selecting credible data and using reliable scaffolding techniques, I justifiably addressed issues of self-indulgence and research meticulousness within an autoethnographic framework. Equally important was the use of multiple sources of data to illustrate my lived

breast cancer experience and intersecting identities. The selected data facilitated the reflexive process and addressed the concerns of trustworthiness and credibility of my personal narratives. In addition, the multiple sources advised by Chang (2008), Duncan (2004), Eisner (1997), Mitchell (2016) and Wood (2016) were associated with exploring personal insights and discovering meanings of knowing. By comprehensively engaging with the multi-layered data, it deepened my personal and professional insights of illness experiences which other research methodologies may not have allowed me to disclose. One salient aspect of psychological practice is the tension of self-disclosure of personal experiences by the therapist within the therapeutic space as well as in research publications. Through an awareness of the complexities surrounding disclosure, autoethnography allowed me to critically reflect on the contribution my disclosure will have on practice and research. As I progressed through the research process, I was able to recognise the value of my voice and acknowledge its small contribution to the field of expert academic voices.

Being in the practitioner-researcher space, opting for creative and innovative "methodological procedures" (Demuth, 2015, p. 126) allowed me to disrupt "the traditional academic voice" (Pathak, 2010). The methodological process prompted my confidence into self-study which became for me a "self-affirming and self-confirming" academic and scholarly enterprise (Kamanos Gamelin, 2005, p. 192). Once again, the practitioner-researcher divide coherently and conclusively demonstrated the interdependency and interactional nature of using autoethnography to frame a study in the human sciences. In addition, it affords a reflection of practice and adds to the existing body of knowledge of improving the quality of professional practice and research. By looking more closely at the autoethnographic process, academics need to acknowledge how the process challenges the

professional status that comes with protection and privilege. These factors may be contributing factors to the late introduction of newer methodologies in psychology practice and research as expressed by Ellis and Adams (2014), Frazier (2012) and Kracen and Baird (2017). Considering that psychology is a reflexive and reflective practice, it can be concluded that there is an overlap with autoethnography. Therefore, it can be viewed as an appealing methodology as it can influence and contribute to the field of psychology.

## Maximising on Intersectional Identities

As a woman who was diagnosed with breast cancer at the age of 32, the tone of autoethnography demonstrated how the ill/healthy body identity transformed itself into a creative and beneficial academic outcome. As explained by Young and Whitty (2010, p. 209), "the more we try to disengage with the body, the more its importance is revealed to us". Through my exploratory leaning in and out of my embodied experience, I was able to systematically reveal and release the hurt and pain and thereby reconnect with the healing self.

As a woman of colour with breast cancer in South Africa, my engagement with the private healthcare system acutely compelled me to recognise my privileged position to access healthcare. A vast majority of the population can only assess public healthcare. Despite the provisions of the South Africa Constitution, such discrepancies within the public healthcare system imperatives often occupied my thoughts. My intersectional identities again privileged me to challenge the healthcare professionals I encountered and finally make the decision as to the composition of my healthcare team. Arguably, the interpersonal relationships between the patient and the medical care team can never be underestimated. It is my firm belief, supported by Lekhuleni and Mothiba (2013), that this relationship needs to be prioritised and

constantly promoted. Accordingly, this study illustrates the importance of advocacy, self-activism, and patient-centred practice, especially within underprivileged communities.

Reflectively during the process of engaging with the PhD study, my identity as a woman of colour drew focus towards redefining my identity of colouredness within my intersecting realities. Acknowledging my position within a racial lens facilitated my reacquaintance with my heritage and the ambiguity that surrounded my identity. This furthered and extended the dialogue within my family and significant others. These dialogues acknowledged past hurts and vulnerabilities that facilitated appropriate healing and healthy acceptance. My relationship with my partner continues to be typified by honouring mutual respect where the patronising of each other's ethnicities and religious practice is non-existent. In my opinion, our shared spiritual ethos creates further connectivities beyond ourselves into our communities.

Undoubtedly, the dual label of patient-survivor offered the opportunity to participate in different community spaces and share my story. Retrospectively, these spaces safely provided me with the opportunity to challenge the normativity of breast cancer and the labels associated with the illness. The intersectional identities became a catalyst for me to declare my discomfort with the label of survivorship. Researchers such as Smith et al. (2016) and Williams and Jeanetta (2016) have argued that the label of survivorship was difficult for participants to articulate as breast cancer is a unique experience and viewed differently by individual women. As a woman who was labelled a Coloured, I questioned the utility of such labels as survivor or warrior, especially as I progressively interrogated my own norms, values, and experiences to reclaim and redefine parts of myself.

Equally important was my patient-psychologist interrelational label as it offered collaborative coherence that ultimately fed into my confidence and advocacy. My voice as a patient became louder and informed my treatment process as my rights as a patient were reasserted and reaffirmed. My voice as a psychologist acknowledged the existing social, cultural and gender norms and illness stereotypes that I believed were confining and dictating. Arguably, my personal experiences rightly positioned me to question the parameters and restrictions of such norms and stereotypes identified in the study. Notably, researchers such as Chang (2008), Ellis and Bochner (2000), Grant (2010), Hayes and Fulton (2015), Liamputtong (2007) and Wall (2016) have discussed the interrelatedness of sociocultural nuances in the construction of self, particularly from an autoethnographic lens. Progressively, my courage to maintain a reflective perspective positioned me to respectfully enter uncomfortable spaces and have difficult conversations concerning socio-cultural norms and practices.

Within such valuable intersecting spaces, I witnessed the utility of critical friends in practice which asserts transformational professional ethics and offers critical reflection. In addition, the critical counsel and help received from friends during the PhD process was invaluable, providing critical reviewer, offering analytical and methodological advice, constantly ensuring my focus remained without distraction (Scott, 2014; Storey & Wang, 2017). I found these supportive spaces assisted in solidifying my commitment to complete the work and clearly, should be considered an essential resource for any PhD candidate.

Within my circle of care, it was observed that my life became messier after my breast cancer diagnosis. Subsequently, the messiness facilitated the exploration of my authenticity and vulnerability. Such authenticity and vulnerability even prevailed within my engagement

beyond my immediate family circle. The acceptance of the evolving self also implicates itself professionally with a quest to constantly examine and interrogate authentic communication. The benefits of such communication continue to be a liberating experience as I vacillate between the neatness and the messiness of daily existence.

## Reflexivity and Reflections: Pivotal in Practice and Community Engagement

It is accepted that the autoethnographic process that challenges the professional status, also brings protection and privilege. The tension between my scientific voice and reflexive voice is thus readily acknowledged as both voices add value within my intersecting identities. As a psychologist, I am positioned as a searcher, an investigator of the other's life story of challenges which requires internal reflection and then external expression. Such a perspective was a suggestion by Frazier (2012, p. 384) who maintained that "psychology research is needed to further explore individual's 'experiences' as fully integrated in the social contexts from which they are produced". Contextualising my intersecting identities has further demonstrated the fluidity and relationality of my being. The complex matrixes of meanings which are socially and culturally embedded cannot be extricated from the wholeness of myself. I was acutely aware that academics are not trained therapists and I possessed the privileged opportunity of being both. By embracing autoethnography, I comfortably prioritised reflexivity as it was an ethos that prevailed even in my practice (Costley et al., 2010; Kemple, 2015; Rosa, 2015).

My habitual practice of reflection has also inspired my clients to see the ultimate value of such an exercise. This skill moves beyond the confines of the counselling room. It ensures constant engagement with the self. An observation made by a client of his experience of my gentleness within the therapeutic space was affirming and I accepted that it

was refined and reframed after my breast cancer experience. Presently, it has become a salient acknowledgement by my clients as a singular reason to continue in therapy as such a gentle persona resonates with them despite the conflicts and severities of their own realities. Being observed as someone who has contributed to their matrix of healing and facilitated the process of journeying inwardly has become increasingly validating for me. Such an individual observation also contributes to my confidence when I deal with trauma and vulnerabilities in community engagements.

From my interaction within the healthcare system as a patient, I reasserted personalised care in improving my relationships within my practice to demonstrate "deeper empathic engagement" which was valued by emerald and Carpenter (2015, p. 748). To extend knowing within a practice space, poetry and photographs have become central to maximise my engagement with clients (McNichols & Witt, 2018). The benefits to clients are to innovate around their own solutions. This satisfies my professional position to witness the client's innovation and to accept their susceptibility as a human condition which removes the negative connotation of vulnerability.

Within my intersecting experiences of vulnerability, I continued to focus on developing my skills and competencies by attending CPD initiatives offered by professional bodies and other associations that promote collaborative learning within diverse communities. A key area of my professional practice I am passionate to develop is that of psycho-oncology as it focuses on psychosocial aspects of cancer. Based on the findings of Edwards and Greeff (2018) and Venter et al. (2012) in South Africa, the materialisation of such specialisation is lacking. However, there are psychologists who are experts in the cancer community. There is an opportunity to explore psycho-oncology as a specialisation in

South African to meet global healthcare trends. This I believe will be an incremental benefit and contribution to local oncology knowledge and practice.

My participation in PsySSA deepened my appreciation for the profession of psychology in addressing matters related to mental health within a culturally diverse country like South Africa. Equally important was my two-year experience as an additional executive member for PsySSA. The experience strengthened my advocacy role, social responsiveness and ethical practice which are some of the core values of the organisation. In addition, I contributed to the national debate to the narrative of healing and the redefinition of healing within South Africa. One such example, I facilitated a regional meeting, dated 20 April 2017, to comprehensively discuss and debate the Scope of Practice of Psychology in South Africa as guided by the Health Professions Council of South Africa. The psychologists in attendance generated further debate on the Scope of Practice that could be potentially confining and such regulation may not promote interdisciplinary engagements and diversity. It became apparent that the tension within the professional community continues to contribute to the narrative on whose voice is prioritised within the mental healthcare community and acknowledging the influential dynamics in such relationships. A reflective article that also contributed to the debate was by Pretorius (2012). Her concluding appeal was for the "transformation of the practice of psychology in South Africa and around the Scope of Practice" (Pretorius, 2012, p. 518). Like Pretorius, I believe there are benefits in creating professional spaces to contextually explore the tensions in the practice of psychology as these tensions interact with the realities of South Africa.

My study contributes to the production of local contextual knowledge and research on women's health which is cognisant of the space of Western knowledge without

condescending to either. These practices of accepting the merits of intersectionality allow for the "goals of liberatory praxis" (Harris & Patton, 2018, p. 20). In particular, the intersecting of the lives of women of colour within the professional identities challenge the dominant ideologies of white-centred scholarship. It is my firm belief that my research is a valuable, reflective contribution as it exposes and interrogates some significant psychological, social, and cultural dynamics (and contradictions) from multi-layered positions of self.

## **In/Completion: The Reflexive Poetic Process**

The use of poetry to capture the reflective process (McNichols & Witt, 2018) and to encapsulate "learning about self and self in relation to others" is promoted by McCartney (2018, p. 145). Hence, my acrostic poetic conclusion as reflected below captures **Self-Other** intersecting: a poem "with its focus on beginning letters" (Frye et al., 2010, p. 591).

Expressed creatively through an autoethnographic frame

Lived visual vulnerability of my breast cancer captured contextually

Family, friends, and communities of care spiritually intersected

Outward-Inward transformative experiences of personal and professional

Troubling dominant discourses in the quest of the Un/Known

Heart. Head. Humour. Healing. I heard it said that I was heroic.

Embracing my merging and emerging identities with reflective acceptance

Re/mission I was tasked, an objective from a list to achieve — a self-study PhD

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## Appendices

### Appendix A

### Daily News 30 September 2008 Interview with Lucinda Johns



### Appendix B

### The C Sisters Book Launch Report 11 November 2010

# Breast cancer survivors share info in free book

JUST what the doctor ordered that was the medical fraternity's response to a new resource book written by the C-Sisters – a dynamic group of Durban women who have had

the launch of their book, from left, Donnee Ness, Saskia Wustefeld, Lucinda Johns, Alex de la Rouviere, Arlene O'Connell and Beverley-Ann Fink.

STRIDING AHEAD: The C-Sisters celebrate

PICTURE: ANTHONY DEWING point for the

information that helped us on our journey," says Wustefeld.

It is not only a "toolkit" for dealing with and understanding breast cancer but a handy reference guide and starting journey ahead,

breast cancer.

Stride to Thrive - A Resource Guide for Breast Cancer in KwaZulu-Natal was launched in Durban and it will be available free or on download to patients who are searching for practical help in their journey to recovery.

The editorial team, Saskia Wustefeld, Alex de la Rouviere, Beverley-Ann Fink, Arlene O'Connell, Donnee Ness and Lucinda Johns, said the birth of the C-Sisters' new baby was exciting.

All the team except one physiotherapist Ness – are breast cancer survivors and the aim of the book is to provide up-to-date information and personal tips for patients and to create networks outside the traditional structures.

"A diagnosis of breast cancer can be overwhelming and while there is plenty of medical information on the disease, women are left in the dark about many issues, like nutrition, prosthetics, psychology and physiotherapy.

"We wanted to share the

they say.

Topics include screening for breast cancer, understanding the diagnosis, treatment options and dealing with your emotions, as well as the practical issues like where to get a wig or prosthesis, what to eat, whether to exercise, and much more. Useful websites, books and local resources are included.

The book has been sponsored by pharmaceutical company Novartis and there is also input by two oncologists and a surgeon. It also includes personal stories.

The book answers many questions that women forget to ask in the doctor's consulting room. It does not substitute professional advice, it complements it.

The booklet will be available free from some oncologists. radiologists and Cansa or on download.

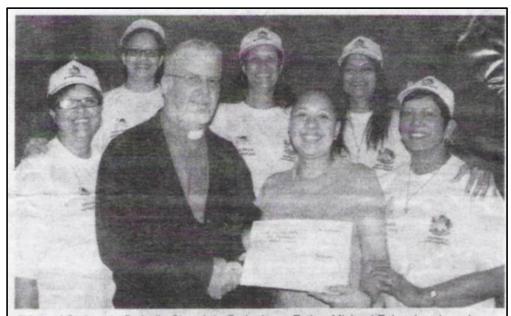
A Zulu translation is planned, as well as a national 2011 edition.

For information or to download a free pdf version, visit www.wix.com/kznbreastcancer/ book Enquiries: 031 563 1136.

THURSDAY-11 NOV. 2010

### Appendix C

### CANSA Walk St Anne's Roman Catholic Church, Clare Hills, Durban



Priest of St Anne's Catholic Church in Sydenham, Father Michael Foley, hands a cheque of R10,030 to one of the beneficiaries, Lucinda Johns from The 'C' sisters, with members of The Reaching Out Sisters, Mary Mei, Brenda Tomlinson, Wendy Daniels, Anne Phillips, Lynette Perumal. (Members of the group, Bronwen Nacken and Penny Lambert absent from pic).

# CANSA walk rakes in R20,060

Sydenham Sports Club, together with a a group of women from Sydenham, "Reaching Out Sisters,' held a successful walk to create an awareness about breast cancer in the community recently.

About 1,000 men, women and children partici-

pated in the race, which took place in Sydenham, with R20,060 being raked in.

Proceeds from the event were donated and shared between the Reach for Recovery organisation and a support group, known as the The 'C' Sisters.

### Appendix D

### Passion Play Report Sun 08 April 2011



## Appendix E

### PsySSA Feedback Letter 22 September 2017

RELAXING STAYS, EXCITING TIMES.
PEERMONT
22 September 2017 HOTELS CASINOS RESORTS
Hilada
Hi Lucinda
you have an amazing
Story to tell
By shattering your silence
you will head not only yourself
but so many others who
feel that though their stones
are not worth telling
you give courage to those
who have so much to say =
but doubt themselves.
you go girl. Good Luck www.peermont.com halitha Reddey

### **Language Editing Certification**

We the undersigned solemnly declare that we have abided by the University of KwaZulu-Natal's policy on language editing. The thesis was professionally edited for proper English language, grammar, punctuation, spelling, and overall academic style. All original electronic forms of the text have been retained should they be required.



### GARY STUART DAVID LEONARD

UKZN Higher Degrees Certified Language Editor
Commissioner of Oaths V3358
31 July 2020



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Student No. 9257646 31 July 2020