

**EXPLORING ISSUES OF IDENTITY FOR ADULT
HAEMATOLOGY ONCOLOGY PATIENTS**

by

Jennifer Marie Lior Stephens

B.S.N. (Nursing), Washington State University, Spokane, Washington, USA, 2007

A.D.N. (Nursing), Portland Community College, Portland, Oregon, USA, 2005

M.A. (History), Portland State University, Portland, Oregon, USA, 1998

B.A. (History), University of Colorado, Denver, Colorado, USA, 1995

B.A. (Anthropology), University of Colorado, Denver, Colorado, USA, 1995

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Abstract

Caring for adult haematology cancer patients can be challenging, and the difference in experience between this cancer subgroup and solid tumour cancers is only recently becoming a topic of investigation as researchers seek to identify and understand fundamental biological and psychological dissimilarities. The issue of identity is one that is of intense consequence for many cancer patients as they move from one state of being to another. This qualitative study was undertaken to generate knowledge about this important concern in a way that would ultimately inform an understanding of how to improve the patient experience of care with regards to identity concerns.

Interpretive description served as the methodological framework which guided a data collection and analysis strategy composed of five consecutive layers. Secondary research included a critical integrative literature review, a historical inquiry, and a secondary analysis of a pre-existing qualitative database. Primary research was composed of semi-structured interviews undertaken with a haematology oncology patient cohort as well as semi-structured interviews with experienced oncology clinicians.

Findings revealed that adult haematology oncology patients co-create and enact new identities that are increasingly aligned with a distinct experience defined specifically by their cancer subtype. Pre-existing identity labels and associated behaviours and expectations generally were viewed by patients as inadequate to fully describe and inform their experience of having a haematological cancer. Knowledge-gathering, linking with others who had similarly unique diagnoses down to a genetic level, and exploring the abstract cellular nature of their disease were just some of the themes that addressed ways these patients engaged with the highly complex and embodied construct known as identity. Several implications for clinical practice resulted from this study and include the importance of recognizing identity as simultaneously a physiological and psycho-social concern that will mean different things to different people at different times in the course of their disease. Implications for further research include advocating for theoretical and substantive knowledge development around identity constructs to generate further understanding of the deeply-rooted, textured relationship between identity and overall well-being.

Lay Summary

Caring for the complex psychosocial and physiological needs of adult haematology cancer patients is demanding. This study explored issues of identity for haematology cancer patients through a multi-layered qualitative study aimed at generating knowledge and novel understandings. Three consecutive layers of foundational secondary inquiry informed primary research with patients and experienced oncology clinicians. By thoughtfully investigating this phenomenon from multiple perspectives, this study accentuated the significance and complexity identity has within the transformative nature of the haematology cancer experience. In considering how identity can be experienced by haematology cancer patients, the findings of this study highlighted multiple opportunities clinicians might utilize to provide more deeply informed care. The implications of these findings include the need for future studies aimed at more fully examining diverse aspects around the relationship identity has with both physiological and psychological well-being.

Preface

This dissertation is an original intellectual product of the author, J. Stephens. The fieldwork reported in chapters 7-8 was covered by UBC Ethics Certificate number H15-01335.

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List of Abbreviations

| | |
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| BCCA: | British Columbia Cancer Agency |
| BC L/BMT: | British Columbia Leukemia/Bone Marrow Transplant Program |
| BMT: | Bone Marrow Transplant |
| CCC: | Refers to the UBC Communication in Cancer Care Database |
| GVHD: | Graft-versus-Host Disease |
| HM: | Haematology Malignancy |
| HSCT: | Haematopoietic Stem Cell Transplant |
| ID: | Interpretive Description |
| LLS: | The Leukemia and Lymphoma Society |
| UCBT: | Umbilical Cord Blood Transplantation |

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Dedication

I am privileged to have been called to service in a profession that is frustrating, challenging, rewarding, chillingly honest, and amazingly awesome. This dissertation is dedicated to the fourteen generous spirits who kindly shared their intimate thoughts and life journeys with me.

Chapter 1: Introduction to the Study

Introduction

Cancer forces an encounter with mortality that can be life transforming. On average, over 565 Canadians are diagnosed with cancer every day (Canadian Cancer Society Advisory Committee, 2017). The emotional and psychological burden confronting the cancer patient is something researchers attempt to illuminate in the face of increasingly complicated treatment strategies, wavering social support systems, and an overburdened health care system. The demand for simplification in a complicated world faced with increasing numbers of cancer patients encourages a generalization of many disease types into one: cancer. The trend in nursing, as in other health care disciplines, has been to either lump cancers under the umbrella “cancer,” or to specialize cancers into their tissue of origin.¹ An accepted practice within the clinical oncology community is to classify oncology diagnoses into two general patient populations: solid tumour and haematological malignancies (HM) (Hui et al., 2014; Hui et al., 2015). According to the Leukemia and Lymphoma Society of Canada (2016), there are 137 types of blood cancer and related disorders including leukemias, lymphomas, multiple myeloma, and different myelodysplastic disorders and neoplasms. A new blood cancer patient is diagnosed every 23 seconds in Canada, and there has been a 25% increase in the number of people living with blood cancers between 2014 and 2016 (LLS, 2016). These statistics make research on these complex diseases imminently essential to improve quality of life and promote deeper understanding of the blood cancer experience.

This dissertation focuses on adult haematology oncology patients in order to explore and analyze their cancer experience through the lens of identity.² Identity for the purpose of this dissertation will be defined broadly as “the condition or character as to who a person or what a thing is; the qualities, beliefs, etc., that distinguish or identify a person or thing”

¹ The Oncology Nursing Society web bookstore offers site-specific nursing care plans for solid tissue cancers including pancreatic, breast, skin, and prostate. Haematological cancers such as leukemia and lymphoma are not represented in this booklist, perhaps because they are a little harder to classify and perhaps because their course of treatment is significantly different than other types of cancer. They are not ‘site specific.’

² Following traditional service categorization in Western health care models, the term “adult” will refer to patients who are age 18 and over.

(identity, n.d.). In this work I reflect on work done by Parnas and Sass around the impact of disease on the self. They maintain that the self is constituted by experience, and that disease significantly disrupts this experience and thereby threatens the self in its existence (2011). Yuan (2012) poignantly exclaims in a guest editorial that the relationship between the science of oncology and the human patient entering care creates a natural divisive gap that requires recognition of the patient's former, and new, self-identity. Both lay and academic literatures corroborate that cancer patients may assume different and unique identity transformations as part of the disease trajectory. There exists a copious amount of literature on disease identity within the context of the social sciences. Associated with the notion of identity are concepts such as embodiment, body image, and self-esteem. Body image is particularly widely investigated by health care researchers in relation to cancer. Flanagan and Holmes (2000) detailed that social norms around cancer associate it with fear, dread, and stigma within both lay and academic literature. One of their findings was that:

Cancer can be seen to threaten personal identity in a variety of ways. Cancer not only impacts upon the identity of the person with cancer but extends, on occasions, to respondents' social contacts who perceive cancer as threatening their own identities. (p.745)

Identities that were once received automatically, for example through social positions, now become deliberate constructions. Identity is no longer a stable core which resides within an individual, but a series of identities formed reflexively through conscious examination and continual reformation of self-narrative. Self-identity and the body become "reflexively organized projects" (Shilling, 1993). Research has suggested that notions of identity may play an important role in how patients make treatment decisions and in how medical staff can address individual concerns (Slatman, 2012).

The impressive volume of identity literature confirms its legitimacy as a field of inquiry for many disciplines including medicine, psychology, medical anthropology, and sociology. To talk about identity is to discuss specifically what makes a thing a thing, or in the case of human identity, what makes a self a self. It is a discussion of essence, of the eternal "who am I" question. Again, the standard dictionary definition of identity is simply, "the condition or character as to who a person or what a thing is" ("identity," n.d.). Locke (1996) asserted with the notion of the tabula rasa that basically *I am my mind*, implying that

self essence was the continuity of thoughts and memories. However, Krishnamurti (1996) and Sartre (2007), among others, noted that one could not be their own thought or memories because the individual is the one that is aware of them. The assumption in most self-identity discussions is that there is something more, that essence referred to previously, that is enduring through time. This is the me/I. Tolle (2008) in *A New Earth* describes the true self as the silent entity that we humans speak to in our minds. This self persists despite changes to the physical body brought on by the passage of time, and yet this self is also directly unknowable. When asked “who are you?” the average person will respond with sociocultural or physical qualities: I am Canadian, I am a woman, I am a nurse, etc. These are qualities of a person, but they are not the person, and yet this is how an individual will talk about their self-identity. To reduce the discussion to known elements, each person is a specific human (*Homo sapien sapiens*) born in a specific place and a specific time under specific conditions. Self-identity is not age, weight, hair color, personality, name, genetic code, or the physical body and yet it contains components of all of these things. Self-identity is also not social identity, although obviously the two are intimately connected (see notions of constructivism and constructionism).

Illness is an example of an identity label. A person is either ‘ill’ or ‘not ill.’ The image and perception of personhood, body, and self can change almost immediately upon identification with the label “cancer.” Being labelled with a disease disturbs taken-for-granted assumptions about the relationship between body and self and identity (Charmaz, 1995). This taking-up of a new way of thinking about self is noticeably different from identity shifts that occur in other life transformations, and in the post-diagnosis phase this imposed and unwanted shift in thinking about oneself may affect many (if not all) aspects of patient care. This can include communication and interaction with health care providers, reliability and availability of support networks, treatment decisions, clinical trial participation, survivorship questions, palliative care, and end-of-life (EOL) choices. A person's identity can be significantly affected by a cancer diagnosis, which can in turn shape their adjustment to cancer (Clarke et al., 2011) and how they construct meaning about having the disease (Willig, 2009). The uptake of a cancer-specific identity by patients may provide insights about how clinicians can improve care and well-being (Sparks & Mittapali, 2004).

The Literature

Although clinically-derived knowledge and a small body of available empirical evidence suggest that many factors influence the health care environment, there is yet little research into the critical role disease identity and related concepts such as embodiment and personification can play in informing nursing care planning as well as direct patient care, decision-making, and potential patient outcomes. That is not to say that the interdisciplinary literature on identity/self-identity and related concepts (embodiment) are not copious – they are, particularly in terms of theoretical writings. Empirical research is less prevalent, although there has been extensive work done in disciplines like psychology and anthropology. For example, excellent work on narrative and metaphor within the self-identity context has been enlightening, demonstrating the severe threat to self that cancer presents (Laranjeira, 2012). Other work has highlighted self-identity issues in the context of solid tumour patients including breast, prostate, colon, and brain cancer patients (Anderson-Shaw, Baslet & Villano, 2010). Most of the research literature contains mixed cancer groups including solid tumour folks (metastases often undifferentiated in the demographics) and lymphoma patients (for example, Henoch & Danielson, 2009; Mols et al., 2012). This work has also been defined by some researchers as “finding meaning” with a disease diagnosis, or “existential distress” as an attempt to incorporate multiple angles of the identity issue (Leung & Esplen, 2010; Ramfelt, Severinsson & Lutzen, 2002).

Work on the corporeal body (proper) using languaging around embodiment has been popular in the past decade as interdisciplinary work on psycho-oncology matures (Ramfelt, Severinsson & Lutzen, 2002; Salamonsen, Kruse & Erikson, 2012; Slatman, 2012; Waskul & van der Riet, 2002; van der Riet, 1999a). Connected with the idea of body is that of physicality and gender, with some impressive research being done on the dynamic of embody/disembody of cancer patients about their physical state of Being (Gilbert, Ussher & Perz, 2013; Griffiths et al, 2012; Gurevich et al., 2004; Lende & Lachiando, 2009; Ollife, 2006; van der Riet, 1998). Within the languaging of embodiment is that of “grotesque body” and abject embodiment, noting the material quality of the self (identity) as reflected in body (Waskul & van der Riet, 2002). Related emphasis on spirituality and the cancer experience captures a specific angle of self-identity as it relates to values and meaning within and

without the context of organized religion (Cole & Pargament, 2004; Gallia & Pines, 2009; Vachon, 2008). Finally, identity is most straightforwardly defined in the literature with categorical emphasis and social-identification as “victim,” “patient,” “person with cancer,” and “survivor” (Park, Zlateva & Blank, 2009).

A thoughtful and extensive literature search has revealed some major, gaping holes in the research literature around self-identity (and even embodiment/body) in relation to nursing (discipline), nursing (practice), and haematology patients (adults and non-lymphoma patients in particular). Carving this analysis down further, leukemia patients are almost entirely excluded from the research, be it qualitative, quantitative, interventional, or mixed, on self-identity and cancer. Furthermore, within the academic literature, exact languaging around cancer patient disease take-up does not currently exist in a way that is satisfying. What seem to be missing are thoughtful analyses on recognizing and languaging identity issues for the haematology oncology patient. The oncology community has not acknowledged subtle distinctions characterizing the identity experience among different cancer contexts, or the way these may be expressed or communicated within the interactive processes of cancer care and coping with cancer. This dissertation examines such issues through thoughtful and informed qualitative research.

Rationale for Inquiry

My own personal journey led me to this dissertation topic. I have been an oncology nurse for over 15 years. During this time, I have worked in multiple healthcare settings and with adult patients in medical and surgical oncology, radiation and brachytherapy, and transplantation including bone marrow transplant (BMT), haematopoietic stem cell transplantation (HSCT), and umbilical cord blood transplantation (UCBT). I have noticed differences in the way both sub-populations of patients talk about and take on the cancer diagnosis, and over time I have grown increasingly curious about how the transcription of disease onto the self affects the cancer care environment. A cancer diagnosis shifts embodiment and self-identity and ostensibly influences decision-making, communication patterns, quality of life issues, and treatment preferences. Despite the complicating existential nature of identity as a study focus, interactions with patients over my career led me to believe that there was something within this phenomenon that deserved attention. Investigating the

phenomenon of cancer identities and how they become assigned to different oncology patient subgroups, as well as the possible relationship or role identity has in the care environment, are driving factors for this research.

I have long suspected that distinctions between solid tumour patients and haematological oncology patients based on sociocultural and historical factors play a role in how patients are cared for. For example, solid tumour patients tend to talk about and focus their emotions on the specific cancer-generating organ: “My left breast,” or “my liver.” Even when disease has metastasized to other organs, the originating tissue type (i.e breast, liver, lung) seems to be the focus of discussion and energy. For this reason, in my practice I have noticed that solid tumour patients tend to take on, or assume, their cancer in a very different manner than haematological malignancy patients. My work in haematology cancer has revealed languaging around cancer that is beyond being organ or site specific. These observations bracketed my thinking and assumptions when developing the research questions. For example, leukemic patients might talk about cancer as “me,” versus cancer as “it” or a specific location. Possible rationale around this could be that a haematological cancer, particularly leukemia or lymphoma, originates in bone marrow and is impossible to pinpoint. Haematological cancers also seem to be harder for people to comprehend on even a rudimentary or layman’s level. How can blood have cancer when blood is not an organ (per se)? Instead of being able to focus their range of emotion on a place, blood cancers demand an alternative vision of the world, and I suspect, of the self. The cancer, thus, is not a localized place, or a cell or organ, or anything slightly understandable. The cancer is, as I have been told in the clinical context, “myself.” Blood permeates the body. If the blood has cancer, then the body has cancer. The body holds the self, so the self can be cancer. Unlike the breast cancer patient who can point a finger at a breast, or mastectomy scar, the haematological oncology patient has nothing else to identify as the focal point of disease except the self. It is everywhere in them.

Further clinical experience suggests to me that adult patients diagnosed with haematological disorders including myelodysplastic syndrome (MDS), leukemias, and lymphomas represent a highly specialized population whose needs reflect fundamental

dissimilarities to the solid tumour oncology population.³ The absence of an organ-based solid tumour combined with a typically chronic disease trajectory and intimidating mortality statistics lead to intense, long-term dealings with the health care environment as patients navigate highly complicated and rapidly changing treatments including hematopoietic stem cell transplantation (HSCT), biotherapies, and intense chemotherapy regimes. Amplified opportunities to develop secondary disease including Graft-versus-Host Disease (GVHD), derivative cancers, as well as a host of possible oncology emergencies such as tumour lysis syndrome (TLS) or microangiopathic haemolytic anemia (MAHA) further complicate the course of haematological cancer while submersing the patient into psychological and physical situations highly distinct from those of patients with solid tumours.

Medical treatments for solid tumours versus haematological malignancies radicalize distinctions further. Solid tumour treatments focus on organ-specific etiology. Solid tumour oncology patients generally undergo localized surgery and/or localized radiation, which may be combined with systemic chemotherapies or biotherapies specifically catered to their disease type. For example, estrogen-positive breast cancers may receive Tamoxifen, a chemotherapy medication that specifically targets estrogen-receptors on cells. Even if this same patient has metastatic breast cancer, their treatment regimen will tend to focus on the original tissue type. Breast cancer metastases are made of breast cancer cells that have moved to a new place (organ) in the body. Haematological oncology patients, on the other hand, will receive systemic chemotherapy (and potentially biotherapies) from the onset. Unlike solid tumour patients who might have a few options for treatment, haematological cancer is everywhere in the body requiring the body to undergo systemic treatment. Options remain sparse for haematology malignancy (HM) patients and might be palliative versus curative, local or systemic. Additional treatments might include transplantation which includes a preparatory regimen potentially including total body irradiation and high-dose systemic chemotherapy. Transplantation is systemic as well, as the cells (haematopoietic stem cells) from either the self (autologous) or a donor (allogeneic) are transferred directly into the body through a central line and circulate the body searching for empty bone marrow in which to settle and populate (engraftment). The health care experience and process for haematological

³ Within this study I will use the phrasing “haematology oncology,” “haematology cancer,” “blood cancer,” (or with less frequency) “haematology malignancy” to denote this specific subgrouping of cancers.

oncology patients can be *distinctly different* from that of the solid tumour patient, thus confirming the medical dichotomy between the two. To me, it is impossible to talk of an identical cancer care trajectory or experience by lumping these subgroups under the umbrella of “cancer.”⁴ Recognizing the different disease processes and health care experience between the two is an important component throughout this study.⁵

Research Questions

The overarching research question guiding this study is: How are identity experiences described and elucidated by adult haematological cancer patients? I will attempt to answer this question by asking three subsidiary questions:

1. How are haematological cancer patients similar to, or different from, patients with solid tumours with respect to the manner in which they reference identity issues as part of their experience with cancer? (COMPARATIVE)
2. How do adult haematological cancer patients communicate their cancer experience with reference to identity? (COMMUNICATION)
3. Is identity the best way to examine this existential relationship between self and cancer, or does qualitative data suggest another angle that might be more inclusive and reflect the disease environment more appropriately within the context of nursing practice? (LANGUAGING)

⁴ Cancer care is termed “cancer care journey” and “cancer care trajectory” within the literature and within the medical practice and clinical reality of oncology. It is the accepted way to talk about the stages a cancer patient goes through from diagnosis to treatment to remission or palliation. This is also related to the cancer care continuum, a notion that is used to talk about survivorship. This dissertation utilizes all three phrases. See Hewitt & Ganz (2006).

⁵ I am by no means asserting that the distinction between solid organ and haematological malignancies are the only factor at play regarding patient embodiment or disease identity. Indeed, even these have some gray areas (such as patients who have both diagnoses) or in patients with cancers of nonspecified origins. However, having worked now with (arguably) thousands of oncology patients this distinction does seem to be both consistent and present as spoken about by patients themselves. My observation of this phenomenon is the origin of the research questions for this dissertation.

Research Design and Methods

The purpose of this project was to conduct exploratory research into the way that haematological cancer patients communicate about their experience of identity from the patient perspective and in a way that may inform nursing practice. I wanted to understand a more complete nature of the phenomenon of identity for haematology cancer patients and the way identity manifested itself as described by these patients. Sound theoretical and methodological frameworks were foundational to the qualitative research process. Sandelowski (2003) confirms that within any qualitative research project, the overall design will be “emergent, or highly dependent on the ongoing results” as the study progresses (p. 796). This type of emergent design is inherent to qualitative research, where an interactive process means that analysis and interpretation are simultaneous with the fieldwork experience. In fact, the fieldwork itself (usually primary interviews) will often shape the very design of the study (Polit & Beck, 2004, p. 60). For this inquiry, interpretive description served as the guiding qualitative methodological scaffolding, and nursing offered the disciplinary lens that informed research design decisions. Constructivist theoretical perspectives oriented the study toward corresponding ontological and epistemological concerns. Thorne (2000) notes that the data collection and analytic process are delicately interwoven and, in some respects, can seem almost indistinguishable. Inductive reasoning remained the process by which qualitative data were interpreted and structured in a way that provided meaning within the findings.

I conducted this study using a design comprised of five layers of research (discussed further in chapters 2 and 3). Interpretive description framed the data collection and analysis process in a manner that allowed for both sequential layers of perspective and concurrent analytic development across the layers (Thorne, 2008). “Layer” within the context of this study is more aptly meant to describe a particular angle of vision from which I examined the phenomenon in question. Within a multilayered qualitative research approach, each layer of research is conducted in a manner that iteratively informs and cross-pollinates the next. Another purpose for this approach is to coalesce unique angles of vision on the same phenomenon in a way that informs the generation of a more cohesive, comprehensive, and thoughtful representation of that phenomenon than would have been possible from a single perspective.

Within this dissertation the five layers of research included a critical integrative literature review, a directed historical inquiry, a secondary analysis of an existing qualitative database, interviews with a patient cohort, and interviews with experienced oncology clinicians. These layers were organized into two phases: Phase One (secondary data collection and analysis) and Phase Two (primary data collection and analysis).

The first three layers were aimed at theoretical exploration and foundation building and constitute secondary analyses (Phase One). The first layer constitutes a critical integrative literature review, followed by a chapter focused on historical inquiry specifically into the haematological cancer experience. The third layer was a secondary analysis of an existing qualitative database (from the UBC Cancer Care Communication Research Program). These three layers of data collection allowed me to investigate how ideas pertaining to identity were referenced within patient narratives about what it is like to experience cancer and communicate with others in relation to, and about, their cancer.

Using these three layers as a foundation, I then engaged in the fourth and fifth layers consisting of primary research (Phase Two). The fourth layer constituted participant interviews with a new patient cohort consisting of adult haematology oncology patients. In this fourth layer I gathered and analyzed original in-depth interview data from a theoretical sample of haematological cancer patients to deepen and refine my understanding of how they experience and reference issues of identity. These interviews provided depictions of how haematological cancer patients language, interpret, and explain what it is like to have haematological cancer and how that might differ from the more commonly understood notions of cancer experience. The fifth layer of research consisted of focused interviews with highly experienced and thoughtful oncology clinicians. Interviews with those experienced oncology clinicians were performed with a carefully chosen sample meeting specific criteria to discuss findings, corroborate impressions, and explore strategies for application of findings to nursing practice. The generalized findings from this study incorporated all five layers into a discussion enriched and deepened by multiple levels of data and reflective analysis in a way that explored an important, but neglected, angle of psycho-oncology nursing practice.

Defining Key Terms

For the sake of clarity and consistency within this dissertation, the term *solid tumour cancer* refers to cancers that occur as masses originating within specific organs (National Cancer Institute, 2012). These tumours are comprised of abnormal tissue, or a collection of cells, that does not contain cysts or liquid portions. Solid tumour cancers are often named for the type of cell that they are made of such as “breast cancer,” meaning that the solid tumours are composed of breast tissue cells. Other examples of solid tumours include melanomas (skin), sarcomas (bone, fat, muscle, blood vessels, cartilage, and connective tissue), organ-specific (such as colon, prostate, lung), and cancers of the central nervous system (glioblastoma and meningioma).⁶ Solid tumour cancers that have metastasized are considered systemic, meaning they have left their in situ environment to travel freely throughout the body. These cancer cells can collect in other organs creating secondary tumour sites but professional oncology language continues to refer to the original tumour site as the primary cancer.

Neoplasms that originate in blood-forming tissues such as bone marrow or immune system cells are called haematologic (blood) cancers. These include leukemias, lymphomas, and multiple myeloma. In this dissertation research I focus primarily on leukemic patients in order to draw the distinction between tumour versus non-tumour subgroups. Leukemias are classified as acute or chronic types and are characterized by abnormal proliferations of leukocytes, or white blood cells. These cells can assemble in tissues such as lymph nodes but are not considered tumour-forming (National Cancer Institute, 2012; Vogel, 2011). For this study, I primarily recruited patients with the following major leukemia subtypes: acute myelogenous leukemia (AML), acute lymphoblastic leukemia (ALL), chronic lymphocytic leukemia (CLL), chronic myelogenous leukemia (CML), chronic myelomonocytic leukemia (CMML), and myelodysplastic syndromes (MDS).

⁶ Clinical environments sometimes classify neurological cancers as a third category of cancer, differentiating between solid tumour and haematological cancers. For the sake of this dissertation research, neurological tumours will remain in the category of solid tumour cancers because, while they constitute neuron masses, these tumours still have an in situ origination point and behave as other solid tumour cancer cells (i.e. they metastasize, cease apoptosis, etc). This seems to agree with the research materials of several research-based organizations including the Brain Tumour Foundation of Canada (<http://www.braintumour.ca/4730/encyclopedia>).

While technically considered haematologic cancers, both lymphoma and multiple myeloma are often associated with pseudotumour sites (Vogel, 2011). For example, multiple myeloma is an overgrowth of plasma cells (a type of white blood cell) which congregate in bone tissue, creating tumour-like masses. Likewise, lymphomas (whether Hodgkin's or non-Hodgkin's classification) occur when the lymphocyte cells (a type of white blood cell) congregate in lymphatic organs such as lymph nodes or the spleen. Both lymphoma and myeloma patients were invited into this study, and the inconsistencies in messaging and communication between lymphoma and leukemic patients was explored at several points to ensure the nuances between the subgroups arranged under the general title of "haematologic cancers."

It is important to note that this study was not created to explicitly compare the experience of solid tumour cancer patients with that of the blood cancer patients. Instead (as indicated in the first subsidiary research question), while undertaking this study I wanted to acknowledge the inherent differences between the two subgroups and focus my attention on those points of potential difference. At no time did I consider this study a purposeful comparative study. Rather, because the larger social umbrella of cancer encompasses both subgroups, my goal was to describe and unpack differences in a way that highlighted the haematology cancer patient perspective *as the most important focus for this research*.

Notions of identity are concepts hotly debated within philosophical, theoretical, and disciplinary contexts. The research conceptual field becomes more scattered with descriptive options when "self-identity" is included. "Self" and "identity" are popular topics throughout the social sciences with vast literature bases in psychology, anthropology, political science, sociology, and economics. These identity-based analyses ultimately evolve into exploration of self-concept, personality, and multiplicity of self (Oyserman, Elmore, & Smith, 2012). Foucault (1970) and Rose (1998) suggested that words shape the phenomenon in question, therefore how identity is used must be thoughtfully considered. One of the main challenges of research which seeks to examine the taking-up of a disease by a person is pondering how self-terms should be defined, used, and addressed by the researcher. Is it possible to even employ these concepts at all, particularly if the patient does not specifically use them to describe their own status? These issues assume even more breadth and complication when united with methodological choices and research strategies. To undertake an extensive

philosophical and empirical exploration of self-concept, embodiment, and identity is not the purpose of this study. Such an enterprise would be more appropriate as an entire program of research within another discipline (say, the social sciences). Instead, this study focused on qualitative research to provide clinically applicable observations and interventions for the applied discipline of nursing. For this reason, careful and purposeful application of conceptual terms to describe the uptake of cancer by the patient/self will be ever-present in discussions of methodology and research fieldwork, as well as in later chapters presenting findings and implications.

Identity is a complex concept, touching on several other related and interchangeable phenomena such as self-esteem, self-concept, self-construction, and self-perspective. For this dissertation, identity is broadly conceptualized to mean the categories individuals use to define who they are, and how they locate themselves in relation to other people (Owens, 2006). Self-identity implies that self is subsumed in identity, in the same way that self is subsumed in self-concept. Identity does not always imply self, and therefore within this dissertation “self” will be defined as:

an organized and interactive system of thoughts, feelings, identities and motives that is born of self-reflexivity and language, (2) [thing] people attribute to themselves, and (3) characteriz[ing] specific human beings (Owens, 2006, p. 206).

This definition of self honours not only existential concerns over *who am I?* but also allows integration of social traits as well as cultural roles and personally-held identity beliefs. The self is distinguishable from identity in that self develops from self-reflection, unlike identity which is specifically considered a socially constructed categorization tool used by each individual as a means to identify with certain social groups and as a way to present themselves to others (Krieger et al., 2015). Further elaboration on the distinctions between self-identity and identity are provided in chapter 5.

Significance of the Study

Long-term survival rates for adult patients with haematological cancers are disheartening. Clinically, long-term survival is defined as someone who is still alive 5 or 7 or 10 years post diagnosis and treatment, with treatment being palliative chemotherapy or aggressive measures such as transplantation (HSCT/BMT/dUCB) (Castillo, Winer, &

Olszewski, 2013; Pulte, Gondos, & Brenner, 2010; Raab et al., 2009; Robin et al., 2003). Multiple factors influence this statistic including cancer type and stage at diagnosis, age, gender, ethnicity, primary or secondary cancer, and comorbidities. Current research suggests that survival rates are low and decrease proportionally with a patient's age, with a rapid decrease in survival noted for patients over the age of 55 (Castillo, Winer, & Olszewski, 2013; Estey, 2012; Juliusson et al., 2011; Robin et al., 2003). For example, 5-year survival rates for Burkitt's lymphoma patients over 60 are estimated at 29% (Castillo, et al., 2013). Similar rates for multi-age adult acute myeloblastic leukemia (AML) patients are given at 21.4% (Pulte, Gondos, & Brenner, 2010). Additionally, the rates of cancer recurrence are startlingly high for haematological cancers and even more so for adult patients. One of the reasons for this is the modern use of the reduced-intensity conditioning (RIC) transplant in these patient cohorts, many of whom are over age 50. A decision for RIC occurs because the oncology team does not believe the patient can tolerate a normal-intensity conditioning regimen. For example, the relapse rate for adult acute myeloblastic leukemia (AML) patients after RIC allogeneic hematopoietic stem cell transplant are estimated at 32% (Schmid et al., 2012). Any experience with transplantation, whether it is full-intensity or RIC, is associated with the highest levels of hopelessness and depression as reported by any oncology patient cohort (Cohen & Ley, 2000; Lee et al., 2005; Leung et al., 2011).

The purpose of outlining these statistics is to corroborate that rates of haematological cancer recurrence and mortality are very concerning for haematology patients. These rates increase with age, so that the populations with the lowest long-term remission or cure rates are the older adults. With statistics like these quoted in the health care literature, it is reasonable to assume that the haematological cancer experience is absolutely life-altering in a way that may be unique within the disease spectrum. While some other cancer diagnoses, such as pancreatic or liver cancers may have worse predicted mortality rates, they may not induce a similar state of crisis for patients. This dissertation seeks to understand the fine nuances between how haematological patients identify with cancer and how they communicate about this transformation with the healthcare team.

Even though medicine has assigned the overarching name of "cancer" to both groups, and rightfully so based on the mechanisms of cancer cell behaviours, patients with solid tumours and haematological tumours suffer in distinctly different ways. This observation has

been repeatedly confirmed in my own clinical practice, and the academic literature also routinely corroborates disparity between the two groups through analysis of issues such as distress, survivorship, and palliative care (see Albrecht & Rosenzweig, 2012).

Haematological malignancies (HM) often involve treatment regimens that are uniquely personalized, highly aggressive, and centered around extensive periods of hospitalization and institutionalization. Additionally, many haematological cancers are discovered as oncology emergencies, requiring immediate hospitalization and commencement of chemotherapy and other treatments. Many HM patients are on a trajectory of being healthy, then fatigued, then fatally ill within a very short amount of time. Other HM patients, such as those with chronic forms of leukemias or with myelodysplastic syndrome (MDS) find themselves facing unceasing treatment and palliation with little hope of escaping the care system and experience constant worry of transitioning to more acute disease. HM patients may receive high-dose chemotherapy, extensive biotherapy treatments, total body radiation, and undergo transplantation (stem cell, bone marrow, or umbilical cord). Several studies on cancer-related distress confirm the impact of distress as significant, lasting several years after initial diagnosis (see Carlson et al., 2004; Jones, Parry, Devine, Main, & Okuyama, 2015). Within their physician guidelines, the National Comprehensive Cancer Network (2012) cite several studies of distress in HM patients attesting that it can lead to depression and anxiety, as well as poor communication with the healthcare team and decreased healthcare utilization.

It is also important to recognize that a cancer diagnosis is highly emotionally loaded. Implications of the diagnosis regarding treatment and prognosis aside, the person immediately faces a temporary or permanent loss of part of the body, and a temporary or permanent loss of function that will result from treatment modalities (Chattoo & Ahmad, 2004). Boundaries between curable and incurable, between palliation and treatment are fuzzy and are often intentionally left undefined by health professionals (Chattoo & Ahmad, 2004). Recognizing the potentially poor prognosis for adult haematology oncology patients, this dissertation acknowledges the importance of psychosocial concerns in the cancer care environment and specifically focuses on the embodiment, or identity-changing aspects of a HM diagnosis within a nursing context.

Summary

This research project seeks to document and interpret common languaging as evident in patterns, vocabulary use, metaphors, and themes used by cancer patients to describe the disease in relation to the body/self. Identification and description of identity issues and how these could affect not only patient care choices but also the pragmatic health care environment can provide valuable insight for both patient and professional communities.

Chapter 2: Theoretical and Methodological Framework

Methodological and Philosophical Orientations

Methodological fore-structure for this research was guided by the qualitative research method of interpretive description (ID) and by the individualized nature of a self-identity focus. The adaptive flexibility of interpretive description provides opportunities for allegiances which lie outside traditional social science theoretical grounding. Regarding nursing research, Sandelowski (2010) confirms that qualitative researchers, firmly grounded in disciplinary theory (which in the case of the current proposal is a nursing lens) must acknowledge their preconceived position. Sandelowski writes that “the mandate for researchers... is to make explicit... where they are when they begin their studies and to be ready and willing to move away from there if their further investigations warrant it” (p. 80). I read this to be a reminder that, while overall attention to sound qualitative process is warranted, a disciplinary orientation is the ultimate driver for research design.

The disciplinary orientation for this research is nursing. Nursing ontology and epistemology provide the initial critical scaffolding of a research inquiry allowing for theoretical options to evolve as new knowledge develops. By this I mean that nursing has a core knowledge which constitutes the disciplinary focus and *raison d’etre*, linked with a social mandate due to the service nature of the discipline. Thorne (2014) defines this as “core disciplinary knowledge,” which evokes a specific lens that can be used to hone a research study through careful and meaningful construction of a research question (and purpose). The research question becomes the focus instead of the research bias of the researcher, and this perspective characterizes the fundamental nature of ID inquiry. Interpretive descriptive investigations, from my understanding, are discipline-driven research which focuses persistent attention to suitable data collection approaches and means of analysis that evolve in an iterative manner to generate knowledge specific to, and subject to, the needs of the discipline and meeting disciplinary epistemological demands (Thorne, Stephens & Truant, 2016).

Lincoln, Lynham, and Guba (2011) propose that qualitative research methodology is coupled with both disciplinary concerns as well as distinct theoretical perspectives. According to these authors, five paradigms (or worldviews) currently dominate the research milieu and include positivism, postpositivism, critical theory (which includes feminist studies), constructivism, and participatory/cooperative. Correspondingly, each of these paradigms carries with it certain assumptions about ontology, epistemology, and methodology. Crotty (1998) cautioned that to make such rigid assumptions disallowed for the existence of paradigms composed of a mixture of theoretical elements. Instead of accentuating paradigms as the root of theoretical scaffolding, Crotty suggests that epistemology is the only foundation from which choices about theoretical perspectives and corresponding methodology and methods can be made. Three epistemologies dominate scholarly research and include objectivism, constructionism, and subjectivism, each representing an explicit belief about how meaning is conceived. Objectivism as an epistemology is generally associated with positivism and postpositivism, embracing the ideology that a disassociated researcher values only scientific rigor and discounts the social impact of a study (Crotty, 1998; Lincoln, Lynham, & Guba, 2011). Realism is the ontological association for objectivists who can conceive only of a single reality that can be measured, studied, predicted, and controlled. Subjectivist epistemology fuses the researcher and participant into a single entity, embracing ontological relativism that is socially and experientially based.

Constructionism, on the other hand, strikes a balance between objectivism and subjectivism in a manner recognizing the intentional and shared co-creation of knowledge by the participant and researcher (Crotty, 1998). Within this epistemological (and ontological) tradition a fusion of critical realism and relativism as ontological principles is possible, suggesting that a true reality exists but it is not directly apprehensible (Nightingale & Cromby, 2002). Rather, reality is comprehensible through contextual meaning-making between an individual and the world. This theoretical positioning lies in opposition to the tidy classifications proposed by Lincoln, Lynham, and Guba (2011), but perhaps represents a category ontologically and epistemologically situated between postpositivism and constructivism. An example of a constructionist theory in relation to a cancer diagnosis is offered by Schaefer-Schiomo and Atwood (2009). They state that the cancer diagnosis presents a re-definitional process in which the patient and their family create a “reality

centered around concepts of sickness and disease” that is both co-emergent and continuous (p. 322).

Taking this discussion further it is crucial for a dissertation on the self as individual, and the associated identity and disease identity that result, to be clear about philosophical scaffolding. Constructivism as proposed by Vygotsky and Piaget claims that the individual constructs their own internal understanding of reality. Meaning, therefore, is individual perceptions of reality taught to the person by society with an individualized “buy in” component in that ultimate perceptions are the result of freewill enacted by the person deciding (unconsciously or consciously) how reality will be interpreted (Bruner, 1987; Derry, 2013; Pass, 2004; Wadsworth, 2003). This is only a slight twist to the constructionist epistemology/ontology as described by Berger and Luckmann (1967), which proposes that meaning is given to objects by a group.

Constructionism deals with the objects themselves, rather than the details of who is viewing (or finding meaning in) the objects (Berger & Luckmann, 1967). Berger and Luckmann’s sociological theory suggest that objects such as a garbage bin, or even gender, take on meaning only when a socially-imbedded human interprets the meaning within a social context. Reality is not objective (realist) but rather is a social construct (i.e. *social ontology* per Burkitt, 1996). Constructivism would shift this to agree that reality is not objective (realist) but is rather an individual interpretation of a social construct that is, in turn, informed by social context. For the sake of this dissertation, both constructionism and constructivism have application and meaning as the proposed research aims to explore the meaning of self, identity, disease within the social context of oncology health care and Western (allopathic) medicine. However, emphasis on the individual is necessary here as my own intention is to determine meaning by the individual of what is happening to them, and thus constructivism will be a predominant ontological and epistemological concern for Phase Two during the primary interviews. By adopting constructivist ontology and epistemology as the basis for inquiry, my intention is to explore personal meaning, but also to explore with participants how they came to that meaning. Constructionist ontology and epistemology, positioning theorizing of meaning from a perspective of patterns across people, may have a greater presence in Phase One due to the secondary nature of the analysis. Subtle, and not so subtle, implications of how much and to what degree society determines reality and meaning

within this context will, of course, be present and will no doubt be explored further as the data collection unfolds.

With specific reference to this dissertation research, Merleau-Ponty (2002) provided a theoretical grounding consistent with constructionist ontology and epistemology as well as an interpretivist perspective. He wrote that the world and objects in the world (be they animate or inanimate) are *real* (a priori) and loaded with meaning that can only be known through interaction with the mind. Therefore, reality can embrace realism (ontology) but this can only be known through relativist interaction of the world with the mind in a way that accentuates transactional (subjectivist) knowledge (epistemology) (Burkitt, 2003). Wrapped within these layers of meaning is the assumption that the person might hold an idea of embodiment of cancer (reality), but it is not until they are asked about what this *means* that the idea becomes, itself, embodied. Thus, it is not outside the realm of theoretical positioning that the interaction with the researcher can co-construct meaning of embodiment and identity for the participant. Herein lies a key distinction between constructionism and constructivism, even though both are linked through a naturalist paradigm (Polit & Beck, 2008). Whereby constructionism embraces the socially constructed meaning through intentional interaction between researcher and research participant, constructivism implies meaning-making achieved in the individual mind with the purpose of the researcher to *interpret* the participant's perceptions (Crotty, 1998; Lincoln, Lynham, and Guba, 2011; Polit & Beck, 2008).

My proposed research endeavours to discover meaning in how cancer patients take on their disease so that practical, clinically-relevant interventions can be envisioned. The creation of nursing knowledge directed towards nursing interventions and nursing best practice is, in my opinion, the main expectation of nursing research. Central to this personal belief is the concept "meaning" as in, meaning to the person (of their body and disease) and meaning in relation to the care environment (both person and nonperson). However, realistic practice recommendations are impossible if individual meaning is not somehow part of a greater social picture of commonality that constitutes a shared reality that can be drawn on for practice recommendations. Per the methodological prescription within interpretive description, the act of merely reciting individual (subjective) reality is not useful for the discipline nursing if generalized themes and meanings are absent. While nurses expound a

goal of individualized care, in the case of nursing research this hinders knowledge generation applicable to groups of patients. Marshall (1996) cautions the qualitative researcher by saying that “improved understanding of complex human issues is more important than generalizability of results” (p. 524). Thorne correctly noted that “nursing always and inherently requires knowledge about patterns and themes within people in general so that it can better inform the care of the unique and distinct individual” (2008, p. 25). Therefore, objective interpretation is necessary in the research process as a means of understanding a social reality generalizable to larger populations. Per constructivist philosophical underpinnings, the individual reflects reality by reflecting society (social ontology) in a way that is both deductive (society down) and inductive (individual up). This blending of theoretical perspectives on the grounds of ontological and epistemological grounds is, I believe, justified within the context of applied nursing research. These ontological and epistemological distinctions, particularly around meaning and meaning-construction, are central tenets of interpretive description as a qualitative research framework.

Theoretical Scaffolding: Existentialism, Phenomenology, and Spirituality

Themes of body, self, spirit, embodiment, and identity within the cancer context naturally evoke theoretical interrogation around issues of being, person, selfhood, personification, spirituality/religion. In qualitative research, natural links exist between these phenomena and phenomenology, the existentialist movement, and spiritual inquiry. For the purpose of this dissertation, all three theoretical lenses seem appropriate and unavoidable guides along the pathway of qualitative inquiry. I will briefly discuss each theoretical position with respect to how it could, and often does, relate specifically to the oncology patient and the cancer care environment.

Existentialism

Socrates offered perhaps one of the first, and most basic, of the existential concerns by saying “one should know thyself” (Solomon, 2004). The existential attitude is one of self-consciousness in which the self confronts the world and realizes the ultimate aloneness of being. And yet, there is being, there is a self. A core concept of existentialism to counter this aloneness is empowerment, and with it, personal responsibility. Existentialism is a philosophical movement that challenges a victim mentality and instead tells us that the

individual is ultimately responsible for him or herself. For the existentialist, to live is to live and to do so passionately (Solomon, 2004). Exploring the notion of the absurd, foremost existential philosopher Camus in *The Stranger* and *Sisyphus* demonstrates that life is its own meaning, and either the individual finds meaning in their own life, or there is no meaning at all to that life (Camus, 1989; Camus, 1991).

Contingency is a notion within existentialism which accepts that the individual is born, lives, and is shaped by society in ways that prevent absolute personal freedom and choice. Within this complex social system, the individual's actual set of choices is highly limited and yet, these choices do still exist. Heidegger's (2008) image of "thrownness" captures this notion that much that happens in our life is given, not chosen (p. 174). In the case of a cancer patient, the very real condition of cancer was not the choice of the individual (despite the fact that they may have, ultimately, made choices that predisposed their genetic structure towards carcinogenesis). This can be termed an existentialist *attitude*, whereby the threat of imminent death caused by a cancer diagnosis forces the individual towards what may have been a previously unexamined life (Solomon, 2004). Existentialist thought says to these patients that, given the circumstances, they can *choose* to exercise personal responsibility and with it, free will, thereby living life to the fullest. This "fullness" is personal, determined by both the individual and the circumstances and stands in opposition to existentialist anxiety in which no self-action is seen as meaningful. In this way, existentialist theory is both a lens for qualitative research as well as a hopeful and optimistic tool for pragmatic application of research findings.

Phenomenology

Most of the literature on self-identity within the academic research context centers on phenomenology and its concerns with lived experience/life-world, including notably the perspective of symbolic interactionism. Arguably, the greatest amount of research that applies in any way to my dissertation topic and interests is from scholars who consider themselves, in one way or another, to be phenomenologists. The relationship is an obvious one, as phenomenology deals with the person as an embodied person, implying an integratedness of body and person (self/essence). The daily world or life-world (per Husserl) or being-in-the-world (Heidegger) is the foundation for individual human existence. Within

this concrete world, phenomenologists like Husserl, Heidegger, Sartre, and Merleau-Ponty claim to find meaning in life experiences by analyzing their intentional structure. Mind-body dualism doesn't exist, but rather the integrated body unit contains both inseparable parts that exist in time and space.

Marcum (2004) wrote that phenomenology was a holistic solution to the “clinical gaze” of modern Western medicine in that it rejects the mechanized model of the body claimed by positivism and perpetuated throughout physician-based health care systems. Illness for the phenomenologist is not the dysfunction of the disembodied body-machine but rather a disruption of an embodied person's life-world. Zaner (1981) coined the term “uncanniness” to describe the ability of a phenomenology-informed physician to cast an empathetic gaze on patient suffering because each human has, itself, a life-world. Uncanniness also describes the fact that humans are contingent beings able to express a “profound sense of bodily alienation which is intrinsic to the experience of illness” (Toombs, 1993, p. 100). The purpose of a person embodied in the illness experience for the phenomenologist is two-fold. First, the mechanized body must be transformed into a lived body that claims bodily identity as whole and not abstracted (objectified) (Marcum, 2004). Second, the textual body that results from medical records (i.e. the history taking, lab work, diagnostics, etc.) must also be transformed into a lived body (Marcum, 2004). This is a bit more difficult to attain. Sveneaus (2000) wrote that the body was a “meaningful phenomenon” that has meaning because it is lived “and not because it is written” (p. 139). These have been very important concepts for the theoretical positioning of my research.

What is perhaps even more useful as a theoretical foundation for research of the cancer patient taking-up of cancer into their self (embodiment?) stems from Heidegger. When a person is diagnosed with a dangerous, and potentially fatal, illness such as cancer, the embodied person must face mortality in a way that shows them that the authentic self is finite (Sveneaus, 2000). The face of death (or illness) creates anxiety (*Angst*) as the base of a life world that is suddenly unfamiliar (or unhomelikeness, *Unheimlichkeit*). Resolving *Angst* reestablishes homelikeness (*Heimlichkeit*), resulting in what Marcum called a healing of the body “even though the diseased body is not cured” (2004, p. 48). This is a critical element to

what I believe is the ultimate purpose of my research -- to find a way to facilitate comfort and peacefulness of the patient when the body is ill and potentially cannot be cured.

Spirituality

The importance of spiritual considerations for the cancer patient (or anyone for that matter) cannot be overlooked. Surbone and Baider defined spirituality as “connected with a higher self and with God and with the Universal Spirit, the Creator, the Life Force or whatever name you desire to give to that Divine energy” (2010, p. 228). Gates (2006) asserted that spirituality was one of the most common themes in cancer patient narratives. This is not surprising considering that a cancer diagnosis opens a direct channel to mortality. A similar scenario was supported in research on cachexic cancer patients by Hinsley and Hughes (2007) who claimed physicality of the body is unified with “other aspects of embodiment: emotions, spirituality, relationships, and social functioning” (p. 88). Van der Riet (1999) discussed the notion of ethereal embodiment as attending to the body (physical) through holistic practices such as meditation, visualisation, and massage. Discussed as poststructuralist methodology, the process of seeing and understanding embodiment through massaging the cancer patient allows for a “reclaiming of ‘the old body’ and an experience of mind and body connection” (van der Riet, 1999b, p. 4). Religious beliefs such as Christianity hold that spiritual embodiment recognizes the physical body and the spiritual body, whereby the body becomes a home for the spirit. Separation of the two signifies disembodiment, therefore human spirituality is characterized by union to body and spirit (embodiment) (Kanis, 2002).

Spirituality as a consideration of nursing care (at a minimum) has been a topic of discussion within the context of an increasingly secularized profession. Existential approaches to identity tend to be more spiritual in nature because they focus on the importance of dialogue and personal *meaning*, whereby the experience of *being with* a disease (such as cancer) acknowledges the holistic nature of the body (embodied/embodiment). Addressing spiritual care in the context of embodiment can be a particularly significant aspect of the cancer trajectory. Sawatzky and Pesut (2005) noted that “much of the insider perspective on chronic illness and end of life has revealed these

challenges often lead to growth on the spiritual path” (p. 29). Purposeful nursing care, then, acknowledges and honours spirituality as an aspect of the cancer journey in some way.

Summary

Theoretical and methodological foundation for this dissertation include applying interpretive description scaffolding, thereby acknowledging the close link between nursing epistemology (core disciplinary knowledge) as central to driving nursing research. To generate new knowledge around the experience of identity for the haematology oncology population, I applied a five-layer data collection and analytical process (described as Phase One and Phase Two). The following chapter will discuss specific details about the layering methodology used to undertake this study and establish criteria by which research was undertaken.

Chapter 3: Research Design

Introduction

The complex and personal nature of this study on the identity experience for the adult haematological oncology patient necessitated qualitative inquiry as a means of exploring the richness and depth of this phenomenon. Qualitative inquiry encouraged collaborative wondering in addition to opportunities for flexibility in methodological choices as new insights and relationships developed (Ellingson, 2009). This research was conducted using the qualitative scaffolding offered by Interpretive Description. Interpretive Description (ID) is a qualitative research methodological framework that aims to generate clinically relevant knowledge through inductive reasoning. ID can be utilized by qualitative researchers to describe, and then inform, the clinical environment by suggesting “tentative truth claims” that can be pragmatically applied to nursing assessment, care planning, and intervention strategies (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004, p. 7). This is accomplished through thoughtful, non-categorical research utilizing several carefully chosen qualitative methods and techniques. Thorne et al. state “the design strategies in interpretive description borrow strongly from some aspects of grounded theory (GT), naturalistic inquiry, and ethnography, drawing on values associated with phenomenological approaches inherent in the methods of data collection” (2004, p. 6). This chapter outlines the specific methodological process for this research, including details on the layered research approach and specifics about method and data collection.

Theoretical Background for Research

The generic process of qualitative research consists of material practices that transform phenomena into representations through generation and collection of data. Data may take many forms including field notes, interviews, photographs, recordings, and reflective memos. ID is situated research that is interpretive because, as in most qualitative research, the observer/researcher must use gathered representations in “attempting to make sense of or interpret phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2011, p. 3). ID guides sound empirical research within applied disciplines for which traditional qualitative research paradigms and methodologies are not particularly well-suited.

Parse, Coyne, and Smith (1985) lamented that, because the historical origins of ground theory, phenomenology, and ethnography lie in different academic disciplines, it is difficult to apply them adequately to applied nursing practice. Echoing the concerns of Guba and Lincoln (1981), Thorne (1991) noted that these methodologies arose because of specific concerns and questions positioned within their associated discipline. In a similar manner, ID emerged as a discipline/*nursing*-specific research strategy to address specific theoretical and applied practice concerns specific to nursing.

ID allows for mixed approaches to data collection and analysis that can transcend the rule structures governing other qualitative research perspectives. For example, my study embraced a phenomenological quality as I sought to describe the phenomenon of identity as a lived experience of blood cancer patients. Thick description is heavily associated with phenomenology (van Manen, 1990). However, nursing practice does not benefit from simply describing phenomena, but rather necessitates that description be turned into action through additional interpretation that is discipline-specific. Thorne (2008) observed that the clinical mind cannot be satisfied with description, but rather pursues associations, relationships, and patterns within described phenomena. The ID theoretical framework that guided this study provided the ideal context by embracing and encouraging creative, credible, and practical research outcomes through allowing logical methodological choices to be driven by the research question, and not vice versa.

Review of Research Questions and Overarching Design

As discussed in chapter one, this project had several overarching goals that informed the direction of research. The study was designed around two separate, but complementary, phases aimed at addressing the main overarching research question: How are identity experiences described and elucidated by adult hematological cancer patients? Subsidiary research questions that further guided research were:

1. How are haematological cancer patients similar to, or different from, patients with solid tumours with respect to the manner in which they reference identity issues as part of their experience with cancer?

2. How do adult haematological cancer patients communicate their experience of self-identity with cancer?

3. Is self-identity the best way to examine this existential relationship between self/cancer, or does qualitative data suggest another angle that might be more inclusive and reflect the disease environment more appropriately within the context of nursing practice?

These additional questions provided complementary angles of vision and understanding within the larger inquiry around identity as experienced by blood cancer patients.

Plan for Data Collection and Analysis

This qualitative study was undertaken using a layered data collection and analysis process. The research process throughout the five layers (two phases) was designed to generate interpretive propositions about how haematological cancer patients experience identity in particular ways while focusing on specifically how they communicated about this phenomenon. Briefly, analysis of the data occurred concurrently with data collection in each layer and continued in an iterative manner extending into the subsequent layers. Findings drawn from each layer of the study were informed by those arising from the preceding layers. Constant comparison, a methodological strategy employed widely in Grounded Theory (Glaser & Strauss, 1967), served as analytical guidance for the layered research approach to ensure reflections of the phenomenon under study were both iterative and inductive. Subsequently, comparisons were made continually throughout the data collection process both intra-layer and inter-layer. Figure 1 details the relationship of the layers of inquiry. Figure 2 demonstrates the multi-layered data collection process.

Throughout research layers 1 and 2, I read and reflected on current academic literature (as a formal integrative review) as well as historical literature around how the phenomenon of identity has been discussed or referenced by cancer patients, and specifically haematological cancer patients, in the past. This perspective was critical in engaging a modern literature review process while acknowledging the importance of historical factors and sociocultural influences on how we form ideas about ourselves. When interacting with

interview transcript data in layers 3, 4, and 5, basic demographic data from the primary interview participants and clinicians, as well as from the UBC Communication in Cancer Care (CCC) database participants, was summarized to describe the sample and provide additional context for analysis and interpretation of the study findings. When working with

FIGURE 1: Layers of Methodological Inquiry

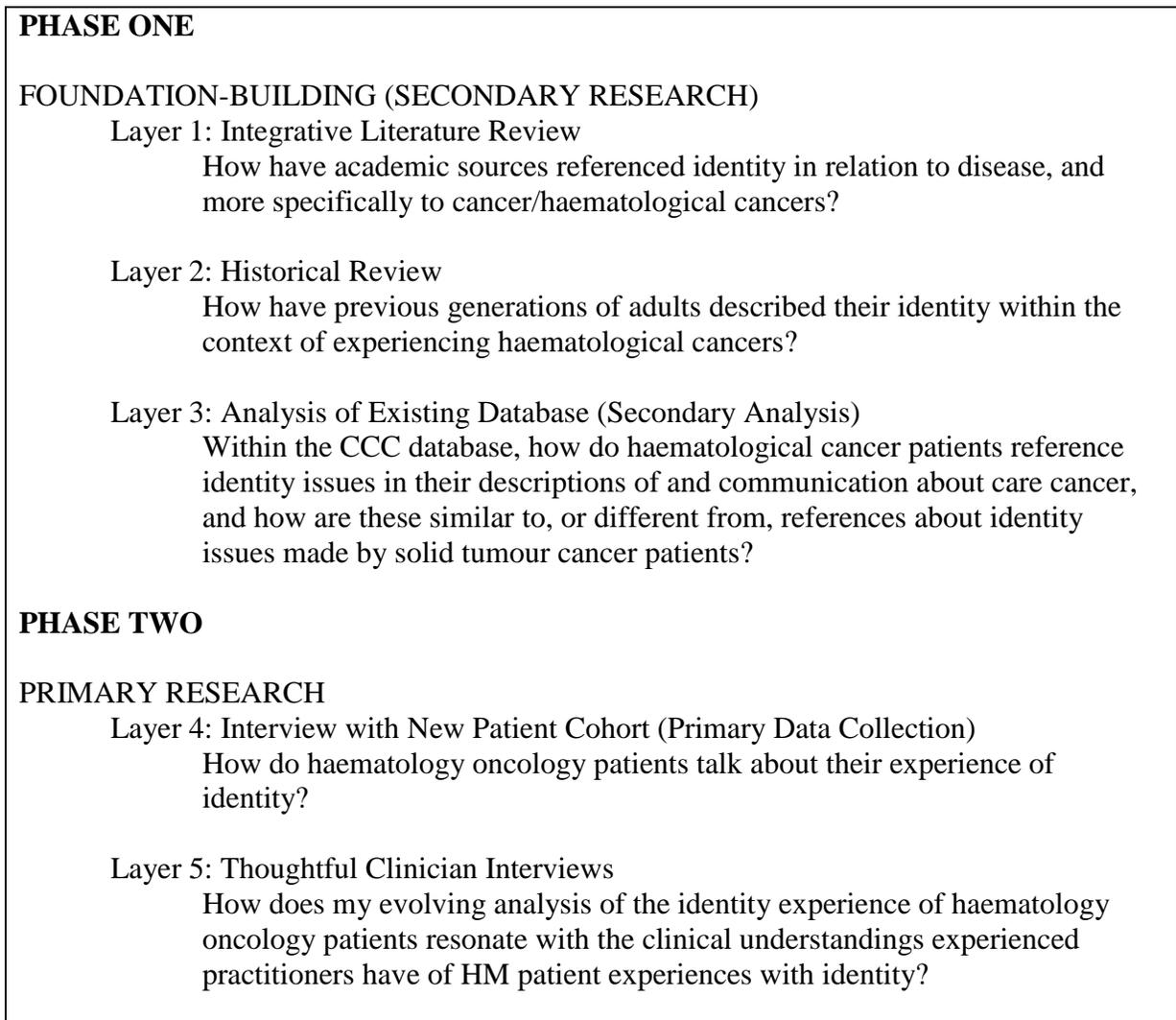
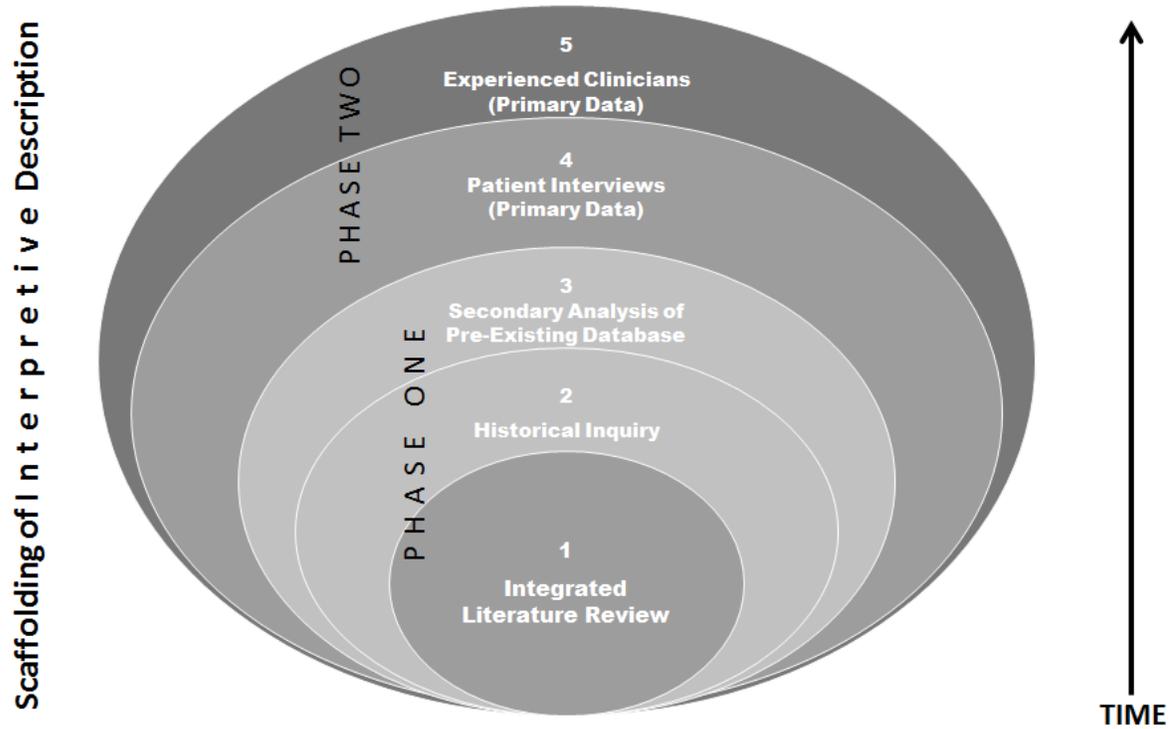


FIGURE 2: Multi-Layered Data Collection Process



This figure demonstrates the interconnected nature of the five layers of data analysis. Phase One layers (integrated literature review, historical review, and secondary analysis of an existing database) occur in a manner that build on each other creating a sound and reflective foundation from which the phase two layers (primary data collection) are undertaken. The final analysis, then, represents an incorporation of multiple layers, perspectives, and complex reflection toward the goal of presenting both an interpretation of identity issues in adult haematological oncology patients that is both pragmatic and unique.

the interview transcripts, both in the secondary (layer 3) and primary context (layers 4 and 5), I applied constant comparison and thorough documentation of analytic thinking (via reflective journaling) to establish an audit trail and to provide a means through which interpretive induction could create meaningful findings. Field notes further documented the narrative development of my analytic reflections during primary research, and collateral items (including journal entries, poetry, writings, photographs, or self-portraits given to me by study participants) were considered an important supplementary data source.

In the spirit of interpretation, I reflected on various theoretical and methodological sources to inform my analytic process. Philosophical influences from fields such as phenomenology, existentialism, and spirituality studies provided points for reflection as well as areas for comparison and theme generation (see chapter 2). For example, identity remains a substantial focus for phenomenologists, but tends to adhere to the context of the phenomenon of identity itself (including how it is experienced and created). The focus of my dissertation research on how identity is experienced has multiple contexts, including the way these patients communicated to health care providers. I reflected on works by phenomenologists whose writings in corporeality (van Manen, 2007), illness (Marcum, 2004), and mortal angst (Svенеaus, 2000) informed my thinking. The notion of lived experience is a component of this research but is not an overarching (driving) concept. Extensive work on identity within the context of disease and chronic disease has been undertaken by academics in psychology and sociology (Symbolic Interactionism, for example), and theories arising from this work also informed my evolving analysis as research progressed. Finally, in specific reference to texts created via transcription of the interviews (both patient interviews and the clinician interviews), I utilized techniques outlined by narrative inquiry to explore the text as narrative in a way that seems appropriate.⁷ Due to the

⁷ The entire story around identity is a narrative about the patient journey with cancer, so it makes sense that the bulk of primary data in this research project will have a narrative quality. Spector-Mersel (2010) advocated for a narrative paradigm as a unique mode for investigating intimate human moments, asserting that narrative inquiry was “full-fledged research” that linked the “hows” with the “whats” on the premise of “the nature of reality and our relationships with it” (p. 204). Methods associated with narrative inquiry allow for a detailed examination of the organization and substance that makes up a personal story, giving reference to psychological, sociological, and historical referencing through an interplay of language and meaning (Wells, 2011). The narrative chosen by an individual is, in the constructivist sense, the story that is “settled on as ‘being’ our lives” (Bruner, 1987, p. 709). The use of metaphor is particularly functional in the work of Laranjeira (2012) around the effects of a cancer diagnosis on self-identity. After intensive narrative inquiry

iterative nature of qualitative research, within the study planning process I anticipated additional considerations of both techniques and concepts. As such I accepted that things (concepts, themes, key ideas) might arise which could have an appropriate place in deepening the research findings during both analysis and interpretation of the findings.

I will now outline the specific methodological strategies used for each of the five layers of data collection and analysis.

Phase One: Secondary Research

Phase One of this study consisted of a thoughtful analysis consisting of three interacting components meant to build contextual richness around issues of cancer identity within the healthcare environment, and more specifically, around the context of communication. The first layer of research constituted a critical integrative literature review, followed by a focused historical inquiry into the haematological cancer experience. The third layer was a secondary analysis of an existing qualitative database (the UBC Communication in Cancer Care Research Program). These three layers of data collection allowed me to investigate how diversity and manner of ideas pertaining to identity were referenced in patient narratives about what it is like to experience blood cancers, and subsequently how they communicated with others in relation to, and about, their cancer.

Since cancer has been a nagging and frightening disease for thousands of years, it appears in the literature at several points throughout history in ways that touch on issues important to this dissertation project. By examining those references and building a foundation based on historical inquiry and an academic literature review seeking references (including quotations) made by patients and interviewers around related questions, my hope was to vastly expand my own understanding of the phenomenon of identity. Insights gleaned from this process were simultaneously useful during the third layer of Phase One, namely the secondary analysis of the UBC Communication in Cancer Care database. References,

research, Laranjeira advocated for metaphor as the most useful tool for the cancer patient in bridging the world of technology and treatment. While the notion of the Ricoeurian narrative perspective of hermeneutics is appealing, I believe that this type of inquiry can only reveal a portion of the larger picture of the disease experience. Narrative inquiry, then, is a useful tool for qualitative research but requires the creation of narrative (rhetoric) which can be heard, read, or viewed and then strategically analyzed (Clandinin & Connelly, 2000; Leggo, 2008).

phrasing, verbal and (if available) nonverbal communications around embodiment and identity were analyzed. Phase One embraced a comparative lens as both solid tumour and haematology oncology patients were examined both directly and indirectly under a generalized “cancer” umbrella. The overall dissertation was focused on haematological oncology patients, so the work of this inquiry was also to produce thoughtful, focused reflection in a way that honoured the spectrum of cancer patients but consecutively prepared for the specialty-focus on the haematology oncology population in Phase Two.

My goal of Phase One, ultimately, was to foster a deepened sense of what was actually occurring within the cancer context of identity in order to inform the questions driving participant interviews in Phase Two. That is not to say that I entered Phase Two with conclusions developed from my Phase One inquiry, but rather that this initial, foundational investigation bolstered methodological and theoretical underpinnings in a way that allowed greater depth of questioning, investigation, and analysis.

Layer 1: Critical Integrative Literature Review

A critical integrative literature review scaffolded this research project in a way that was both meaningful and provided legitimacy for exploring identity issues within the cancer context. The main question that guided the literature review was, how have academic sources, and specifically nursing, referenced identity in relation to cancer (general) and haematological cancers?

Academic research literature from the past decade was accessed via library searches, on-line searches, reviewing citation lists, collegial networking recommendations, and searches of EBSCO, PUBMED, CINAHL, and other databases. The goal was to further establish a base of what existed in the literature previously, as well as to create an integrated discussion of the state of the literature today. Sources were reviewed for applicable themes and topics based on a hierarchy of applicability to the dissertation topic (identity in haematology oncology patients). Identity discussions from other disciplines and specialties, such as sociology or solid organ transplant, were consulted as a means of stimulating additional keywords, concepts, thinking, and potential avenues for exploration. Concepts related to identity, such as body image, embodiment, and personification, were also examined within the literature to inform the original research question. I became quickly

aware that the vast body of literature on this collection of topics is extensive, and therefore careful reflection on the stated research questions ensured adherence to the research focuses (identity, disease identity, chronic disease identity, cancer identity). This critical layer illuminated gaps within the literature, and firmly grounded this study's contribution to both exploratory and descriptive research as well as serving as a concrete foundation from which to launch the other layers of inquiry.

Layer 2: Historical Inquiry

Following the critical integrative review of the academic literature, a historical inquiry of select primary and secondary sources (including medical textbooks, published journals and letters, literature, newspapers, and oral history transcripts) constituted the second layer of data collection and analysis. Historical inquiry is based on asking a specific question of the historical record (Quigley, 1979), and while I did not intend a formal stand-alone historical inquiry, I made an effort to fully explore the historic record as a means of deepening my reflections on identity as experienced by adult haematological cancer patients. My question driving historical inquiry was similar to the main research question: how have haematological cancers been characterized and explained in the past in reference to issues of identity?

The purpose for this historical inquiry was foundational as well as informational, and a review of primary source and secondary source materials was performed in an effort to locate specific references to identity (or similar terms) in adult (and in some cases, pediatric) cancer (writ large) and haematological cancer patients. Works of fiction and nonfiction were referenced in this research phase to provide both context and reflective material. Unlike the literature review which included pediatric resources as well as multidisciplinary references, the historical inquiry aimed to be very specific in purpose to establish a baseline of knowledge from which to build further analysis and investigative techniques. In this way, the historical inquiry was focused as a *review* of empirical sources as a “collective and theoretically informed inquiries into selective aspects of the past” (Fulbrook, 2002, p. 6). As expected, this historical inquiry served as excellent background to the modern academic research that constituted a proper literature review. I did not perform a history of identity for patients with haematological cancers, but rather my intent was to draw on historical inquiry

methods as an alternative way to explore how issues relating to identity have emerged in the various literature forms over past generations. The emphasis of this layer was on sociocultural, political, and in some ways philosophical groundings.

As an innovative component of qualitative research, by including historical inquiry as a specialized layer of my research process I examined sources that directly and purposefully informed the foundational base-building of this research dissertation. I did not intend an exhaustive search of historical records, although the resulting chapter is impressive in scope and content. Rather, I planned to undertake this layer of research with the sole goal of this review serving as an *auxiliary and complementary component* of the integrative literature review and as a foundational and informative component on which to undertake the primary interviews with patients (layer 4). I wanted to reflect on fictional, biographical, and theoretical literatures of the past to investigate how they might reveal something about how humans have considered or reflected on identity issues in the context of cancer and specifically haematological cancers.

Sandelowski (1999) described that all qualitative research contains a temporal component. I believe a historical inquiry and subsequent review contributed contextual richness around the issues of cancer identity as experienced through time in a way that was both unique and enriching to qualitative research. Since cancer has been a devastating human disease for thousands of years, references to it appear in the literature at several points throughout history in ways that touch on issues and themes important to this overall study. By examining these primary sources, I bolstered an evolving analysis of the identity experience of adult haematology oncology patients by investigating how this phenomenon has changed, and how it has remained the same, over time. By incorporating and intermingling different timelines and reflections of past and present through research in layers 1 and 2, I was able to develop a richer foundational understanding of how identity has been experienced and communicated about by patients with haematological cancers.

Layer 3: Analysis of Existing Database

Insights gleaned from the above historical and literature analysis processes served useful to guide qualitative method applied to secondary analysis of the UBC Communication in Cancer Care (CCC) database (Thorne et al., 2014). This qualitative database includes interview transcripts from 125 adult cancer patients who provided more than 500 interviews over a 7-year period (2005-2012). The goal of the interviews contained within this database was to understand and explore the changing communication needs and preferences for cancer patients across the cancer trajectory (Thorne et al., 2014). The driving question for this third layer of research was, to determine, through accessing this preexisting database, how do haematological cancer patients reference identity issues in their descriptions of and communication about care cancer, and how are these similar to, or different from, references about identity issues made by solid tumour cancer patients?

The main criterion for inclusion in the Phase One (secondary research) portion of this study includes patients who consented to, and gave, interviews to the UBC Communication in Cancer Care team over the course of the research program's existence (UBC BREB H09).⁸ This involves a patient cohort of over 600 patients in the period enveloping 2000 to 2013. Patients interviewed as part of this database were over the age of 18 years old and had a variety of cancer diagnoses. Additionally, patients included in this database have been interviewed as part of the UBC Communication in Cancer Care research program at any state in their disease trajectory, from initial diagnosis to remission, survivorship, or end of life and palliation.

From the CCC database, I examined a set of interviews from 15 haematology oncology patients matched with 15 demographically similar non-haematology cancer patients. This strategy was employed with the assumption that matching subsets would provide some control for age and gender while yielding useful and perhaps unique insights. This takes into consideration that there exists a data set for both subgroups that was sufficient and rich enough to provide substantive interview data from which identity and other cues around embodiment and body image (for example) could be gleaned. By examining transcripts from both solid tumour and haematological cancer subgroups, I aimed for a

⁸ Dr. Sally Thorne, primary investigator (PI) of the Communications in Cancer Care research program, confirmed that the team linked earlier approvals from when the project was first approved by ethics committees and continued to have the approvals confirmed annually.

comparative reference for further probing, expanding clarification, and seeking deeper meaning from the data in a way that honoured both.

References to identity, including specific and nonspecific verbalizations (such as pronouns or saying the actual disease), phrasing, verbal and (if available) nonverbal communications around identity and associated themes (such as body image, embodiment, personification, being/Being) were inductively analyzed. For example, I looked at questions like: how often do haematology oncology patients reference themselves, and how do they do this with language? Was this similar or different to how the non-haematology oncology patients reference themselves? As more transcripts were read, constant comparison was again utilized to stimulate reflective thinking and deeper reading.

Summary: Phase One

The overarching goal of the first three layers of data collection was to foster a deepened sense of what occurred within the cancer context of identity in order to inform the questions driving participant interviews in layer four and five. Each of these three levels deepened my reflections on the phenomenon of identity, and enabled a more sensitized fine-tuning of the primary data collection undertaken in layers 4 and 5. That is not to say that I entered primary data collection and analysis with specific conclusions, but rather that the initial, foundational investigation from the first three layers of data collection and analysis informed and clarified multiple ideas, theories, and methodological and theoretical underpinnings as a means to further pursue optimal depth of questioning, exploration, and analysis.

Phase Two: Primary Research

Using these three layers as a foundation, I then undertook the fourth and fifth layers consisting of primary research. The fourth layer represented participant interviews with a new patient cohort consisting of adult haematology oncology patients. In this fourth layer, I gathered and analyzed original in-depth interview data from a judgement sample of haematological cancer patients to deepen and refine my understanding of how they experience and reference issues of identity. I anticipated that these interviews would provide depictions of how haematological cancer patients language, interpret, and explain what it is

like to have haematological cancer and how that might differ from the more commonly understood notions of cancer experience. The fifth layer of research, following my discussions with patients, was comprised of focused interviews with a purposeful sample of highly experienced and thoughtful oncology clinicians. These interviews were performed to gather new objective knowledge about the care environment, provide a new perspective about identity as expressed by this patient subgroup, discuss specific findings, corroborate impressions, and explore strategies for application of findings to nursing practice. The findings from these additional two layers of primary research were incorporated into a discussion that was enhanced and deepened by multiple levels of data and reflective analysis.

Layer 4: Interview with a New Patient Cohort

I personally conducted and digitally recorded (voice-only) face-to-face interviews with a new patient cohort of 14 adult blood cancer patients. These interviews were semi-structured, open-ended, focused, and exploratory in nature. In all cases, the interviews assumed many qualities characteristic of a phenomenological interview structure (by asking “why” and probing for deeper detail) as well as a narrative analysis strategy for requesting more detail and description to capture an experience into words and expose appropriate languaging. The question driving this primary research and analysis was: how do haematology oncology patients talk about their experience of identity?

The participant interview component of this research project necessitated initial purposeful (or judgement) sampling. Assuming that in a study of a human phenomenon of this complexity, the decision that no new data are expected seems inherently arbitrary, I rejected the notion of “saturation” as an appropriate outcome (Bowden, 2008). I instead accepted the concept of *sample adequacy* and my initial recruitment goal was an estimated 10 thoughtful and reflective research participants (Malterud et al., 2016; Morse et al., 2002).⁹ Specific criteria for inclusion and exclusion in the study can be found in Appendix A. During

⁹ The ultimate purpose of this research was to examine the general population of adult haematological oncology patients rather than to examine a controlled situation or to describe the relationship of independent and dependent variables. Marshall (1996) recommends that the qualitative researcher initiate a study using several sampling techniques including maximum variable sampling, which seeks a broad range of participants, to critical case sampling, or subjects with specific experiences. As the data collection process progressed, a thorough sample review was undertaken to determine the composition of the research participant cohort (theoretical sampling). At that time, purposeful sampling of a specific haematological cancer type, gender, or age sample was commenced to ensure a balanced interview database.

recruitment I reserved the option for flexibility within the final number of study participants for this layer, and my decision to conclude the study depended on arising circumstances (as discussed in chapter 7). My commitment was to continue recruitment and/or subsequent interviewing until the interpretive data set I accumulated provided me with something meaningful to say about the phenomenon. Luckily, there was a great deal of enthusiasm from patients to participate in interviews. This research layer was designed to interview key informants, namely particular adult people with a particular health situation. Similarly, opportunities to access collateral data did arise on multiple occasions during the study and these items were considered within the context of the story accompanying them, but it is important to note that the primary data source for this layer of inquiry was the transcribed and live recordings of the individual interviews.

Recruitment of Participants

Recruitment of participants commenced with the distribution of a letter and associated flyer through key stakeholder personnel in the cancer clinics and hospitals in British Columbia (BC, Canada), focusing on units and programs with the BC Cancer Agency (BCCA) and the BC Leukemia/Bone Marrow Transplant program (L/BMT). This letter introduced the researcher and explained the research project with associated clinical outcome goals. As I am actively involved in the local, provincial, and national oncology nursing communities, as well as being long-employed by the L/BMT program, the process of negotiating entry into the field was uncomplicated and straightforward.

Additionally, I posted flyers and notices on bulletin boards in local cancer clinics and in-patient and out-patient settings as an additional means for recruitment. Local BC chapters of national organizations such as the Leukemia and Lymphoma Society (LLS), the Canadian Cancer Society (CCS), the Canadian Association of Nurses in Oncology (CANO/ACIO), the Canadian Partnership Against Cancer (CPAC), and the Canadian Bone Marrow Transplant Group (CBMTG) included research participant requests (specific to the guidelines outlined above) in their newsletter and social media feeds. Finally, I requested that colleagues distribute flyers detailing the study during provincial haematology oncology patient support groups, focusing on those operated by local LLS.

Potential participants who responded to these queries received an initial informational letter explaining the study. They were given an opportunity to ask questions or voice

concerns with the researcher. The initial information letter and consent made explicit the fact that choosing, or not choosing, to participate in the research study would in no way effect their health care delivery. Individuals who expressed a desire to participate, and who met the inclusion criteria, were emailed the informed consent statement. They were asked if they had any questions before signing the form (see the Information and Consent Form - Patient Participant, Appendix D). The participants were notified that they could choose to leave the study at any time. Discussion of ethics and other considerations in relation to the interview process and method follow.

Interview Techniques

Due to the intensely private nature of the conversation, initial interviews were conducted in private, personal places where the participant felt most comfortable. In some instances, this was the participant's home, but in about half of the cases we met in off-site locations (like coffee shops). Emphasis on safety for both the researcher and the participant included recommendations by Thorne (2008) and Paterson, Gregory, and Thorne (1999). I digitally recorded each interview and made sure that the participant was fully aware of the recorder. I worked quickly establish rapport and foster a comfortable, safe environment while collecting demographic and disease-related information. Foundational themes and content from the first three levels of data collection and analysis informed the semi-structured interviews through the utilization of a guide laced with potential topics and questions to stimulate a focused discussion (see Appendix B for the interview guide). For this reason, initial interviews were not boundaried by a rigid timeframe, and this looseness allowed for natural conversation and cultivated a free-flow of thoughts. My sensitivity to the patient's time and comfort parameters meant that most interviews ended up lasting 60-90 minutes.

Preliminary interviews were specifically planned as semi-structured to ensure desired information was obtained without placing too many pre-existing restrictions and thus choking a natural flow of conversation. This method was vastly different from the unstructured, unstandardized interview technique suggested by Waskul and van der Riet (2002) for studies of embodiment and existential concerns. However, I felt strongly that organizing the interview and tentatively drawing from a set of questions (i.e. semi-structured) triggered from my in-depth Phase One inquiry allowed for conversation that was both free-

flowing and directed to the point of ensuring key themes were explored. This also allowed for the conversation to flow according to the needs and preferences of the patient. The semi-structured approach also allowed the opportunity for the interviewer (myself) to listen for specific language cues from the participant that led to further, deeper questioning. By asking each participant the same question, or general question, consistency in data collection was achieved allowing for direct comparisons between responses.

Before going into the field, I undertook extensive background preparation in interview and research techniques. Specifically, I reviewed several research methodologies utilized by skilled researchers for engaging in topics like body, body image and self-identity as well as recommendations around phenomenological and philosophical interview techniques. Merleau-Ponty (2002) recommended that the focus of a phenomenological interview was to encourage description that was as inclusive and exhaustive as possible, carefully avoiding any attempts to analyze or explain within the moment. Kvale and Brinkman (2009) recommend twelve qualitative research interview techniques based on phenomenological principles that impelled themes arising from the interviews beyond a descriptive purpose. These themes include specificity, awareness of meaning shifts and changes, and holistic relationship of the participant to their life world. Additionally, Kvale and Brinkman suggest that a qualitative interviewer engage in deliberate naiveté as well as mindful consideration of co-creating a positive experience. Approaches such as those detailed by Merleau-Ponty and Kvale and Brinkman corroborate rich descriptions as the primary goal of qualitative interviewing (Denzin & Lincoln, 2012).

In my original proposal and consent, I allowed for the possibility of a second interview. Per qualitative recommendations, I anticipated that additional interviews might be needed depending on the research situation. Before exiting the interview, I assured the participant that they were free to decline further participation at any time. Once the interview was completed, I immediately proceeded to a private setting to write field notes in the manner of a reflective journal. This journal was valuable in establishing a traceable pathway of my thinking and reflection on the interview experience. This journal was used to document a short reflexive synopsis of how the interview unfolded, as well as to record initial analytic insights arising and to capture additional questions or items to consider. In some cases, follow-up conversations over the phone and email clarified points garnered in

the first interview for additional clarification or elaboration as my interpretation of what I was learning through these interviews evolved.

Data Management

Within a short time after the interview, I had the interview recordings transcribed verbatim. Any collateral data referenced or collected was scanned (or downloaded as a digital image) and added to the NVivo™ database in digital form. This collateral material was also documented in the field notes in a way that reflected both the stated intention and the context in which it was shared by the participant. Interview recordings were transcribed verbatim either by the researcher (myself) or by a paid transcriptionist following recommendation by Thorne (2008). In the case of an outside transcriptionist, I listened to the recordings while reviewing the word-by-word transcription to ensure accuracy and (as closely as possible), intention and context. This method is part of a naturalistic transcription technique which attempts to preserve the "talk-in-interaction" (Hutchby & Wooffit, 1998, p. 13). These transcribed interviews were uploaded into the NVivo™ software program. The ability to focus on words, sounds, and periods of silence rather than just printed text is a technique that offers the qualitative researcher opportunity for deeper reflection and enhanced engagement with the interview material as narrative and storyline. The process of transcription has largely been ignored in qualitative research, and yet its presence can have a startling impact on the entire qualitative process. Oliver, Serovich, & Mason (2005) describe how a qualitative research team misinterpreted the text-written snuffles and grunts made by an interviewee during a taped interview transcribed by a third-party transcriptionist using naturalistic transcription techniques. The research team enthusiastically discussed what the snuffles meant in the context of the spoken words, thoroughly analyzing how and which words overlapped the disturbing sounds. Finally, entertained by the exchange, the interviewer chimed-in that the sounds had nothing to do with the interview topic at all. Instead, the interviewee had a terrible cold. Therefore, I believe the nature of the existential query being undertaken in this study necessitated locating the transcription process within the interviewer/interviewee context in order to create a naturalistic transcription text. The research questions should, ultimately, drive the choice for transcription in the same way they drive the overall research process (Oliver, Serovich, & Mason, 2005). If a denaturalized text

is needed for further analysis, this can easily be achieved using the original transcription project. However, my deep-knowing of the interview context, conversation, collateral data, and subsequent involvement in the transcription process extended my understanding of the material in a way that would not have otherwise been possible.

Layer 5: Thoughtful Clinician Interviews

As a fifth layer of data collection, I engaged in directed interviews with experienced oncology clinicians. The driving question for this layer of data collection and analysis was: How can insights of experienced oncology clinicians around issues of identity for haematology oncology patients contribute to an understanding of this phenomenon?

Corroborating with the application potential prescribed by interpretive description, the research products of any nursing study should be sound enough that a nursing clinician would find them sensible. Subsequently, these products of research (called “tentative truth claims”) would be consistent with the nursing process (assessment, diagnosis of a problem, planning interventions, implementation, and evaluation of interventions) as well as “keeping with recognized standards of evidence, logic, and ethics” (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004, p. 7). The purpose of including experienced oncology clinicians in this study was multifactorial. First, the clinician has both an etic-outsider (to the self) lens as well as an emic-insider (within the healthcare system) focus that contributed an additional layer of data to supplement and complement previous layers of findings. Interviewing experienced clinicians with intense bedside familiarity of haematological oncology patients was also intended to impart supplementary ways to consider an evolving understanding of the process and practical meaning of identity for blood cancer patients. Further, I expected that experienced clinicians would have direct knowledge of the relative frequency of various thematic patterns within their clinical practice. My assumption (based on professional experience) was that clinicians who demonstrate thoughtful interest and concern of the patient-as-person can serve as exceptionally valuable resources in generating reflective and practical commentary with respect to any recommendations or implications for direct patient care interventions. I also framed this layer of research with the underlying belief that clinicians would have the specific and unique ability to critically contemplate the phenomena of expressed patient identity concerns and provide novel input that would refine and

strengthen my thinking. The ability to utilize such a rich resource allowed the disciplinary lens of nursing to be fully present as a tool to augment the qualitative analysis process. Finally and as a methodological factor, interviewing clinicians served to strengthen study credibility indicators (Thomas & Magilvy, 2011). According to Thorne (2008), such member checking helps build confidence towards the dependability of the research findings. Qualitative research concerns around reliability and validity include meaning-in-context, recurrent patterning, and confirmability (Leininger, 1994; Lincoln & Guba, 1985; Patton, 2002; Tobin & Begley, 2004). As a mindful researcher, the goal of generating high quality research underpinned this entire project.

Sampling Strategy

A purposeful sample of 7 highly experienced haematology oncology clinicians was recruited for this layer of the study. This sampling seemed reasonable in building and reinforcing credibility of this project. The participants were considered experienced in the sense that they:

- a) had over five years of full-time experience in care of the haematology oncology patients,
- b) were working regular hours as a bedside nurse in either an inpatient haematology oncology unit (including a transplant unit) or in the outpatient day clinic setting, or in a work capacity where they regularly interact with this patient population, and
- c) expressed keen interest in psychosocial issues within day-to-day operations of patient care work.
- d) were nurses or members of the interdisciplinary team working closely with haematology oncology patients in a way that allowed them access to the patient experience. In this study I interviewed one social worker with extensive experience and knowledge about haematology oncology patients.

Interview Techniques

After all four preceding layers of research were completed, I drafted an interview guide to ensure consistency of responses around certain key themes and ideas that had arisen thus far in the study (see Appendix C). One-on-one interviews with highly reflective and experienced clinicians were a means to advance findings further, moving from single case experiences to more inclusive meta-reflections based on exposure to multiple cases over time, thereby seeking greater understanding of the identity phenomenon as it appears within the cancer care environment. I conducted these interviews both face-to-face and over the phone. The information and consent form presented to clinicians reflected the key points that were also included on the document used for the patient participants (see Appendix E). Field notes (via reflective journaling) were made during and immediately following the interview. These interviews were digitally recorded and transcribed shortly after the interview ended. Directed questions and comments around findings from the first four layers of data collection and analysis were discussed when appropriate, but generally questions and themes were drawn from, and paralleled, the primary patient interviews. For example, I had anticipated making general statements about identity as well as reporting some of my impressions and evolving thematic analysis to these clinicians. I then asked them to reflect on this analysis with the aim that their input would enlarge upon, critique, and/or expand my thinking, accepting that each had wide experience but also a unique subjective view of my overall research focus. The clinician participation in this study provided an added perspective to the experience of patients with blood cancers, and this layer of research is more fully explored in chapter 8.

Phase Two: Supplementary Strategies for Data Collection

Self-Reflective Journal (Field Notes)

The use of a reflective journal by the researcher is commonplace now in qualitative research data collection strategies (Finlay, 2002; Ortlipp, 2008). While researchers may engage in the reflective journaling process in different ways, it is generally agreed upon as part of the work of qualitative research that the journal will be used during and after interviews to collect researcher reactions, contemplations, ideas, questions, and notes that

require follow-up with the participant. Reflective journaling by the researcher is considered a key component for generating transparency in the research process, providing “a research trail of gradually altering methodologies and reshaping [of] analysis” (Ortlipp, 2008, p. 696). This journal can also become a critical component of the data analysis process as a technique for avoiding bias and increasing reliability and rigor (Rolfe, 2006; Thorne, 2008). Within the context of this study, reflective journaling (field notes) was undertaken with both the patients and the clinicians (layers 4 and 5).

Narrative Development and Analysis

Narrative analysis can also be a valuable tool for examining the cancer experience. The entire story around self-embodiment and identity is a narrative about the patient journey with cancer, so it makes sense that the bulk of primary data in this research was imbued with a narrative quality. Spector-Mersel (2010) advocated for a narrative paradigm as a unique mode for investigating intimate human moments, asserting that narrative inquiry was “full-fledged research” that linked the “hows” with the “whats” on the premise of “the nature of reality and our relationships with it” (p. 204). Methods associated with narrative inquiry allow for a detailed examination of the organization and substance that makes up a personal story, giving reference to psychological, sociological, and historical referencing through an interplay of language and meaning (Wells, 2011). The narrative chosen by an individual is, in the constructivist sense, the story that is “settled on as ‘being’ our lives” (Bruner, 1987, p. 709). The use of metaphor is particularly functional in the work of Laranjeira (2012) around the effects of a cancer diagnosis on self-identity. After intensive narrative inquiry research, Laranjeira advocated for metaphor as the most useful tool employed by a cancer patient in bridging the world of technology and treatment. While the notion of the Ricoeurian narrative perspective of hermeneutics is appealing, I believe that this type of inquiry can only reveal a portion of the larger picture of the disease experience. Narrative inquiry, then, is a useful tool for qualitative research but requires the creation of narrative (rhetoric) which can be heard, read, or viewed and then strategically analyzed (Clandinin & Connelly, 2000; Leggo, 2008).

However, I caution that I am not specifically using narrative inquiry as a formal qualitative research method per Clandinin and Connelly. Portions of their methodological

argument and recommendation have proved useful in data collection and analysis, but this dissertation is not a narrative inquiry.¹⁰

Collateral Data

During the primary interviews, other forms of data arose naturally as part of the highly personal and existential nature of the line of inquiry. Such data variants have been referred to as “collateral data” and include:

- a) patient journaling
- b) ethnographic participatory visual methods such as photovoice (where the participant is the photographer)
- c) self-portraiting
- d) sharing of family photographs
- e) genealogical sharing (such as charts)
- f) poetry
- g) forms of artwork (besides self-portraits)
- h) reference to books or articles they found helpful or informative

Due to the intensely personal and transitory nature of the self-as-being cancer, utilizing other forms of data within the interview context to assist in capturing notions of identity and disease embodiment enhanced the depth and richness of the data. For example, photo-narrative and art therapy has been used by researchers like DeShazer (2012) and Sibbett (2005) to explore embodiment after cancer diagnosis. Photo elicitation (known also as photo interviewing and photofeedback) is a strategy used by Oliffe and Bottorff (2007) with prostate cancer survivors to explore the experience of having the disease. In photo elicitation photographs usually taken by the participant (photovoice) are discussed during an interview in a way that is considered empowering and emancipating as participants can make their experiences visual. Oliffe and Bottorff suggest that utilizing alternative methods such as photovoice in qualitative research can encourage participants to reveal a great deal more

¹⁰ I had the pleasure of attending a full-day workshop with Dr. Clandinin in Edmonton, AB in 2012. While I find many aspects of this method (or as some now argue, paradigm) intriguing, I want to be very careful about appreciating aspects of Narrative Inquiry which have informed certain of my methodological application approaches with an awareness that I was not fully taking up the epistemological orientation of this specific qualitative method.

about their illness experience than would normally be granted (p. 856). Per interpretive description, predetermined designation of such explicit methods at the beginning of research is thought to shape data collection strategies and analysis in ways that might be counterproductive towards engaging openly with the phenomenon in question (Thorne, 2008). Instead, I prioritized a natural conversation arising from the interview process to drive other methodological choices in a way that supported the goals of this project. I also maintained keen awareness that the use of such visible expressions of identity could be more representative of embodiment, thereby deviating from my stated intention to seek a more conscious, mental experience of identity. More on the collateral data collection and analytical process within the context of this research will be included in the discussion chapter (chapter 9).

Data Analysis

Qualitative research entails a process of inductive analysis whereby observations of individuals are used to generate knowledge about broader generalizations and theories (Denzin & Lincoln, 2012). Specific observations made by the researcher using various qualitative method and methodological traditions allows for the detection of regularities and themes, which can then be consolidated into tentative hypotheses. Content analysis, constant comparison, and thematic analysis can be utilized as data is collected and new interviews are planned (Sandelowski, 1995b).

ID strategy recommends that, in order for qualitative research to be successful and useful, immersion in the data should occur prior to initiating a formal coding process (Thorne, 2008). While I planned to follow coding guidelines to some degree within the data analysis portion of this research project, detailed line-by-line coding recommended by grounded theorists such as Strauss and Corbin (1998) was not appropriate and thus not undertaken. Instead, coding aimed for a more comprehensive, open-ended and theme-focused approach indicative of ID methodological flexibility. The goal for data analysis was generally broad-based coding occurring over several passes, each intended to penetrate further into the meaning and essence of the phenomenon under study. In this way, data analysis was an evolving and active process inviting experimentation and creative thematic investigation (Thorne, 2008). Demographic data was collected and entered the statistical

software program, SPSS.¹¹ The use of NVivo™ software in this project was around data storage, coding, and linking, and this application of software provided further opportunities for data analysis. NVivo™ allowed digital photographs and other images to be linked to specific interview transcript data. These multimedia sources were also coded mimicking the same coding structure used for text. Query functions in NVivo™ generated cross-referencing between text and images that further encouraged fresh or alternative methods for analyzing content.

Issues of Qualitative Rigor

Interpretive description aligns with the positioning of validity, bias, and reliability under the umbrella of “qualitative rigor” as originally proposed by Lincoln & Guba (1985). Thorne et al. (1997) noted that “from our perspective, a caring discipline such as nursing has a special obligation to ensure that the rigor of its research findings is above reproach” (p. 176). Rigor is upheld by systematic avoidance of things that can result in potentially deficient analysis such as “going native,” “premature closure,” “bloodless findings,” and “overdetermination of pattern” (p. 176). Reflective journaling, as well as thoughtful coding and constant comparison during data collection and analysis, are methods used to ensure qualitative rigor. Within ID research, “the best interpretive descriptions will pass what has been referred to as the ‘thoughtful clinician’ test” and integrity of the interpretive process “will always generate more credible findings than will rigid adherence to the ‘gamesmanship’ of rigor” (Thorne, Reimer Kirkham, & O’Flynn Magee, 2004, p. 17).

Oncology Clinician Interviews

The semi-directed interviews with experienced clinicians comprise important components towards rigor and validity. Although not the main motivator for accessing the knowledge held by these clinicians, being able to discuss findings from previous research layers was useful in generating knowledge around identity and the patient experience. A small sampling, based on criteria outlined below, seemed reasonable in building and reinforcing credibility of this project. This was particularly important because of the applied

¹¹ SPSS is a statistical program used primarily for quantitative research. While my project is strictly qualitative, the specific demographic functions and chart-creation abilities of SPSS have made me favour it over those available in NVivo.

nursing lens applied to all aspects of this research (from research question development to strategies to data collection and analysis). Qualitative research concerns around reliability and validity include meaning-in-context, recurrent patterning, and confirmability (Leininger, 1994; Lincoln & Guba, 1985; Patton, 2002; Tobin & Begley, 2004). As previously stated, knowledge translation objectives for this research emphasized clinical nursing interventions as a *raison d'être*. Interviewing experienced clinicians possessing bedside familiarity with a wide variety of oncology patients was intended to provide understanding around the process and practical meaning of identity for blood cancer patients. Clinicians in particular who demonstrated thoughtful interest and concern over the patient-as-person were exceptionally valuable resources in generating reflective and practical commentary with respect to recommendations for practice implications arising from the data analysis and subsequent findings that develop within this study.

Issues of Qualitative Validity and Credibility

Since ID allows for multiple methods and methodologies to be employed in the research process, grounding validity (or reliability) in some manner is necessary to justify how using techniques from diverse disciplines can be combined to form a credible research study. Thorne (2008) suggests four areas which enhance credibility in ID-driven studies. First, *epistemological integrity* suggests the research process must stem from research questions that are consistent with chosen methodological perspectives. To achieve this, ID methodology adopts basic philosophical underpinnings of naturalistic inquiry as a theoretical framework, thus solidifying epistemological agreement (Thorne et al., 2004, p. 5). Second, *representative credibility* reflects a notion of validity in which the suggested truth claims of a research project remain consistent with sampling methods. Triangulation can add critical value under this point (Tobin & Begley, 2004). Third, *analytic logic* is associated with reliability (or replicability) whereby an audit trail allows for potential future scrutiny of data. The reflective journal is an excellent example of this (Thorne, 2008). Finally, *interpretive authority* on the part of the researcher is critical to establish study credibility. Interpretive authority also speaks to honest disclosure of bias and the ability of the researcher to create trustworthy interpretations. Methods such as concept mapping, memoing, and reflective

journaling (as discussed in the previous section) are means to decrease researcher bias and increase the credibility of a research inquiry, and each had a place within this study.

Additional methods recommended to improve credibility in ID research include moral defensibility, disciplinary relevance of the research question, the pragmatic obligation to create relevant research projects, contextual awareness of the researcher, and pursuing a goal of probable truths (as opposed to absolute truths). Ultimate responsibility for credibility falls to the researcher in choosing the ‘best’ methods to address a specific question. Ravitch and Riggan (2012) capture this notion expertly by stating that “ultimately, the utility and impact of your research will be determined by what you have to say, how clearly you say it, the strength of your argument, and the evidence that supports it” (p. 159). This phrase aligns with Lindlof and Taylor (2011) who assert that “researchers do not use methodological instruments. They *are* the instrument” (p. 9). The integrity of the researcher-as-person and as-scholar becomes the test or measure for reliability and validity in qualitative research. Within the context of ID and generic qualitative framework, reason and rigor are therefore integrated. The integrity of this research lies with careful data collection, thoughtful data analysis, and ethical representation of the interpretive findings.

Ethical Considerations

Procedural Ethics

Tracy (2010) notes that ethical considerations are not just a means to an end in qualitative research, but that ethics are the ultimate purpose of inquiry. Secondary research phase data inquiry was contained within the ethical approval for work by the BC Cancer Care Communication research program. Primary research phase ethical approval was received from multiple entities including the University of British Columbia (UBC) Behavioural Sciences Screening Committee (specifics on this are in chapter 8).

All data collected including the digital audio recordings, any graphic art materials, photographs, hardcopy transcripts, and other materials that could be considered sensitive have been kept confidential and in a locked filing cabinet accessible only by the researcher. Participant anonymity has been mindfully maintained throughout the transcription process using code names on all field notes, transcripts, audio recordings, and associated file materials. Upon the completion of the research project, interviews that have been consented

in their entirety will be incorporated into a master database through collaboration with the Communication in Cancer Care Principal Investigator. These interviews are unidentifiable and kept confidential as part of this database. Additional materials collected as part of the research project will be retained for a period of at least 10 years, so the findings can allow for secondary analysis with possible incorporation into knowledge translation activities and publications.

Relational Ethics

Due to the personally intrusive nature of qualitative inquiry, discussions around relational ethics require that researchers are ever-mindful of their “character, actions, and consequences on others” (Tracy, 2010, p. 847). Researchers should engage in reciprocity with participants in a way that is mutually-beneficial and positive. Gonzalez (2000) suggests that the researcher-as-human is an investigative tool, and as such, has potential to become personally engaged with participants in a way that violates a professional research relationship. In the case of highly-personalized and sensitive topics such as identity, embodiment, and spirituality there exists a risk that participants can become emotionally upset or unstable (Clancy, 2011). Cancer patients considered to be persons who are potentially vulnerable, therefore necessitating additional ethical considerations (McIlpatrick, Sullivan, & McKenna, 2006). As a researcher, during interviews I was able to provide emotional support and remind the participant that they had the right to terminate involvement in the research at any time. I was also prepared to offer referrals for professional counselling, additional information, or support; none of the participants asked for such material.

As a practicing nurse, there was also a risk that participants would assume a role as patient or have unrealistic or confused expectations of a nurse-as-researcher role (McConnell-Henry, James, Chapman, & Francis, 2009). Since I work as a registered nurse clinician for the inpatient unit of the Leukemia/Bone Marrow Transplant program of BC, it happened that I knew the names of several participants and had been working at the time they were being cared for in the BMT program. Aluwihare-Samaranayake (2012) discusses possible ethical issues for both the researcher and participant that can arise from the researcher-as-clinician role. In this case, reflectiveness and critical consciousness are strategies promoted to maintain a transparent and ethically-responsible research process.

Steinke (2004), a clinical nurse specialist (CNS) researcher, emphasizes potential ethical dilemmas developing from confusion over the researcher's role when in the clinical environment. She recommends that "the nurse must clearly delineate their role as care provider versus their role in the research study" (p. 90). During layer 4 data collection with patients, none of the participants were actively receiving care on the unit where I worked. Since that time, two patients that participated in this research were admitted to my unit (between April 2017 and January 2018). Due to the nature of blood cancers, I anticipate seeing several of the patient participants in the future. While it is never possible for me to entirely avoid participants while on duty, there are strategies that I adopted to promote confidentiality and respect of the researcher-participant relationship. A primary measure has been to request from the leadership team that I not be assigned to the direct care of these patients, and as such, will not be assigned to the primary or associate care nursing teams. Further, the researcher (myself) must be careful to avoid therapeutic misconceptions which can arise from the assumption that participation in the research study, and subsequent familiarity with the researcher, will garner special privileges or care (Steinke, 2004). Due to the unique nature of nursing, the risk of meeting a research participant in the clinical environment remains real and can be ethically managed with thoughtful preparation.

Exiting Ethics

Exiting ethics encompass with how researchers leave the research process and work to disseminate their findings. Consideration has been made throughout this study to uphold participant integrity and to represent stories as accurately and respectfully as possible. This is particularly critical due to the highly personal and sensitive nature of identity, as well as the potentially stigmatizing diagnosis of haematological cancer. Utmost care has been taken to faithfully represent the essence of meanings and knowledge conveyed by the participant during the research process, with vigilant attention given to total anonymity and honest representation in both academic and lay circles.

Possible Limitations of this Research

Since this section occurs at the commencement of the study, I outline here some potential limitations considered before undertaking the research. I recognize that my

expertise as an oncology nurse working as a clinician is both a strength and limitation to this research project (Fouka & Mantzorou, 2011; Higgins et al., 2010). A strong background in the clinical environment has provided an intimate relationship with patients that may, or may not, develop in the similar way during a research interview outside of this same environment. Since this research proposal topic is chiefly based on my extensive interaction with patients in clinical settings ranging from home care to outpatient clinics to acute and critical care inpatient units, there is some concern that my role as bedside nurse grants me certain privileges into the embodied patient-self that would not be as easily achieved in the researcher/participant relationship. My decision to proceed with a tiered study analyzing secondary data *before* delving into primary data collection is part of an attempt to compensate for this potential shortcoming.

Both the literature review and study structure reflect an adult-specific orientation, and based on methodology, this subject lens may be honed further through modifiers such as gender. For example, Marshall (1999) noted that the lived experience of a woman will be distinctly feminine, but does she always experience her body as feminine or female? Oliffe (2006) has asked similar questions about men's embodiment experience of prostate cancer. Further questions could arise during the research process over issues such as language, culture, geographic locations, and potentially, access to health care. Ultimately, the distinction between solid tumour cancers and haematological malignancies might foster, or hinder, research inquiry by presupposing differences where they either may or may not exist. By separating out cancer subgroups as the core concern for inquiry, certain presuppositions and assumptions are made which may require additional consideration to ensure this distinction is valid. Further discussion on study limitations and strengths is offered in chapter 10.

Summary

This study has been purposefully arranged as a layered qualitative inquiry composed of five separate and consecutive levels of data collection and analysis aimed at providing a broad vision of the phenomenon of identity within the haematology cancer patient experience. In this chapter, I have discussed the methodological groundings and rationale for each layer of inquiry, as well as having outlined general details of the way research was

undertaken. This chapter contained a discussion around strengths and limitations of this study, rigor and validity concerns, and concluded with some important reflections on ethical issues. The following chapter (chapter 4) presents the first layer of inquiry, namely a critical integrative literature review, thus commencing Phase One secondary research.

Chapter 4: Critical Integrative Research Literature Review (Phase One: Layer One)

Introduction

A critical integrative literature review is a method used to summarize theoretical or research literature in a way that can provide a more complete understanding of a particular phenomenon (Broome, 1993). Within nursing, an integrative review can build on and expand nursing science by informing both research and practice (Whittemore & Knafl, 2005). For this dissertation, a critical integrative literature review (secondary research layer one) serves as an essential component for theoretical exploration and foundation building meant to inform the additional layers of research and guide my interviews with patients and clinicians. As an element of this layered qualitative exploration, the critical integrative literature review is meant to make sense, organize, synthesize, and analyze extant theoretical literature on the phenomenon of self-identity within the context of a haematological cancer patient in a way that offers a fresh perspective (per Torraco, 2005). Within the context of this dissertation, my goal is to synthesize a coherent conceptualization of the nature of knowledge in the field of identity studies as it specifically relates to cancer and communication over the last 25 years.

The Review

Purpose

Methodological standardization for undertaking an integrative review is emergent and an increasing number of scholarly articles have sought to create coherent models to provide sound foundation around the concept of integration (Murray & McCrone, 2014; Smith, Profetto-McGrath, & Cummings, 2009; Whittemore & Knafl, 2005). The integrative review for this dissertation was strongly deductive in that it was initiated by casting a wide net to allow reflection on all the ways in which the phenomenon of identity and its associated concepts (like embodiment, body image, personification) have been considered within a cancer context. Narrowing the literature from a huge number of articles down to a more specific sampling reflects a focus on specific aspects of the identity essence that relate and align more closely with the research questions for this dissertation. To guide this integrative literature review, I consulted the literature on both recommend process and quality examples. Russell (2005) and Whittemore and Knafl (2005) are two sources regularly cited as

exemplars. These authors propose five procedural steps that should constitute a formal integrative literature review, and I followed their lead in this study. These steps included:

- 1) problem formulation
- 2) literature search (data collection)
- 3) data evaluation
- 4) data analysis
- 5) interpretation and presentation

With reference to the problem formulation stage, theoretical and empirical research in the past 25 years around identity and cancer is complex and rich, ripe with seemingly unrelated variables, themes, issues, and populations. The purpose of a critical integrative literature review is being descriptive and thoughtful about existing research in a way that integrates knowledge about a phenomenon into a coherent story meant to inform a specific research question. Within this dissertation, the results of a critical integrative literature review provided an important knowledge base that was meaningful by highlighting knowledge gaps and providing legitimacy for exploring identity issues within the cancer context. The question driving the critical integrative review was: how has academic research referenced identity in relation to cancer (general) and haematological cancers over the past 25 years?

Definitions

For this chapter, a literature review will be defined as a thoughtful synthesis of past knowledge on a topic that identifies important knowledge gaps and biases while suggesting future research directions (Rowe, 2014). The critical integrative review served as the overarching design allowing reflective appraisal of the literature as well as categorical analysis of identified empirical research. Reflecting on the blurred lines between a myriad of literature reviews, Grant and Booth defined a critical review simply as one which “aims to demonstrate that the writer has extensively researched the literature and critically evaluated its quality” (2009, p. 93). Russell (2005) described integrative reviews as the process of systematically analyzing and summarizing the research literature in a way that is both detailed and thoughtful to identify gaps in current literature as well as build bridges between

related disciplines and areas of work. Stevens (2001) noted that the integrative literature review is one of the only means to develop evidence summaries appropriate to answer focused clinical questions. Examples of reviews that provided structural and procedural guidance for the review process included Kaiser (2008) and Adams et al. (2011), but during data collection and analysis it became apparent that the nature of identity as a phenomenon required flexibility regarding explicit review protocol around the selection and treatment of relevant literature.

Rationale

An integrative literature review of an existential concept is particularly helpful in revealing omissions or deficiencies in the existing literature that can drive thoughtfulness and reflection around (re)framing research on a phenomenon (Torraco, 2005). Within this dissertation, coalescing research from different fields in a way that made sense to nursing practice was done within the rich context of a thoroughly-examined and analyzed strategy allowing for interdisciplinary, multi-methodological synthesis. A flexible approach allowed for broad and critically reflective grounding of a vast body of literature in a way that sufficiently enhanced the foundation of both additional secondary research and later primary research undertaken on the phenomenon of identity. Simply searching an academic database for the terms “embodiment,” “identity,” and “cancer” will yield many diverse articles. Most scholarly articles written on embodiment and identity in the context of cancer focus exclusively on specific diagnostic groups, such as breast and prostate cancer, and apply disciplinary lenses of psychology, ethics, philosophy, anthropology, and nursing (for example, Bergoffen & Weiss, 2012; Oliffe, 2006; Salamonsen, Kruse, & Eriksen, 2012).

The issue of self-identity within the context of cancer and communication is complex and multifaceted with diverse concepts, languaging, and disciplines. Each type of literature review (including integrative reviews, systematic reviews, meta-analyses, and qualitative reviews) would provide a different perspective through which to examine the phenomenon in question within the extant theoretical or empirical literature (Pai et al., 2004). These forms and styles of literature review and systematic review are changing rapidly, creating tensions between camps seeking to formalize technical structure. Formal systematic reviews are often built around exclusion criteria, with an alternative being reviews that seek to be inclusive and

reflective about the greater body of work available. This literature review, while following many of the prescriptive processes supported by an integrative approach, represents the later and may be considered a non-protocol driven review (Sandelowski, 2007). I sought to be systematic in the way I was undertaking the review, generally following the recommended steps outlined by Whitemore and Knafl (2005), but this was not intended as a systematic review in the formal sense.

To situate this dissertation within a larger body of research, an inclusive critical integrative review of the published academic research literature seemed appropriate for several reasons. First, integrative method allows for the combination of distinct methodologies including descriptive and interventional research, or experimental and non-experimental (Whitemore & Knafl, 2005). An integrative review thus allows qualitative and quantitative studies equal grounding when considering their reported results and conclusions. Second, inclusiveness of methodological diversity allows for a literature review that can more confidently inform evidence-based practice within nursing. The process of critically reviewing several similar research articles allows for reflective and comparative analysis. The term “integration” in this sense allows for arising data from reviewed articles to be systematically organized around holistic themes and meaning-making. Regarding clinical practice, reflections and recommendations are simultaneously available for reference and as a foundational aspect of developing a research project. Finally, the methodological process of performing an integrative review supports specific steps and strategies that can enhance rigour in terms of project data analysis, synthesis, and research conclusions. Regarding complex and existential projects such as identity, self-concept, or meaning making, the integrative review allows for essentially unrelated topics and articles to be culled and examined as an integrated whole, yielding (in some cases) the development of relevant and useful interpretive models (Park, 2010).

Search Methods

A systematic review aims for both an exhaustive and comprehensive literature search which requires careful pre-planning and pre-structuring (Grant & Booth, 2009). While this review was not systematic in a formal sense, I did undertake considerable pre-planning. Attempting to adhere to recommended guidelines for conducting a credible integrative

literature review, the first step in this process was to consider what was known and unknown about identity within a cancer context. A large body of knowledge and understanding around self-identity exists in disciplines such as sociology, psychology, and anthropology. Incorporating self-identity concerns of a patient within the context of nursing practice became a focus for the discipline in the late 1990s, perhaps lending itself to the increasing emphasis on psycho-social interventions and similar existential concepts such as spirituality, religion, emotion, lifeworld (per Benner), lived experience, and hope. A broad understanding of the quality, nature of research and theoretical leanings is critical to building knowledge that can potentially prove useful for nursing practice. Due to the volume of resources available on identity, related concepts and terms were explored. Although the focus remained on identity for haematology oncology patients within a very specific context, the research literature captured identity studies for similar groups such as solid organ transplant patients and those with chronic diseases. Concepts related to identity such as body image, embodiment, and personification were also examined within the literature search as collateral data informing the original research question, but these materials were not considered relevant unless they specifically referenced identity.

The hierarchical process described in integrative review methodology has provided direction for narrowing the search significantly, allowing only key research articles most related to my own research interests to be analyzed critically and thoughtfully. It should be noted that there is extensive non-pedagogic writing on identity within the context of cancer and disease. This can include internet-based sources (such as websites, blogs, postings) as well as editorials, lay journal articles, and the like. So-called “soft” literature was referenced when appropriate within this literature review, but only in the context of adding depth or richness to an observation. This material adds to the overall personality of this research project and will be further examined in chapter 5 (Historical Inquiry). Within this model, the narrowed concepts arrived at from a formal integrative research review are re-expanded within the knowledge gained from woven reflections on additional, non-research, literature. Such a contraction/extraction/expansion model of literature review is quite novel but recommended by authors including Moreira (2007) as a strategy to both disentangle and qualify data. The hermeneutic framework presented by Boell and Cecez-Kecmanovic (2014) for a literature review informed much of the process of inquiry. Namely, these authors

detailed how a systematic review encompasses careful moderation of two entwining processes: search and acquisition, and analysis and interpretation. The goal of the researcher, then, was to read as much as possible and develop a rich understanding of the literature to strengthen credibility for a comprehensive and insightful literature review (p. 273). Thus, a sense of the review processes and their relationship was helpful in analysing articles and pulling out their meaning and importance around the study questions.

An extensive search of the literature was undertaken with electronic databases and book/textbook indexes and citation lists. The primary key term was “identity.” This key term was combined with other terms and phrases: cancer, oncology, self-identity, embodiment, illness, disease, chronic, leukemia, haematological (hematological), meaning, meaning-making, self-concept, personification, and communication. The terms “nurses,” “nursing,” and “healthcare provider” were used to capture additional literature more specific to the question driving this review. This process of keyword searching was modified down to stricter parameters based on search results. Databases included Medline, UltraMed, Ovid Medicine, Embase, CINAHL/EBSCO, Healthsource/EBSCO, Eric, ProQuest, Dynamed, Pubmed, PsycINFO, and Google Scholar. The scope of this search included peer-reviewed journal articles, textbooks, books, and articles published in professional organization journals. The process of interjecting terms in the search process was both to find additional articles (inclusionary) and later to exclude articles by honing the search results (through adding text and/or punctuation that told the search engines to find highly specific results).

Inclusion Criteria

There exist many multidisciplinary articles and books (chapters) that refer to identity with specific reference to disease and illness. To organize this material in a manageable and meaningful way, stringent screening criteria were applied with the overall goal of finding a very specific group of articles that could best inform the specific research directive of this integrative literature review. A deductive process whereby literature was purposefully excluded using specific criteria was applied and only academic research studies were included in this review. The articles were published, or translated, into English. The country of origin for the literature was considered but did not play a major role in either including or excluding a study. Due to the nature of chapter 5 being a historical inquiry, the literature

reviewed was limited to 1990-2015 (25 years) with the purpose of capturing contemporary representations of cancer patient experiences. Grey literature like conference proceedings and dissertations or masters theses were included in this search only when they correlated with the overall purpose of this research layer (layer one). Included articles had to predominantly focus on identity or components (or subconcepts) of identity including body image, personification, or embodiment in relation to cancer or other chronic or debilitating disease. Deductive processes required searching cancer as both a general and specific term with the rationale of discovering what cancers have captured the attention of researchers and therefore detecting gaps and omissions. Articles that added a component around communication in the healthcare setting and utility of identity as a healthcare marker were prioritized. One article that described identity from the caregiver perspective was included as it described both caregiver and patient identity experiences in a way that captured components of communication and cancer. All disciplines were considered in the literature review search including psychology, sociology, anthropology, medicine, and nursing. This inclusive approach was a means to explore a vast spectrum of knowledge around identity, focusing down to the chronic disease and cancer context.

Procedure

Initial database searches using general keywords yielded in several thousand results. Acknowledging that these keywords could be found in titles, descriptions, abstracts, and reference lists, it became practically necessary to tighten the exclusion criteria as well as significantly restricting search parameters. Further carving away at keyword searches by adding in tighter controls and qualifying parameters allowed an initial list of potentially interesting and applicable articles to develop. Reference lists were also manually searched to identify additional relevant articles. Each potential article was screened according to its compliance with the purposeful inclusion criteria. This process involved a hierarchical procedure whereby articles were screened based on their title and abstract. The full manuscript was examined prior to determining final inclusion. Articles that did not comply with defined criteria were discarded at each stage of the search process.

Search Outcome

In total, an in-depth literature search yielded 54 papers of which 29 were deemed appropriate to include because of a close relationship with the overarching research question for this review. For each of the 54 articles, a thorough reading was done to ensure that it fit the inclusion criteria. Further honing of this initial batch was done to ensure that only the most highly qualified and appropriate research papers were included in the final data collection and analysis ($n=28$ plus one review). There was one integrative literature review included on existential concerns among cancer patients, with the focus being on self-identity as the critical element for examination and by which to measure existential questions (Hench & Danielson, 2008). Per integrative review recommendations, data was extracted into a comprehensive chart outlining the major theoretical concerns and key findings for each article (see Appendix F in table format).

For the sake of data analysis, research papers were then grouped according to their study design: qualitative ($n=21$), mixed ($n=2$) and quantitative ($n=5$) studies. Most of the studies dealt with cancer ($n=24$), although four studies ($n=4$) were included because of their high-quality exploration of theoretical and empirical issues around identity. These studies explored the devastating impact disease (fibromyalgia, lupus, chronic fatigue, and chronic pain) can have on identity. The articles in this integrative review feature descriptive studies, many containing explorations and pieces of developing theoretical components (Murray & McCrone, 2014).

Synthesis

The findings of 29 papers were extracted, grouped according to research type (integrative review, qualitative, quantitative, mixed methods) and summarized in a narrative matter around five themes. Care was taken with direct comparison or meta-analysis of findings due to differing definitions of identity. Critical appraisal of the studies was not systematic but rather reflective of the logical need to determine the strength and quality of each research study to construct comparable parameters.

Results

The volume of articles available seemed to legitimize the importance of studying identity within the cancer context. However, several concerns and glaring omissions

included: leukemia and haematology oncology patients (as part of representative samples), nursing (as a discipline), and applied practice (in this case, communication with the healthcare team). The literature search provided a general picture of what research into identity and cancer currently looks like from a multidisciplinary perspective. This meta-level analysis provided a strong foundation for reflection on the multifactoral ways in which identity is considered, studied, and manifested within the cancer context through lenses of different disciplinary paradigms.

Six descriptive themes emerged from a review of the literature. These included: a diverse definition of identity, predetermined identity labels with a focus on survivorship, the temporal nature of identity, identity reconstruction, physiology as identity, and generalized *cancer*. Each of these themes is discussed below.

Diverse Definitions of Identity

The 29 articles highlighted in this literature review failed to achieve consensus on *identity*. For example, less than half ($n=12$) of the articles provided a working definition of identity even though it was a phenomenon being studied. Components of identity were present but there seemed a hesitancy to define identity; rather, identity was characterized within most research studies by labels or indicators or relationships between existential concerns and other equally ambiguous concepts. This (purposeful?) ambiguity was confirmed by the integrative literature review by Henoeh and Danielson (2009) whereby identity is described in the 109 articles they reviewed as a relationship of existential qualities like meaning making, faith, beliefs, love, belonging, forgiveness, purpose, hope, harmony, and others. Within the articles that did not specifically define identity, synonyms such as self-concept, meaning, or selfhood were consistently substituted. Interestingly, a few research studies concluded that identity was personality (Clarke, McCorry, & Dempster, 2011; Persson & Hallberg, 2004). Kreiger et al. (2015) differentiated between identity and self by noting that the self was born of self-reflection, while identity was a socially-constructed categorization tool used to group people and provide a public image. Therefore, the notion of self-identity was a misnomer in which the private self was combined with the public self, the outcome being communication which was, in turn, synonymous with identity (see the Communication Theory of Identity by Owens, 2006).

As evident in the above thematic discussions the very definition of *identity* is both wandering and diverse, both subjective (personal/conceptual) and objective (social/theoretical/empirical), and seemingly difficult to define while being simultaneously obvious. For this reason, comparing research studies on identity seems simple on the surface because of the naturally presumed universal definition being something like “the condition of being oneself, or itself, and not another” (“identity,” n.d.). Thus a label of identity (for example, survivor or victim) is an expression of this uniqueness of the oneself, but it is a social label pertaining to expected roles, behaviours, and lifestyles. Within the research literature there are other components of identity related to social roles, but which are more demographic (personal) in nature. This includes gender, reproductive roles (i.e. mother, father), and lifestyle choices (i.e. smoker, jogger), for example. Therefore, identity is both straightforward and awkwardly complicated.

The vision of diversity captured by the thematic title reflects my impression from the research literature that a specific definition of identity is impossible and possible at the same time. Much in the way that electrons change when they are observed in the double-slit experiment of quantum mechanics, identity is a concept that exists but changes when we observe it because of the need of researchers to label the phenomenon.¹²

What can be gleaned from the whole represented in this literature review is best stated by Claek, McCorry, and Dempster (2011) who thought identity was the essential concern of the individual about differentiating from others. Skott (2002) furthered this by noting that identity comes from interactions with the physical environment and with other people from within a culture. These exchanges form perceptions of external reality and internal self which is basically a perception of the world. Therefore, identity is both personal choice (a label someone puts on themselves) as well as a socially mandated concept. Fife (1994) captured this succinctly in a study of 38 cancer patients by noting that the self living with cancer performs ongoing evaluation of the social environment and the role that should (and can) be assumed. Likewise, the social world responds to the self when a new dimension (cancer) is added to the personal identity, creating the social identity a “cancer patient” (p. 315). The application of identity labels can switch through time, place, status (illness/health), gender

¹² Trying to singularize a definition of identity may also be as complicated as asking nurses to define their epistemology. Nursing (as a profession) has a sense of what nursing knowledge is, yet scholars have been unable to define what that actually is in a way that is meaningful (Thorne, Stephens, & Truant, 2016).

(man/woman), and other variables. Ultimately, most of the articles under review reflect the process of identity as a co-construction that is only partially the conscious choice of the individual who must capture multiple identities into a self (or new self) at any given moment. For some researchers this is described as “biographical work” (Mathieson & Stam, 1995) or “craftwork” (Kaiser, 2008) or “biographical disruption” (per Bury, 1982; Hubbard, Kidd, and Kearney, 2010) whereby an individual is continually rewriting their own autobiography.¹³ Biography is a component of identity, but not identity itself. In many cases the relationship between self, identity and other components such as personality remain conflated.

Predetermined Identity Labels: Focus on Survivorship

A common aspect of both qualitative and quantitative studies is that the researcher must build from preexisting framework or variables to collect survey data about the phenomenon of interest. There must exist some way to talk about something in order to ask questions about it and subsequently collect data. Within the quantitative studies and mixed methods studies ($n=5+2$) examined in this literature review, consistent identity labels were used to gather data.¹⁴ Various surveys were constructed, or utilized, because their questions pointed to variables that were applicable to specific identity labels. The labels consistently employed by researchers seemed to reflect socially-accepted models for behaviour around the phenomenon of identity and cancer. These labels also suggested survey framework was specifically determined in a way that would reflect and support these predetermined labels. Several authors have pointed out that post-cancer identities have been predominantly guided by the discrete set of identities offered by the survivorship model (Bellizzi & Blank, 2007; Chambers et al., 2012).¹⁵ The literature surveyed may confirm this statement. Throughout the

¹³ The use of a singular “their” is becoming more popular in modern writing as a more specific way to discuss an individual’s perspective. Reference sources include: https://en.wikipedia.org/wiki/Singular_they and <http://www.americandialect.org/2015-word-of-the-year-is-singular-they>

¹⁴ I am using the terminology “labels” here as an umbrella term to talk about social self-descriptions. These self-descriptions are often comprised of role-identities and include social roles (father, mother, nurse), social attributes (Catholic, male), stigmatizing characteristics (alcoholic, cancer patient), socio-biographical categories (retired teacher, ex-wife), and social types (playboy, intellectual, bird lover) (per Thoits, 1991).

¹⁵ Survivorship in the cancer context defies consistent definition (Chapman & Wiernikowski, 2011). According to the National Cancer Coalition for Cancer Survivorship (n.d.), survivorship begins at the moment of diagnosis and continues throughout a lifetime. The U.S. Center for Disease Control and Prevention (CDC, 2015) defines survivorship as starting at the time of diagnosis and extending throughout a person’s lifetime and includes both the patient and their support network. The Canadian Association of Nurses in Oncology (2011) defines survivorship as commencing when a cancer treatment has been completed.

literature review, identical references to six identity models existed despite differences in social context, methodological framework, disciplinary focus, or the researcher's background. These six recurring social identity models and associated labels were: patient, person who has had cancer, victim, survivor, member of the cancer community, and conqueror. It should be noted that these labels occur frequently in the cancer/identity literature (lay and academic) and seem indiscriminate of cancer type, age of participant, gender, or other socio-demographic considerations.

Predetermined labels present in popular psycho-oncology surveys (COPE, FACIT, Psychological Well-Being subscales, for example) were presumably employed in quantitative and mixed methods studies to serve an end-goal – to accept or reject preordained identity labels. Park, Zlateva, and Blank (2009) provided an excellent example of this in their study on self-identities after cancer. In this study they employed numerous quantitative measures to determine the degree to which participants aligned, or misaligned, with predetermined labels. Positioning *patient* as a “neutral identity,” their results supported that *victim* was associated with poor adjustment to post-cancer changes and a depressed psychological well-being. Interestingly, it is easy to extrapolate that the patient (i.e. someone who is ill) is the neutral, and therefore being ill is neutral, or central point (0). The positive becomes past (health) and the negative becomes future (unknown). In developing a similar study, Zlateva, Park, and Blank (2009) revealed the methodological decision of utilizing a survey with four predetermined identity labels and asking participants to use a Likert scale to rate how much they did, or did not, relate to the specific identity. What these researchers concluded from the data was that multiple identities can be used simultaneously and for differing reasons ranging from physiological functioning to coping strategies.

Of the 21 qualitative studies in this literature review, most adopted some configuration of these same six identity labels in their data analysis and discussion. Routinely the labels “survivor,” “patient,” and others occurred as both self-descriptions and research themes. These labels, similar or identical to those found in the quantitative literature, embrace the contemporary survivorship model prevalent in research and cancer care (Chapman & Wiernikowski, 2011; Vachon, 2001). In fact, most of the literature around identity embrace *survivor* as the driving concept (Park, 2010). Considering the ongoing disagreement over how survivor should be defined, this predominance highlights the

temporal nature of identity studies while simultaneously demonstrating ambiguity around who should be considered a survivor, and who retains the power of label assignment (i.e. self-identified or researcher-identified or health care system identified).

Temporal Nature of Identity

One of the strongest themes throughout this literature review embraced the passage of time. Identity routinely was based on time and references to past, present, and future. Asbring (2001) clarifies this by asserting that time is a spectrum on which the disease identity is projected, and therefore identity shifts along the spectrum depending on where people are in the trajectory of disease. Asbring called this “biographical disruption.” Mesquita, Moreira, and Maliski (2011) state that cancer identity is a function of the stage of treatment: life before, life during, and life after. The self-acceptance of identity labels (survivor, etc.) is based on the specific time the person is asked what label they are (or were) taking-on. This merges well with the implication of authors like Vachon (2001) that identity arises from the time within the cancer trajectory that a patient realizes that they are a survivor. Hubbard, Kidd, and Kearney (2010) suggested that a cancer diagnosis was related to both the timing of illness (associated with grief or loss, for example) as well as the stage of life for the individual (i.e. teenager, adult, geriatric). These authors, along with Cho and Park (2015), assert that older people experience cancer very differently than younger folks, implicating age as a critical variable within identity studies.

Another temporal dimension noted in the research reviewed was that of rebirth. Several studies described how participants viewed cancer as a transition, a challenge to identity as well as a death of the old self (for example, Clarke, McCorry, & Dempster, 2011). The re-birth of the self through new identity-taking was a major transitional aspect of the cancer trajectory, and again follows the passage of time flowing from a starting point (diagnosis). Bellizzi and Blank (2007) stated that the cancer experience formed the most significant part of a person’s life, more important than perhaps other personal events like marriage or the birth of a child because it cut so deeply to the core of the self by threatening mortality.¹⁶ The projected and assumed post-cancer identity (present and future) is continually shaped and defined by the cancer experience (past). Zletava, Park, and Blank

¹⁶ Chapter 5 discusses how fear of cancer is deeply entrenched in the historical record.

(2009) touched on this aspect by noting that their research indicated identity as “patient” is most closely aligned with treatment, namely that those closest to treatment see themselves as “patients” but that this label fades as treatment becomes a thing of the past.

Identity Reconstruction

Each of the articles included in this literature review referenced, directly or indirectly, the transformative effects of a cancer or chronic illness diagnosis as identity reconstruction, identity-altering, role erosion, or identity loss. Namely, in order to be socially viewed as a survivor, one must undergo an identity reconstruction. In many cases, the success of the transformation can be associated with the identity label that is assumed. For example, Park, Zlevata, and Blank (2009) stated that persons who seemed to adjust well to cancer labelled themselves as “survivor,” while those who reported low well-being self-identified as “victim.” In her integrative review of the literature on meaning making, Park (2010) discusses how articles on meaning-making within a cancer context seem to imply an immediate and ongoing identity reconstruction. Gillies and Neymeyer (2006) defined identity reconstruction as a shift in personal biographical narrative because of a stressful experience. Successful cancer survivorship occurs in the literature when the cancer experience is integrated into self-concept in a way that the individual (“survivor”) constantly appraises the cancer threat and potential for reappearance during their lifetime (Zebrack, 2000).

Physiology as Identity

There was a tendency in a handful of qualitative studies, because of the overriding methodological focus on narrative and metaphor, to recognize important issues around the corporeal body (for example, body image, embodiment, engulfment) and the relationship that cancer has with the body and identity formation. For Waskul and van der Riet (2002), identity is the fluid interaction between the process of being that was both the person (i.e. self) and the physical body. Identity is the process of self-identifying what is self and what is not self. For Waskul and van der Riet, cancer is an alien intruder or “it.” For Charmaz (1995), illness is objectification of the body so that changes in physical appearance bring

about changes to identity. The body's appearance, therefore, triggers social response which triggers personal identity formation and perseverance.¹⁷

It is within similar studies that personification and anthropomorphizing developed as viable concepts within which to discuss identity. Skott (2002) pointed out that cancer is often spoken about as either a military exercise or as food (i.e. eating), both actions of personhood and of bodies.¹⁸ Shahar and Lerman (2013) proposed the term "illness personification" to describe how people live with, under, and outside chronic illness. As humans tend to frame experiences with an "us versus them" stance, these researchers assert that patients will assign illness a human role and then position their identity in relation to this (i.e. attacker versus victim). Engulfment by Beanlands and colleagues (2003) comes to define the merging of self-concept and illness for haematological cancer patients receiving bone marrow or hematopoietic stem cell (HST) transplantation. Extrapolation further implies the body is engulfed along with self and self-concept into a new (physical) body with a new self-identity.

Generalized "Cancer"

Within the discipline (or specialty) of oncology, solid tumour and haematological cancers are differentiated from each other (Chizuza et al., 2006; Hui et al., 2015) (see chapter 1). This is certainly true in terms of how health care is structured, with separate units or beds for haematological cancer patients, and in how treatment is allocated within the cancer care trajectory. Additionally, as pointed out by Hui and colleagues (2015), end-of-life care and palliative options are often different for haematological patients who face a unique and challenging disease trajectory. Within the literature examined and specific to the context of identity, haematological and solid tumour patients were generally lumped under the term 'cancer.' Out of the 29 articles examined, 13 articles discussed "general" cancer with haematological cancer patients (usually suffering from lymphoma) grouped alongside solid tumour patients in the research participant sampling. Haematological cancer patients constituted only a small proportion of the overall sample size. Of the remaining articles featuring a research sample containing cancer patients, only two articles dealt *specifically*

¹⁷ One has but to recall the phantom in "Phantom of the Opera," or the beast in "Beauty and the Beast" or Frankenstein or Quasimodo to understand the social and cultural implications of the physiological appearance on one's personal identity.

¹⁸ The background to these concepts will be explored from a historical standpoint in Chapter 5.

with haematological cancers (Beanlands, Lipton, Schimmer, Elliott, Messner, & Devins, 2003; Persson & Halberg, 2004). The remaining articles examined identity in relation as a component specific to breast cancer ($n=3$), brain cancer ($n=1$), prostate cancer ($n=3$), colorectal cancer ($n=1$), pancreatic cancer ($n=1$), and esophageal cancer ($n=1$).

Including haematological (mostly leukemia and lymphoma) patients with solid tumour patients in creating a homogenous disease called *cancer* is a characteristic of the literature. In terms of how identity should be examined then, the overarching assumption of the literature (almost 50% in this study) was that identity changes within the context of cancer were the same. Identity, then, is based on overarching disease (cancer) versus type of disease (breast cancer or leukemia, for example). Perhaps when developing sampling strategies, researchers imagined that ‘cancer is cancer is cancer’ and therefore considered the inclusion of both subtypes of cancer into one amalgamation sound sampling practice, strengthening validity and rigour concerns by diversifying the sampling spectrum. It is unclear when reading the literature if this grouping of haematological cancers and solid tumour cancers was ever considered important or influential. What was clear from this literature review was that cancer can be considered (consciously or unconsciously) bifurcated: a singularity (*cancer*) and a dichotomy (solid tumour and haematological). Depending on how the research study was developed, cancer as “it” fails to differentiate between type of cancer and for many researchers (such as Waskul & van de Riet, 2002) this distinction might not make a difference in the self-identity as all diseases (all cancers, in this case) are universal in their assault on the corporeal body.

Discussion

Within this literature review the predominant methodology utilized in the qualitative studies was grounded theory, and subsequently symbolic interactionist scaffolding was common. Most qualitative studies included some form of narrative analysis, although specific reference to formal narrative inquiry (as a qualitative method) was largely absent. Phenomenological studies were relatively rare except in the case of nursing research, despite their connection to exploring the lived experience of a specific phenomenon (in this case, identity). The two mixed methods studies utilized the rich descriptive narrative to be found in qualitative work with the quantitative data provided by questionnaires still struggled with

elements such as defining identity and making study results clinically applicable. Identity and identity transform are certainly some of the most important outcomes of a cancer diagnosis. Questions around identity alter a person completely. Who am I *now*? was a question that evolved inevitably within the narratives recounted in reviewed articles. Accepting the practice recommendations of the researchers who made clinical suggestions, identity was a fundamental component to personal well-being and effective communication with the health care team.

Identity is intertwined with a variety of metaconcepts including sexuality, life experience, biographical disruption, body image, gender, age, and the like. Undertaking the literature review search revealed a multitude of possible search terms that eventually yielded knowledge about identity, and yet, many of these were not at first obvious. Terms like embodiment, meaning, spirituality, personification, quality of life, and self-concept are not identity directly, but generate information about identity and identity concerns. Identity can perhaps best be described as a person's self-description within a specific context (Mathieson & Stam, 1995). The context of this dissertation is nursing, haematology oncology, and adult *persons with cancer*. Therein lies one of the critical components of examining identity as a component (and in the context) of illness. While many of the articles included in the literature review moderately mentioned or alluded to the condition of illness, the absence of the critical identity discussion over ill versus sick (or healthy versus nonhealthy) seemed awkward. Work around trying to pinpoint a label such as “survivor” or “victim” seems overshadowed by something much more obvious, such as someone calling themselves “sick” or “ill with cancer.” Sontag (1978) launched her novel *Illness as Metaphor* with the fundamental dichotomy of the kingdom of sick and kingdom of well. It is from this basic vantage point that other identities, metaphoric or not, can be created. Skott (2002) reminds us that the preoccupation with cancer that occurs with diagnosis leaves little room for the consideration of self, eradicating self-determined identity and necessitating that the patient search social norms for identities they can easily assume (i.e. survivor, patient, person with cancer). Thoits (1991) laid the foundation for this type of thinking when writing about identity-relevant stressors. In this way, considering the physical and mental fatigue of the patient undergoing treatment, a homogenization of identity into six labels that can be chosen from may make sense. Identity for the sick patient can be described as prepackaged and

ready for choosing, and re-choosing, as time and energy and physical condition allow. Considering the six dominant identity labels recognized in this literature review, I wonder if there are other labels missing from the discussion.

Regarding the research question for this integrative review, carefully analyzing narrative in some sense is critical to capture the essence of identity in relation to cancer. The empirical literature seems to routinely accept the dichotomy of cancer patient versus cancer survivor (Hewitt & Ganz, 2006). I am convinced that while the quantitative studies provided some clear labels around identity (survivor, patient, person with cancer, conqueror, victim, survivor, member of the cancer community), additional identities or thinking about identity might be possible. Deepening thinking about identity is evident in a landmark study by Shahar and Lerman (2013) that emphasizes the human tendency to anthropomorphize experiences. These researchers developed the notion of ILL-PERF (abbreviation of “illness personification”) to describe how people will ascribe human characteristics to a stressful condition. Immediately, the violence and war-time metaphors of cancer come to mind. Cancer is the “it” by which a dichotomous relationship (us versus them) can be established.

Potential Knowledge Gaps

The overarching question driving this integrative review was, how has academic research referenced self-identity in relation to cancer (general) and haematological cancers over the past 25 years? This integrative literature review detailed how disease (specifically cancer) is referenced in the research literature specifically around issues of identity and cancer. Three things are striking about a review of the current state of knowledge and are significant within the context of the overall research project. First, work on identity within the cancer continuum has been carried out mostly by non-nurses. The disciplines of psychology, sociology, and anthropology (to name a few) dominate the cancer-identity discussion, but each discipline contains within its epistemology specific goals, motivations, and concerns for research (Thorne, Stephens, & Truant, 2016). Ironically, the profession that works closely with the corporeal body in oncology clinical practice -- nursing -- is underrepresented in the academic literature on this phenomenon. This also means that nursing-specific interventions that constitute driving components of the care trajectory are

lacking. Within this literature review, nursing studies constituted about a third of the represented disciplines ($n=10$).

Second, most work on cancer identity has been done with solid tumour patients, predominantly colorectal, prostate, and breast cancers. Inclusion of other cancer types such as lymphoma was relatively rare and was within the context of a broad research sample of mixed cancer subtypes. Hematological cancer patients were scarce within current research literature when it came to the phenomenon of identity, particularly within nursing research or when coupled with the component of how they communicate about their cancer identity. Persson and Hallberg (nursing, 2004) and Beanlands et al., (medicine, 2003) were the two research studies exclusively featuring haematology oncology patients (lymphoma and leukemia). This is very important to explore because of the work of researchers like Bellizzi and Blank (2007) whose research on identity within the cancer context revealed that different types of cancer resulted in different types of identity-making. Their example is a comparison of esophageal cancer and prostate cancer patients where they noticed that post-cancer prostate patients will generally not include their cancer as part of their life story. If this is the case, and if even solid tumour patients will report their identity experiences in different ways and with different inclusion/exclusion criteria, it suggests that a study of identity for the haematological patient as an independent cancer subtype may produce knowledge that is (so far) concealed in the current research literature.

Third, because most of the work done on cancer patients is by non-nursing researchers, there exists a nuance of cancer diagnosis and surrounding environment that is (unintentionally) missed. For example, the grouping of all cancer patients under one umbrella “cancer” misses subtle opportunities to finely drill into specific conditions. The general researcher interested in things such as chronic illness, for example, may not be interested in these gentle differences between oncology patients. However, for a professional oncology nurse interested in practice-specific interventions, these subtleties within the patient experience are critically important to improving the care environment.

Fourth, regarding the temporality of identity, methodological choices for research should consider if timing of interview/s is essential to gathering meaningful data. Within this literature cohort, there is a healthy mix of cross-sectional versus longitudinal study designs. Cho and Park (2015), Hubbard, Kidd, and Kearney (2010), Persson and Hallberg (2004) and

Park, Zlateva, and Blank (2009) specifically structured their studies to incorporate multiple time points (for example, a time 1/getting ill, time 2/treatment, and time 3/survivorship). These researchers placed emphasis on the entwined relationship between identity and time after diagnosis. Yet, these authors did not discuss comparisons between identity over the two (or three) time periods, implying that identity can be monotone and relatively stable. Accepting that identity has a relationship with time, does the study have to be longitudinal to make sense? Does the participant sampling have to be at the same place with regards to time to foster validity and rigour?

Fifth, this literature review revealed an inherent irony to identity studies. Through both quantitative and qualitative research methods there was a flattening of individual stories into a singular mass of larger sociocultural labels. Identity is about the maintenance of the self, the label someone places on the self (per Paek, Zlateva, & Blank, 2009), but research puts all the selves together into a whole that ultimately erases the individual self for the purpose of being able to generalize. Research is undertaken with the need for discovering patterns and prevailing trends about a phenomenon in order to describe and analyze it for the sake of guiding clinicians' best efforts. However necessary, this fact of inductive research seems contrary to the desire of patients to be "viewed and known as an individual and not just a tumour or slab of meat devoid of personality" (Clark, McCorry, & Dempster, 2011, p. 103). This may be particularly true if identity is defined as communication, as asserted by social psychologists like Owen (2003) and Kreiger (et al., 2015). The question arises, how can we describe identity for a patient who is no longer communicating because of their disease process? Within the context of hematological cancers, and particularly those who are critically ill (such as many allogeneic transplant patients with graft-versus-host disease), communication can be minimal to sparse. How do these patients then self-identify? Do they have an identity that is outside physical and psychological suffering? Does one have to speak about identity in order to have identity, or rather, what makes identity real (i.e. a real phenomenon)?

And finally, within the literature search some important cultural and social themes were generally absent or played a minor role in data collection and analysis. Identity deals with life/death, past/present/future, illness/health while shaking the basic socio-demographic foundations of the cancer patients (employed/unemployed, man/macho/woman/feminine,

mother/father). Yet, while components of temporality and sociodemographics were present in many of the research articles, existential issues of mortality and spirituality did not constitute major themes under the key search terms. Instead, existential concepts seem to be lumped under “meaning” and “meaning making,” and while they share discussion components with identity, seem to take on a slightly different nature. The relationship between meaning and identity is intriguing and troublesome in that neither has definitive boundaries, but rather merge and blend in a way that challenges research parameter-setting.

Review Limitations

As with any integrative literature review there exist limitations. Combining qualitative and quantitative analyses opens the researchers to lack of rigour, potential inaccuracy, and bias (Whittemore, 2005). To minimize these concerns, recommendations and guidelines for scholarly reviews were carefully considered and followed when appropriate (Whittemore & Knafl, 2005; Moreira, 2007; Murray & McCrone, 2014). Coinciding with an interpretive description methodological framework, strict adherence to protocol was not appropriate; rather, I employed a more fluid process of gathering articles into a collection that ultimately revealed how academics create meaning-making around identity in various contexts. This critical literature review was a subjective, disciplined engagement of the research literature. Second, the inclusion criteria were both necessarily vast and constrained, and similarly, exclusion criteria developed out of necessity to cull and further hone search results. Again, this is a positive sign that identity was important within the academic context as a useful and interesting topic for research. Articles included this review had to be very specific, and that specificity had to be obvious within the title or abstract of the article. Due to the extensive nature of the search process, the articles chosen were most appropriate to the review research question and constituted published academic research articles. Finally, the search strategy was limited to electronic sources, and therefore yielded articles from primarily digitized academic journals. Collateral searches in databases (such as Amazon.com) revealed chapters and books featuring scholarly research on identity, and this material was used as a reference point. However, this literature search was (necessarily) extensive but not exhaustive and therefore publication bias potentially exists.

Due to the sheer volume of materials found when searching the keyword “identity” research articles that were too narrowly-focused onto an oncology treatment side effect (like lymphedema from surgery for breast cancer) were excluded. Articles that were outside the timeframe (pre-1990) were excluded but set-aside for possible inclusion in chapter 5 (historical inquiry). Articles were excluded if they strayed too far from the research focus, or if they seemed unclear or of poor quality with an ill-reasoned argument. Articles were also excluded if they concerned relatives, healthcare professionals, cancer communication (specifically without reference to identity or similar concepts), or pediatric patients. As discussed there were six cancer identities (labels) currently within the literature (Cho & Park, 2015), but specific academic research into separate identities (such as “survivor”) was not included in this review. Articles on similar disease topics (such as solid organ transplant, chronic diseases) were included only when they strongly contributed to the knowledge around the literature review research question. The decision to include, or exclude, these articles was subjective and therefore open to bias. Editorials, theoretical reflections, and other academic pieces were considered only within the context of enhancing and escalating knowledge gained from the integrative review, but these items were not included in the formal review process.

Conclusion

The purpose of this critical integrative literature review focused on concepts around cancer, identity, communication, and nursing was to create a strong theoretical and empirical foundation for continued layers of qualitative research. This critical integrative review constitutes the first layer of the research focus for this dissertation.

One of the most valuable components of this review was confirmation of a study focused on haematology oncology patients. The volume of identity work in the cancer context confirms that there was interest in this relationship but clinical value in examining how identity impacts the health care environment, specifically regarding communication with the caregiving team. Identity is a multifactoral term and perhaps dual identities – cancer patient AND haematological cancer patient -- create duelling social expectations around behaviour, appearance, and other psychosocial factors. Another benefit of this review has been a deeper inspection of the term "identity." With so many components depended on

multiple disciplines and disciplinal foci, defining identity remains both clear and obfuscated, and may be highly contextual. Context, in this instance, can be circumstantial, disciplinal, professional, or just existential in a way that challenges meaning-making. Identity within many of the articles contained in the literature review was *like* lived experience, but it wasn't lived experience. It is like *lifeworlds* but not exactly because it is a part of the lifeworld rather than the lifeworld itself. A social constructivist viewpoint (on which this dissertation is based, see chapter 2) defines identity as something that an individual consciously or unconsciously constructs for/about themselves for the benefit of others within a social and bodily context (Carbaugh, 1996; Gergen, 2000). This critical integrative review has further confirmed the complexity and density of this definition. Further analysis of the background of cancer and cancer identity followed in the historical review presented in chapter 5.

Chapter 5: Historical Inquiry (Phase One: Layer Two)

Introduction

Identity is naturally historical. Identity does not exist by Immaculate Conception, dropped from the heavens into unsuspecting victims without context or origin. Rather, both in a personal and social sense, identity is constantly created and recreated by morphing layers of change steeped in time and experience with realities. Identity is not created in a singular moment but reflects the entirety of someone throughout their life(time). Therefore, identity does not magically come into being with the diagnosis of cancer, but rather, joins with other aspects of identity to create a new multi-factorial identity. Salevouris and Furay (2015) describe the intimate and irrefutable relationship between identity and history:

Not only is it impossible to escape history, it would be catastrophic to try. Imagine for a moment what life would be like if you totally lost your memory. You would, in a very real sense, have no sense of belonging - no family, no friends, no home, no memories to guide your behavior, no identity. In short, you would no longer "be" you. (p.6)

In a greater sense, history is society's collective memory. Identity is shaped through life experiences, including where someone is born, their region, culture, ethnic background, social class, and family. The study of history provides the "bearings" by which a society and an individual achieve personal(ized) identity (Salevouris & Furay, 2015).

Sandelowski (1999) stated that all qualitative research contains a temporal component. Within this dissertation, context is everything – and context is temporally based. As shown in the integrative literature review, identity is based on time (past, present, future). Identity is also socially situated. Therefore, a component of personal as well as socio-cultural identity is based on time and the historical process that resulted in identity thinking at the moment. Where we are today in terms of disease (and specifically, cancer) identity is based on the accumulation of time juxtaposed with social, cultural, ethical, political, and economical forces of the past. Relevant and thoughtful historical analysis of a phenomenon is critical for well-balanced and deep understanding that honours both context and personal

experience. As well, historical investigation elucidates the human condition in a way that fosters empathy and open-mindedness (Colby, 2008; Salevouris & Furay, 2015).

The purpose of historical inquiry as a component of a larger qualitative research project is foundational as well as informational and contextual. Polit and Beck confirm that, “nurses use historical research methods to examine a wide range of phenomena in both the recent and more distant past” (2014, p. 273). Such an inquiry consists of a probing review of primary source and secondary source materials to locate specific references to identity (or similar terms) in adult (and in some cases, pediatric) haematology patients. The integrative literature review dealt with modern academic research on identity within the context of disease (1990-present). A historical inquiry aims to establish a baseline of knowledge founded on nonfiction, fiction, and theoretical documents of the past from which further knowledge as well as analysis and investigative techniques will be drawn. In this chapter, I explore the historic record (pre-1990) as a means of deepening reflections and observations on identity within the specific context of adult haematological cancer.

Method

Historical inquiry is based on asking a specific question of the historical record (Quigley, 1979). The research question driving this chapter is: how have haematological cancers been characterized and explained in the past in reference to issues of identity?

Several subquestions immediately arose which contribute to the depth and rigour of this inquiry. How has cancer (specifically haematological cancers) and cancer identity been talked about in the past? What can be learned from this historical analysis that illuminates the current discussion around cancer identity? Due to the expansive nature of history in relation to addressing such broad concepts, this chapter will progress with an in-depth presentation of biomedical history as related to cancer. Sociocultural references and discussion form an integral part of this history, and examples of how cancer was perceived will be given. After this foundation has been established, a final section of this chapter will deal precisely with a socio-intellectual history of identity and studies of the self and personhood. The hope of texturing the data in this way is to create a deep knowledge base of the social, biological and

medical history of cancer against which the examination and development of identity over time is highlighted.

Much in the way that the integrative review precisely, and necessarily, narrowed the field of academic research literature into a manageable database, a historical inquiry of this scope requires similar restrictive criteria.¹⁹ Cancer has been in the literature since the beginning of writing, with first reference being around 400 BC when Hippocrates coined the Greek term *karkinos* ("crab") to describe the appearance of a vascular-proliferic tumour. The goal of this inquiry is, by no means, a sweeping review of every piece of cancer literature to date but rather of literature critical to answering the research question at hand. Therefore, any relevant literature or collateral data such as art, drawings, photography, sculpture, anatomy texts, and the like that pertains directly to fostering understanding about haematological cancer are included. Historical, for the sake of this chapter, is defined as pre-1990 (including the early postmodern period) and beyond (or behind, as the case may be). Relevant is defined as a piece of evidence that adds to meaning-making either through having made a contemporary impact or having a particularly important and unique stance on the topic of haematological cancers. Every effort is made to examine primary sources, but excellent secondary sources are included when appropriate. Solid tumour cancers, which of course constitute most of the documentation until the identification of haematological/blood cancers in the 1800's, are included to paint a vibrant and complete tapestry of cancer-understanding over time. As will be demonstrated by the review, the differentiation of cancer into liquid and solid in the nineteenth century offers tremendous insight into our thinking about cancer care and identity today.

Finding Haematological Cancers in the Literature

Most of the cases of historic and prehistoric cancer come from data found in bones. Paleoarchaeologists speculate that there exists about 200 suspected cases of cancers found in archaeological evidence comprising mostly of knobs (osteoblastic) or indentations (osteolytic) on bone (Johnson, 2013). Types of cancers that appear in this archaeological record include prostate cancer, breast cancer, rectal cancer, osteosarcoma, nasopharyngeal

¹⁹For this dissertation, the BC/AD designations will be used (as opposed to BCE/BE). A lack of designation refers to the AD period.

carcinoma, and other solid tumours (many resulting from metastasized primary solid tumour sites). While solid tumour cancers are found throughout history in a variety of documents, non-bulky haematological cancers (such as some lymphomas, leukemia, and multiple myeloma) can only be known about through descriptions of their clinical presentation. These cancers generally do not metastasize into solid tumours, and the masses they create (such as in Burkitt's lymphoma) are soft tissue and, except for multiple myeloma which tends to form palpable lesions on living bone, leukemia and lymphomas fail to create easily-identifiable bony impressions. In these cases, only a careful autopsy (post-mortem) reveals bony indications of blood cancer. For example, the oldest case of leukemia is reported in a 7000-year-old skeleton of a woman, aged 30-40, whose disease was identified by stealth researchers as unusual "loosening" of interior bone tissue in her sternum and upper humerus (Senckenberg, 2015).

The idea that a cancer could be in the blood (i.e., liquid) was simply unthinkable until scientific inquiry was able to establish and describe reality beyond the senses. Previous to the discovery of human cells in 1665 by Robert Hook and red blood cells in 1672 by Anton van Leeuwenhoek, the development of cancer was largely mysterious and identifying haematological cancers specifically improbable (Pillar, 2001). The father of leukemia is credited to John Bennett, who named "leucocythemia" in 1844 to describe an accumulation of purulent leucocytes visible under the microscope. Thus, the first real notion of a haematological (blood) cancer was visualized, realized, and named.

Characteristics of Haematological Cancers

To look for haematological cancers previous to 1844(ish) is an exercise in sleuthing. Like a fossil pressed into soft stone, the actual cancer does not exist in the literature and all the researcher has to go on are reflections of the real thing. A solid tumour is identifiable, either visibly protruding from the body or hidden within to be revealed through surgery (or dissection, as the case may be). It is a mass of cells intertwined with vasculature, clearly not normal or of the person. Many cancers, such as those of the breast, can become fungating as they break through the skin and descriptions of these cancers are easily found in the

literature.²⁰ It is more difficult to identify haematological cancer for the simple fact that, as a blood disease, outward signs beyond clinical presentations are impossible to diagnose. Leukemia, for example, can present with fever, swollen glands (lymph nodes), sudden and extreme weight loss, nosebleeds, bleeding from the rectum or from the gums (called spongy gums in historic literature), easy bruising, night sweats, bone pain, extreme fatigue, pallor, and occasional tenderness with swelling in the left abdomen (splenomegaly). Persons with leukemia can often be sick with a respiratory illness (cold or flu) and never recover but rather linger and eventually succumb. Acute leukemias are fatal rather quickly, usually within 48 hours to a few weeks of developing initial symptoms. Chronic leukemias are slower to develop and symptoms can easily be mistaken for other diseases even with the benefit of modern medicines. Clinically, chronic leukemia is associated with organ infiltration and enlargement of the liver (hepatomegaly), spleen (splenomegaly), and lymph nodes (lymphadenopathy).

The first physician to perform autopsies of patients who passed away with swollen lymph nodes was Thomas Hodgkin in 1832 (Hellman, 1991). Today, lymphoma is the most diagnosed haematological malignancy in the world. Lymphoma, both Hodgkin (of which there are 6 types) and non-Hodgkin (61 types identified), occurs when the lymphoid system develops neoplastic cells. Lymphoma is only slightly more identifiable in the historical literature starting about 1666, and this can be attributed to the presence of painless enlarged lymph nodes associated with fever, night sweats, unexplained weight loss, persistent itchy skin, and extreme fatigue (Ortiz-Hidalgo, 1994). The bulky tumours of Burkitt's develop in the abdomen, and occasionally throughout the body leading to a host of other signs and symptoms like constipation, abdominal tenderness, or dyspnea.

Multiple myeloma is an overgrowth of abnormal plasma cells (a type of white blood cell) within the bone marrow. These cells crowd the bone marrow and interfere with the creation of hematopoietic stem cells, causing deficiencies in all three progenitor lines (white blood cells, red blood cells, and platelets). Multiple myeloma weakens the bones and

²⁰ Anne of Austria (1601-1666), Queen of France and wife of Louis XIII, is an example of a historical figure who suffered terribly from fungating breast cancer (Androustos, 2005). Detailed notes and memories were kept of the disease diagnosis and progression by Madame de Motteville (1902), a close friend to the queen and courtesan. These are some of the first extant writings about cancer as a personal disease from a subjective perspective.

especially the pelvis, vertebrae, sternum, and ribs, causing micro and macro fractures, softened bones, and deformities. As can be imagined, multiple myeloma is extremely painful and can cause renal failure due to hypercalcemia from excessive osteoclasts.²¹ While multiple myeloma is a haematological disease, the primary source of action is within the bone marrow, and many consider it a boney disease for this reason. The first description in the written literature of multiple myeloma (called ‘mollities osteum’) was by Samuel Solly in 1844, but accounts of osteolytic lesions on bone have been found in the archaeological record in Egypt back to 3200 BC (Kyle & Steensma, 2011).

In each of these diseases, the historic inquiry into haematological cancer begins with broad strokes, narrowing quickly and only after enormous technological advancements in the past 150 years. Understanding must come from pondering the historic presence of “cancer” as it was grasped and explained by contemporaries, tracing how that knowledge came to shape what is known today as *haematological cancer*. This is a critical point, *because identity for the haematological cancer patient correlate to the socially-identified disease* (per social constructionism) (Conrad & Barker, 2010). Without a name, culture (society) could not create the construct whereby to understand the disease. That is not to say that cancer, and predominantly solid tumours, have lacked personal identity considerations for indeed this is certainly not the case. The following historical inquiry examines the cancer temperament (associated with melancholy) and the arising ‘cancer personality,’ but it is not possible to attribute this specifically to anything other than cancer-proper. It is more appropriate to say that before the name “cancer” was applied to a cluster of symptoms we now associate with haematological malignancies, the association with cancer by the patient (including all that ‘cancer’ encompassed) was impossible.

An Early History of Cancer

The first identified cancers, as alluded to above, were solid tumours, both malignant and nonmalignant. A breast cancer sustains the honor of being the first recorded case in history, identified by Egyptians around 1600 BC in the Edwin Smith Surgical Papyrus

²¹Hypercalcemia creates crystal deposits in the blood, which are distributed throughout the body as painful accumulations. Gout can occur because of hypercalcemia, as can kidney stones (renal calculi). Patients with hypercalcemia also exhibit painful and thick urine from the excessive calcium.

(Breasted, 1991). Amazingly, the Smith and even older Ebers papyrus (1937) dated to 1500 BC distinguished between benign and malignant tumours. Described by Hippocrates (c. 460 to c. 370 BC) as a "crab," the term *karkinos* (καρκίνος) soon met with an additional Greek term, *onkos* (ὄγκος), which described a bulk or mass. Presumably, Hippocrates borrowed this term from Greek theatre where the *onkos* was a topknot worn on the top of a mask in a tragedy and represented a pressing concern on the mind of the wearer ('onkos,' n.d.). Similarly, the Greek New Testament translates *onkos* as weight or encumbrance (Hebrews 12:1). The Roman physician Celsius (c. 25 BC to 50 AD) translated *karkinos* into 'cancer.' It took several centuries before cancer in the literature became associated specifically with an unnatural and painful growth, ulcerated or not, that spread throughout the body.²² These tumours were usually associated with a cluster of clinical manifestations including fatigue, fever, and extreme weight loss.

Without microscopes and associated understanding of cellular mechanics, Hippocrates described the human body as composed of four cardinal fluids ('humors') each unique in character, viscosity, and color (red, black, yellow, and white). Illness resulted when one or more of these fluids were unbalanced. The Greco-Roman physician Galen, who practiced around 160 BC further classified illnesses as disorders attributed to specific humors, and it was he who classified malignancies as an excess of black bile (*melas knole* or *melaina chole*). Much of this thinking also came from the notion that blood (and other humors) did not circulate in the body, but rather were used up or became stagnant (Karpozilos & Pavlidis, 2004; Mattern, 2013). As an oily, viscous humor, black bile congealed into a matted mass because of a systemic malignant state that could not be cut out as it would simply flow right back into the emptied space (Mattern, 2013). While Hippocrates had described *karkinos* as "best left untreated, since patients live longer that way," Galen agreed that the pervasive nature of black bile made it impossible to remove a tumour with surgery.²³

²²In the early modern period (1500-1789 CE), 'cancer' appears in the literature to specifically reference the malignant disease. 'Canker' and 'cancre' were also used, but in a manner which generally described bodily ulcers and lesions. A discussion of the etymology of terminology is available in Skuse (2015).

²³Indeed, from identification as crab-like tumors covered in blood vessels (the angiogenesis trait of cancer), cancer was long associated with Galen's suggestion to forgo surgery. Bertipaglia, the most influential surgeon of the fifteenth century, noted that "those who pretend to cure cancer by incising, lifting, and extirpating it

Within humoral medicine, the environment was critical to developing and defeating illness. Illness, according to Galen and others, occurred as the result of humours being out of balance with each other (Karpozilos & Pavlidis, 2004). Basic conditions (hot/cold/dry/wet) often merged with the notion of constitution which was further teased out in the vastly expanded Greek Medicine Wheel of the European medieval period. This wheel was comprised of the four humors, graphically coupled with other qualities such as season (spring, summer, fall, winter), time of day (midnight, sunrise, noon, sunset), stages of life (youth, adulthood, maturity, old age), and direction (north, south, east, west). Constitution of the Greeks became morphed into temperaments by both time and culture, and medieval physicians developed an expanded view of temperament in relation to different humors.²⁴ Phlegmatic temperaments were associated with white humor (phlegm), choleric with yellow bile, and sanguine temperaments with blood. Perhaps ironically, as pointed out by Mukherjee (2010) in *The Emperor of All Maladies: A Biography of Cancer*, the only other disease associated with black bile was depression (*melancholia* in New Latin).

It was interesting that black bile became associated with cancer (physically present tumours) at the same time it was responsible for melancholic symptoms, which are strictly psychosomatic ('hypochondria') and lack physical evidence. Regarding a woman who complained of feeling ill but failed to produce physical symptoms, Galen wrote, "I came to the conclusion she was suffering from a melancholy dependent on black bile, or else trouble

only transform a nonulcerous cancer into an ulcerous one.... In my practice, I have never seen a cancer cured by incision, nor known anyone who has" (Mukherjee, 2010, p.29). Gale, an English surgeon in the sixteenth century, wrote that "of blacke cholor, without boyling cometh cancer, and if the humor be sharpe, it maketh ulceration, and for this cause, these tumors are more blacker in color" (cited by Mukherjee, 2010, p. 49). As Galen had noted, incising or cutting a tumor often resulted in an infected or prolifically-bleeding ulceration. Other critical components of Greek medicine that have historical context include bloodletting and temperament.

²⁴Throughout the Renaissance period, Catholics marked special bloodletting days within the calendar of saints. In fact, the patron saint of cancer is St. Peregrine, born in Italy around 1260 CE. A priest of the Servite order, St. Peregrine Laziosi contracted cancer of the foot and, despite several treatments, was recommended to have an amputation of the affected leg. The evening before the surgery, St. Peregrine was cured when a vision of Jesus reached out a hand to him and he lived another 20 years. The prayer to St. Peregrine reads, "for so many years you bore in your own flesh this cancerous disease that destroys every fibre of our being, and who had recourse to the source of all grace when the power of man could do no more" (Novena to St. Peregrine, n.d.). Catholic officials credit the miracle of healing to a "softening of the heart" so that energy could be rechanneled into serving the Gospel (Foley, 2016). This perception ties in with the persisting notion of temperament, a Renaissance elaboration on the theory of constitution propounded by Galen.

about something she was unwilling to confess” (as quoted in Jackson, 1969). It is unclear from a thorough search of the literature the relationship between melancholy (depression) and cancerous tumours in these early centuries. However, in the medieval period and Renaissance a developing relationship between the two started to materialize in a way that may have influenced the patient’s lived experience of cancer. The notion of temperament in relation to cancer blossomed in the Victorian period (1840-1900). Early cancer history, or rather a written history of solid tumours, proceeded in much the same way which an emphasis on tumour development as an outcome of imbalanced humours until the early 1800’s.

Early Treatments of Cancer

While Galen's influence was strong in the early centuries of the Renaissance, by the later period a movement towards surgical incisions, extractions, charring, compresses, tinctures, and poultices became popular (Conrad, 1995). Ambrose Paré, a sixteenth-century French physician, used smoldering irons to char tumours and used smears of sulfuric acid to treat them. Compression of the tumour with lead plates was thought to be useful. Apothecaries noted numerous systemic and local treatments for cancer including tincture of lead, arsenic extract, rasped ivory, hulled castor, ipecac, and senna. Alcohol and tincture of opium were used for pain. Paste of crabs' eyes, goat's dung, crow's feet, and tortoise liver were purchased at enormous prices by individuals desperate to be rid of their mass/es. Anne of Austria’s breast cancer was treated with belladonna and burnt lime, hemlock ointment, as well as arsenic paste (Motteville, 1902). It should be noted, however, that these were used for patients with protruding solid tumours, perhaps including bulky lymphomas. With limited understanding, it might be concluded that patients with any disease were treated with some combination of similar elements. Nobili et al. (2009) noted that most modern anticancer agents are derived from the same plants described in the historical record.

Bloodletting

Bloodletting, also known as purging or bleeding, was used throughout antiquity for cancers well into the 19th century. Presumably first developed in Egyptian culture around 1000 BC, bloodletting was developed as a means to balance excessive humors that were

(presumably) causing illness. Galen developed a complicated system advising how and where on the body to perform bloodletting based on age, constitution, weather, and geographic location. Apoplexy (internal bleeding), fever, and headache were conditions particularly susceptible to bloodletting (Conrad, 1995). The Talmud described similar reasons and procedures for bloodletting, and the Prophet Mohammed outlined a procedure of bloodletting using cupping technique.

Blood has been seen historically as a cure for disease rather than a carrier (or cause) of disease. Symbolically, an ill person would (heroically) withstand bleeding as a means of achieving wellness. Within the context of humoral medicine, blood was hot and wet, the means for distributing nutrition and heat to the body. Therefore, blood contains the vital force necessary for life: “The life of the body is the blood” (Genesis 9:4). Oral consumption of blood for the purpose of gaining vitality and energy is well-documented and includes, for example, Roman leaders drinking the blood of fallen gladiators (Maluf, 1954). As described by Tavassoli (1980), poets, healer, and philosophers over the centuries have described an intimate relationship between blood and life. That blood is a cure rather than carrier of disease changed markedly with the invention of the microscope and the discovery of blood cells (in the 1700’s). Transitions in culture and identity followed suit as blood became disease-filled rather than a means of youthful energy.

Non-Western Traditions

The Greeks, Egyptians, and Romans were not the only societies writing on cancer. The Babylonian *Code of Hammurabi* (1750 BC) and the Chinese *Rites of the Zhou Dynasty* (1100-400 BC) contain references to solid tumours. The Indian *Ranayana* manuscript dating to 500 BC also references solid tumour treatments and corresponds to understanding about differences in tumours described in the *Atharva veda* (2200 BC) whereby a swelling of internal organs seen on the body surface (*Arbuda*, meaning tumour) is differentiated from a non-healing ulcer (*Asadhya vrana*). Following the humoral theory of Hippocrates and Galen, the *Sushruta Samhita* (200-300 BC) described human beings as three humors: *Vayu* (air), *Pitta* (bile), *Kapha* (phlegm), and blood (Loukas et al., 2010). Disease was caused by disequilibrium of these fluids. The *Sushruta* differentiated tumours (*Arbuda*) into four subtypes – *Raktaja* (suppurating malignant tumour), *Mamsarbuda/Medaja* (malignant

tumour of soft tissue, muscle, or fat), *Adhyarbuda* (metastatic growth), and *Dvi-arbudo* (a pair of hard, painless contiguous tumours). Internal tumours and glandular swellings were referred to as *Gulma*. Treatments in the Ayurvedic system were also highly similar to Galen and included maggotification, blood-letting, and cauterization. Herbal medicines were also commonly used.

Beyond giving sociocultural context to experiences that have been global in its perspective, the purpose of detailing the *Susruta Samhita* text is to suggest that Indian medicine better understood the potential for haematological cancers. The *Gulma*, for example, is strangely reminiscent of Burkitt's lymphoma which produces internal tumours (mostly in the abdomen) and glandular swellings (lymph nodes). It is not clear the social implications of this knowledge, and under this current dissertation exploring Ayurvedic knowledge around cancer is not a priority, but it does imply knowledge of haematological factors that took centuries to discover within Western tradition.

The Cellular Revolution and Descartes: 1500's-1700's

Up until the early modern period, understanding of the medical, anatomical, and physiological processes that took place with what would eventually be identified as haematological cancers was rudimentary. Much was based on magical thought, humoral balances and imbalances, and scant evidence culled from autopsies. These, for the most part, revealed pus and inflammation whose mechanisms were totally obscured (Pillar, 2001).²⁵ Robert Hooke, Curator of The Royal Society of London, was the first to identify cells under a microscope.²⁶ He described the structure of plant cells in his book *Micrographia* published in 1667. This book is revolutionary in the sense that it unlocked a new world and allowed for a complete paradigm shift in scientific thinking. Anton van Leeuwenhoek read this work with great interest and was able to grind lenses into shapes that allowed him to see the first human red blood cells in 1674. White blood cells, termed 'the globuli albicantes' were described by Joseph Lieutaud in 1749.

²⁵Dr. Beal described pus in the blood as "leukemia" in 1729, and Dr. Lower described the same thing in 1749. However, the official description of white blood cells through microscopic analysis was made in 1749 by Lieutaud (Pillar, 2001).

²⁶The compound microscope was invented in 1590, and achromatic lenses were developed in the 1830's.

The seventeenth century brought with it a time of transition. Advancements made during the Renaissance allowed the human mind to conceive of the body and self in a new way. With cultural and social shifts in technology came a shift in thinking from a humoral (blood) cause to lymphatic theory. The transition wasn't easy for societies deeply comfortable with thinking about humour imbalances for 1300 years, but in 1543 Andreas Vesalius failed to confirm the existence of black bile during an intensive and thorough autopsy. Previous to this, autopsies were banned by the Catholic Church, and when physicians started doing them again in the mid-1500's it was via the handiwork of a barber surgeon who would relate what was present. Vesalius crafted the *De humani corporis fabrica libri septem* (1543) which is considered to be a ground-breaking masterpiece of anatomy by doing the autopsy and overlooking the resulting drawings himself. Within the seven tomes several theories held by Galen, including the existence of black bile, were shattered. In 1622 Gasparo Aselli discovered lymph, and a few years later (1626) William Harvey published a comprehensive study on blood circulation. Lymph replaced black bile as a cardinal biological liquid and Rene Descartes (in 1647, *The Description of the Human Body*) suggested that lymph gave rise to cancer, thereby causing confusion over the origins of cancerous tumours (Kardinal & Yarrow, 1979).²⁷

Drawing from these amazing advancements in physiology, Frederick Hoffman and George Stahl proposed that life is the continuous exchange and circulation of blood and lymph. The source of movement was God acting through a force called *anima*. The so-called lymph theory postulated that benign tumours were caused by local coagulation of lymph in tissues, and malignant cancers arose from fermented and degenerated lymph. The deeply respected Dr. John Hunter, a Scottish surgeon, confirmed that tumours grew constantly due to alterations in density, acidity, and alkalinity as lymph was thrown by the blood into body tissues (Moore, 2005). As with Hippocrates and Galen, the lymph theory gained ground quickly and remained the dominant source of cancer etiology (as it was understood) well into the 1800's.

²⁷The Dutch professor and colleague of Descartes Francois de la Boe Sylvius is credited with furthering this notion, suggesting that a highly acid level in lymph fluid was responsible for cancer tumours (Yalom, 1997).

Social History

Skuse (2015) points out that practitioners in the early modern period did not view cancer as multiple diseases. Rather these physicians saw cancer as a disease located in diverse body sites (breast, womb, chest) but created by the same mechanisms. Furthermore, cancer was viewed as sentient, a thing that bit, ate, and grabbed at the human host, taking on the characteristics of the proverbial crab. During this early modern period momentum increased towards cancer's association with the wolf and the worm (maggot or caterpillar), creatures associated with eating, secrecy, and ravenous behavior (Skuse, 2015). These animals were also associated with the devil, hell, and devilish things, which at a time of great religiosity was particularly troublesome.²⁸ In some cases, fresh meat was placed on a tumour or ulcer as a sacrifice to the cancer with the assumption that the disease would stop eating the patient and consume the meat instead (Bonet, 1684). Skuse describes that the idea that cancer was transmittable or entered the body from the outside is unsupported in the extant literature (2015, p.e-1547). In fact, the cancer-worm and cancer-wolf were both creatures/afflictions brought on by the self and by self-behaviour, most notably from guilt. Whereas the black bile accumulated to provide the body of cancer, the cancer animal became the essence of cancer, the *anima* separate but born of the host.

Behaviour associated with excess became entwined with cancer in this period, partly due to the extreme creativity and lavishness associated with the Renaissance. As discussed previously, black bile was associated with melancholy (*melaina chole*) by Hippocrates and Galen. In the 1587 *A Worthy Treatise*, cancer was characterized by 'veines swollen rounde about with melancholicke bloude' (Guillemeau, A.H., & Bailey, 1587, p. 40). The relationship was based on a persistent assumption of hypochondria, whereby the emotion (depression) affected the body (soma) via the mind (psyche). Moses Maimonides wrote in *The Regimen of Health* in the 1100s CE that, "it is known... that passions of the psyche produce changes in the body that are great, evident, and manifest to all" (Bar-Sela, Hoff, & Farus, 1964). This implies social constructionism, of course, whereby the label of disease

²⁸Worms feature heavily in the Bible as creatures that torture the souls of those who have angered God, and Medieval clergymen described hell as a place where venomous worms and adders would gnaw at sinners (Skuse, 2015, p.e-1654). There is some association between cancer and the devil in modern religious movements as well. This will not be explored in detail within this Chapter, but I accept that this relationship may surface during data collection in Layers 3 (secondary) and 4 (primary).

immediately precipitates a course of events springing from social associations with the word/disease. Today we may argue that the medical theory (disease independent of time and place) is correct, but our ancestors did not treat disease in a similar matter. Schwartz (1987) extensively explored historic literature and *belles lettres* and found that during the early modern period (1500 CE to 1789 CE) the assumptive relationship outlined in humoral theory transitioned into psychopathology. A melancholic personality describes one who undergoes mental suffering because of stress or strain, someone who has a depressive temperament, someone who is sorrowful. These were points of causation for the development of cancer, associated similarly with the accumulation of black bile (as with blackened thoughts) presuming that cancer was a sympathetic disease. Authors have suggested that cancer, for many centuries, was a disease of female breasts, and women were uniquely vulnerable to the disease due to their inherent depressive natures (Skuse, 2015). The standard contention that cancer was attributable to personality and behaviours became even more popular in the 1800's, due to both understanding and misunderstanding of the new data generated by researchers.

The Birth of Haematological Cancer: The 19th Century

Kampen (2012) made a strong argument that the very first case of leukemia in the medical literature was described by Scottish surgeon Peter Cullen. In 1811, he wrote a paper on a case of “splenitis acutus.” A year previous, a 35-year-old man had come to his door with complaints of abdominal pain, fever, rigors, chills, and night sweats (Cullen, 1811). As with historical tradition, Cullen performed five sessions of bloodletting, noting that the first three times produced a whiter blood serum that was milk-like. Subsequent treatment with calomel (mercury chloride) produced recovery, and Kampen speculated that Cullen was the first to describe a patient with chronic leukemia. A small handful of other patients with peculiar blood ailments were described in the early nineteenth century literature (Pillar, 2001).

A critical juncture in the history of both haematological cancers and cancer in general was contained in a report published by John Hughes Bennett dated March 19, 1845 and titled ‘Case of Hypertrophy of the Spleen and Liver in which Death took place from Suppuration of the Blood’ (Bennett, 1845). Bennett’s description of the altered blood in the case of patient John Menteith was one independent of inflammation and pus, and he described that the

whole mass of blood had been similarly affected. He described this condition as leucocythaemia, or abundance of white blood cells in the blood. Combined with a post mortem report, the description of blood under the microscope yields a modern-day diagnosis of chronic granulocytic leukaemia (Pillar, 2001). In 1847, Rudolf Vichow applied the term ‘leukaemia’ to describe the condition whereby white blood cells proliferated in a blood sample, and this was carried forward in the medical literature. Vichow described that leukaemia originated in either the spleen or lymph, an understanding which persisted until the discovery of the haematopoiesis (both red blood cells and white blood cells) within bone marrow by Ueber Neumann in 1868 (Cooper, 2011). Neumann is also credited with discovering that the bone marrow produces stem cells, which in turn develop into other cell lines.²⁹ Giulio Bizzozero coined the term *blutplatchen* in 1882 when he discovered platelets and their function in coagulation. That is not to say that these discoveries were immediately heralded as definitive and correct, and that people’s lives changed dramatically. In the late 1800’s, the incredible pace of scientific innovation and subsequent publishing was astounding. Today we understand these concepts to be the ‘correct’ ones, but in the late nineteenth and early twentieth centuries the public was questionably informed on scientific matters and sociocultural understandings of microscopic pathophysiology were undoubtedly primitive.

Cellular Cancers versus Tumour Cancers

With primary evidence of solid tumour cancers in existence for thousands of years, cancer (general) is clearly not a new or modern disease. It would be more logical to discuss how types of cancers may have changed over time in relation to the specific genetic, environmental, and cultural influences in a given period of time. For example, lung cancer has been linked to tobacco smoking, which people have been doing for hundreds of years. Perhaps rates of lung cancer have increased in the last century due to filtering of tobacco smoke or other factors, but this is simply hypothetical because cancer statistics are also a modern phenomenon. What is known is that cancer rates increase significantly as people get

²⁹Previous to this, dualists such as Paul Ehrlich asserted that cells were created in the spleen, bone marrow, and lymph nodes (Cooper, 2011; Maehle, 2011). Using advanced staining techniques, he did discover that stem cells differentiated into different blood cells and is therefore credited with initiating the era of haematology in the late 1800’s.

older, and people in Western countries are (statistically) living longer in the modern age (Mathers, Stevens, Boerma, White, & Tobias, 2015). Cancer, and primarily haematological cancers, is dependent on diagnosis by modern techniques and equipment, and presumably cancer diagnoses have thus increased over the last one hundred fifty years in correlation to advancements in both medical technologies and paradigms.

Democritus hypothesized that everything was composed of smaller indestructible and invisible particles of pure matter in 400 BC. The idea that blood contained smaller elements to itself was, perhaps, impossible to confirm until the development of the microscope. Robert Hooke, Curator of the Royal Society in London, identified the first human cells in 1665 using a crude microscope but it wasn't until the 19th century when intense research around the composition and action of body cells was fully explored. Since haematological cancers are cellular cancers, any understanding or knowledge around these diseases was not possible without specific technological devices and scientific knowledge. Even today in our modern (post-modern) world, medical practitioners can only diagnose a haematological cancer after intense study of cellular data. For this reason, it can be reasonably argued that haematological cancers are (for all intent and purposes) *modern* cancers as their very existence is only possible, verifiable, and understandable using modern technology. That is not to say that haematological cancers did not exist before the 19th century when they were first described in the literature with some precision. Indeed, it would be naïve to assume that no one previous to this was afflicted with a haematological cancer. However, it is simply impossible to confirm the existence of haematological cancers with any kind of certainty before the radical and impressive advancements in both microscopic analysis and medical knowledge of the early Victorian period. Pillar (2001) has gone so far as to suggest that, “looking back, there was nothing in the literature to reveal any clinical cases which might be suggestive of a diagnosis of leukaemia before the nineteenth century” (p. 282). While this assertion seems highly unlikely, it does contain the acknowledgement that leukemia didn't exist as we know it today. Therefore, it seems reasonable to assert that diagnosis of haematological cancers is a *modern cancer construct* lacking history, context, and depth of human experience.

This stands in stark contrast to solid tumours, which have been in existence in the literature for 3000 years (at least). Solid tumours represent an ancient disease, carried

forward in name and description for centuries. Olson (1989) references many historical personalities that suffered definitively from solid tumour cancers throughout history: Sigmund Freud (squamous cell carcinoma), George Gerschwin (glioblastoma), Ulysses Grant (squamous cell carcinoma), Napoleon (gastric carcinoma), Tutankahum (adrenal cancer). Virchow's discovery of cells stands as one of the most influential paradigm shifts of the modern age, because by making cancer a cellular disorder it made the disease solid, localized in origin, and unique to the afflicted cells. No longer were magical liquids, affected effluvia, or other means such as personality the cause of cancer; cancer went from being mysteriously systemic to being observably specific (Patterson, 1987). Despite the amazing ability to understand most forms of cancer better with the advent of the microscope and cellular science, the 1880's and 1890's have been described as a time when cancer was "riddled with controversy and bewilderment" (Patterson, 1987, p. 21). Emerging acceptance of the germ theory of disease (supported by discoveries by Louis Pasteur and Robert Koch) further muddled matters in this way by proposing (and then promoting) the notion that illnesses had specific etiologies (and that a parasite must be responsible for cancer). As explored in this chapter, previous to this the notion that certain individuals were predisposed to certain diseases was widely accepted, and disease (like cancer) was envisioned as dependent on a disruption of balance that effected one's constitution. This fundamental shift in social thinking about disease has been blamed, by various authors, on the increasing "medicalization" of society. Patterson (1987) describes that the notion of 'specific etiology' led to specialized medicine, impersonal medical technologies, and the worship of doctors. The germ theory of disease also contributed to the neglect of social and cultural prevention of disease and was credited at the time as removing disease from a broader constellation that included medical as well as nonmedical interventions. Thus, the late nineteenth century reflected a time when the mind and body, the spirit (*anime*) and machine (*corpus*) were divided in a way that is accentuated in modern healthcare.

Causes for Cancer: Nineteenth Century Opinions

For much of human history, cancer patients were often shunned and stigmatized. Fear was not so much that cancer was contagious, but that a cancer patient was a reminder that anyone could get the disease. It is worth noting that in the late 1800's there existed multiple etiologies for cancer including environmental (pollution, tobacco, "germs") and genetics (the "cancer family" or as Kipling Rudyard called it, "the family complaint"). But ultimately the reason for contracting cancer in the face of these exposures was personal disposition, which could be either acute or chronic (Cairns, 1978; Moscucci, 2005; Patterson, 1987). One's identity as a member of a "cancer family," such as was attributed to the Bonapartes (for example), led to a social and personal distress over certain impending fate. Likewise, with environmental factors that affected both working class folks unfortunate enough to be in a high risk profession or persons of stature who could afford luxuries already associated with head and neck cancer (cigars and chew tobacco).³⁰ The wealthier classes became particularly associated with cancer resulting from luxurious eating and lazy dispositions combined with the stress of gaining, and maintaining, financial success. The relationship between temperament and cancer is perhaps a remnant of earlier associations between the two. The pre-modern/pre-Romantic (1800's-1950's) ideal of good character was one of self-control and limited personal expressiveness. Kant wrote in *Anthropology from a Practical Point of View* (1798, 2006 translation) that passions are "cancerous sores for pure practical reason" and are "often incurable" (p. 166). This association between cancer and anger (or other suppressed emotions) was popular in the Victorian period and into the twentieth century (Lehman, 2015; Sontag, 1978).

A cancer destiny was possible, and probable, *if* the constitutional aspect arose in correlation with circumstantial etiologies. Constitution, defined as the aggregate of physical and physiological characteristics related to health, involved disposition, temperament, and related personality traits, and could be acute (stress) or chronic (depression). Ultimately the notion developed by Galen, Hippocrates and others embracing the humours (melan chole, or depression, black bile) persisted. Cancer identity in the nineteenth century, then, was tied to physical etiology as well as constitution – the two symbiotically intertwined to create disease.

³⁰Ulysses S. Grant, the famous American General and 18th President, contracted squamous cell carcinoma of the throat from which he died painfully in 1885.

Physician James Copland summed this notion by writing, “although irritating agents of any description may give occasion to its appearance,... there must have previously existed cancerous diathesis, or constitutional disposition, in which it almost always originates” (1858, p. 285). Physician Walter Walshe argued that external influences on an individual were accidental and incidental, but that a “constitutional aptitude” was a “necessary condition” for cancer to take hold (1846, p. 168). In writing on the throat cancer of Ulysses S. Grant, his physician Dr. Douglas noted that smoking provoked the illness, but a recent financial crisis made him finally fall to the disease. “Depression and distress of mind was an important factor,” he noted (Pitkin, 1973, p. 30). Dr. Charles Childe wrote in *Control of a Scourge* (1906) that there must be something else besides stress that precipitated cancer, but acknowledged that stress can weaken the constitution to the point of vulnerability:

If your enemy cancers attack you, he will come as a ‘thief in the night,’ he will assault you unawares in the dark.... His earliest thrusts are the weakest. He plays with you, teases you for a while. This is the one weak point in his attack, your only opportunity. He gives you breathing time. Your sole chance is to seize the moment and strike an unerring blow for your life. (p. 276)

The stigma of cancer as a sinister invader persisted, and in many ways accelerated, as the centuries passed.

By the late 1800’s, cancer was described in the popular literature as fire, an invading army, and a criminal, slightly different metaphors compared to the worm and wolf of the early modern period (Patterson, 1987). Rudyard Kipling wrote extensively on cancer, reflecting the social morale of his time in a way that characterized the disease as ruthless, insidious, torturing, and something to be feared above all else (Dillingham, 2005). In his short story *The Children of the Zodiac* (1891), cancer the crab is described as “the eating of a smothering fire into rotten timber in that it is noiseless and without haste” (n.p.). Here the ‘rotten timber’ represents someone who is susceptible to the gnawing jaws of cancer (fire), for (following the analogy) sturdy and healthy timber would not so easily succumb. Dr. Willard Parker published his scientific analysis of 397 breast cancer patients and concluded that “great mental depression, particularly grief, induces a predisposition to such a disease as cancer, or becomes an exciting cause under circumstances where the predisposition had

already been acquired” (1885, p. 58). Sir Herbert Snow interviewed 250 cancer patients at a London Hospital and concluded that cancer occurred due to nervous system flaws. Stress induced cancer, he wrote, and this proof was evidenced in that cancer was more prevalent in nervous women and could be found more commonly in cities and in the elderly (1883, pp. 25-31). The role of the cancer patient was to maintain a courageous acceptance of their fate.³¹ In this sense, personal responsibility for getting cancer lies in the susceptibility of a weakened temperament, and once infected, the person was resigned to accept their destiny with grace. In his 1873 book *On the Curability of Cancer*, Gerhard von Schmitt confirmed that:

With regard to the causes of cancer we must at the outset profess our entire ignorance. The general opinion amongst pathologists of the present day, and one we fully endorse, is in favour of its constitutional origin. (p. 20)

VonSchmitt, physician to patients such as French author Alexandre Dumas, attributed “constitution” (“depressive passions”)³² to a cancer etiology, but included family history as well as gender (“sex”), age (over 80), climate,³³ predisposing diseases such as anemia and tuberculosis, and “advanced civilizations” as associative causes. Quoting Dr./Sir Astley Cooper, “it is the state of mind and body which predisposes to this disease. The mind acts on the body, the secretions are arrested, and the result is the formation of scirrhus” (1873, p. 22). Excess and lack of personal control, as seen with intake of alcohol, smoking, or even childbearing, were also popularly attributed to cancer: “It would seem that spinsters and married women who bear no children are more subject to cancer of the breast than those who

³¹There is perhaps no greater example of literature, both fiction and nonfiction, around cancer social identity than the hundreds of articles and books written about Ulysses S. Grant in the late 1880’s. The point of many of these writings was to emphasize how he was dealing with his throat cancer diagnosis with great poise and quiet reserve (Patterson, 1987). This reflected a social ideal that the patient should accept their diagnosis and adopt a pragmatic acceptance of their fate.

³²Von Schmitt references the work of Dr. Astley Cooper, who wrote in his “Lectures on diseases of the breast” that grief and anxiety of mind were highly associated with breast cancer. As quoted in von Schmitt, “fully three-fourths of the cases arise from grief and anxiety of the mind” (p. 22).

³³According to von Schmitt, South American and the West Coast of Africa were cancer-free regions (1873, p. 23).

have large families, whereas women who indulge their desires beyond the bounds of moderation are said to be more particularly liable for cancer of the womb” (p. 22)³⁴

Growing fear of cancer was accentuated by two sociocultural movements in the late 1800’s including general acknowledgment that cancer was becoming more common, and an increasing denial of death attributed to both technological progress and economic growth (Patterson, 1987). Combined with escalating emphasis on medical science and the rise of doctors, it made for an interesting shift in social consciousness around cancer in the twentieth century. With the discovery, and thus “birth” (epistemologically-speaking) of haematological cancers in the 1800’s, patients were thrust into an established dialogue and mythology about cancer. As the century progressed, the differences between solid tumours and haematological cancers became ever apparent with far-reaching improvements to surgical oncology. With use of anesthesia in 1846, surgical technology rapidly progressed. Most impressive in cancer care was the radical mastectomy developed by physician William Halsted of Johns Hopkins University in the 1890’s. By this time, not only was infected tissue removed but neighboring lymph nodes as well, as concepts around metastasis had progressed to a greater level of understanding. Still, by the end of the century a cancer diagnosis often meant exploratory surgery, and despite the advances in clinical skill, pain control, and hygiene, the notion of going under the knife to obtain a diagnosis must have been terrifying.

Indicators of Haematological Cancer

Markel (1984) speculated that the first case of acute lymphocytic leukemia in the literature that is identifiable through the clinical description is in the fictional account of Paul Dombey, lead character in the 1848 novel *Dombey and Son* by Charles Dickens. His quickly failing health is characterized by severe fatigue, agues, abdominal pain, and rapid weight loss. The 1873 book *On the Curability of Cancer* by von Schmitt offers a comprehensive listing of known cancer sites at the time (looking at 9,112 cases). The list contains references to ‘spleen’ and various references to bones (‘hip,’ for example, where tumours or other abnormalities may have been found and attributed to cancer) (p. 24-25). There is an absence of blood references, although several lymph organs are included (‘tonsils,’ ‘armpit’), and

³⁴It might be interesting to note here that an overwhelming majority of clinical writings on cancer, particularly in the Victorian Age (1840-1900) were of breast cancer. Von Schmitt’s work is no exception.

cancers for which there was no understanding or physical tumour were lumped in the category “cancers without any designation of organs” (p. 25). In finding haematological cancers in the literature, particularly before and just as their discovery was becoming noted, it is important to focus on two physical signs of disease: anemia and splenomegaly.

The Anemia Connection

The historical existence of anemias is easier to trace, mainly because the signs and symptoms are so obvious and include malaise, fatigue, pallor, shortness of breath, headaches, dysmenorrhea (or amenorrhea) and syncope (Pillar, 2001). These could have been confused with or associated with haematological cancers as anemia can be a symptom associated with most cellular and bone marrow dysfunctions (including leukemia, multiple myelomas, and lymphomas). Therefore, crafting a (hypothetical?) history of haematological cancers depends strongly on tracing the history of anemia; however, despite the assertion by Pillar (2001) that anemia is directly correlated with blood malignancies, there are several anemias which are not cancers (for example, sickle cell anemia). Anemias are also associated with bleeding disorders, which may or may not have been associated with the presence of an undiagnosed haematological cancer. For example, writings from the Talmud dating from around 200 A.D. reference failed circumcisions of baby boys who died from excessive or abnormal bleeding. The New Testament describes a woman who had hemorrhaged for 12 years before the hem of Jesus’s garment swept against her and healed her. Abu Khasim, an Arabian physician in the 900’s, described families where male members died of extensive and unstoppable bleeding after suffering traumatic injuries. Dr. John Conrad Otto published an article in 1803 which described cases of male bleeding as hereditary, and this is certainly the first published discussion of clotting factor deficiencies. Therefore, to draw conclusions about the relationship between anemia (and associated anticoagulation disorders) and haematological cancer is provoking but requires caution in drawing broad conclusions.

Anemias including chlorosis (hypochromic anemia, also known as ‘green sickness’) are documented in both fictional and nonfictional literature for the past several hundred years and are associated generally with delicate temperaments: virgins and slender, weakly women (Guggenheim, 1995). The relationship between anemia and temperament harkens back to the Greek association of temperament with environment and the humours, and the relationship

between haematological disorders like anemia (and cancers) become intimately intertwined in the 19th and 20th centuries.

The Spleen Connection

The spleen has been described in the literature for centuries as the enigmatic source of laughter, a seat of emotions as diverse as joy to melancholy and depression (McClusky, Skandalakis, Colborn, & Skandalakis, 1999). Described by Maimonides in the *Mishneh Torah* (Law of Forbidden Foods, 6:9), the spleen is flesh that resembles blood. Modern science has demonstrated that the spleen plays a key role in immunosurveillance and hematopoiesis (blood cell formation). In most individuals, the spleen is not palpable and therefore largely goes unnoticed. In certain diseases, however, the spleen can become enlarged (splenomegaly) and painful, and this is particularly the case in some haematological cancers such as chronic lymphocytic leukemia or in lymphomas. In severe cases the spleen can rupture causing profuse bleeding into the abdominal cavity and death. Modern medicine treats splenomegaly with chemotherapy, radiation, and surgery.

Hippocrates and Pluto both wrote on the anatomy, purpose, and function of the spleen. It was Galen, however, that linked the spleen specifically to black bile. Aretaeus the Capadocian described the spleen as a filter for black blood (1836, p. 325). The Italian physician Mondino (1270-1326) wrote that the spleen filters the black bile, “the crude melancholic humour” (1925, p.70). As with Galen’s time, the Renaissance period described the spleen, and maladies associated with it, as cold and dry (McClusky, Skandalakis, Colborn, & Skandalakis, 1999). If the spleen was associated with laughter and high spirits, people with splenomegaly were perceived as the essence of splenic disorder: cold-hearted, cold-bodied, dry-humoured, low in spirits (melancholic). Thus, social identification of persons with haematological cancers such as CLL or lymphomas would have been associated (presumably) with these characteristics from the involvement of the spleen in their disease. The role of the spleen changed somewhat with the discovery of leukemia and lymphoma, which by the 1860’s were associated with splenomegaly (and vice versa).

It was also in this period that lymphoma tumours were discovered to be separate from splenomegaly, and Spencer Wells (1866) described the differences between the two. He also

attributed the large numbers of leukocytes found in the spleen of haematological cancer patients to have been created by the spleen itself. By the mid-Victorian period, the spleen was transformed from the recipient of black bile to the originating organ of leukemia (leucocythemia) and lymphoma (McClusky, Skandalakis, Colborn, & Skandalakis, 1999). This idea was quickly transformed by the work of Ernst Neumann who discovered in 1868 that bone marrow dysfunction was the source of these diseases and not the spleen. This translation from spleen (organ) to bone marrow (organ?) as the originator of disease had an insidious impact on how haematological cancers were socially and culturally classified. No longer was an organ, potentially removable (spleen), responsible for disease, nor were humoral classifications still applicable. In the case of leukemia and lymphoma, and later multiple myeloma, a clean, identifiable, contained organ was no longer involved; rather, the mysterious entity encased in bone (bone marrow) but ultimately filling the entire body (blood) was to blame for these terrible and often deadly diseases.

The 20th Century: Modern and Post-Modernism

A drive for positivism characterized the early 20th century, embodying the modernist ideal for logical, rational thinking. Because of the push for new innovations coupled with increases in secularism, the modern period is associated with incredible advancements in technology. As a result, an explosion of medical thinking, diagnostics, and treatments resulted from a Cartesian dualism (substance dualism) and atheism. Being able to morally and ethically justify research on the body-machine was now becoming bereft of the previously limiting factors around damaging the earthly vessel of the heavenly soul. Such philosophical modifications to popular thinking allowed research to occur with both animals and humans that previously would have been considered unethical and immoral. The result is that the 1900's can be called the age of haematological cancers – they already hold the title of the “Cancer Century” (Leaf, 2013, p. 36). Now recognized for what they were, namely malignant changes to stem cells and resulting blood cells, an explosion of research, writing, and speculation marks the past 100 years in a way that mirrors a morphing social vision of these diseases. Coincidentally, the rise of haematological cancer mirrors the rise of modern medicine, a transition associated with increasingly impersonal treatments, highly mechanized diagnostics, and god-like worship of physicians (Mukherjee, 2010; Patterson, 1987).

Haematological cancers, then, by their very existence (ontologically-speaking) represent modern medicine, both its worst and finest traits.

Mukherjee (2010) provided a thorough history of the rise of oncology as a medical specialty and sociopolitical phenomenon in the past 150 years, and for the sake of this chapter only key details are required. Suffice it to say that the first cancer hospital in the U.S. was the New York Cancer Hospital, founded by investors including John Jacob Aster III, and opened in 1887 to serve women.³⁵ Symptoms of haematological cancers (undiagnosed, of course) had been treated with arsenic trioxide since 1786 when Thomas Fowler successfully used the chemical (dubbed Fowler's Solution) to relieve agues, persistent fevers, and headaches. Arsenic had been specifically used to treat chronic myeloid leukemia as early as 1865 in Germany by Heinrich Lissauer (Hunter, 2007). Despite the relatively short remission period, arsenic has persisted as a frontline treatment for leukemia since this time. The discovery in 1900 by Karl Landsteiner of human blood groups improved success rates of blood transfusions, which had a dramatic impact on the care of haematological oncology patients in the twentieth century (Landsteiner, 1901). William Rontgen discovered x-ray technology in 1895, and for thirty years they were used in the treatment of leukemia (Pillar, 2001).³⁶ The early twentieth century also witnessed an increase in epidemiological research, and by the 1930's cancer statistics proved to be increasingly reliable and available. As a result, the number of new cases of haematological cancers grew significantly, presumably due to new and improved laboratory instrumentation allowing impressive accuracy for counting blood cells (a process called haemoglobinometry). Sternal marrow aspiration was undertaken by Mikhail Arinkin in Germany in 1927, providing improved diagnosis of haematological disease. In 1933, R. P. Custer developed the bone marrow biopsy techniques that are still used in modern oncological medicine.

By the 1940's, leukemia remained a fatal disease and frustration over treatment reverberated in the medical community (Pillar, 2001). No doubt, socially a diagnosis of

³⁵Interesting to note was that Dr. Fordyce Barker, a physician of Ulysses S. Grant, made the dedication of the new women's cancer ward by noting that, "cancer was not due to misery, to poverty, or bad sanitary surroundings, or to ignorance or to bad habits, but a disease afflicting the cultured, the wealthy, and the inhabitants of salubrious localities" (Gray, 2003).

³⁶A monumental study by Minot et al. in 1924 suggested that x-rays were only helpful to patients with chronic leukemia or lymphoma and were of no use in patients with acute leukemia.

pediatric or adult leukemia was viewed with tremendous trepidation. Public crusades in the 1930's against cancer had politicized the disease to the point of national importance. In the United States, for example, a National Cancer Institute was created in 1937 by an act of Congress, "to provide for, foster, and aid in coordinating research related to cancer" (National Cancer Institute, 2016; Rettig, 2005). Other countries were similarly drawing cancer into the greater sociopolitical stage: the Canadian Medical Association formed a National Study Committee on Cancer in 1931; the Cancer Hospital Research Institute (now the Institute of Cancer Research) was founded in 1909 as the center of cancer research in the United Kingdom where previous cancer wards had been created in the late 1800's. In March 1937 *Fortune* magazine featured a story titled, "Cancer - the Great Darkness" in response to growing public demand that more attention be given to cancer at a national funding level (Hayter, 2003; Leaf, 2013). The additional point of this and other public health campaigns for the first decades of the 1900's was to encourage patients to seek early medical care. The rationale being, as it is today, that a quick diagnosis of cancer leads to rapid treatment and improved outcomes (i.e. catching the cancer in an earlier stage of development). This is particularly true for solid tumour cancers. Unfortunately, haematological cancers are more insidious and diagnoses were increasing at an alarming rate by the mid-1940's.

It was during this time period that militarization metaphors developed around cancer. In 1931, the Ontario Health Minister described cancer as "Bolshevik" cells because they disobeyed ordinary rules and spread among healthy cells to "corrupt" them (Archives of Ontario, 1931). Joseph-Ernest Gendreau described cancer as "a formidable menace that comes to use like a mighty and monstrous chariot de Djagernath, with its sinister pagoda and its wheels of swords, daggers, and knives," (1935, p. 22) emphasizing an aggressor/victim mentality that was increasingly popular. The idea of lawlessness associated with cancer cells slowly crept into the media and literature in a post-World War I environment and this socio-political association of cancer to anarchists was a reflection of a greater sentiment reflecting both fear and a loss of control. On *The Cancer Problem*, W. Banks wrote in 1929 that "antiforces in every country" should unite to "combat a dreaded foe" (p. 3.) Patterson (1987) labelled this period as a time of "cancerphobia," which is an accurate way to describe the general unsettled feeling around a perceived increase in cancer cases. Negative attitudes were accentuated by the personal experiences of cancer patients, and cancer was viewed as

unremitting and progressive, a disease which brought about terrible suffering, disfigurement, pain, social isolation, and undeniable death (Hayter, 2003). An autobiographical article in the *Saturday Night* journal described that being a cancer patient was isolating, cut off from society due to fear, ignorance, and pity ('A Sufferer,' 1930). H. V. Morton's book *The Heart of London* featuring qualitative interviews undertaken with cancer patients at the Free Cancer Hospital in London (England) described similar personal suffering and social identity, stressing the disappointment and dismay of patients shocked at "the unthinkable depths to which your fine, strong body could sink" (1925, p. 41).

The Rise of Chemotherapy

As mentioned previously, physicians were universally frustrated with progress in cancer by the 1940's. Despite the increasingly sociopolitical nature of the disease, along with amplified public funding towards finding 'the cure,' it seemed cancer treatment was still rudimentary. The increased support and funding provided by social campaigning paid off, but real success in chemotherapy for cancers is attributed to World War II programs of research (DeVita & Chu, 2008). In 1948 a paper published by Dr. Sidney Farber described aminopterin (methotrexate), the first chemotherapy with real (albeit temporary) remissions for children with acute leukemias. In 1943, Alfred Gilman and Louis Goodman, pharmacists at Yale University, collaborated with surgeon Gustav Lindskog to administer nitrogen mustard (mustine) into the spine of a non-Hodkin's lymphoma patient. Again, remission was temporary but provided enough hope to stimulate researchers to explore other drugs for cancer treatment, and particularly for use with haematological cancers. This relationship seems appropriate enough, since surgery and radiation remained the dominant paradigm for cancer treatment in solid tumours until the 1960's. Haematological cancers, lacking identifiable or localized growths, require systemic agents (i.e. pharmaceuticals), and it is indeed these cancer patients that have benefited the most from chemotherapy (and now biotherapy) agents.³⁷ The growth of chemotherapy applications and drugs has continued to

³⁷The first chemotherapy cocktail was administered to pediatric leukemia patients in 1953. Called "VAMP," the program contained vincristine, aminopterin, 6-mercaptopurine, and prednisone. The remission rates were highly impressive at 60% and bolstered support for chemotherapy regimens as front-line treatment (DeVita & Chu, 2008, p. 8649).

this day, and a more full history of chemotherapy can be found in Mukherjee's *The Emperor of all Maladies* (2010) as well as Devita and Chu (2008).

It wasn't until the late 1960s that the concept of cure for cancer was realized amidst an environment where researchers using chemotherapy were considered fringe lunatics (DeVita & Chu, 2008). Many of the chemotherapy cocktail programs developed in the 1950's and 1960's are still in use today (including VAMP, MOMP, and MOPP).³⁸ Remission rates for haematological cancers, and particularly lymphomas, improved across the board. By 1970, Hodgkin's lymphoma was regarded as curable with drugs in both adults and children (DaVita & Chu, 2008). Also, by the 1970s the use of adjuvant chemotherapy (defined as chemotherapy used after surgery to destroy remaining cancer cells) and neo-adjuvant chemotherapy (chemotherapy given prior to surgery in order to shrink tumours) were becoming popular for solid tumour patients. Enthusiasm for chemotherapy as a viable, and critical, component of cancer treatment changed the social, political, and cultural implications of the disease dramatically. Instead of cancer being "the great darkness," hope that cancer could ultimately be defeated utilizing the tools of treatment (chemotherapy, radiography, and surgery) existed in a way never known in human history. Confidence led to the declaration of war on cancer by U.S. President Richard Nixon in 1971 when he signed the "National Cancer Act" in which the focus was on the "conquest" of cancer (Vanchieri, 2007).³⁹

Several articles have detailed the way in which this fundamental, metaphor-driven change in viewing cancer has significantly altered social and personal identity of cancer patients (Coleman, 2013; Hogdkin, 1985; Marshal, 2011; Oronsky et al., 2015; Reisfield & Wilson, 2004; Skott, 2002; Sontag, 1977; Teucher, 2003). Reisfield and Wilson emphasized the importance of metaphor in the medical context, noting they are extremely powerful in the

³⁸MOMP describes a protocol for Hodgkin's lymphoma that includes nitrogen mustard, vincristine, methotrexate, and prednisone, and MOPP is similar except it uses procarbazine instead of methotrexate.

³⁹The association of cancer and war was reputed to be first published in a December 9, 1969 document by the Citizens' Committee for the Conquest of Cancer led by publicist Mary Lasker. Lasker and her group published full-page advertisements in *The Washington Post* and *The New York Times* entitled: "Mr. Nixon, you can cure cancer." The ad reminded readers that the U.S. spent more money on military matters in a day than were spent on cancer research in a year. The ad continues, "surely, the war against cancer has the support of 100% of the people. It is a war in which we lost 21 times more lives last year than we lost in Viet Nam last year. A war we can win and put the entire human race in our debt" (see Coleman, 2013, p. e-32). Nixon did not ever use the phrase "war on cancer," even though most literature attributes it to him.

practice of medicine and the illness experience (2004). As shown in this chapter, throughout history metaphors of various types (crab, worm, wolf, eating, other) have been attributed to cancer. The modern (and post modern) periods are no exception, and indeed frame the conversation around current data collection on cancer patient identity. “The sick man sees everything as a metaphor,” said prostate cancer patient and autobiographer Anatole Broyard in his *Intoxicated by my Illness* (1992, p. 34). With the rise of pharmaceutical companies and explosion of chemotherapy drugs from 30 to over 300 in the past 40 years, the war is one that has an ever-increasing arsenal of possibilities for the goal which is total tumour eradication (Oronosky et al., 2015). This is not to say that a military analogy is only referenced in cancer – within Western cultures, war has been declared on an enormous number of perceived social threats (War on Drugs, War on Poverty, War on Crime, etc.). What has happened, however, and as evidenced by the research literature review in chapter 4, is that identity concepts adopted by cancer patients tend to reflect (in some way) the militarization of cancer. For example, 'victims,' 'warrior,' 'fighters,' are set to 'win a war/fight/crusade against cancer' and 'conquer' the disease. The motto for the American Cancer Society (2016) is “join the fight against cancer.” Sontag wrote, “with the patient's body considered to be under attack (“invasion”), the only treatment is counterattack” (p. 64). A superhero/good guy metaphor has developed around stem cells saving cancer patients from cancer (i.e. the bad guy) (Burns, 2009). The mission of the Canadian Cancer Society (2016) includes “the eradication of cancer.” The Cancer Council of Australia (2016) wants to “beat cancer.” Cancer Research UK (2016) wants to “beat cancer sooner.” The adoption of a military emphasis on cancer care can even be seen in the way that cancer patients identify (self and social) after 'battling' cancer; namely, they are 'survivors.' The survivorship model of cancer care, which is now prevalent, is directly linked to this modern idealization of tumour eradication and 'winning' a traumatic event. Likewise, when someone is not a winner they are (in the context of cancer) dead and therefore have 'lost the battle with cancer' (see for example Leaf, 2004). The best way to examine the war on cancer, and its subsequent relationship with cancer identity, is through the amazing parallel of the rise of the cancer-self. At no other time in history has cancer been so written about, both in fiction and nonfiction, then in the last 40 years.

The “Cancer Personality”

These sentiments of fear, isolation, discouragement, shame, suffering, and pessimism are aspects of a greater cancer patient identity in the early 1900's, interlinked with the persistent notion that cancer (as with any disease) was somehow an expression or natural result of personal character. Sontag (1977) captured this pre-modern philosophy when she said, “disease is the will speaking through the body, a language for dramatizing the mental: a form of self-expression” (p. 44). The ideal candidate for cancer within this paradigm was someone who was repressed, dissociated, prudent, passive, “one of life's losers” (Sontag, 1978, p. 48-49). Take for example William Auden's 1937 poem in which the proper “clothes buttoned up to her neck” spinster Edith Gee is diagnosed with advanced sarcoma from which she dies on the operating room table. Upon reflection, this tragically sad poem reflects the pre-modern notion that proper people, “good” people, particularly those who are unmarried, live piously, and shun pleasures, will be chased down by “the bull,” in this case the metaphor for cancer. It is an interesting reflection at a time when social mores were being shattered in lieu of more open, more permissive, cultural values (Young, 2002).

Even physicians of the day were becoming increasingly convinced, through scientific studies, of a presumptive relationship between personality, identity, and cancer. The notion that temperament, linked with the black bile (melan chole) of Galen's time, was ultimately responsible for cancer witnessed scientific backing within the academic community starting in the 1950's. Perhaps the foundation had been laid earlier, however, with the “discovery” of stress in the 1930's. Historic articles from the period show increasing interest in psychosomatic disease and the impact certain emotional states had on physical well-being. Wittkower (1938) was one of the first researchers to suggest that psychological abnormalities could precipitate disease by showing a relationship between mental anguish and ulcerative colitis. Quickly the application of stress to other diseases including cancer and coronary artery disease became popular conference topics, and psychosomatic disease development was very much a topic of conversation by the popular declaration of war on cancer (Karren, Smith, Gordon, & Frandsen, 2013). One of the first articles to link cancer with psychological

factors was published by Eugene Blumberg and colleagues in 1954.⁴⁰ Their research tells us a lot about patients at a time when cancer patients were still very much hidden and silent. The Blumberg, West, and Ellis wrote:

We were also quite impressed by the polite, apologetic, almost painful acquiescence of the patients with rapidly progressing disease... In fact, our impression is that the very development of cancer in man might conceivably result from the physiological effects of long-continued inner stress which has remained unresolved by either outward action or successful adaptation. In other words, it seems that human cancer could represent, at least in many instances, a nonadaptation syndrome (1954, p. 277).

Leukemia, at this time, had been shown to be a disorder for adaptation (Blumberg, West, & Ellis, 1954). Success in treatment of cancer was noted in those patients who were successful in avoiding or reducing emotional stress. These researchers wrote that the average cancer patient suffered rapid growth of cancer, and these folks were “consistently serious, over-cooperative, over-nice, over-anxious, painfully sensitive, passive, and apologetic personalities” who had “suffered from this pitiful lack of self-expression and self-realization all their lives” (1954, p. 285).

Regarding haematological cancers specifically, William Greene published a widely-cited article in 1966 titled, *The psychosocial setting for the development of leukemia and lymphoma*. This article constitutes a meta-analysis of extant literature available at the time, which was only three published studies. Greene notes early that “there is no common personality type or conflict situation evident” after reviewing the participants (N=109 over three studies) (1966, p. 794). What these haematological cancer patients did have in common, Greene concludes, was that they recently experienced “a large number” of extremely stressful events (p. 800). For men causative factors were the loss of the mother figure (actual or wife) or the loss of self-esteem related to injury, a change at work, operation, or retirement. For women, cancer diagnosis was preceded by the start of menopause, the loss of a major family

⁴⁰An interesting observation about the case studies in this article is that each contains chemotherapy regimens for treatment. While rudimentary when compared with what we use today, it is interesting to see the very early attempts of oncologists to treat acute disease with radiation, surgery, and adjuvant chemotherapy (nitrogen mustard given intravenously).

figure (husband, mother, father, child), or a loss of work. Several quantitative charts indicate that the time frame involved is several weeks to 47 months before the cancer diagnosis, with 12 months as the median (the prodromal period). What is most intriguing about this work is that Greene attributed many symptoms of leukemia and lymphoma (nausea, vomiting, abrupt weight loss, fatigue, anorexia) to the *psychological condition* and not to the actual cancer. Research on haematological cancers and psychosomatic causes seemed, at the time, to confirm these theories (Dunphy, 1950; Olmer and Gascard, 1951).

A 1977 article on personality and disease summarized research done in the 1940's by Dr. Caroline Bedell Thomas of John Hopkins University School of Medicine (Arehart-Freichel, 1977) which concluded that "cancer victims are low-gear persons, seldom prey to outbursts of emotion. They have feelings of isolation from their parents dating back to childhood" (p. 62). Her evidence came, reportedly, from studies of personality in individuals both before and after cancer diagnosis. Dr. Samuel Kowal's historic retrospective in the same time period provided evidence that "always much trouble and hard work" were key characteristics of patients who developed cancer throughout the centuries (1955, p. 3). Breast cancer research seeking psychosomatic links can be found in the 1950's and well into the 1990's featuring particular emphasis on female vulnerability to distress and grief as a precursor to cancer (see for example, Forsen, 1991; Greer & Morris, 1975; Meyerowitz, 1980; Watson et al., 1991). Therefore, the mid-1900's were similar to previous generations in attributing cancer to constitution with some relationship to other factors such as heredity, climate, age, and gender. The message of the ages was (somehow) it was the *individual's* ultimate fault for getting cancer. Did they worry too much? Drink too much? Have too many children, or not enough sex? In the pre-chemotherapy age, personal responsibility for cancer led oftentimes to stoic, quiet withdrawal from society as the 'right' thing to do. The development of chemotherapy regimens in the 1940's, however, shifted cancer identity considerably from private to public in a way that has revolutionized cancer care.

Another feature of the research literature in the mid-twentieth century was the so-called Type C personality, also known as "Type 1" (as opposed to Types A and B and D and a growing list of others). By 1995, Fernandez-Ballesteros noted that there were over 300 peer-reviewed journal articles and 68 books and chapters dedicated to the Type C personality

(2001, p. 1439). The 'C' stood for 'cancer,' and represented current medical thinking about the role of psychosocial factors in acquiring the disease. Morrison (1990) captured the essence of the cancer personality by describing it as the obvious interrelationship between mind, body, and emotions. He noted, "stress seems to play a key role in the generation and continuation of cancer and there appear to be cancer-prone personality patterns associated with the propagation of increased stress levels" (p. 28). Type C personality is described in the international research literature as someone who exhibits the following characteristics: a tendency to suppress emotions like anxiety and anger; a bland, emotionless presence; find it difficult to cope with stress; developed feelings of hopelessness and helplessness; depression (Eysenck, 1994; Hurtado, Martín, & Sanz, 1993; Temoshok, 1987). Eysenck noted that, "there appears little doubt that psychosocial determinants constitute an important risk factor for cancer and interact synergistically with other risk factors such as smoking, genetic influences, etc." (1994, p. 167). The key in many of research studies seems to have been the interplay between Type C personality types and external factors (many of them a result of the personality) that would constitute habits or addictions such as tobacco use or substance abuse (Grossarth-Maticek, Eysenck, & Vetter, 1988; Malec, Romsaas, & Trump, 1986; Sasaki et al., 2000; Temoshok, 1987). It can be extrapolated to some degree that to be diagnosed with cancer meant assuming socially-determined identity traits (based on personality), and therefore patients may have been prescribed with personality attributes and presumed behaviours that were real, hypothetical, or a combination. As discussed in chapter 4, there seems to currently be a prescribed way of behaving and talking about oneself as a cancer patient. The same seems true in this (near) historic context as well, as to contract cancer meant presumably that one was weak-willed, had suffered grief, etc.

Research on personality type and cancer occurrence hit a feverish pitch in the 1990's but has since faded in popularity. While there is still discussion in the literature over the propensity of different personality types for specific cancer types (for example, Type D personality is supposed to be more susceptible to breast cancer and show greater morbidity, see Batsele et al., 2016) current research seems to be around the degree and manner in which certain personality types deal with cancer (Harper et al, 2014; Husson, Denollet, Oerlemans, & Mols, 2013; Perez et al., 2014; Shun et al., 2014). A longitudinal quantitative study of a cohort of 1139 participants over 16 years (1994-2009) suggested strong correlations between

cancer occurrence and three factors: suppressed emotional expression (Type 1), rational/antiemotional (Type 5), and hostility (Lemogne et al., 2013). Type A personality factors showed a surprisingly low rates of cancer diagnoses. Similarly, Type D (“distressed”) personality has received some attention as a major indicator for cancer because of poor coping styles (Cardenal, Cerezo, Martínez, Ortiz-Tallo, & Blanca, 2012; Husson, Denollet, Oerlemans, & Mols, 2013). Much of this research harkens back to the attempts of physicians and philosophers throughout time to explain the “why” behind cancer. Despite amazing modern technologies, the discovery of stem cells, and the ability to manipulate DNA, cancer defies reason and explanation. Continued emphasis on the action of the individual, whether purposeful or not, in the development of cancer persists.

The Postmodern Cancer Identity: Man is Cellular

The transition of the modern era to postmodernism is well-documented in the literature. This label is used to describe a general sociocultural movement that represented a departure from previous social trends. Where there was once confidence and optimism about the future, social anxiety and pessimism arose. Where earlier Western society focused on discovering universal Truths, social justice, and equality, irony and neo-liberalism embraced individualism and moral relativism. Constructivism replaced positivism in both the arts and culture. The resulting social thinking morphed ideas around what was acceptable for cancer patients including how they could behave and respond to their disease. The project of cancer became highly personalized with increasing self-reference as a standard for dealing with illness.

By the 1970’s, three theories had emerged as potential causes for cancer: viruses, environmental, and biological. Beyond the chemotherapy cocktail, the greatest achievement in the so-called war on cancer has been the development of epigenetics, biotherapies and pharmacogenetics, each of which is linked directly to understanding cellular dynamics and manipulations (Chabner, 2011; Mukherjee, 2010). Chemotherapies (and specifically, cytotoxic medications) work because they target specific points in the cellular reproduction cycle. For example, methotrexate is a popular chemotherapy used in a wide variety of settings – from rheumatoid arthritis to leukemias – and it works by blocking dihydrofolate reductase (DHFR) in the cell, which prevents DNA synthesis. This action wasn’t understood

until the 1970s and seemed more a mystery than scientific fact. The discovery of the oncogene in 1969 by George Tordaro and Richard Hubner from the National Cancer Institute was a critical turning point because it identified actual mutated genes that can cause cancer. Other genetic discoveries followed suit. For example, retroviral RNA transcription as a cause of human cancers was proposed in 1970 by Howard Temin and David Baltimore, and the bacterial (*H. pylori*) cause of gastric cancer was proposed in 1984 by Barry Marshall and Robin Warren. Parallel to this research on potential causes of cancer and the actual reasons why DNA mutated was the screening and prevention effort. Details of this will not be examined in this dissertation but suffice to say that both movements were based on the ancient ideology that finding cancer early meant it had a greater chance of being (to assume the words of Richard Nixon) conquered. Mammogram research trials in 1970's Sweden and the U.S. demonstrated that these screening programs could significantly impact mortality rates. By the 1990's, international screening programs and protocols existed for breast, prostate, lung, and colorectal cancers (Gohagan, Prorok, Hayes, & Kramer, 2000).

In about 150 years, oncology research and practice has gone from discovering the cancer cell to being able to manipulate the microscopic functions of individual cells. This is quite stunning, and socially this transition has had a major effect on the self in cancer that we are still trying to understand. What it means to have cancer, now, is that your own *genetics* have turned against you. Historically people have had some understanding of humours going bad, accumulating into tumours, and being stagnant. Folks might have even had some understanding that certain personality types were prone to attack by cancer (cue visions of Miss Gee). However, with the age of cellular dynamics came confusion and deepening mystery. If the individual is supposed to be responsible (ultimately) for their cancer and be a part of its treatment, the entire solution must be undertaken at a level beyond comprehension and beyond visibility. If it is not humours, if it is not a wolf or worm, if it is not stagnant fluids, then *what* is the focus of humanity's declared war?

The Rise of the Cancer-Self

A thorough examination of the historic literature, both non-fiction and fiction, reveals a shocking development in the 1970's: the rise of the cancer-self. Related to social changes emphasizing individualism and personal exploration, the rise of the cancer-self is easily seen

with a literature search. Previous to the 1970's, the autobiography or published personal reflections of a cancer patient was relatively rare. As seen with historical figures such as Anne of Austria, Sigmund Freud, and Ulysses S. Grant, usually cancer patients were written about by others in biographical, clinical, or literary forms that discouraged personal reflection unless it was documented by others as narrative or story-telling. The individualism and social justice movements of the 1970's changed all of this, and it transformed both cancer care and the cancer experience. Thomson noted that by the 1970's society (as an entity) had lost the ability to constrain, “and individualism becomes a matter of self-absorption and the quest for self-development. The dominant meaning of individualism is that of uniqueness, or cultivation of the inner self” (2000, p.3).⁴¹ Patient narratives (or autobiographies) published in the 1970's were the first in what has become an increasingly popular way for patients to express their frustration, fears, victories, and legacy. The introduction of the internet in the 1990's and associated explosion in social media (blogs, websites, chat rooms) has allowed cancer to become mainstream and easily accessible (Herndl, 2006).

Thus, the past forty years have witnessed an explosion in cancer identity as a key aspect of academic and popular literature in a way that was impossible and unheard of previously. Some of the finest examples in the post-modern library include Susan Sontag's *Illness as Metaphor* (1977) and Lochlann Jain's *Malignant: How Cancer Becomes Us* (2013). Woven throughout are socially-relevant and reflective cues to identity and cultural thoughtfulness around cancer, and many of these embrace a militarization and 'othering' of the disease. Sontag reflected that cancer attached to symbolism in the 1970's in a way that reflected social mores, including that it was “nature taking revenge on a wicked technocratic world” (p.70). Cancer is, she reflected, nature declaring war on the increasingly unnatural world created by humans, and the most technology advanced suffered most from high rates of cancer. As can be recalled, writers (mostly physicians) have attributed cancer to

⁴¹ The concept of individualism began in the seventeenth century as a new political philosophy. Individualism paralleled the rise of mechanistic science and atomistic philosophy, and itself represents the atomistic conception of society whereby the individual is the primary reality and societies are collections of individuals. Before this philosophy, community was seen as the higher form of unity to which the individual person was totally subordinate. Carried towards extreme in the later 20th century (and into our current epoch), individualism leads to a doctrine motivated towards anarchy and self-as-celebrity. We (post post-moderns) see this today in the popular Western (and arguably international) notion that the state (body politic) should not interfere with individual liberty. See more discussion on this as it relates to cultural development in Sheldrake (1989).

industrialized nations and technologies since the 1600's including tobacco, alcohol, coal, pesticides, luxury, laziness, and more recently, x-rays, television, microwave ovens, and cellular phone transmissions. Swirling ideas around temperament as a reason for cancer continued to persist in the 1960's and 1970's, perhaps only falling out of favour in recent years as a valid area for research.

Transplantation and Biotherapy

It could be hypothesized that the rise of the 'self' in cancer could be in response to an increasingly medicalized system that views the body at a cellular (and organ-ic) level matched with social emphasis on the individual. The stem cell transplant, pioneered in 1957 by E. Donnell Thomas and colleagues at Columbia University (Mary Imogene Bassett Hospital), involved the allogeneic infusion of bone marrow directly into the bones of leukemic patients who had previously received chemotherapy and radiation (Thomas, Lochte, & Ferrebee, 1957; Thomas, Lochte, Cannon, Sahler, & Ferrebee, 1959). Previous to this, patients were fed bone marrow or spleen tissue as a means of treating leukemia, anemia, and chlorosis (Ezzone, 2009). Results of these early bone marrow transplants were positive but temporary, as patients succumbed within a few weeks to leukemia recurrence and subsequent infections and bleeding events from pancytopenia (Thomas, Lochte, Cannon, Sahler, & Ferrebee, 1959). Further developments in the 1960's including the discovery of human leukocyte typing (HLA) improved both allogeneic and autologous transplantation techniques, but poor outcomes in the post-transplant period due to graft-versus-host disease (GVHD) complications discouraged many patients and physicians. Improved chemotherapy drugs, antibiotics and understanding around GVHD encouraged more transplants in the 1970's and 1980's. Ezzone (2009) reports that by 1986, more than 5,000 transplants were performed in the United States. These remained predominantly bone marrow transplants, but increased understanding around blood collection and stem cells resulted in the first peripheral blood stem cell transplants to be performed in 1988 (Kessinger et al., 1989). The use of haematologous stem cell transplantation (HSCT) became increasingly popular for some solid tumours (like germ cell tumours) as well as haematology oncology patients in the 1990's and early 2000's, both in adult and pediatric populations (Ezzone, 2009). Improvements in standards of care, medical technologies, understanding of blood cellular components and

qualities, improvements in medications (such as the development of colony stimulation factors), initiation of GVHD prophylaxis, and preparatory conditioning regimens have resulted in the increased use and popularity of HSCT as well as the application to older patients and more challenging cancers.

For haematological oncology patients, the last 150 years have seen tremendous and swift changes all based on technologies, sociopolitical philosophical changes, and the discovery and understanding of the cell. These diseases have been identified, named, classified. Yet our understanding and labelling of a ‘cancer patient’ has actually changed very little, focusing still on solid tumour cancers. Patients have been privy to more competent diagnoses and improved treatment regimens through increased application of chemotherapy and radiation treatments, cumulating in the ultimate transformation of self: transplantation. Autologous transplantation refers to the removal of stem cells from the patient, and the reinfusion of these cells after marrow-ablative chemotherapy. The goal is that normal, non-cancerous stem cells will have a chance to inhabit the bone marrow and the immune system will remove any remaining circulating cancerous cells. Allogeneic bone marrow and stem cell infusions refer to finding donors with similar genetic traits and transplanting the alien marrow and cells directly into the patient. Most recently, stem cell transplantation using umbilical cord cells has become popular for very difficult haematological cancer patients, including those who are geriatric or have complex or unique genetic qualities. As can be seen, each of these examples deals with highly technological, complicated, revolutionary, modern techniques that focus on curing at the cellular (DNA/RNA) level. The self is actually removed (via chemo-ablation and total body irradiation) and replaced. Transplant health care professionals euphemistically call the transplant date a patient’s “second birthday.”

Similarly important for patients undergoing modern oncology treatment is the recent discovery and broad application of so-called *biotherapies*. Improvements in laboratory techniques coupled with research interest in the function and properties of cells resulted in the first articles discussing biotherapies in the 1990’s. Defined as the fourth modality of cancer treatment, biotherapy refers to a therapy that uses biological agents or approaches to modify a host’s response to disease (Polovich, Olsen, & LeFebvre, 2014). As explored in this chapter, shifting ideas around causes of cancer in the 1900’s implicated a failed immune

response, and as early as the 1950's researchers discovered interferon, a substance released by white blood cells in response to some viral infections (Coleman, 1996). Dedicated research in subsequent decades on how to stimulate a host's own immune response against cancer cells coupled with improved molecular biology techniques and allowed for the mass production of highly specialized recombinant proteins. These cytokines include interleukin, interferon, and colony stimulating factors. Monoclonal antibodies (such as Rituximab), now a highly popular biotherapy for a host of cancers as well as other immune diseases (such as rheumatoid arthritis) were added to the cancer treatment arsenal in 1997. There are numerous articles and books on biotherapies applied to cancer and haematological cancers, and a thorough analysis isn't necessary for this chapter. Suffice it to say that biotherapies are highly specific components of the immune system, created in a laboratory environment and administered to patients intravenously or through subcutaneous injection, and are one of the most promising and popular components of treatment today. Their use in haematology oncology patients includes those with chronic lymphomas (CLL and CML), hairy cell leukemia, and some forms of acute leukemias and lymphomas (depending on their subtyping).

An examination of historical literature reveals a knowledge gap around psychosocial research on the impact of technology and a cellular-emphasis on the patient. This dissertation study aims to address this omission by using identity as a lens. Now that I have presented a biomedical and sociocultural history of cancer, I will tighten my focus on that sociocultural context of cancer as it pertains to identity. In doing so I will highlight the identity concerns by tracing some of the major philosophical discussions that have brought us to the so-called 'fractured' self we know in the post-postmodern world.

A Brief Intellectual History of the Self

Several scholars describe the self in our modern world as "fragmented" and "disintegrated" (Barresi & Martin, 2008; Olson, 1999). The fragmentation of the self is traced to the early twentieth century, but roots for this disintegration lie even farther back in time. Ancient Greeks (around 400 BC) often equated the essential self to the concept of *psyche*, or immaterial soul. Homer and Plato both considered the psyche as the immortal self that would be separated from the body at death as a complete substance and thereby pre-exist

before incarnation in another body. The soul described by these early philosophers in such works as *Phaedo* ensured that the changes undergone during one lifetime are maintained and reborn into a new body. The notion of a psyche is embodied further in the humoral theory of medicine with the triumvirate of soul, body, and mind working together as a symbiotic unity. Hippocrates (460-370 BC) who, as an animist, stated that the soul originated in the heart and that the soul and body could not exist without each other. Aristotle (384-322 BC) was more interested in human nature than he was in individual humans, but he did further develop the notion of the soul as special to humanity. Plants and animals had souls, but these were inseparable from their physical forms. The human soul, by contrast, had a rationale part (*nous*) that was separable and persisting after death of the body but the extent of what this *nous* carried with it is not fully understood (Barresi & Martin, 2008; Sorabi, 2006). Several other ancients tried to tackle the topics of self and soul, but it wasn't until Lucretius (circa 95-54 BC) denied existence of a material soul in his poem *De Rerum Natura* that the idea of a persisting personality in a soul past death was impossible. Lucretius felt that upon death the immortality of a soul was irrelevant "once the chain of our identity had been snapped" (1951, p. 121). Overall, however, according to intellectual historians Barresi and Martin (2008) the classical Greek and Roman people were not really interested in surviving bodily death.

It was not until ideas about self and soul were taken up by Christian thinkers such as St. Augustine (354-430) from the first to twelfth centuries that a self-persisting after death became a passionate focus for the living (MacDonald, 2003). For several centuries European intellectuals accepted this view that each human had one soul linked to one body. In the thirteenth century, St. Thomas Aquinas (1225-1274) tackled persistent questions by debunking animism and stating that the soul did not originate in the heart and it could exist without a body but not as a complete substance. For Aquinas, all living things had souls but only humans could develop their souls through the action of free will. Therefore, the notion of a formless soul was suggested, one that had no formal human shape and that did not require (or desire) human concerns after corporeal death.

What we have for many centuries of Western history is a society that was generally convinced that they had a soul, and that this soul would persist after death in one way or another (MacDonald, 2003). Actions during life would affect, positively or negatively, life

after death (per Christianity). In the sixteenth and seventeenth centuries, the rise of modern science disputed Aristotelian animism on all fronts. René Descartes (1596-1650) is widely credited as the first philosopher to replace the word soul (*anima*) with mind (*mens*). As touched on earlier in this chapter, Descartes turned understanding of cancer on its head by rejecting humoral theory and suggesting instead that cancer is caused by stagnant and acidic lymph. Likewise, Descartes rejected the existence of a soul and instead wrote that self is the mind. The corresponding mechanical theory is known as substance dualism. Dualism required a rigid separation between mind and matter (body) whereby the body is a material substance without thought or feeling. The mind, as the seat of intelligence, is nonphysical and nonspatial, a thinking spiritual substance. Descartes said that the mind occupies a nonphysical realm and is channeled by God into the body through the pineal gland, which decodes information and directs it to other parts of the body. Thus, the separation of body and mind created fertile ground where the body was transformed into a machine that could be acted upon, autopsied, mutilated, and assaulted without concern for existential matters. Without this important leap in thinking, the medical advancements described earlier in this chapter would never have been possible. It was also, however, the beginning of a movement that destabilized the very notion of self (Barresi & Raymond, 2008).

John Locke (1632-1704) developed complex notions about personal identity as a response to Descartes, introducing the notion of memory and consciousness as being the source of self and the components of personal identity. This relational view of identity was heralded by a handful of proponents in the eighteenth century including David Hume (1711-1776) who argued in *A Treatise of Human Nature* (1739, book 1) that the idea of a self that was persisting and substantial was an illusion and that the mind was a fictional construction. The idea of self, he claimed, was socially constructed to serve certain purposes to the benefit of society. Continued philosophizing throughout that century and the next journeyed into the realm of what would become the science of psychology. Johann Friedrich Herbart (1776-1841), for example, thought that the idea of self developed from human experiences with their body activity creating information about themselves (body) in relation to the world in which they interacted. Research on children suggested to several thinkers such as Alexander Bain (1811-1877) and James Mark Baldwin (1861-1934) that children become aware of others before they become aware of themselves (the subjective). The self is only possible by

understanding what is *not* self, and that would be other people in society (relational identity). This concept is, of course, the central philosophy in Georg Hegel's (1770-1831) *Phenomenology of the Spirit* (1807) whereby self-consciousness arises in an individual through reciprocal and dynamic relationships with others who, in turn, verify the existence of the self-consciousness in the individual and therefore in each other.

These philosophers continued to adhere to a singular, unified self that existed but suspicion about this self was growing. Barresi and Martin (2014) describe that analytic philosophy and phenomenology were slowly, but surely, haphazardly introducing the idea that immediate experience was untrustworthy. These authors contend, "it became commonplace to suppose that immediate experience must be understood as a product of social and historical influences and, hence, may need to be cleaned of misleading accretions" (p. 49). William James (1842-1910) wrote *Principles of Psychology* in 1890 and expounded the notion of a personal self which was a composite of both an object (me) and a subject (I). The self-object could be further subdivided into material self (experience), social self, and spiritual self (brain). Personhood, which up to this point had been rarely discussed in the literature as being different from a self, was the "incessant presence of two elements, an objective person, known by a passing subjective Thought and recognized as continuing in time" (James, 1890, p. 371). The notion of the subdivided self persists into the modern times, as does emphasis on a social milieu as necessary for the construction of self-identity. Jean-Paul Sartre (1905-1980) noted that an individual isolated from social involvements was an abstraction. Martin Heidegger (1889-1976), Edmund Husserl (1859-1938) and Ludwig Wittgenstein (1889-1951) all agreed that the self does not exist in private consciousness, but rather is created by engaging in worldly activities. Sigmund Freud (1856-1939) was also interested in the self and human psychological development. In the spirit of phenomenology, his work assumed a real self that existed behind an externally-expressed personality. Knowing oneself required uncovering qualities of the 'real self' which could be done with dream analysis, exploring mental slips, and psychotherapeutic procedures.

It is worth noting that during this period, the concept of identity was really a non-concept. The *Chamber's English Dictionary* (1872, p. 398) defined identity as, "the state of being the same." Gleason's (1983) semiotic history of the meaning of identity reveals, quite shockingly, that the modern meaning of identity came about rather suddenly in the 1950's

coinciding with increasing public interest in personality, gender, and race. Erik Erickson (1964) developed a new idea of *identity* as the merging of psychological needs of the individual (psycho) with the conflicting needs of society (social). This essentialist definition of identity embraced Cartesian dualism and allowed room for a unique human soul/spirit. Therefore, by the second half of the twentieth century, the postmodernist movement characterized by feminism, post-colonialization, and acknowledgement of ethnic, gender, and sexual differences brought about a thorough deconstruction of self into the concepts we recognize today: self-esteem, self-knowledge, self-image, self-identity, self-reference, self-consciousness, *ad nauseam* (Barresi & Martin, 2014; Martin & Barresi, 2008). The result is a contemporary confusion of self with blurred lines from discipline to discipline. Olson (1999) attempted to find a unifying definition of self in the literature and conceded that definitions between disciplines were so different and unrelated that there was no hope of a singular understanding.

Within the postmodernist (and now post-postmodernist) model, defining self is constructivist ontology composed of two realities: alpha reality (objective world of matter and energy) and beta reality (subjective world, the mental world of beliefs) (Voelker, 2017). Several present-day scholars who work exclusively on questions of self and self identity as contained within these realities have determined that theories of self contain three major dimensions: experiential, ontological, and social (Martin & Barresi, 2008; Seigel, 2005). Experiential refers to the first-person experience of the self and on what the experience of self is really like for a human (as opposed to non-human animals). The ontological dimension focuses on what kind of thing the self is and if it exists at all. Where Descartes (and Christianity) embraced a thinking, conscious, immaterial substance as self as transferred into the brain by an external God, current vision of the human self embraces the notion of a material self either as an organism or constituted by an organism (Barresi & Martin, 2014). Finally, the social dimension of self explores how individual humans related to each other socially. Included in this dimension are studies of how infants develop self-awareness, narratives of self-identity, ideals of a good life, issues of social responsibility, and similar socially-driven concerns. The social dimension is how people understand the self as self and as a person engaged in human personhood. These three dimensions represent an atheistic twist on William James' Victorian era model of material, social, and spiritual self.

Understanding beta reality is the focus of most contemporary thinkers who place the self in the organic, material brain (ontology dimension, alpha reality) and seek to understand the association with immaterial social and experiential dimensions. The existence of an organism is *essential* for the beta dimensions to occur, thus implying that existence of the self after death is impossible (as spirit, anima, etc). Neuroscience suggests that self is both everywhere and nowhere *in the brain* (LeDoux, 2002). Emphasis today is on the material world of the living and on a human demigod who can defy death and nature through technology, resulting in what has been titled the “narcissism epidemic” (Twenge & Campbell, 2009).

It is thus within the current context of a disunified self and self-important worldview that emphasizes materialism and the corporeal body along with the singular importance of *self* that cancer patients, and specifically haematological cancer patients, find themselves. In many ways, cancer presents an affront to the idea of self, damaging notions of self-preservation, self-reliance, and self-control. To be a human demigod is to be able to control death with technology, and when it is revealed that this might not be the case, a flood of phenomenological, existential, and spiritual themes come to the forefront.

Discussion: Historical Implications for Cancer Identity

Haematological cancers such as leukemia and lymphoma must have existed in human history, but it wasn't until the technology developed that allowed their nature to be assessed that they existed in the sense of becoming real in the social (collective) mind. This discussion is ontological, as the reality is that they have existed but social constructivism dictates that these diseases did not exist *socially* until they were identified and named in the 1840's. Persons with haematological cancers before this understanding were perceived, and self-identified, as a cluster of symptoms and outward appearances rather than the medical labels we know today. In this chapter I have traced the biomedical and social history of generalized cancer, the discovery of haematology cancers, and have expanded on sociocultural labelling and discussions that related to real or potential identity issues.

This historical inquiry has allowed several major threads to be teased from the historical record, including the discovery (for all intent and purposes) that haematological cancers are old but, in reality (per social constructionism) are *relatively modern*. Despite the

focused review of the literature offered in this chapter highlighting cancer for the past two thousand years, cancer previous to the modern age was relatively rare (Rosalie David & Zimmerman, 2010). Contemporary thinking holds that as much as 75% of cancers can be linked to environmental factors, tobacco and alcohol use, and pollution occurring since the beginning of the Industrial Revolution some 250 years ago (Halperin, 2004; Lilienfield, Pedersen, & Dow, 1967). Add in questionable dietary additions (like chemicals and preservatives) and lifespans expanded by decades, and statistically-speaking, cancer is more prevalent in our modern age. Early on, several distinctive tumours have been associated with industrial functions including scrotal cancer in chimney sweeps (in 1775 by Dr. Percival Pott) and nasal cancer in those using snuff (in 1761 by Dr. John Hill) (Rosalie David & Zimmerman, 2010). Today cancers are linked to smoking (lung), alcohol (liver, pancreatic), radiation (leukemia) and a host of other causes from genetics to viruses. Johnson (2013) writes, “there is something comforting knowing that cancer has always been with us, that it is not all our fault, that you can take every precaution and still something in the genetic coils can become unsprung” (p. 2). He is, of course, referring to solid tumours, which can be documented as truly being ‘with us’ for thousands of millennia.⁴² The situation is a little less clear for haematological cancers, which theoretically have been with us for the same amount of time, but ontologically and epistemology came into existence 150-years-ago. This fact has tremendous conscious and subconscious implications for the oncology haematology patient, including the inability to easily locate themselves on a historical timeline and the stark fact that their disease and treatment are directly related to the cell. The cell, therefore, takes on metaphoric and personal implications that have not been adequately explored in academic literature

In many ways, haematological cancers occur within a modern context but carry with them many of the labels and assumptions developed around generalized cancer. Identity for haematological cancer patients is saturated in time, literally, as it is time (and invention) that created them in the first place, ontologically speaking. One must be a modern (i.e. someone born after the invention of the steam engine) to (technically) have a haematological cancer,

⁴²The earliest evidence for human cancer exists in a 4-million-year-old fossilized bone of *Homo kanamensis*. Discovered by Louis Leaky in 1932 in Kenya, the left side of the jaw contained a large osteosarcoma (cancer of the bone) (Johnson, 2013).

so referencing ancient Egyptian texts or knowing that your ancestor so-many-years-ago might have suffered similarly (as what happens with solid tumours) is impossible. It is my intention to incorporate questions around historical context into my primary data collection interviews, seeking understanding around a concept of identity that is by its *historic nature* different than solid tumour cancer patients.

Cancer as Person

As discussed in this chapter, cancer has long been anthropomorphized in two ways. The first was the relationship between cancer diagnosis and temperament, and the second in that cancer has been portrayed as sentient, animalistic yet at the same time clever and thoughtful in the same way as a human. The wolf, the worm, the crab are animals and yet their behaviours were distinctly *human*. Mukherjee captures this essence of personhood succinctly by titling his book, *The Biography of Cancer*:

In writing this book, I started off by imagining my project as a “history” of cancer. But it felt, inescapably, as if I were writing not about *something* but about *someone*. My subject daily morphed into something that resembled an individual – an enigmatic, if somewhat deranged, image in a mirror. This was not so much a medical history of an illness, but something more personal, more visceral: its biography.
(p. 39)

More so than any other disease, cancer has been given human attributes and characteristics in a way that almost give it human form, a human essence. Perhaps it has taken the post-modern focus on self for us (as a species) to reach this understanding of cancer.

The increasing postmodern emphasis on the personal is reflected in Jain's intimate auto-inspired writings about her breast cancer experience. She noted, “cancer, in all its nounishness, refers to everything....and nothing...” and post-treatment “the main tumour s were gone: *cancer* had only just begun” (2013., e-book loc. 165/6934). Cancer, then, is more than disease and society and technology, more than a war. Jain suggests that cancer is a process instead of a destination: “Cancer *is* our history. Cancer has become us” (2013, e-book loc. 242/6934). Within her personal narrative new identities emerge for cancer patients including 'cash cows' and victim in regard to a capitalist system versus a disease. Cancer is

“the pathology report, the prognoses, the scars, the data and graphs, the looks on parents' faces, the shiny hospitals with their infusion rooms and IV drips, the marches and fundraising” (e-book loc. 382/6934). Therefore, if we adopt Jain's current hypothesis, the modern vision of cancer is beyond disease, tumours, humours, wolves or crabs, and it is beyond the personal, beyond embodiment – it is one of total being. If cancer is identity, literally and figuratively, how does this play out for the cancer patient?

Person as Own Cause for Cancer

Historically, cancer was associated with certain personality types or with strong emotions (such as grief). Because cancer has been attributed to temperament/constitution for so many centuries, it is assigned to specific people with certain personality traits and thus cancer was a disease caused by overlying personality traits of the self. These could be people who are excessively nervous, depressed, or those with recent trauma, or those who have an undue amount of stress that they are unable to handle. Therefore, historically cancer identity has been linked with temperament in a way that has become politically-incorrect to pursue academically. Today and since the 1700's, cancer has been increasingly associated with behavior and personal lifestyle choices such as alcohol and tobacco use, environmental, and occupational. In an era of individualism to the point of narcissism (in some cases), the notion that the person (i.e. you) are responsible for your own cancer is becoming increasingly popular (Nettleton, 2013). Cancer is now an illness that people are responsible for, and the individual must work to avoid through self-surveillance (i.e. screening, doctors visits). Therefore, the modern cancer experience is one of 'individual responsibility' entwined with a survivorship identity (Gibson et al, 2014; Kaiser, 2008, Willig, 2009; Willig, 2011). As pointed out by Gibson and colleagues (2015), identity is now closely tied to the notion of treatment transitions (for example, active treatment to end-of-life) and self-responsibility, and these concepts hold critical implications that negatively impact the survivorship experience.

The very nature of haematological cancers has kept them hidden and mysterious throughout history until the invention of the microscope, thus confirming their (continued) nature of indiscernibility. Even today, most cancers are diagnosed on or near the surface of the body when visual symptoms become obvious – weight loss, a large protruding mass, a painful area, a non-healing wound, bleeding. Some haematological malignancies (like

leukemias) do not create obvious surface aberrations and are therefore invisible, and this gave our historic counterparts grave concern in a similar way it bothers modern patients. In this way, leukemia is particularly insidious and confusing for patients because it truly is *silent*. Only the symptoms point to the fact that something is wrong. For their sake, lymphomas and multiple myelomas may create masses (albeit lesions on bone or swollen lymph nodes), so in many of these cases there is a physical manifestation of disease. Quickly, however, diagnostics determine it isn't the "usual" solid tumour to be blamed, and thus these patients also enter the unknowing realm of being blood (or "liquid") cancer patients.

Blood as Vitalism

The meaning of blood as a symbol has also changed over time.⁴³ As discussed, blood was seen for millennia as a means for a cure (mostly by bloodletting, which allowed regeneration and new blood to flow unopposed). The notion that blood was a carrier of disease had radical implications on social understanding of blood. To consider that most of Western culture is based on a Christian sociocultural tradition, this biblical phrase takes on new meaning: "the life of the body is the blood" (Genesis 9:4; Leviathan 17:11). The agent of cure became the harbinger of doom. The haematological cancers (leukemia, lymphoma) are just some examples of how the invention of the microscope changed social view of blood, its purpose, content, and abilities. Blood as a carrier of disease (literally) is also an accompanying modern discovery that arose from scientific understanding of diseases such as anemias and infectious blood-borne agents like malaria. In his book *Blood* (1998), Douglas Starr divides the cultural history of blood into three eras: blood magic (antiquity to early 1900's), blood wars (1920s-1960s), and blood money (1960s to present). His point is to show how increased understanding of blood, courtesy of the researchers in the eighteenth and nineteenth centuries, changed the sociocultural and political understanding of blood as both a symbol and resource. Throughout, however, blood has retained its association with vitalism, the ability to carry within the essence of the creature in which it flows (2012, e-reader loc.

⁴³ The symbolic meaning of blood is important for this dissertation as a component of overall understanding patients have about their disease and what it means to them. It is the central tenet of a blood cancer, after all; however, a thorough analysis of blood as a sociocultural and political resource is not expanded on in this dissertation. It can be noted that most of the academic literature on blood deals with history of blood as a clinical topic, i.e. blood transfusion (or resource to be used). For example, see Bradbourne, 2002; Heir, 2002; Learoyd, 2012.

231/554). Heir (2002) makes the important distinction that blood has historically been a mystical substance composed of spirit, soul, or energy, and not as the identity of the individual or of life itself. Transferring this idea to haematological cancers (and disorders), if the blood carries disease what does that say about the essence of the creature? This intimate relationship between the meaning of blood and its symbolism for the haematology cancer patient is unexplored in the literature, but absolutely reflects a critical and intriguing element in regard to psychosocial disposition as well as treatment choices and overall reaction to disease.

Somatization and the Cancer Body

Somatization describes illness as “a culturally constructed experience of disease” (Zimmerman, 1995, n.p.). The medical anthropology and medical sociology conceptualization of somatization (illness as lived experience informed by culture) versus disease (as an analytical construct describing a biological condition) arises from closely analyzing the historical relationship between emotion and physical manifestations of disease. Identity, then, is really about the somatization of cancer (for this dissertation), in that identity is a component of the larger culturally-constructed and influenced experience. Throughout history, the relationship between cancer and animals, particularly animals that can bite and gnaw, is striking. Skuse (2015) pointed out that during the Middle Ages and early modern period, wolves were “consistently associated with the extinction of the self” (p. e-1516). Historically then, self-identity is literally and figuratively eaten by cancer. As the body was being attacked so was the person: their essence, being, social standing, ability to work, personality, and support network. Cancer attacks the entire person including the physical, social, mental, and emotional aspects. Cancer has implications for each of the three post-postmodern dimensions of self: experiential, ontological, and social. Since I have established that many of the cancer narratives and metaphors used historically applied to solid tumour cancers, it is intriguing to understand and explore how these same visions and symbols are (or are not) embodied in our modern haematological cancer patients.

Summary and Application

This chapter represents a historic inquiry into how blood cancers have been characterized and explained in the past around issues of identity. To frame this complex discussion, I first reviewed and reflected on biomedical developments and associated sociocultural elements for cancer and concluded with a discussion of major concerns related to identity and the experience of blood cancer. As layer two of this study, this research has contributed contextual richness and context around cancer identity as experienced over the course of time in a way that is both unique and enriching to the conduct of qualitative research. Since cancer has been a devastating human disease for thousands of years, references to it appear in the literature at several points throughout history in ways that have shaped our modern sociocultural understanding of the disease. Through incorporating and intermingling different timelines and reflections of past and present in through research in the first two layers (Phase One), I have developed a rich foundational understanding of identity within the context of haematological cancers. Subsequently, the following chapter presents a secondary analysis of an existing database of cancer patients which constitutes the final layer of Phase One research. As this chapter was affected by knowledge gained from layer one research, I anticipate that future research layers will incorporate the historical understandings around cancer, blood cancers, and identity developed in this historical review. Completion of Phase One research will signal subsequent development of semi-structured interview questionnaires used for data collection with patients and clinicians in Phase Two research. At this point in my study, I anticipate that future research layer discussions and findings will be deeply affected by foundational knowledge gained from both the integrative literature review and historical inquiry.

Chapter 6: Secondary Analysis of an Existing Qualitative Database

Introduction

This chapter (which constitutes layer three of Phase One data collection and analysis) is a secondary analysis of qualitative data from an existing database on communication in cancer care. This qualitative secondary analysis was undertaken to explore themes of self, personhood, and identity in cancer patients within the context of patient cohort. The goal of this qualitative secondary analysis was to identify issues for haematological cancer patients to subsequently investigate further in the new primary interviews undertaken in Phase 2 of the current research (both with patient and clinician cohorts). The secondary analysis also was positioned within this dissertation as a focused and thoughtful way to generate novel evidence data, indicate gaps in knowledge, and formulate original insights about identity issues among patients with haematological cancer, which was done by exploring the way in which their reports about communication with health care professionals reflected aspects of their experience. This chapter first discusses secondary analysis as a form of research inquiry, then details the methodological and theoretical considerations used to conduct this analysis. The chapter closes by detailing the research findings arising from secondary analysis. A discussion of findings follows, including implications that these had for the overall dissertation purpose which is to focus attention on identity as a strategy for better understanding the haematological oncology patient's experiences.

Background to the Research Strategy

Hinds, Vogel, and Clarke-Steffan (1997) recommended secondary analysis as a means of exploratory analyses that could supplement subsequent primary data collection. Gaining momentum as a legitimate form of qualitative inquiry since the 1990's, secondary analysis of an existing database is often referred to as qualitative secondary analysis (Thorne, 1994). A new research question is applied to a database of qualitative data gathered for a previous research study (be it interview transcripts with or without collateral materials such as research diaries, field notes, or questionnaires). Sandelowski (1997) described qualitative secondary analysis as a strategy for getting the most benefit from existing data sets in a way

that allowed additional research questions to be asked of data originally created for a different purpose. Thus, a new study can be related to the original research study questions, but it may also constitute the creation of a fresh research question that is thereby applied to the existing database (Heaton, 2008). There exist three modes of data sharing within qualitative secondary analysis: formal, informal, and self-collected (Heaton, 2008). Formal data sharing refers to the use of data by researchers who did not have a role in the collection of the data. Informal data sharing reflects a similar use of data by researchers who were not part of primary data collection, but who interact with the original researchers in a way that can create additional layered meaning due to increased availability of contextual knowledge. Self-collected data sharing refers to the use of a researcher's own database for a new purpose or to validate their own previous findings. The qualitative secondary analysis represented in this Chapter reflects a desire to investigate a new research question utilizing the information data sharing modality, as the primary research team is both available and interactive in terms of providing information or context as needed.

The research question for this secondary analysis was: how do haematological cancer patients reference identity in their descriptions of, and communication about, their cancer? This research was undertaken to expose a potential dichotomy of opposing experiences: that of solid tumour patients and of haematology cancer patients. This strategy was chosen as a way to frame this dialectic and ultimately generate some understanding of similarities and differences in both cancer subgroup experiences. Through my reading of transcripts from both subgroups and comparing and coding the data, patterns emerged during analysis of the data in a way that signaled some key differences in descriptions and experiences. Reflection on these coded themes then allowed for a more precise and focused examination of the haematological cancer patient experience around identity and self.

In determining fit between a dataset and question for secondary analysis, it is critical to consider the original methodological orientation of the data collection process including the interview design. Over or under emphasis of themes is possible in a secondary analysis that is not properly grounded in the research design and implementation process (Thorne, 2013). Thorne (2013) also emphasized the importance of familiarity of the secondary analyst with the nature of the data in the fullest sense possible, not only in regard to the original

health phenomenon (in this case, communication with health care providers), but with the data in its fullest sense including idiosyncrasies and assumptions of the research team that created and produced the research product. An informal data sharing relationship (per Heaton, 2008) was established when I had the privilege of working directly with the UBC Communication in Cancer Care team for several years in research planning and discussion meetings (2010-2012) and served as research assistant in transcribing and coding interviews. This experience allowed me full access to the interview database and the opportunity to intimately know both the researchers and the data in a way that would not have been possible in a formal data sharing environment. Therefore, acknowledging the limitations of secondary qualitative analysis posited by Thorne (2013) in regards to knowing the database and research team intimately as to avoid misinterpreting themes, mistaking issue relevance, or crossing ethical lines through excessive fabrication, I believe that my personal involvement with the research team and their goals and methods for research as well as familiarity with the inclusive database helped safeguard against these potential pitfalls in analysis.

Methods

Dataset

This sub-study represented a qualitative secondary analysis from interview transcripts within the UBC Communication in Cancer Care database (CCC). This database consists of individual qualitative interview data gathered from three linked studies conducted between 2001 and 2013 which focused on patient perceptions of what was helpful and unhelpful in relation to cancer communication with health care providers (Taylor, Thorne, & Oliffe, 2015). The three studies represented sequential steps in the overarching CCC research program. Study 1 (2001-2004) consisted of interviews with 200 cancer patients undertaken through face-to-face recorded interviews as well as telephone, email, and focus group interviews. This data informed Study 2 (2005-2009) which involved highly detailed longitudinal interviews with a patient cohort of 63 newly diagnosed cancer patients. This study extended five years to track changes in communication patterns and needs over the course of cancer care. Study 3 (2009-2013) expanded on the longitudinal cohort recruited in Study 2 and involved recruiting a new patient cohort of 62 participants with metastatic disease as well as those self-identified with “diverse” communication needs (Taylor, Thorne,

& Oliffe, 2015, 111). Each study was conducted with continuous ethics board approval, and consent forms were explicitly written with an open-ended option for ongoing secondary analyses. Participants across the three study arms totaled 325 and represented a wide variety of demographic, disease, and treatment options. The overarching goal of interviews contained within this database was to understand and explore the changing communication needs and preferences for cancer patients across the cancer trajectory (Thorne et al., 2014).

Subset Sampling and Inclusion Criteria

The database for this secondary analysis constituted a subset of transcripts strategically drawn from the original larger University of British Columbia Communication in Cancer Care database as described above. To try and better understand the haematological cancer patients' experiences as potentially different from that of patients with solid tumours, a strategically selected matched data subset was created. This allowed reflection on the multiplicity of experiences represented by both subgroups, generating different reference points within an overall complex structure of the experience of identity. I examined 30 interviews existing of two sets: 15 haematology oncology patients matched with 15 demographically similar non-haematology (solid tumour) cancer patients (see Table 1 for details). This method of matching subgroups took into consideration the sufficient and rich information available within each subset and provided substantive interview data in which to search for clues and references to identity. Closely matching subgroups allowed for a comparative strategy that generated useful and unique insights which informed the overall inquiry. My intended purpose was not an explicit comparison between solid tumour patients and blood cancer patients because I assumed, naturally, that there would be considerable commonality within the experiences. Rather, the purpose of examining both kinds of cancer patients was to bring into clear relief those aspects that seemed distinctive about the experience of the blood cancer patients.

Table 1: Demographic Qualities of the Matched CCC Database Subgroups

| | Solid Tumour Cancer Patients | Haematological Cancer Patients |
|------------------------|-------------------------------------|---|
| Age Range | | |
| 30-39 years | 1 | 2 |
| 40-49 years | 0 | 0 |
| 50-59 years | 8 | 8 |
| 60-69 years | 5 | 4 |
| 70-79 years | 1 | 1 |
| | <i>n=15</i> | <i>n = 15</i> |
| Gender | | |
| Male | 6 | 7 |
| Female | 9 | 8 |
| | | |
| Diagnoses (primary) | | <i>All are classified as “haematological” or “blood” in the CCC database.</i> |
| | Breast: n=4 | Multiple Myeloma: n=1 |
| | Lung: n=4 | Hodgkin’s Lymphoma: n=2 |
| | Gastrointestinal: n=2 | Non-Hodgkin’s Lymphoma: n=7 |
| | Prostate: n=2 | Leukemia: n=4 |
| | Kidney: n=1 | Unspecified: n=1 |
| | Endocrine: n=1 | |
| | Appendicile: n=1 | |

Methodological Considerations

This secondary qualitative analysis constituted the third of three preliminary layers of this study and was designed to build a perspective on multiple angles on the nature of the experience of self and identity for haematological cancer patients. Through scholarly literature, a historical literary review, and analysis of existing accounts, these three layers of interpretation set the stage for subsequent data collection with patients and clinicians. Key findings from the integrative literature review (chapter 4) and historical inquiry (chapter 5) provided fundamental concepts, terms, theoretical groundings, and thoughtful impressions for examining the matched datasets drawn from the larger Communication in Cancer Care database. This multilayered foundational grounding granted structure and a means for examining an existential and highly subjective concept like identity within a dataset created for another purpose (i.e., that of helpful and nonhelpful communication with healthcare providers). That is not to say that these exact themes or terms were the only indicators of identity explored within the dataset, but rather that these themes and terms triggered the identification of elements in the data that could be considered related to identity and identity issues. Overall, I employed logical inference strategy, whereby findings from previous chapters were considered a useful way to facilitate coding the data while simultaneously assessing the appropriateness of inclusion or exclusion within this study. For example, from the integrative literature review (Phase 1, layer 1), I was sensitized to the potential that nutritive references and role erosion might be cues for aspects of identity. Similarly, the importance of sociocultural labelling within the research literature signaled the potential use and role of terms like “victim,” “survivor,” “conqueror,” and “member of the cancer community” by participants. Some ideas that came forward from the historical inquiry (Phase 1, layer 2) included the significance of time and temporality to identity, not only on a personal level but also within the constructs of a greater social narrative. The intertwining relationship between the person and cancer throughout history also alerted me to a range of notions about self-surveillance, personality, emotions as well as how lifestyle choices and physical appearance can affect personal identity.

Thorne (2016) describes the analysis process as vital, saying “knowing your data means dwelling in it repeatedly and purposefully and developing a relationship with it” (p.

167). In order to find meaning and relationships between data bits and organize them into groupings, several sorting options were employed. By examining transcripts from both solid tumour and haematological cancer subgroups, careful attention was made to references around identity that expanded clarification and deepened meaning from the data in a way that honoured both. However, the risk of reading too much or too little into the text was ever-present as a secondary analyst, and therefore a more structured approach to analysis method was necessary. I therefore modeled a systematic method to informally guide the analytic process based on logical steps suggested in thematic content analysis and meta-analysis processes as proposed by authors McCormick, Rodney, & Varcoe (2003) and Riegel and Dickson (2016). This included a preliminary reading of the transcripts to envision a collective whole of the cancer experience. The transcripts were then read in subset groupings and references (both specific and non-specific) to identity based on themes previously identified were flagged both in both hardcopy and in NVivo™ software (version 10.0). Reflexive journaling was used throughout the analytic process to capture questions arising, critical reflection points, key themes, and explore dialectical relationships. Line-by-line coding was not used (as would have been done in Grounded Theory, for example), but rather general references and concepts were coded to allow grouping and comparison.

In doing this qualitative secondary analysis I paid attention to both explicit and indirect references to identity. Included among these were specific and nonspecific verbalizations (such as saying disease name or never mentioning this fact), phrasing, verbal and (if available) nonverbal communications around identity and associated themes (such as body image, embodiment, personification, being, self). For example, reiterative questions I considered while reading each transcript included how haematology oncology patients referenced themselves, and how did they use language? How was this similar or different to how the non-haematology oncology patients referenced themselves, or was there evidence of a kind of continuum? As I examined more transcripts, constant comparison was utilized to stimulate reflective thinking and allow deeper reading. Attention was given to the context and location within the flow of conversation that the references to self, disease, or identity were found. Finally, pronouns and other self-descriptive phrasing were carefully analyzed with the purpose of understanding how the patient spoke about self when not being asked specifically to describe their personal situation or disease.

Comparisons, discrepancies, and similarities between these two cancer subgroups highlighted ways in which haematology cancer patients were the same or different than their solid tumour colleagues, but also served to expand knowledge around the identity experiences of haematological cancer patients. By comparing similarly-coded sections in the matched subgroups during the data analysis, and by comparing the different nature of language, narrative, and metaphor between the two subgroups, I was able to identify several themes. In cases where it seemed appropriate to highlight a specific apparent deviation in experience between the solid tumour and haematology patient cohorts, I have featured data and quotes from both subgroups to illuminate the key observations.

Findings

This qualitative secondary analysis was developed to explore observations around identity issues for generalized cancer patients, and then to pursue specific identity concerns expressed by haematological cancer patients in a way that would illuminate aspects to explore further in the new primary interviews undertaken in Phase 2 research (both with patient and clinician cohorts). Chapter 5 introduced three dimensions of identity used by modern researchers to discuss identity in a way that honors both inherent complexities and an attempt at theoretical integration. To review, these dimensions included the ontological (what kind of *thing* is the self), experiential (first person experience of self), and social (relational). The integration of these complex dimensions constitutes what is known as the *embodied* self. Drawing on these three dimensions to stimulate my insights with respect to the material, I observed what seemed to be some unique identity concerns expressed within the data sets by haematological cancer patients. Findings in this study were, therefore, organized around themes that encompassed all three of these dimensions: self with cancer (*ontological*), the abstract self (*experiential*), the suffering self (*experiential*), and the disconnected self (*social*).

Self with Cancer

Within the interdisciplinary literature on identity, the notion of an ontological dimension embraces the actual material self, the physical, corporeal body serving as the organism on which social and experiential dimensions are enacted. Ontological inquiry asks,

what kind of thing is the self? Participants talked about cancer by referencing their physical *self*, the disease they had, and the effects the disease had on them. Within the data, lymphoma patients referenced their “tumours,” in general terms, often associating the more troublesome tumours (or bulky masses which were actually lymph nodes swollen with cells) with specific anatomical locations (for example, left abdomen or inguinal). Multiple myeloma patients spoke of bone pain and referred to the location of their pain as the focal point of concern. Leukemia patients were unique in that they did not refer to organs or precise locations on the body. As data from this secondary analysis suggests, leukemic patients spoke predominantly of blood and blood counts referencing (in many cases) specific cells and cell types (i.e., white blood cells, neutrophils) and they discussed their cancer in terms of labwork and stages of treatment. The leukemic patients within this dataset referred to their disease as “this disease,” “a serious condition,” or simply, “cancer.”

Several participants did not mention their specific cancers (for example, “acute myeloid leukemia”) but instead used other phrases such as “this disease,” “a serious condition,” “blood cancer,” and simply “my cancer.” Some used the acronym only, such as “CLL” or “NHL.” Others used the more general informal title: “Hodgkin’s” or “non-Hodgkin’s” or “lymphoma” referring to non-Hodgkin’s lymphoma or “leukemia.” For patients with leukemia, attempts to describe their disease were often focused around side effects of both disease and treatment and tended to trace the passage of time. For example, one patient discussed self in terms of shifting white blood cell counts and of being “acute” rather than saying *leukemia*. Absent from the data were active self-concept phrases like, “I am a leukemic,” for example, or “I am lymphomic,” although participants did talk about themselves in terms of “patient” and “survivor” quite consistently.

Peering more closely at these labels, cancer was described as an outside entity that had entered the body and thus the self. Reviewing a CT scan with her physician, a patient noted in the images that, “it is running all over my body, this lymph node and this one and it’s not just a spot and then I said, Oh my God.” Another lymphoma patient explained, “clearly, it wasn’t... until I went to a conference a month later, a daylong conference that I understood that lymphoma covered infections that are spread throughout the body and tumour s.” Still another Hodgkin’s lymphoma patient pointed out the complexity of the situation by saying,

“you know, these tumour s that are all over the place. . . .” This ontological notion of the physical body as penetrated by *something else that is not self* persisted, even through the invader was (in reality) a manifestation of the physical self in that cancer is a mutation of body cells. Therefore, as an ontological consideration, consideration of the self with cancer can be described as related to cancer in a way that cancer is not self, but somehow an expression of self intertwined with the experience of living with cancer.

The Abstract Self

This notion of the cellular was further fleshed out by a process of abstractification, which constitutes an experiential dimension of self. Abstractification refers to analogous way of looking at things in which something exists only in its idealized form. It can also refer to a process of conceptualizing abstruse subjects in a theoretical way in order to clarify and create meaning. This makes sense within the context of an experiential dimension of self, which describes the first-person experience of self-hood. The focus of the experiential is on explaining what the human experience of self is like, and what role these experiences play in everyday living as a human being. Furthering the ontological dimension of self with cancer, analysis of the interviews revealed that patients tended to discuss their disease experience in terms of what happened at an abstract cellular level. Blood cancer was often a discussion about cells, blood work, laboratory test values, and cell type. This makes sense within the context of the original data collection process which focused on communication with health care professionals, therefore encouraging discussion about a biomedical experience. Overall, lymphoma patients discussed blood cell counts to a lesser degree than the leukemic patients, and more closely resembled solid tumour patients in that they tended to reference bulky tumour-sites or swollen lymph nodes. Without being able to mention specific organs, many lymphoma patients spoke of confirmed tumour sites (*confirmed* because they had been visualized through diagnostic imaging) as well as palpable swollen lymph nodes (cervical or inguinal locations predominantly). A patient with mantle cell lymphoma, a rare type of non-Hodgkin's lymphoma that affects the B-cell (a type of white blood cell) noted that the only sure way to follow disease progress was to follow blood counts. A Hodgkin's lymphoma patient stated that, “cancer makes you the personal caregiver of your cells, not just the body,

[you] focus on the cellular.” A lymphoma patient described that the purpose of allopathic medicine was to maintain “the cellular body” and the “cellular structure.”

Patients with leukemia tended to talk about themselves and their disease almost exclusively by referencing lab values to describe explicit cell levels. Specifically, they discussed the complete blood count with differential (CBC with Differential) values and how this changed throughout the course of their disease and treatment. For example, they referenced something about WBCs (white blood cells) of 0.9, hemoglobin of 89, or platelets of 24. Each leukemic patient (n=4) in this data set carried a journal in which they had written their daily lab values, claiming the purpose of this record was so they would be ready to discuss their condition and progress with fellow patients or health care providers. When speaking about their disease, leukemic patients positioned themselves against this numerical background and painted a picture of symptoms and associated treatments through which they envisioned their leukemia. The lab values (numbers) captured the essence of their level of wellness or illness on any given day. Any mention of an organ or anatomical place was about a symptom, and not to the cancer itself. These references to cancer were rather numerical, medical, and pathophysiological, reinforcing a notion that cancer was external to the self and could be described in emotionless, personless terms.

Laboratory blood work values cited frequently by blood cancer patients sought to inform about the personal status of disease within a highly medicalized languaging and knowledge base required to understand haematology cancer. By doing so, blood work and associated allopathic medical terminology only served (unintentionally perhaps) to make the cancer more mysterious to others outside the biomedical realm. This abstruseness was particularly true within a common metaphor found among the haematological cancer patients who referred to themselves as “machinery.” One Hodgkin’s lymphoma patient stated, “They’re my mechanic..... I’m the client,” implying a business-like relationship of a broken vehicle (body) that needed to be repaired. This same patient later noted that “the doctor is my mechanic. He’s working on me. I’m his client. He needs to treat me very well. I’m essentially paying this person.” This patient seemed to see the doctor as an extension of cellular processes, a reflection perhaps on a lack of control that he (himself) had over his own cellular

body. The notion of paying the physician then gave the impression of a grasp for control. Another leukemia patient made a similar comparison:

I go to see my dentist on a regular basis because they're health care professionals and all of them, my dentist and my eye doctor and my regular GP I've got a lot of respect for them and so it's like maintaining a machine, if you, if you take a piece of machinery or equipment and just use it and use it and use it, never service it, never maintain it, sooner or later it's just going to drop dead, oh well it was working yesterday, well that's, uh, so I'm quite comfortable with the health care professionals....

The patients reflected in the above examples were speaking about experiences within the context of health care communication and how they wanted the HCP to communicate with them. It is interesting to note, however, that in each of these instances a direct comparison was made to body (self) as machine. As discussed in chapter 5 (historical inquiry), this could challenge a sociality-accepted view of Cartesian (subjective) dualism in which the body (machine) was separated from the self (soul, anima). Instead, the separation of soul from body allowed the participant to rationalize the cancer as *other* and allowed for a sense of control to occur by incorporating a third party (physician) to repair a broken body. The data did not contain references to animals, invaders, thieves, and other anthropomorphized creations as done throughout history.

Blood cancer patients in this study also reflected abstractification over the *type* of disease they had. Several participants indicated confusion experienced by haematology cancer patients at diagnosis about what "blood cancer" meant: How can blood, a liquid, have cancer? For example, a patient described being told she had lymphoma instead of stomach cancer. She felt relieved, telling the doctor, "Sounds to me, it's not that bad,' but I've no idea about that." This same patient asked for her lab values: "then I took the report... and ask[ed] my GP at the ward but at first she said, 'what is lymphoma?' So then I said, 'I don't know.'" Similarly, another lymphoma patient described the moment when his physician told him he had lymphoma: "he said, lymphoma is a kind of cancer...he allayed those fears in me when he said it's treatable and curable and at that point I was not really knowledgeable about

lymphoma.” Another lymphoma patient who presented with diffuse stomach discomfort stated that:

my oncologist told me I had lumps in my stomach.... and she says, 'well I told you several times you had lumps in your stomach,' and I couldn't, I couldn't, it wasn't until I went to a conference three weeks later that I understood that I was diagnosed with lymphoma and I remember, 'what's that?' I had no concept of lymphoma, what's cancer?

A multiple myeloma patient was overwhelmed at a diagnosis of something he had never heard of before. He noted, “of course I’d heard of leukemia and lymphomas but I’d never heard of multiple myeloma, I don’t know what the hell it was!” A Hodgkin's lymphoma patient attended a conference on lymphoma, only to find out he was in a conference for non-Hodgkin's lymphoma. It was a case of mis-identity:

Um, I got, um, do you have cancer, um, I haven’t really been told I have cancer because I have lymphoma. What’s that? It’s a type, oh you mean Hodgkin’s lymphoma and it’s no, there’s different, there’s different, lymphoma actually is a, at the conference they talked about lymphoma being the hugely expanding area of cancer maybe, uh, in the community, um, so that’s a separation from the Hodgkin’s aspect.

This patient followed up this anecdote by likening lymphoma to the French language, telling the interviewer that he didn’t understand either. This could indicate a reference to seeking control, because although foreign at first, French is a language that could be learned with proper training and perseverance. In this example, self-identity was linked with the precise type of lymphoma (Hodgkin’s) and not to the general cancer of lymphoma. In this way, abstractification of the cancer self was indicated by reference, again, to the cellular level of disease as identity as well as the highly biomedical definition. As discussed above, abstractification might express a desire or effort by the patient to regain some control. By accepting the body as abstract, this might have allowed them to align more with physicians and the healthcare team which, of course, were the only ones able to help them treat their disease.

The Suffering Self

Pain is now understood as a multi-dimensional entity with a multitude of qualities including sensory, affective, motivational, and cognitive components (Kumar & Elavarasi, 2016). Pain is closely associated with the cancer experience. Lymphoma and multiple myeloma patients all spoke of experiencing physical pain as a central component of their disease. In every instance, pain was referenced as a local and specific phenomenon. Pain was central to discussions around comfort, treatments, and palliative care. For example, a young Hodgkin's lymphoma patient described the experience of pain in her hip and lungs as the primary indicator of disease, and subsequent treatment with chemotherapy aimed to shrink masses in this area. Return of pain in these body locations indicated she was out of remission. Another lymphoma patient called her disease "the lumps" and spoke exclusively of affected body organs, even though the organs themselves were not diseased but were rather affected (or compressed) by lymphoma tumours. Pain was also a major social indicator of disease. There were multiple examples within this dataset where pain was the primary presenting concern and marked entry into the health care system. For example, a NHL patient went to her doctor with "left hip pain." Another lymphoma patient had stomach pain. A mantle cell lymphoma patient presented with sore lumps in her breast and groin. Many patients felt a need to discuss pain as proof of having disease, as justification for their behaviour or appearance.

The pain described by these participants, while somatic in the sense of being caused by both treatments and disease, also encompasses a highly complex array of psychological mental pain and emotional anguish. This could be considered pain associated with *suffering*. Kumer and Elavarasi (2016) describe suffering as the experience of pain coupled with the "vulnerability, dehumanization, a loss of sense of self, blocked coping efforts, lack of control over time and space, and inability to find meaning or purpose in the painful experience" (p. 88). From the interview texts reviewed for this secondary analysis, most of the cancer patients demonstrated qualities generally associated with suffering, and in some cases with iatrogenic suffering. Many spoke of the dehumanizing nature of cancer, expressed mental anguish and depression, and embarked on a variety of coping mechanisms that were not always healthy or helpful. A leukemia patient described her experience of suffering as, "I've

given up so much of what it meant to be who I am and I haven't replaced it with meaning... Everyone else has a life and leukemia isn't their life." This statement reflected a notion of a lost identity, or perhaps stolen identity. It also hinted at a social disconnect brought about by the blood cancer, one which signaled those who had leukemia (self-identity label) versus those who did not have leukemia.

Suffering seemed to be taken up in the context of outward appearance of being or not being sick. Haematological cancer patients often explored the notion of 'looking sick' as a critical element in the overall cancer experience, and the ability to hide being sick or having cancer allowed them to resume (at least publicly) their pre-cancer identity. A participant with non-Hodgkin's lymphoma described it best by stating, "I don't externally look like I have cancer; however, that may be, you know, but I think people have a very general idea of what they think cancer patients look like." Reflected here was a notion of discordant identity, one in which the private and public spheres were incongruous. The physicality of disease was particularly noticeable within data from leukemia patients who routinely described their outward appearance and related the social impact this had for them. The loss of hair (alopecia), Cushingoid appearance (after chronic steroids, which is usually associated with allogeneic transplantation and lymphomas), extreme weight loss with possible cachexia (an aspect of progressive disease and chemotherapy), and pallor associated with both disease and treatment left one young leukemia patient feeling that, "I'm not happy with the look, I don't even know if it's the actual pounds because it's a, you're so blown up, I mean I feel like a cartoon character." A chronic leukemia patient mentioned that as long as he wasn't feeling ill, "I prefer people treat me normally... most people are not aware I have any medical problems because my energy level is so good and I am not anemic." A young leukemic patient noted:

I have to say and again I think it's because I look so ill that people are really, they champion the cause by greeting me and talking about the illness, it's so much of my life and then I fall into it, I can't stop it, you know, after I'm like why did I do that and you're always critical of something.

Notably, many leukemia patients spoke substantially about how they *looked* as an identifying quality for having cancer, a signal of their search for social legitimization through feedback about physical appearance. A man with chronic leukemia noted that because he didn't look

sick while in remission it was easy to be “secretive” about cancer, including with his family, and that people could “treat me normally.” He stated:

I’ve kept this to myself but it’s worse for the people that care about me to know that I have the disease than for me to know I have the disease so at the moment the only people in the public that know about it is my GP, Dr. [name] other than people I’m dealing with and my girlfriend knows, my lady friend and I had to tell her because we were, I booked this trip and we talked about it a long time ago, around Christmas and it was kind of stalled when I found out something was wrong.

Suffering for the blood cancer patients was diverse, representing not only the biomedical physical suffering (and pain) of disease and treatment but also suffering as an emotional and psychological reality. Dragojilvic and Broom (2017) explored the many angles encompassed by the act of suffering, concentrating on the body presence as an agent of suffering that was both internal (physical, mental, emotional) and external (social, political, cultural). The interviews contained a variety of these angles of suffering. The chameleon-like ability to project physical appearance (to some extent) fashioned an unconscious identity crisis in which existential well-being seemed threatened. Participants seemed to be asking, “who am I to be?” and “what am I supposed to look like?” The data did not illuminate issues around existential suffering beyond suffering related to self-perspective. Rather, the data did extend the notion of outward suffering into the social dimension of self through the extension of the physical self into the material world.

The Disconnected Self

Another social dimension of identity acknowledges the unquestionable significance that society, culture, and human relationships have on the individual. Within this study, careful attention was paid to data indicating how haematological cancer patients interacted with other human beings, and particularly how they positioned themselves in relation to others. The self ultimately is a social creation, both reflecting inwardly and back at society, co-creating a sense of identity of what it means to be a human with a blood cancer. In analyzing the data, an overarching question was: how did the blood cancer patients relate

socially with others? The notion of a disconnected self describes the overarching sense of isolation and disengagement expressed by the participants.

Consistently, medical treatment of blood cancer patients includes chemotherapy. Post-chemotherapy the patient's marrow becomes suppressed (termed myelosuppression) and enters the nadir period, so-called for the time when blood cell counts drop and subsequently may cause neutropenia (defined as an absolute neutrophil count below 1.0 microliter of blood). During times of neutropenia, patients are particularly susceptible to infection due to a lack of immunity cells (white blood cells), and therefore are encouraged with preventative care measures that will decrease chance of infection. Patients are encouraged to avoid including crowds, sick people, children, and close proximity to others. Lymphoma and leukemia patients described social isolation and heightened suspicion of others who might be infectious. In an interview with a mantle cell lymphoma patient, she noted that when her white cell count was low she stayed away from everyone:

... they [neutrophils] only went up to 0.3... I mean I stayed home for a good ten days. I didn't go out at all because through this whole time I've done so well not to catch... [anything]... you know my, my friends are all trained. If they, anybody has a cold or flu, we don't get together. My grandchildren I have not seen. I've seen them only once and we've been really careful.

Another patient with Hodgkin's lymphoma described feeling vulnerable in the cancer clinic:

I got there and was ready to start and she [the nurse] sort of yelled down at me across about five patients, X, you're not having chemo today, your counts are too low and so I, I was aware that it was kind of like I don't really like having that information delivered openly not that I need to be ashamed of it but perhaps come over and tell me that and my mum was horrified that she did that and I just sort of continued to have the conversation and I kind of went, oh ok and then she was like, no you... what did she say... it was something like you've tanked or you've bottomed out. Your counts are zero. So immediately I'm alarmed because I'm thinking, oh my God if I don't have any white counts I'm obviously, you know, quite open to infections and whatnot. I'm immediately panic stricken.

Thus, even within a cancer clinic space, the haematological cancer patient carried increased risk for contracting a devastating infection from other (fellow) cancer patients or from others in the clinic. This reflected a feeling of isolation and suspicion external to the body and self, integrated as part of the environment in which the haematological cancer patient existed. The body was fragile and, to protect this fragility, patients entered a social exile, expected to adopt a solitaire identity to place themselves outside of the main group *for their own good*. In this way identity was expressed as both isolated (solitary, excluded) but also as vulnerable. A sense of no longer being a part of the crowd, or in many cases of seeking to avoid others over fear of infection (and thus mortality), relayed a sense of being ripped away from that comfort of being part of the herd. In this sense, a disconnected self conveys identity that is lonely, exposed, weak, and anxious, and control in this case was gained through isolation rather than trying to integrate with others (including patient colleagues).

Discussion

This qualitative secondary analysis was conducted to answer the research question, how do haematology cancer patients reference identity in their descriptions of, and communication about, their cancer? In doing this analysis I chose to create a dichotomy between solid tumour patients and haematology cancer patients by examining matched data sets drawn from an established research database. This method was strategically selected to highlight commonalities and differences between the two subgroups, although the findings described above were specifically speaking to the blood cancer experience since that is the focus of this study. Three dimensions of identity utilized broadly in contemporary literature around identity were used in this analysis to provide structure and build cohesiveness in order to theoretically illuminate the various aspects of self. Introduced in Chapter 5 (historical inquiry) these dimensions included the experiential (first person experience of self), the ontological (what kind of thing is the self), and the social (relational). Findings discussed in this analysis were the self with cancer (*ontological*), the abstract self (*experiential*), the suffering self (*experiential*), and the disconnected self (*social*). I will now unpack these themes and investigate some comparisons drawn between solid tumour and blood cancer patients.

The ontological theme “self with cancer” represented the persistent references of participants to their physical self experiencing cancer. Understanding that the biomedical classification systems of cancer have subdivided the disease into two major subgroups – solid tumour and haematological – it is clear from this analysis that solid tumours are specific to the physical body place of the tumour. Patients in the matched solid tumour group were organized in the original study according to primary tumour location and also spoke about themselves specifically referencing this place in the body. Breast cancer patients spoke about breasts, prostate cancer patients spoke about prostates. As such, there is a sociocultural understanding (generally speaking) of where this place is, so when these patients described their cancer even the name conveyed a shared knowledge. People know where breast is, the prostate, the lungs, and so on. The emphasis on cancer as connected to a body-location was evident in both the chapter 4 integrative literature review and in chapter 5 (historical inquiry) because it is the way that cancer has been historically titled. The issue then comes from introducing a cancer that is not easily identifiable with body place. This languaging is intimately tied with the second theme of “the abstract self,” which described some of the experiential elements of having a blood cancer. Since communal languaging and social knowledge is about solid tumours existing in a body place, the idea of having cancer that is liquid and not associated with place is disturbing. For example, several of the blood cancer patients expressed that they had not even been told they had cancer, but rather received their specific diagnosis of NHL or leukemia. For the solid tumour patients, there was no question. These patients were told they had cancer in an organ: sarcoma (cancer of the muscles), lung cancer, and so on. The greater social context of cancer does not have a way to frame this kind of cancer, thus why there is the phrase “liquid tumour” for example, which is meaningless in the sense that blood cancers are without measurable masses that are understood as traditional tumours. Therefore, seeking that *place* about which to place their cancer in the body, the matched data in this research showed the haematology cancer patients as focusing on enlarged lymph nodes and on cells. Cells are, after all, physical and organic, and while not as simple to talk about as lungs or breasts, it is possible for members of the lay society to envision a cellular structure (no matter how rough). This research has really convinced me of the importance for the cancer patient to locate their disease within the body as a critical

component of the cancer experience. Identity in this context was then drawn from that decision to locate cancer physically and to maintain social labelling based on this decision.

The third theme of “the suffering self” described another angle of the experiential component of a cancer diagnosis. The data in this research revealed that most cancer patient participants experienced some level of what would be considered suffering within multiple dimensions (emotional, mental, and physical). The matched datasets suggested to me that patients with solid tumour cancers tended to experience more physical pain related specifically to their cancer type and treatment, although blood cancer patients (such as those with multiple myeloma) can experience intense physical pain due to disease as well. Therefore, comparing or measuring pain was problematic except for psychological pain and emotional anguish which are more associated with suffering in the literature (Dragojlovic & Broom, 2017; Kumer & Elavarasi, 2016). Within this comparative research, superficially it seemed to me that blood cancer patients tended to use phrasing associated with suffering more so than the solid tumour patients and did so more generally within the context of appearance (body image). Aspects of physical appearance remained unchanged by blood cancers, allowing patients the ability and choice to maintain (what one participant called) a “normal” identity because no one could tell how sick they really were. This could also be true for many solid tumours as well, however, so in regard to the notion of “suffering self” it remains difficult to really differentiate between the two cancer subgroups within the context of a secondary database analysis. For this reason, a “suffering self” is meant to honour these important components of the blood cancer experience that I intend to explore further in the primary research undertaken as Phase Two.

The final theme of a “disconnected self” investigated aspects of the social dimension of the cancer experience. Both cancer subgroups affirmed the importance of support networks and close relationships as integral to their success as a cancer patient, in terms of mental or emotional health (or lack thereof) as well as to aspects of understanding how identity was changing for them. The most striking aspect of a social dimension of the identity experience for these patients was the ways in which blood cancer patients prioritized their sense of isolation in a way that was not found in the solid tumour interview transcripts. Universally the condition of having haematological cancer involves pharmaceutical

treatments, oftentimes chemotherapies or biotherapies which produce some level of myelosuppression. The vulnerability, or perceived vulnerability, associated with immunosuppression led many of the patients to communicate a sense of being disconnected or separated from the greater whole of society. Within the selected transcripts, the blood cancer patients related anxiety and concern over interacting with others predominantly because of this sense of being vulnerable to potentially deadly infections. This is quite a different phenomenon than experienced by solid tumour patients, many of whom undergo surgery or radiation and may avoid myelosuppressive drugs altogether during treatment. This sense of susceptibility to unseen dangers carried by other people conveyed a sense of isolation from those same people in the name of self-preservation. Therefore, vulnerability was just a piece of the puzzle: that vulnerability created suspicion and heightened awareness of the physical body and its location within a social environment. Identity in this case seems to have been as an outsider, even if this was perceived only by the patient through their anxiety over decreased cell counts. To increase the sense of disconnect, because the patient could not self-test to determine the function of their own immune system, the participants related having to rely on the medical system to inform them of their status. For this reason, the overwhelming sense of anxiety over vulnerability expressed by several patients led them to persistently disengage from society even when they may have had normal white cell counts. The disconnected self was constant in this way, never able to actually reconnect with others and especially with the stranger society as a whole because of the nagging question of, what if?

What this secondary analysis also cultivated was inquisitive reflection on what was missing from the data. Chapter 4 (integrative literature review) contained several of the same themes identified here including generalized cancer references and components of physiology as identity. Generally absent from the secondary data were traditional identity tags that dominate the literature and our collective social ideology of a cancer identity: warrior, victim, and the like. The self-identity tags that were used by participants when referring to themselves were that of *patient*, *client*, and *survivor*. The most common way that participants spoke about themselves was as a cancer patient, although oftentimes the haematology patients would specify their specific disease: Non-Hodgkin's lymphoma patient, acute leukemia patient, and so on. A patient is a person under medical care. Nestled within a

definition of patient is *patient*, the synonym for non-complaining, resignation, and passiveness. Patient is also the label that is most expected when someone enters the medical system to receive care, particularly within a public healthcare system.⁴⁴ Within this study, the three dimensions of identity used to frame data analysis referred to an identity experience of a “person,” which honours the active, autonomous, and capable nature of the patient as a human being. At this point in my study, reflecting on the data findings of three layers of data analysis, it seems that the fractured identity labels of *patient* and *survivor* preclude referring to someone as a “person”. Yet the person-as-the-self expressed all three dimensions of identity when communicating about various aspects of their disease experience. Therefore, I wonder if the use of terms like *patient* and *survivor* are (intentionally?) meant to shed aspects of identity in a way that outwardly reduces person-hood and creates hierarchy based on being identified with a medical diagnosis. If someone is a *patient* they may internally identify as a person, but externally (socially and relationally) they will be identified as less-than-person. The taking up of relational identification as patient, client, or even survivor may reflect persisting hope and desire for connection in a way that would be life-saving. Capitalistic in nature, these labels could signal metaphors within a medical system which requires subjugation to receive (potentially life-saving) treatment.

Finally, two components of identity were hinted at within the data but not explicitly referenced: time and memory. Time seems to play a role for the haematology cancer patient, namely time away from diagnosis and position along the cancer care trajectory. It is unclear from this analysis, however, how time factors into the experience of cancer with reference to identity. Memory, on the other hand, is critically important for the persistence and moment-to-moment creation of self. If the self is a narrative self, and memory is narration, then memory may well be self. As discussed briefly in chapter 5 (historical inquiry), several theorists believe the self totally dependent on the existence of memories of the same, identical body in action. Memory changes over time, fading and emphasizing different aspects of life experience. Therefore memory (and corresponding time from event) have roles to play that were not apparent from this data. The impact of memory on identity for the

⁴⁴ The term “client” is most used in private healthcare systems such as in the United States where the expectation is that the ill person is receiving a service for which they are paying. Client was used in this data, however, with reference to the mechanic shop and the person with cancer needing to be fixed by the mechanic (physician).

haematology cancer patient may be more important from the perspective of time passing, but memory may have a role in aspects of suffering as well. The interviews examined in this study contained the important element of the point of inflection, namely that time when the patient received their cancer diagnosis. The text contains elements of before cancer and after cancer, and this historical perspective can't be seen until it is reflected on at a future time. Identity changes at the point of inflection, but this change is not realized until some point in the future when the person is able to look back retrospectively and create that divide between the now and then (or the cancer/pre-cancer) self.

This secondary analysis represented an interesting perspective on identity as a component of the haematological cancer patient experience. Specific questions about self, identity, disease, and embodiment were not included in the originating semi-structured interview process but arose organically. Therefore, references and knowledge gleaned from this data provided a glance into languaging, social expectations around the cancer experience, and perhaps subconscious reflections of the experience. The fixed nature of the data resulted in a loss of opportunity to explore more deeply the statements by participants that included direct or indirect references to identity. However, this expected gap allowed for conceptual mapping and foundation-building in anticipation of primary data collection built addressing such concerns. Within the context of the overarching dissertation work, any limitations present in this secondary analysis instead represented excellent thought-provoking opportunities for further reflection and groundwork for primary data collection.

Moving Forward

A primary goal of the first phase (layers one to three) of data collection and analysis in this dissertation was to develop a deep and rich foundation of theoretical, historical, and empirical knowledge which would inform the second phase (layers four and five) of primary research. The results from each layer of research thus far have generated important knowledge, insights, and questions into the phenomenon of identity, but also specifically inform the greater research question around haematological cancer and patient identity experience. As stated, an explicit secondary purpose of the first phase was the formulation of semi-structured interview guides for both patient and clinician participants that were highly informed by a deep knowledge base. An elaboration on the ways in which insights gleaned

from all aspects of this initial phase informed the strategy for data collection in the subsequent phase will be provided in the next chapter. Fisher (2011) recommends prudence to the clinician-turned-researcher when describing the shifting identity and its influence on research findings. She asks that the researcher foster awareness in using an interview guide, noting that it reflects back identities of both participant and researcher that should be cautiously and reflexively considered both in process and retroactively. The line of inquiry represented by both reflects a thoughtful analysis and contemplation of what it means to have blood cancer, and how can this experience be more deeply explored in a way that illuminates the person-self.

Each of the three levels of Phase one research prompted my reflections and thoughts on the phenomena of identity, enabling a more sensitized fine-tuning of primary data collection in layers 4 and 5. That is not to say that I entered into primary data collection and analysis with specific conclusions; On the contrary, the initial three-layered investigation was highly informative and necessary for such a complex and deeply personal topic. This layered research technique clarified the kinds of methodological and theoretical underpinnings to allow optimal depth of questioning, exploration, and analysis going forward. Identity is a concept that is both precise and confounding. I think the inherent complication of studying identity was well-served by a complex, multilayered research process developed to reveal angles of identity as a phenomenon that could have been easily or naively neglected.

Chapter 7: Haematology Oncology Patient Interviews (Phase 2, Layer 4)

Introduction

This chapter will describe the findings from the interpretive description study on aspects of the haematology oncology patient experience from the perspective of identity. The research question for this layer of research was: how do haematology oncology patients communicate their experience of identity? In this layer of primary research (Phase 2, layer 4), I performed, transcribed, and analyzed original interview data from a sample of patients with blood cancers in order to deepen and refine my understanding their experience of identity. The interview strategy and subsequent analysis of the transcripts was informed by the theoretical positioning and findings from Phase 1 of this dissertation project (layers 1-3). Findings within this study describe the experience of having a blood cancer, how these experiences might differ from more commonly understood notions of the cancer experience, and how identity concerns were addressed within a larger picture of psychosocial health and well-being. I have organized this chapter to begin with a description of the adult blood cancer patients who participated in this study. This is followed by a review of methodological considerations and strategies originally presented in chapter 2 as well as findings gleaned from this primary research.

Sample Description

Recruitment of haematology oncology patients to participate in this research constituted both convenience and purposeful sampling. After receiving ethics approval from the UBC Office of Research Services (REB H15-01335), the BC Cancer Agency Research Program, and the Vancouver Coastal Health Authority Research Program (V15-01335). Recruitment for this study occurred between December 2016 and February 2017 and constituted a flyer posted within the inpatient unit and daycare unit of the Vancouver General Hospital Leukemia/Bone Marrow Transplant Program (Vancouver, BC). The flyer and information about the study was also posted by the BC Chapter of the Canadian Leukemia and Lymphoma Society (LLS) in their weekly newsletter. My original recruitment goal was 10 thoughtful and reflective patients who adhered to very specific inclusion criteria (provided in Appendix A). The inclusion criteria included patients who were adults (over the age of 18),

spoke English, and had been diagnosed with a haematological (“blood”) cancer. At the onset of recruitment, convenience sampling was done in order to begin interviews and generate data. Also, early participants proved useful in directing their colleagues to contact me about the study. As the recruitment and interview process continued, I became more thoughtful about recruiting patients from underrepresented haematology cancer subgroups. Thus convenience sampling transitioned to purposeful sampling as a means for ensuring a rich and diverse sample. Additional recruitment strategies were outlined in chapter 3.

In total, 17 research participants contacted me to participate in this study and 14 followed through with interviews. Recruitment was closed when I felt that a broad and deeply informative amount of data had been collected from patients throughout the haematology oncology spectrum per Bowen’s sampling strategies (as described in chapter 3). Additional consideration of sample size was provided by Malterud and colleagues (2016) who wrote that deeply rich qualitative interviews can have sufficient “information power” from which to generate informative findings. Similar to this, Morse and colleagues (2002) discussed a similar strategy called “sampling adequacy,” which recommends the consideration of a number of factors when closing recruitment in a qualitative study. Among these factors, the quality of data, scope of study, and nature of the topic contribute heavily to sampling decisions. Additionally the “amount of useful information obtained from each participant, the number of interviews per participant, the use of shadowed data, and the qualitative method” are critical considerations in determining when a study should be closed (Morse, 2000, p. 3). In this study, although I recognized that maximal variation might not be achievable my goal was to obtain a sampling with sufficient diversity within the blood cancer context to allow me to reflect on the phenomenon.⁴⁵

Demographic details of the patient cohort are provided in Table 2. Participants ranged in age from 21 to their late 60’s, and most patients were in their 50’s and 60’s when

⁴⁵ Maximal variation in a qualitative study can be best described as purposeful sampling aiming for heterogeneity. In this strategy the researcher aims to recruit a small number of cases that will maximize diversity in a way that is relevant to the research question. The point of maximal variation sampling is to find participants that are as purposefully different from each other as possible. In this study, I recruited patients with blood cancers, and attempted to seek out those with diversities in their experience and diagnosis. However, I recognized that any smaller sample would be incomplete with respect to the full diversity of patient experience..”

diagnosed which correlates with general cancer occurrence statistics. Most of the haematological cancers (neoplasms) were represented in this study, and patients with leukemia (both chronic and acute forms) constituted the most common participant (n=8 combined). Half of the participants were recipients of a haematopoietic stem cell transplant (autologous, n=2; allogeneic, n=5).⁴⁶ Despite the fact that recruitment flyers were posted on an inpatient unit and acute daycare unit, no patients within one year of diagnosis responded to recruitment attempts. Half of the participants were within 1 to 3 years of their original diagnosis, and most of these were in remission after having received or receiving ongoing treatment. The remainder of participants (n=7) were diagnosed with their blood cancer over 3 years ago and therefore constituted survivorship in the aspect of chronic disease (as in chronic leukemias) or ongoing remission. For many participants, developing a blood cancer meant a major change in lifestyle, with 5 of them having to quit full-time employment and enter early retirement. Three of the four youngest members (21, 31, and 48 respectively) of the haematological cancer patient cohort were able to continue with their pre-diagnosis activities (attending university, working full-time, and homemaker), while the fourth was forced into early retirement (age 26) due to chronic complications from graft-versus-host disease post-allogeneic transplantation. All of the cohort aged over 50 years went into retirement if they had been previously working full-time, although many reported being able to participate in volunteer activities or part-time work as their energy allowed. Relationships remained largely intact after diagnosis except for one participant who reported that stress from cancer was the main cause for her divorce. Additionally, family members remained constant from the time of diagnosis to the interview including the presence (or lack thereof) of children or grandchildren.

⁴⁶ An autologous transplant refers to the transplantation of stem cells that were gathered from the patient themselves. Autologous transplantation can be done in both out-patient and in-patient settings, and does not contain the same level of risk for side effects as an allogeneic transplant. The so-called "allo" transplant refers to the transplantation of cells from another person. The donors of allogeneic cells are matched as closely as possible to the cellular make-up of the patient, and can be either related or unrelated. Allogeneic transplants are only done in the acute care hospital environment and carry high risk for graft-versus-host disease and a host of other complications.

Method

In this new patient cohort, the primary data collection method was interviews conducted by myself and digitally audio-recorded in most cases (n=13). The interviews were semi-structured and based on the interview guides developed after deep foundational analysis of research in Phase 1 (layers 1-3). (See Appendix B for the interview guides.) Data collection and analysis occurred concurrently, allowing for subsequent interview questions to be tailored to specific concepts or questions. In most cases I adhered to a general phenomenological style of interview which seeks to ask “why” with intention to elaborate on interesting comments or themes. Each face-to-face interview (n=13) lasted 60-90 minutes. These interviews were then transcribed using a naturalistic transcription technique by both myself and a hired professional transcriptionist. This technique involves transcribing verbatim the interview in a way that allows a “talk-in interaction” (Hutchby & Wooffit, 1998, p. 13). One interview was done over email in the form of a chain that allowed for initial responses to be clarified and elaborated upon. The final transcript of this interview was constructed by myself using the original text responses. Transcripts were copied into a continuous MS WORD file and into the NVivo™ (v.10) software program in order to allow multiple and diverse opportunities for data analysis.

Collateral data in the form of journal excerpts, photographs, trinkets/collectibles, or digital images of art (mostly drawings) was shown to me as an aspect of the interview in all cases. Many times participants encouraged me to collect a digital image of what they were referencing, and the associated graphic file was saved along with the participant’s transcript in the research project database. At the closure of each interview, I requested verbal permission to contact the participant for further details, information, or clarification. Positive permission was granted in all cases. Several of the participants (n=10) contacted me post-interview through email with additional information, stories, and details. Most of this collateral material includes copies of journals kept during treatment or highly detailed medical histories. This material remains in the database and was commented on in field notes.

Developing the Interview Guides

When developing the interview guides, the explorations of Phase One inquiry were critical in generating more thoughtful questions that would also be sensitive to the highly existential and personal nature of an identity study. For example, one of the most important things to do in the patient interviews was to establish a timeline of how each person saw, remembered and described themselves before diagnosis, during treatment, and in their present state. A biographical timeline arose in chapter 6 as important in honoring and understanding the role of time and memory in relation to the identity experience. Questions 1 and 2 specifically address the importance of time by asking the patient to: tell me about yourself (#1) and how was your cancer diagnosed (#2). Another important component of identity that arose in all three levels of Phase One research was around the social definition of identity and cancer. For example, throughout this exploration, notions of defining cancer and identity labels for cancer patients has been a recurring theme. This sensitized me to the importance of social and cultural context (both modern and historic) as well as language. Within the interview guide, question #3 (What does it mean to have a blood cancer? Have you heard of [patient's cancer type] before and in what context?) specifically asked for the patient to talk about their understanding of cancer. Additionally, question #7 (How do you talk about [cancer type] to other people? What do you tell them, and do you think your responses have changed over your cancer journey?) inquired about the way in which the patient shared information with others. Finally, another major recurring theme of all Phase One research is that of place or environment, being a place in the body or position of the patient in the world. Question #4 (For some cancers, such as prostate or breast, people have an identifiable body part to locate their cancer in. In a haematological cancer such as yours, it isn't quite like that. How has it been for you to have a form of cancer that is not located in a specific body part?) specifically asked where the cancer was in the body. Overall, the Phase One research sensitized me to language, social positioning, and contextual aspects that I might otherwise would not have thought to ask.

Table 2: Demographic Qualities of the Haematology Oncology Patient Participants

| | Haematological Cancer Patient Cohort (N=14) |
|---|--|
| Current Age Range | |
| Below 30 years | 2 |
| 30-50 years | 2 |
| 50-70 years | 10 |
| | |
| Gender | |
| Male | 5 |
| Female | 9 |
| | |
| Diagnoses (primary) | |
| Multiple Myeloma | 1 |
| Non-Hodgkin's Lymphoma | 3 |
| Chronic Leukemia (CML, CLL) | 3 |
| Acute Leukemia (ALL, AML) | 5 |
| Myeloproliferative Neoplasms (MPN) ⁴⁷ | 1 |
| Myelodysplastic Syndrome (MDS) | 1 |
| | |
| Haematopoietic Stem Cell Transplant Recipients | |
| autologous | 2 |
| allogeneic | 5 |

⁴⁷ The inclusion of a patient with Myeloproliferative Neoplasm (MPN) was made because the patient was told by her haematologist that this was a "chronic blood cancer." MPN is classified as a chronic haematological cancer in the literature, but can sometimes also be classified as a malignant blood disorder in some circles. The nature of this debate is not important to my research because my work focused on what patients understood their cancer to represent.

| | | |
|---|--------------------------|--------------------------|
| N/A | 7 | |
| | | |
| Stage of Cancer Journey when interviewed | | |
| Diagnosis to 1 year | 0 | |
| From 1 year to 3 years | 7 | |
| 3 years to 5 years | 2 | |
| Greater than 5 years | 5 | |
| | | |
| Major Day-to-day? Activity | Time of Diagnosis | Time of Interview |
| Retired/Unemployed | 6 | 11 |
| Employed full-time | 6 | 1 |
| Homemaker | 1 | 1 |
| Attending university | 1 | 1 |
| | | |
| Relationship Status | | |
| Divorced | 2 | 3 |
| Married | 9 | 8 |
| Not-married (single or with partner) | 3 | 3 |
| | | |
| Family Status | | |
| No children | 4 | 4 |
| School-age children | 2 | 2 |
| Grandparent | 8 | 8 |

Data Analysis

Data analysis and interpretation were guided by the inductive framework suggested by Interpretive Description. Constant comparative analysis was employed to analyze and code data using highly generalized categories and themes. The use of generalized themes was to allow for preliminary examination of potential groupings and patterns without premature closure on meanings. A preliminary analytic structure developed during the interviewing process which formed the basis for exploration of commonalities and points of divergence in the reported individual experiences. As data collection and analysis continued further exploration of patterns and key concepts allowed for more precise coding of the transcribed text. As themes were identified and clarified, reexamination of the transcripts ensured their basis was grounded in data. This was further complemented by rereading the transcripts and listening to the audio moments of key reference points in the interviews. Concurrent analysis of field notes, personal reflections, and collateral data strengthened some groupings and bolstered logic. This iterative analysis process represents part of the validation process of constant comparative analysis, and therefore was used to strengthen the research report and data evaluation process.

Findings

Participants in the study echoed several of the themes identified as components of self and identity as described in Phase One (layers 1-3) of this research. The interviews were framed with the three dimensions of self - ontological, experiential, and social – in mind and were present in how I questioned and interacted with the patients. Therefore, a deeper understanding of the subjective experience of having a haematological cancer was sought. Reflective analysis of the data suggested three major themes with consequent components that were representative of the experience of identity for this patient cohort: origination, deconstruction, and reconstruction. These themes frame the patient description of their identity experience on multiple and complex levels while acknowledging important identity signifiers such as memory and the passage of time as integral components to the experience being a living human in the world. These themes themselves may seem settled on a sequential timeline, but that was not necessarily the case as the below discussion will show; instead, the themes are meant to introduce some order to the multidimensional and

multifaceted notion of identity as subjectively experienced by the haematological cancer patient.

Origination: The Mask of Sick

The notion of origination captures discovery and the bringing into existence of something that was not previously known. It is an origin story. For each of the participants in this study, the story of the origins of their cancer was critical to tell, and for me to know. In every case, the story was not just about the actual event of being told their diagnosis sitting in the doctor's office, but included the months (and in some cases, years) of background narrative about activities, habits, hobbies, and illnesses. The signs and symptoms of feeling unwell were conveyed in intense detail so that the event – the origin of cancer signaled by receiving the diagnosis – was positioned within their tapestry of life to demonstrate 'this is who I was' so that the context of the 'who I am now' could be properly understood. Identity within this context was not a singular thing, but rather a journey that included the pre-diagnosis, the diagnosis, and the post-diagnosis. Each participant revealed that there was a transformed self that arose as they stopped being *healthy* and entered, per Sontag and Edwards (2013), the kingdom of the sick. Labels tended to recede during this early period as patients quickly adopted the designation of "patient", but what the participants did emphasize was a transformation from healthiness to sickness. One participant called this a "mask of sick" explaining that the diagnosis forces a person to socially (outwardly) transform into someone who is sick but the sickness is itself a mask over the real self (the healthy self, the normalized self) that is now obscured by the expectations of what it means to be sick. The mask was both metaphorical and real in the sense that the person's physical body legitimately suffers from a blood cancer.

The theme of origination speaks first to that critical transition from health to patient and the associated identity concerns that participants emphasized. Second, this theme teases out the incredible drive to create a new and unique identity based on the blood cancer diagnosis. Finally, the theme of origination introduces the perception of blood cancer as systemic and of the self which will lead us into the theme of deconstruction in which this new self must be explored and redefined in a meaningful way.

Transformed Identity

Contained within the “mask of sick” is imagery around the transition from a healthy person into someone who has a haematological cancer. The most obvious way this transformation revealed itself was through the languaging and labelling around claiming the cancer as their own. Each participant was asked how they told people about their blood cancer. None used the word “cancer” by itself. Instead they used a variety of phrases such as:

- “I have blood cancer. And then I just say leukemia. I—well, I say I had acute myeloid leukemia.”
- “I say, ‘Yeah, I had—I’ve had a kind of blood cancer.’”
- “Imbalance. I call it an imbalance [of the blood], because that’s what I think it really is.”
- “... generally I would say I have leukemia.”
- About angioimmunoblastic T-cell lymphoma: “I guess I told people I had—well, I thought the name was so impressive. Some people, I told them what I had, they were just—it would take up the whole sentence, so I had to tell them that.”
- “I say lymphoma, and if people don’t understand what lymphoma is, I tell them it’s a blood cancer.”
- “I don’t get into a lot of description about the leukemia itself when I talk about it because I notice that when you say the word leukemia to somebody, they get ‘[gasping sound].’ You know, there’s a moment where they think, oh, my God, because it has a reputation.”
- “We say CML all the time. We don’t say cancer.”
- About hairy cell leukemia: “I told them—I felt people knew what leukemia was. They might not know that there’s so many different

kinds. I didn't know that. And I just said I had leukemia, this is the kind of leukemia I have.... I didn't really like the label of cancer.”

One participant so loathed the word cancer because of its social connotations (as explored in chapter 5) that she was angry:

They call it the Cancer Lodge. The cars have ‘cancer’ on it. Fuck off. What are you trying to reinforce here, healing or cancer? The cars should be called the healing cars. The Lodge should be called the Jean C. Barber Lodge. All that stuff erodes your normal, healthy train of thought, when you’re constantly bombarded with this word. It has just so many connotations.

How someone self-labelled was a major social indicator of identity since it communicated individual experience and place in the world. Therefore, the data in this study indicated a strong preference for the disease name versus a generalized label of ‘cancer.’ The disease name (label) itself signaled the transformation of identity from health (someone without disease) to someone with disease, reflecting (reluctant) ownership over this new identity as someone who was sick with a specific disorder.

Every participant in this study conveyed language, knowledge, and terminology that reflected ongoing remnants of Cartesian dualism and the mind/body disassociation, reflecting sociocultural acceptance of the dominant medical paradigm of reductive physicalism. Therefore, much of the narration around the diagnosis and subsequent changes to the self were couched in twinned terms of a separated machine/organism (body) and spirit (mind). There seemed a struggling sense of purpose in finding a way to frame the disease as organic, and hence potentially both controllable and repairable. A participant noted increased attentiveness to his body due to having blood cancer noting, “I’m—well, I’m more aware of the machine. If I—I think before, if my knuckles were stiff or my elbows, I’d go, ‘Yeah, yeah, yeah.’ And now I’m going, ‘Okay, the GVHD [graft-versus-host-disease] is in the knuckles today.’” Another explained that blood cancer meant the parts of the body-machine were not working right: “if you look at our bodies, it’s just a biological machine. They’re, you know, units all working together to have a cohesive body working and going in one direction, right?” In each of the interviews, participants noted various aspects of parts of the

body as complex, intangible, “out of control,” and needing to be fixed. A gentleman related his body to his motorcycle concluding that, “I’m, you know, working my way through recovery. Like, I’m recovering from my body’s, you know, malfunction.” A sense of a new self, a transformed self, was also expressed by a middle-aged woman with leukemia who frankly stated:

I’m happier than I’ve been in many years. I have found peace in my life. I don’t sweat the small stuff. I don’t have sex anymore, so that’s really, really a huge thing, but I’ve turned it into a positive thing because now I have energy in other ways. And my decisions in life aren’t influenced by my hormones, which is really good, because I was a very passionate person, and I probably made some stupid decisions because of that, you know? And so that is interesting. Actually, my vagina has sealed shut. Yeah.

What was conveyed in this conversation was an almost death, or succumbing, of the female/woman to blood cancer in a way that removed the usual purpose of the body parts and thus desexualized/dehumanized the body to the point of neutrality. This quote also harkens back to historic assertions that passions of the body (hormones, sexuality) were causes of cancer; thus, cancer eliminated these passions allowed this participant to make better decisions (more calculated, like a machine?). This increased awareness of the body as abstraction will be explored under theme of deconstruction, but here the notion of transformed identity captures the sense of increased attentiveness to the physical body necessitated by the haematological cancer diagnosis.

One of the major instances of transformed identity due to changing significance of the body was around appearance. Most participants talked about how their physical appearance changed, or didn’t change, and how this related to their ability to relate to society and meet social norms. A gentleman with lymphoma explained, “I could be tired and I could have bad memory, but it wasn’t—apart from my hair, wasn’t a physical representative example of being—label of being ill.” There was a contrast noted in the data in instances when people didn’t look sick, or rather, when they didn’t appear to meet social expectations of what a ‘cancer’ should look like. A patient with leukemia recounted a visit to her children’s daycare: “So some people were saying how good I looked. I didn’t have the energy to stop and correct them, because I didn’t want to go on about how sick I was, yet—so I think people have in

their heads an idea of what cancer looks like, and I wasn't necessarily that example."

Transformative identity, then, was personal in the sense that identity was about the individual experience of being ill – fatigue, nausea, vomiting, weight loss, pain – but also contained components of how this illness was reflected by society through expectations around physical appearance.

As explored in chapter 4 (integrative literature review), some authors have sought to study the explicit embodiment of cancer through imagery including the 'grotesque' and 'malformed,' but within the present study these ways of talking about the self were just not present.⁴⁸ Identity, then, was almost hidden unless it was discussed openly upon which time the participants would use the disease name (for example, CML, HCL, MDS). This label (the diagnostic title) signaled two things to me. First, that patient were entering into a rationalizing process of abstractification around what their disease was and how to talk about it. I will discuss this within the theme of deconstruction. Second, by accepting and using such specific medical terminology about their disease participants were signaling that they were *unique* and *different* from both other diseases -- other cancers, and indeed, from other leukemias (or lymphomas, or blood cancers as the case might have been). I will now explore this notion of unique identity to show that participants not only transformed their identity from healthy to sick, from non-cancer patient to cancer patient, but also grasped the most specific identity possible in order to create a new identity that would make them special.

Uniqueness

Uniqueness here is used to describe not only a sense of being a singular person who is unique in the world, but also of being part of a distinctive shared experience within the haematological cancer patient cohort. The participants seemed to emphasize a desired recognition for being special (the individual with cancer), being a part of a particular disease (the individual having a specific blood cancer), and being part of a distinctive group collectively titled "cancer patient." During the interviews I was repeatedly struck by statements such as, "I was a bit nervous to go to the Leukemia Society meetings because I didn't necessarily want to just associate myself with people who are sick." The "sick,

⁴⁸ As noted, most research deals with solid tumours, thus confirming differences in experience and identity between the cancer subgroups.

of course, were haematological cancer patients, but what I was hearing reflected an insidious belief that the participant was somehow *different*. Different than solid tumour cancer patients, which I will explore in the upcoming section on the systemic self, but different too than other blood cancer patients. Despite learning that most (if not all) of the participants talk about their cancers in terms of “blood cancer,” it seemed incongruous that they would then feel different than other blood cancer patients. A patient with leukemia noted, “it is also odd to go to the Leukemia Society meetings where all the leukemias are so different that I have no idea of some of their stories, and some of the things that people are talking about don’t relate to my condition at all.” A participant with MDS (myelodysplastic syndrome) related how important it was to attend support groups for haematology cancer patients: “it’s good to go into those things because people—a lot of people have different blood cancers as well. And so I enjoy it because I get to hear their experiences and kind of differentiate between all the different blood cancers.” Another person with CML expressed similar sentiment about support group meetings saying:

I would want to go and have somebody like me who’s gone through it tell—like, kind of, you know, give their own kind of story of how they went through it and—because you have a similar blood cancer. So in a way, for—after going through it, yeah, I mean, I would hear other people’s other types of blood cancer stories, but if prior, I would probably prefer to be in a leukemia group.... like, people wouldn’t be able to relate as well because they might have different procedures and stuff like that to go through that may not be similar to theirs, and so they can’t really relate their blood cancer.

An aspect of transforming identity in this study was participants taking on new labels to describe themselves, be it blood cancer or their general umbrella diagnosis (leukemia, MDS, lymphoma, etc). Participants further drilled down into the generalized diagnosis to their specific type of cancer based on genetic analysis. For example, one older male participant with angioimmunoblastic T-Cell lymphoma explained that after he was done with active treatment, he reached out for support. Finding someone *exactly* like himself proved difficult. He recounted:

I need to talk to people that have been through what I've been through, and especially having what I have. Because at hockey, I talk to a guy that had the B-cell lymphoma, so I was able to talk to him, and I found that very useful. It's not the same kind. So I got ahold of her [at the Leukemia and Lymphoma Society] and I said, 'Can you put me in touch with people that have my cancer, who have been through the same thing?' So she did, and I guess we're—we are such a rare breed that one guy was in New York City, one guy's in Seattle, Washington, and then there's a gal over in Coquitlam. And so I got all excited. Oh, I got some people I can talk to.

What was most interesting about these narratives was that in many cases the treatment regimens, be it chemotherapies or biotherapies or even stem cell transplantation, were generally similar and included many identical components. The data in this study gave the impression that identity as a blood cancer patient, then as a patient with a specific umbrella blood cancer, was not satisfying enough to address personhood or interpersonal connections. An additional layer based on genetic markers or cell morphology was required in order to precisely label the individual. Extrapolating further, this precise identity as a person with, for example, angioimmunoblastic T-cell lymphoma or hairy cell leukemia, resulted in kind of group identity. Group identity in this context gave patients a distinct sense of a coming together with people they could best relate to and communicate with who would understand their *unique experience* of having a specific blood cancer. Taken alongside the context of a seemingly hyper-individualist expression of being special and specific in the world of cancer, the participant narratives reveal a tension between wanting to be part of the unique blood cancer cohort while at the same time desiring to be special in their own experience of their disease.

The sense of group uniqueness also fostered a sense of safety and hope for some of the participants. Each detailed a struggle with anxiety over their diagnosis, and one young patient noted that knowing those who shared her specific cancer was critical in helping her cope with treatment. She said:

that actually really helped me because I was like, oh, my God. Like, there's people out there who have this and they're okay....I really hung onto that, like, counting the people that I knew. I would constantly do that, like, these weird, like, repetitive

things, like, counting the people I knew who had it and who were okay, and like, I kind of had these little rituals that I would do to try and, like, stay positive.

In this sense, knowing others with the same diagnosis down to genetic similarities conveyed a sense of calmness or heightened anxiety depending on how the cohort members were doing. Another young patient who connected with colleagues experiencing ALL through on-line blogs and webgroups related that, although he longed for contact with others who had his disease, there was a downside. This participant related:

My buddy who I talked about earlier, he—his leukemia came back and he passed away this fall at 24 years old, so that was very tough. That was super tough for me, and again, drove home how incredibly lucky I am, and how incredibly blessed I am that I was able to be treated, because I miss my buddy, and I know that he fought hard and long...

Thus there was both comfort and caution expressed as part of the group experience of having a haematology cancer and identifying as part of a specific disease community. To be a part of the group normalized the cancer experience. An ultimate irony of this group experience is the level of control asserted over associations with others. What I mean by this is that if another person with the unique diagnosis was doing well, this could distill hope for a similarly favourable outcome. If the similarly unique colleague was not doing well, this could emphasize despair and mortality. Again, the tension between being a unique self and being part of a unique group and subgroup of cancer patient was ever-present.

Cancer as Systemic

When asked about why it was so important to relate to others with the same (and as exact as possible) haematology cancer, several participants noted issues around the systemic qualities of the diagnoses. Unlike a solid tumour, a blood cancer had no *place* and was *invisible*. This languaging was used over and over again by participants as a way to not only talk about their cancer but to also differentiate themselves from other cancers. One participant noted, “so it’s different from, like, if you have a breast cancer or something which are very visible kind of cancers.” Another explained, “if you say prostate cancer, people can envision what a prostate is, or breast cancer, people have a vision of a tumour, mass inside of

a breast, and it's very easy for us to have a conversation.” A participant with AML voiced her concern that:

... you kind of feel sorry for yourself with a blood cancer because it's flowing, right? You got something here that—you know, you got a hunk on your nose, so they can take it off, they can, you know, get it out. But when it's blood, I mean, it's insidious, right? I mean, where's it hiding now, you know? Like, so that was a bit scary, about having a blood cancer.

In this example the transmission of sentient qualities of cancer is highlighted, harkening to historic notions of cancer personification. Another participant confirmed the differences by agreeing that, “because that's the stigmatism between having a tumour, you get it removed, you know, the mass is gone.” An older man with AML discussed other differences he felt were important:

But having not had the experience of having a choice between removing or having a lesion or removing something, and not seeing it, it does—there—I think it is different for people with leukemia because it tends to be pervasive throughout your body. It's not localized, so in other words, I've got this in my stomach, but my leg's fine, or I've got this on my leg, but this arm's fine. It's—it tends to be everywhere. So I always felt it was very pervasive.

Closely following diagnosis, differences between blood cancers and solid tumour cancers become apparent not only in treatment options, as pointed out above, but also in the place of cancer. This gentleman described his leukemia as “everywhere” and “pervasive.” In this case, if the leukemia was everywhere the participant might locate his identity as entire body, and thus his lived experience as one of leukemia-as-body. If the body is defined as self and “I” talked about, then the “I” is leukemia or represents leukemia in some sense. Another participant explained the frustrating nature of having a blood cancer that didn't have a ‘place’ associated with it. He talked about troubles convincing others he was sick, saying:

When you say you have an issue, like you have a disease, how can they [society] identify? Like, there's no identification. If you say you have cancer—that was the big thing. Oh, you have a tumour. Okay, great, you can work on that tumour. But when

there's nothing visible, it's like having an invisible disability, that you look fine. You look fine. Oh, you're a bit tired, yeah, but there's nothing else wrong with me that we can see. And it's really hard to explain to someone.

Within this statement is the point that the societal relationship to cancer is one of visibility, both of tumour (mass) and of expectations around appearance (weak, pale, thin, for example). Social meaning remained lacking around a blood or 'invisible' cancer.

Similar notions of blood cancers being systemic were found threaded throughout the data. A young man with leukemia said, "it was scary to me, knowing that my blood was so screwed up and my blood was such an essential part, and it was not an isolated part of me. Like, it wasn't, like, in my finger or something. Like, it was flowing through me, and so that was scary." Another realized, "I knew I had a blood disease, I thought, this is complex. Like, blood is from your tip of your head to the toe, right?" The fact that a blood cancer was, literally and figuratively, everywhere in the body seemed to make it more elusive, frightening, and almost essential to the self. It also made remission more obscure. A participant with lymphoma relayed his concern that when a tumour was removed surgically, it was gone, "whereas the blood, like, how do you know what's happening to my blood? Like, where is any potential cancer problem? It's still there. But with a tumour, at least, it's gone. Like, the baseline is zero."

The systemic quality of haematological cancers led participants to wonder about the qualities of the cancer itself. An older woman with a myeloproliferative neoplasm (MPN) contemplated the nature of her malignancy articulating that:

I would say my cancer is in my blood. It's all over me. So yeah, I would—like you said, it was all over me. It was—it was not limited to a certain area, to a certain time of day that it would, like, hit me harder. Like, it was constant. Constant, and I was covered in it.

This same patient also thought that the systemic nature of her disease was responsible for variety of diffuse symptoms: "It's throughout my whole body. It impacts—I get headaches where I've never had headaches before, and they come—they come without notice. Boom, you know. And it's my whole body. Sometimes my legs won't work right, sometimes my

arms won't." The nature of the cancer being everywhere seemed to give some participants a sense that they were being consumed, echoing historic sentiment about the active agency of cancer in general. The nature of cancer being systemic also invited a sense of uncertainty. One participant articulated that, "I think some friends definitely would have said that it was eating away at me, that they could tell how this was draining me, how it was just leaving—sort of eating away what I was and the shell—and just leaving a shell of me during that time." Thus cancer was eating away at both body and *person*, namely the identity of who this individual human being was and leaving a shell (body) that was devoid of the original (pre-diagnosis) self.

Origination really refers to not only diagnosis of the blood cancer, but to an unwelcome and shocking initiation of a journey for survival. The self as it has existed is suddenly thrust into having to change in order to endure. Participants in this research were unique in their solutions and adjustment to this existential crisis, but each also described the subthemes presented here of transformation, uniqueness, and some kind of acknowledgement of the systemic nature of their cancer. For these participants, the cancer was more than just a localized place, but rather constituted the whole of their organic body. The cancer in their blood and comprising their blood permeated their body, bringing a sense of self and meaning that they believed made them different in the world of cancer and other diseases.

Deconstruction: The Disintegrating Self

The next theme, titled "deconstruction" conveyed the breakdown of the person-self into components, reflecting the moving away from the origin story of cancer and instead focuses on adaptation strategies and reconfiguration of identity towards a new self (reconstruction). To deconstruct is to breakdown something into constituent parts. Deconstruction is dismantling with the purpose to understand a new or deeper meaning, especially when it is different from previous understanding. Deconstruction evolved as a theme for this study through analysis of the participant data which revealed a very complex post-diagnosis process that involved breaking down the meaning of blood cancer into parts from which new identity, and new meaning, could arise.

The first step of deconstruction was confusion and unawareness around which knowledge was then sought. In the case of the participants in this study, each had little, if any, background or knowledge of haematological cancers before their diagnosis. This ignorance led to research and discovery, but alone this knowledge did nothing to address their identity crisis. It was not until the process of abstractification, whereby the blood cancer was broken into small units that could be personally associated with the self, that the participant grasped building blocks for a new identity. The abstractification described by the participants around cell types and blood work required imagination to construct understanding. Finally, imagined narrative around abstract concepts of things like cells allowed the participants to further deconstruct their disease into an associative languaging that personified their experience. Invisible cells were acknowledged as part of the self, and cancer took on a personal identity (like “Isabelle” or “Hansel and Gretel” or “invader”). Deconstruction is therefore reflective of sense-making, of trying to make sense of the cancer diagnosis and subsequent changes to identity that occurred by breaking the subjective situation into parts – each part was not the self, but reflected a part of the self. A younger male patient captured the alignment between deconstruction and identity when he said, “I would say that there’s nothing like breaking someone down to the core to really make them reevaluate their life ...” Such a process was critical for every participant as they reached towards reconstruction, or the process by which the self-identity was rebuilt after being destroyed by the blood cancer diagnosis.

Unawareness

One of the most pervasive qualities of a haematological cancer diagnosis noted from the data is that of an initial unawareness about the disease. Of course, everyone knew the word ‘cancer.’ The actual diagnosis, however, was mysterious on both a personal and social level. Many of the participants relayed that they had never heard of their disease before. A female participant noted an experience that is eerily similar to others collected during patient interviews. She stated:

PARTICIPANT: And he [the GP] said, ‘I’m sending you to a specialist and he will do some tests.’ And he just said I had leukemia. I walked out the door, and my husband was sitting in the—in the waiting room. I walked right past him, I went to the—to

the—to the elevator, and he comes running, ‘What’s the matter? What’s the matter?’ And I couldn’t talk. I didn’t know what to say. I went home and for three days I cried.

INTERVIEWER: Did you know it was cancer?

PARTICIPANT: I knew—leukemia, I knew it was—I don’t even know. I knew it was cancer and had something to do with the blood....

Another participant communicated a similar feeling of confusion and fear saying:

I had heard about leukemia, but I did not know very much about it. I knew it was a disease or a cancer, but to me, I had no knowledge of diseases and cancers, and sort of the only knowledge was that some could be treated by, like—like Terry Fox, amputating his leg, stuff like that, like, where—and then other stuff, in terms of leukemia with the blood, you can’t amputate blood. I had no idea what was going to happen.

It was one thing to have cancer, but as the participants in this study related, it was quite another thing to have something that was so *different* from a ‘regular’ (i.e. solid tumour) cancer diagnosis. One of the participants explained:

I was just—you know, I wasn’t aware of—like, that’s the thing is, like, now, having to go through the leukemia, my family didn’t—like, nobody really knows blood cancers very well. Like, you know, they’re expecting you have a lump on your, like, that’s cancerous or you know, like, some sort of mass inside you that’s, like, a tumour or—like, or they don’t necessarily get the blood cancer. And so especially since it’s not as prevalent, like it’s not so, like, visible either, right? So—and then—yeah, so I definitely had to educate myself for one, as well as my family and friends because they weren’t—like, leukemia is not talked about as much as, like, breast cancer or like, you know, other things like, you know, prostate cancers or skin cancers. Like, you tell somebody you got skin cancer, they, you know, are very, like, aware of what that is, and kind of what it entails.

Thus the lack of knowledge about blood cancers was experienced by both the patient and society, adding to the anxiety about what they were experiencing. Similarly, without having that immediate relationship with cancer as curable or easily treatable as experienced by solid tumour patients, blood cancer patients had to create identity for themselves. What I mean by this is that there is a social expectation around what it means to have a solid tumour cancer: surgery, maybe radiation, maybe chemotherapy, but ultimately a public perception exists about what treatment looks like, what cure looks like, and what the cancer itself looks like (a mass, a lump, a black spot, a tugging of the skin, a bulge, and et cetera). The solid tumour cancer patient can also cut out or remove the tumour, or at least this is a dominant social perception even if it is medically impossible. With a blood cancer, there is no option or ability to cut anything out of the body because the cancer is merged in the body such that it cannot be physically removed. This provides a sense of being somehow merged with the cancer, and blood cancer patients in this study definitely expressed anxiety over the fact that they couldn't just "get rid" of their cancer.

An additional angle on being unaware is that of being unaware of one's own body, at least at a conscious level. Several participants agreed that the diagnosis was difficult because it alerted them to a lack of awareness of their own body. One older man stated, "Initially, I was really, really upset about my body letting me down, and they told me I had cancer at least for seven to 10 years before it was diagnosed, and it—I felt it was a huge betrayal of my body, of thinking I knew myself, thinking I knew my body." Without outward signs recognized by society as 'cancer,' some of the chronic blood cancer patients experienced symptoms for years without appearing sick. In these cases, unawareness became part of the deconstruction experience as they pondered how they could have missed being diagnosed sooner.

Abstractification

For the blood cancer patients in this study, they didn't know what their blood cancer was and they were unsure how to frame their new identity because it just was so abstract. This sense of abstract, insidious, mysterious, and unseen became the means of identity for these patients. A participant with AML (acute myelogenous leukemia) highlighted the disadvantage of a blood cancer because, "yeah, because it's harder. You can't point to

something and say, ‘This is what it looks like.’” The process of deconstructing their diagnosis as part of the process of identity-discovery was described like a research project focused on the cells responsible for their disease. One older man stated, “my knowledge of blood cells had been just from, like, science class. So I knew sort of that there were different parts.” Because haematology cancers are cancers involving the blood cells, participants generally focused on the bone marrow (where stem cells are produced), stem cells, and blood cells (white blood cells, red blood cells, and platelets). Due to the fact that most of the blood cancers involve the white blood cells, differentiation was further made into what specific type of white blood cell was involved (neutrophil, T-cell, B-cell). Thus when describing their specific cancers (as discussed previously) the participants focused on precise cell types like hairy cell or T-cell that not only made them unique from other cancer patients, but allowed an identity to be built around a very abstract and specific cell. One patient even discussed the importance of his specific DNA saying, “So I don’t feel I’m the same person. I can’t. It’s hard to quantify, but I know physically I’m not. Like, I think that my DNA’s different somehow.” Talking about intangible concepts such as cells and DNA was required by the participants in this study, but they struggled to explain themselves in relation to something they couldn’t see or really understand. One older male participant explained the precise dysfunctional cell type for his lymphoma, but he struggled to understand what was really happening inside his body. He summarized by saying:

My lymphocytes went crazy, and you got your T-cell lymphoma, you got your DSL lymphoma, the T-cells tell the B-cells what to do, and my T-cells got out of control, and then you know, it manifested itself in my lymph nodes. So you know, like, too much of a good thing is crazy, like, you know, because your body is just doing all these magnificent things and it’s taking care of yourself, so the average person doesn’t even realize that’s going on. I didn’t know I had all these things in my body and how many billions of these things are zipping around, commanding, go here and search that out and kill that thing and do this and do that.

The actions of the cells are understood on a textbook level, but they themselves are abstract, unseen, unable to be observed (outside of a laboratory environment) and therefore exist in an imagined reality. Another participant stated that their white blood cells, “don’t do the job, and

so if you don't have those white blood cells to do the work, you just have these, like, kind of, like, fake cells that are floating around you that your body just kind of, you know, will—pretty much can't fight off anything that comes its way.”

What is a cell? What does it look like and what are its qualities? These kinds of questions persisted throughout the interviews whereby many participants developed imaginary ways to envision their cancer to make the abstract real, at least in their minds. One male patient with leukemia said:

I need[ed] to do something, so I started to visualize the—a black—like, a big, overlarge blood vessel with a lot of healthy red things and then black things, and to me the black things were the leukemia, and I started to either look at them getting devoured, blown up or shrunk or some—as a way to kind of feel like I was doing something for myself. And I—but when I spoke to other people, I don't think I really vocalized it as a blood disorder, but that's how I internalized it, was in my mind, was I was always looking at healthy red instead of not healthy black.

Adopting social expectation that black is bad (or evil), this participant then created a mental image to deal with their cancer by which he could see (in his mind's eye) the cancer being destroyed. Another middle-aged woman with lymphoma clarified her struggle with trying to understand her cancer. The only way she could envision her new identity was by transforming the cancer into something reasonable, which for her became morphing her body cells into amphoras.⁴⁹ She said, “they're beautiful. And they were all grey, and they were lined up, and some of them were falling out and jumbled and broken. And so I would come in with whatever medicine or positive vibes or feelings, and I would turn all the amphoras into a beautiful terracotta colour and get them all repaired until they were beautiful again, and that was basically my cells repairing.” Another participant visualized pictures he had seen in a textbook of cell types, choosing imagery that would help make the abstraction of cells more meaningful. He explained, “so I visualized these cells being busy and you know, and I was thinking of the apoptosis and the macrophages and so on, and saw the macrophages helping,

⁴⁹ Amphoras were ancient storage jars in which the neck of the pot was narrower than the body. The amphoras most likely to come to mind are Greek and Roman vessels that were two-handed and whose exterior was generously decorated with scenes from mythology.

and to clean up, you know, the macrophages became my buddies to clean up the cancer cells, and so on.” A participant with leukemia expressed how difficult it was for her to understand what was going on in her body. She struggled with the imagery saying, “that’s something I kind of picture travelling throughout your blood and whatever, but for some reason, lymphoma, like, you think of, like, these spots, like your nodes or like, your—in your chest or your—I don’t know.” This confirms the systemic nature of blood cancer, the insidiousness of being ‘everywhere’ in the body as I identified earlier, but also elaborates on the abstract nature of the disease to the point of being intangible. A patient with double-hit lymphoma described his vision of cancer:

We all do have free radicals, right? And if the immune system is compromised, these free radicals, you know, turn into cancer, you know, and try to eat you up, right? So we have it already inside, well, like germs and viruses and everything, you know? So it’s the good and the bad. It’s like I see the body as a universe itself, you know, that basically instead of we live in this universe, but we also have an internal universe with all the good and the bad.

The cancer was created by free radicals imbued with action of living beings (eating). The universe of the body was permeated with qualities assigned to humanity -- good and bad -- with nature represented by the neutral. The humanized cancer was thus a bad presence in the universe-body.

The only way patients knew the progress of their disease was by, and through, interaction with the medical system, predominantly through bloodwork. A female participant noted that the entire disease was mystifying:

My blood, and I think I didn’t get that really in the first year because I didn’t understand—I didn’t know what the blood work was for. I mean, I knew CBC, but I didn’t understand about PCR and getting the molecular testing done for that first year. I didn’t—I just didn’t clue into anything.

As referred to earlier, a participant explained that tumours can be surgically removed whereby, “that tumour is gone. Whereas the blood, like, how do you know what’s happening

to my blood? Like, where is any potential cancer problem? It's still there. But with a tumour, at least, it's gone. Like, the baseline is zero." The need for surveillance bloodwork is continuous for haematology cancer patients. While the duration of time elapsing between bloodwork eventually widens as they are further out from diagnosis and treatment, the need persists indefinitely. For these patients, the baseline will never be 'zero' or cured. Therefore, the disease itself is measured numerically – the good news, the bad news, and even hope are captured with numbers representing certain cell counts. Specifically, the differentiated white blood cells (most specifically neutrophils) were a critical indicator of disease status. Other blood cells such as platelets and red blood cells predicted potential side effects and physical feeling. Almost every participant in this study spoke about their current bloodwork, tying their identity as well, healthy, sick, or unwell to those treasured figures. One female participant with MDS said, "when the numbers dropped... I think, zero, zero, zero, zero, zero, I remember I felt zero, zero, zero, zero, zero." After each cycle of chemotherapy, another participant noted that, "I don't know how normal that is, but by day seven, you could see one—zero to point one, to point one, point two or whatever, and it was how were the neutrophils, how were the neutrophils, you know?"⁵⁰ After chemotherapy, routine diagnostics are used to monitor disease in the body. A participant said, "at the worst of it, the expectations of numbers going up or going down, what are the benchmarks? So we do this benchmark at this time, so we do a bone marrow biopsy...." A bone marrow biopsy is not only uncomfortable, but it indicates if remission has ended.

The very intangible nature of blood cancers necessitated reliance on the medical system for knowledge, and it also required the imagination to sculpt understanding. By this I mean that patients with blood cancer can only know the status of their disease through bloodwork and highly technical laboratory testing. This is different than solid tumour patients who can self-monitor their disease through tangible, personally-accessible means such as assessing tumour growth or exhibiting new symptoms (such as a new pain or icteric skin). In this sense, cultural languaging around the cancer became critical in the process of

⁵⁰ After receiving chemotherapy, patients will go into a downturn with their bloodcounts which will cumulate in counts reaching their lowest level between days 7 to 14 after chemotherapy started. This lowest point is called the nadir. Usually this period is when patients are the sickest and when they are the most susceptible to infection and complications. Nadir lasts a few days at which point the blood cell counts start to recover and begin an upward trend again.

sense-making. A final part of this process of deconstruction was that of personalization of the cancer in an effort to comprehend the role of cancer-in-self.

Personification

An abstracted self captures the fullest essence of a deconstructed self. In the absence of understanding and social mores around behavior, abstractification of the disease into cells served as a coping strategy to gain identity by attempting to identify the cancer in a way that was meaningful. This methodology of disease anthropomorphism was discussed in chapter 5 in the historical review, where the idea of relating cancer to a living thing (worm, wolf, invader) was very popular in past generations. Every participant in this study embraced some level of abstractification in communicating about the experience of having a blood cancer. Over half of the participants took this abstractification into cellular components and counts further, attributing human-life qualities to their cells. As part of the deconstruction process, this represented a new level in which the impersonal quality of the cells was rejected in favour of anthropomorphism. The personified cells could be named, talked to, described, bargained with, manipulated, and rationalized in a way that provided a sense of coping. One middle-aged woman with leukemia described her process of personalizing her body cells in a way that allowed her to channel her fear. She recounted that:

It's in my blood. Yeah, in my blood. Yeah. I also had a tumour. I called him Tommy. Tommy the tumour. And Tommy and Luke [sic. Leukemia] came to the party and they weren't invited, so I had to evict them, and they left. And they took their shitty friends with them.

This same participant provided narrative around her life being a party that was rudely interrupted by cancer. She said, "I really thought that I'd had a party and some people got called that shouldn't be there. That's how I framed it in my mind. And it wasn't that they were essentially bad people. They just didn't belong at my party, and they caused trouble, so they had to go." Another participant with lymphoma described how she had envisioned the cancer like an invader in her body, having entered into her from the outside. She stated:

I almost thought of it as, like, a terrorist in my body. Like, you know—you know when you talk about—because you hear a lot of news about terror attacks, and it's

about, like, something that's, like, in your body and it can go away, but then it could come back at any time, and so you're always on alert. Like, you're like—yeah, that's kind of how I pictured it, like this invader...

Thus a very classical image, one that has been recorded in historical works, of an insidious invader, something bad coming into the body from the outside, was embraced as a way to explain not only the disease but the constant state of alert that haematology cancer patients are in after entering remission. A lymphoma participant with two swollen lymph nodes in her neck confirmed that she had named the unwelcomed visitors and spoke to them regularly. She said:

We named them Hansel and Gretel because we—I understood they were from Germany, and so Hansel and Gretel became, 'How are Hansel and Gretel today?' and 'How are they moving in your body?' Like, it just—it really was about just visualization. It wasn't about battling, it wasn't about winning. It was about, oh, so how are they today? Where are your neutrophils, where are your red blood cell? Oh, they must be moving in, they must be getting comfortable....

In this example, the participant wanted to almost become friends with her tumour-visitors in an effort to personalize them, rationalize their presence, and work to decrease her stress by giving her cancer a face and a name. She recounted that this allowed her to soften her anger towards the cancer cells since they were familiar, almost friendly. Similarly, a participant with lymphoma described calling the disease 'Isabella': "Well, my original bone marrow had a name. I named her... In my pelvis. And she resided there, and I nurtured her while I was going through the aza [sic. Azacitadine], to like, 'Come on, girl, you can do this.'"

Other participants in this study related that the systemic nature of their cancer meant that it was themselves, and thus personalized the cancer by taking it as an equal part of their self and being. One woman with leukemia said, "I was a co-creator to this, me, [name redacted], whatever. So I always felt that I had to bathe it in light, I had to give it healing energy, I had to love it, rather than the enemy approach that just doesn't fit me." Another man with leukemia related a similar feeling saying, "I really feel I worked with my cancer.' I—it was a—being my own body and being part of me, I always felt I had—we had to cooperate,

rather than be enemies.” A young woman with lymphoma talked about her autologous transplant. When she received her own stem cells back during the transplantation she acknowledged the return of her own cells as helpers: ““Let’s envision these cells that are coming back in me. They are my own cells, are welcome, and they’re coming back. Let’s envision them, that they are healthy and strong, and wanting to help me.’ This is my—this is my—they’re my helper to come back to make me healthy and strong as the—you know?” The vision of the self as helper to the self really involved the patient as personifying the cancer as self, and the solution as self. One participant explained that their blood turned on them: “your heart’s working, it’s pumping blood and stuff like that, so blood is your being, right? Yeah. And then it turned on me, you know?” The blood as systemic being turned on the self (patient), implying sentient intention on the part of the blood which was the self – was the self then turning on the self? Several participants echoed similar sentiment which echoed previously discussed the idea that the cancer was self-caused, and therefore personified as the self.

Finally, a few of the participants attributed life-like qualities on their cancer cells but not as human beings, but rather as creatures or characters. One man related the cancer to the demise of the wicked witch from the *Wizard of Oz*. He said, “and so I thought of it, like, that’s the image I kind of had, this thing that wasn’t, like, solid but kind of mushy, and it was just kind of melting as I was getting the chemo.” Another participant with lymphoma described her cancer cells as “bugs.” She explained that the individual cells were, “like a bug. Something like that, floating around. Those little white cells, they were—they were invaders.” Again, invading provided imagery of the person being attacked and penetrated by an outside source (“invader”), and the use of a noun to describe this thing (cancer) gave the notion of a single invader rather than reflecting the reality of cancer as a huge host of uncontrolled cells within the body. The single invader called ‘cancer’ personified a very complex disease deconstructed into something that could be more easily understood within a personal and social context.

Deconstruction, the purposeful tearing down of self to find new or deeper meaning, has been discussed here within the larger context of identity for the adult haematology oncology patient. Analysis of the data provided by research participants created imagery of a

self torn apart through the subthemes of unawareness, abstractification, and personification. It wasn't as though the cancer erased the personal identity or sense of self, but rather, a process of discovery and dissection of self was necessary in order for participants to create meaning and find sense in their highly personal experience.

Reconstruction: The New Normal

The final theme of reconstruction represents the rebuilding of identity and notions around self after being destroyed – or damaged – by the cancer diagnosis. Reconstruction refers to a process of putting things into good order, which captures the positivity and sense of hope for the future expressed by the participants in this study. Addressed within this theme are notions including relinquishing control after diagnosis through isolation and entrance into a medical system characterized by its focus on the science of cancer and the manifestation of disease through the physical body and its markers. Subsequent vulnerability produced fear, suffering, and anxiety of both existential and empirical natures. Participants described various models modicums for finding and regaining control over their self, body, and identity in a way that would allow what one person described as “the new normal.” Since each of these participants was a survivor in the medical sense, they all conveyed hope, optimism, and sense of accomplishment manifested by a notion of reconstruction.

Regaining Control

Loss of control over circumstances is difficult, especially when it comes in the form of relinquishing control over the body due to illness. One participant explained, “This—it—you know, my—just take a couple bad cells and start going crazy, and they just—there—it—body didn't control it, right?... It's just body out of control.” For participants in this study, the loss of control produced by a haematological cancer diagnosis assumed several forms but most notably through a profound sense of isolation and an unwanted entrance into the medical system. In light of such a complex and confusing disease, participants universally felt they didn't have a choice. One man said, “and that's what the doctors are there for. They're there to come out with new procedures and clinical trials that will help, you know, us as a race kind of have a better quality of life. And that's why I would rather sit and have more trust in doctors and nurses in giving me any more information because they're—they do this

for a living.” The profoundly dangerous and potentially fatal presence of a blood cancer facilitates immediate entrance into the medical system as a ‘patient’ as soon as the cause for troubling symptoms is identified through labwork. In almost every case, participants presented at the GP or clinic with fatigue, a persistent cold or flu, trouble breathing, strange bruising and bleeding, and other insidious signs of a potential blood disorder. At some point, the physician ordered blood work (drawn at a laboratory) and it was this blood work that triggered the fateful call to come into the office. Final diagnosis of a haematological cancer is achieved only after a bone marrow biopsy; this is a very uncomfortable procedure in which bone marrow is extracted via needle from the pelvic bone. The bone marrow is analyzed under microscope by haematologists and lab technicians and a diagnosis is determined. Therefore, the entire process of diagnosing blood cancer involves the medical system and cannot be achieved without entering into this system. Treatment with chemotherapy or a biotherapy commences almost immediately, and the patient is made to know that without this treatment their chance at survival (or long-term survival) is significantly reduced. Thus, entering the health care system is one of relinquishing control over mortality and physical being to the *other*. A young man with leukemia explained, “they put in my Hickman line tube and a bunch of stuff immediately to sort of get my diagnosis under control because it was insane. But I—yeah, no, I didn’t really know what was going on.”⁵¹ Another patient with leukemia said the diagnosis had made her realize, “we don’t have as much control as sometimes we maybe want to think we do over things.” Another woman said that she insisted on keeping the amber necklace of her long-dead mother with her, even when she went for radiation noting, “I think it helped me to have a little bit of control. It helped me of normalizing a little something. There was so much that I had no control over anymore, and just normalizing some things for myself was important.” Yet another participant reframed the entire experience of treatment altogether calling it a job in order to retain a remnant of control-via-perceived choice:

I pretended that I’d won a job, that I’d tendered for a job, a contract in Vancouver, and it was a job that I had to do. I didn’t know how long it was going to take, it was going to be tough some days, it was going to be brilliant some days, and I was going to meet

⁵¹ None of the participants mentioned a bionic or mechanized or robotic identity, despite having large central lines (central venous access) devices.

a lot of people, and that's how I coped. It was a job. It was a job that I had to move for, and I had to dedicate myself to, and that's the only way I could handle it because it's really fucking scary.

Transfer of control over to the health care system was, in every case, grounded in hope of survival just as it is for almost every other disease or condition (traumas, for example) that afflicts humankind. The process of reimagining the blood cancer into a familiar identity of being a worker and having a job seemed to provide a sense of comfort as well as asserting control over the situation. In general, workers do have control over their job, work environment, and retain the ability to quit at any time. The data also contained references to loss of control over the physical body. One participant described how, during treatment for lymphoma, he totally lost control over his own body: “So the night sweats and chills, which is really scary thing to happen to you where you get so hot and then you're instantly frozen cold, and you're just uncontrollably shivering and shaking. You can't stop that.” Similarly, the side effects of blood cancer and treatment caused an altering of physical appearance in that the patients may have lost the ability, or desire, for basic activities of daily living (ADLs). Outside of the health care system and back in their own space, a few participants described how they sought to reclaim their former self. A middle age woman with leukemia described how the disease was identity-altering. She explained, “so I get tired of seeing this in the mirror. I get tired of looking at my emaciated body. I get frustrated when I can't do stuff. I dress up because I love clothes, and I have unusual things. And I dress up and then I try to fix my hair.” The desire to normalize again was a way to take back control from the disease, and to reclaim a life that was beyond being just a patient.

Entering into the health care system led to a loss of control and increased vulnerability which emphasized feelings of isolation. Isolation, and more notably a social isolation, was a finding explored in chapter 6 (secondary analysis) in reference to isolation forced on the individual due to real threats to the body and health (from contracting illness from others while neutropenic, for example). An expanded sense of isolation was expounded on in this study whereby participants explained that they lost control of their ability to choose their own environment, an experience that was amplified during active treatment. One participant said, “so you lose your sense of self because you can't—there's no identifying

against anything else except your immediate surroundings.” There was a sense of isolation and disidentity not only from the self, but from family and friends, and from the ability to be in a familiar environment. A young male participant explained, “I’m ripped out of living at home. I’ve lived at home my entire life. I was prepped to move to university, which was going to be with friends so it was hopefully supportive, and now I’m at a hospital by myself in the dark, like, dealing with all this stuff going on in my mind.” He added that, “I’m also, like, an extrovert so I need to be with people to feel recharged, and being by myself... being by myself and a lot of alone time was really, really hard.”

For participants in this study, regaining control when feeling so isolated (physically and mentally) was expressed as finding a way to be alone with the cancer in a way that could ease anxiety and produce meaning. One participant noted, “I don’t call it ‘my cancer.’ It’s not mine. It occurred to me. I don’t possess it. And that helps a lot.” Again, as discussed previously and referenced in the context of the processes of personalization and origination, the cancer was an invader that came from the outside as an occurrence because the person made themselves vulnerable (through too much stress, retiring, etc.), therefore one that could theoretically be removed. De-personalizing the cancer into something non-self allowed, at least in a few instances, for the participant to regain control and start to form an identity beyond being a cancer patient. Participants also explained how regaining themselves by embracing control happened when they actively engaged with the treatment process in the only ways they could: visualization and using the imagination. After abstracting the cancer into cellular components and, in some cases, personalizing these cells into a being that could be reasoned or communicated with, many participants sought to regain their self by attempting to control the cancer. A younger woman stated that she felt more like “herself” when she regained power over her leukemia. She did this through visualization saying, “I especially visualized my cells being healthy and being able to help me through this. I sent lots of positive thoughts and feelings to my harvested cells to be strong and well.” Another middle-aged woman with leukemia related that she decided to enact control on her cells by embracing positivity:

I want you and everybody to know that there’s life after cancer. You’re not dying of cancer. You’re living with something that happened, and it’s not a death sentence.

And just don't give up. Don't give up. It's worth not giving up. It's worth it. It's sweet. It's—life is beautiful, and we're only here for a short time, and you might as well make the best of what you get, if you can, you know?

The process of deconstruction of the cancer was really a fundamental step in learning how to cope with a blood cancer, and represented an attempt to regain control of the body and self in a way that could convey meaning to the experience. After struggling through origination of a transformed identity and trying to understand what that meant through deconstructing the experience and finally giving up control of their bodies to the health care system in order to receive treatment, many of the participants described a process of regaining control as critical to finding their new identity.

Overcoming Vulnerability

This reconstructive process can be described as expected and deliberate in the way that participants assumed they would be different as a result of the cancer diagnosis. The effort and pathway towards this reconstructed self was not as obvious; however, with each participant navigating the process in unique ways that embraced the notion of control. An additional way in which patients tried to find their new normal is through overcoming vulnerability in which the participants described the process of finding acceptance of their physical and psychological defenselessness to the disease. In order to form a new normal identity and life, the participants broadly emphasized how they had to prevail over the dissolution of immortality represented by the cancer diagnosis. Western cultures emphasize personal responsibility and control over the body as machine. For example, with a cancer diagnosis (or any disease, for that matter) the person has failed in the sense of normal operations, forcing health care to paternalistically take over. Many participants expressed, with painful acknowledgement that they had failed themselves by being “too stressed,” “too busy,” or “not grateful enough” and that is why they got cancer. Rather than blaming society and the increased environmental toxins, the increased radiation in the atmosphere from communications, or pesticides being used to grow food, each of these participants in one manner or another *blamed themselves and their choices* for their blood cancer. Their action to deal with the cancer that they felt they caused (in some way) was to acknowledge their (perceived) role in developing the blood cancer, acknowledge their physical vulnerability

resulting from personal action, and then actively seek methods to deal with these shortcomings.

My impression was that, in one manner or another, each of these study participants had reflected on the aspects of their own lives and behavior that might have contributed to their being vulnerable to the disease. The youngest participant in this study noted, “I—during high school, like, I never smoked, I like, barely went to parties, I wasn’t sexually active, like, nothing like that. So I was—there were days where I was thinking, like, did I do something wrong?” Chapter 5 (historical inquiry) expounded on similar concepts like the Type C personality, spinsterhood, depression and melancholy (*melan chole*) that have, for centuries, plagued cancer patients as reasons for developing the dreaded disease. Many participants noted that the cancer was their *own body’s* way of teaching them a lesson. An older man with lymphoma summarized this idea best by saying: “I really believe that this was brought to me for a specific reason that I needed to learn some shit. And I always say it’s like the big whack on the head. Smarten the fuck up. Okay. And I’m lucky that I got a chance to rebuild and redo.” This reflects an ongoing, persistent perception that the person gave themselves blood cancer. The means are extensive within this dataset and include: too much drinking (alcohol), eating too much sugar, being too stressed out, working too much, being too selfish, and not being religious (enough). Compounding this is a sense that the participant, as an individual, was also responsible for vigilantly monitoring their disease. A woman with CML noted, “And it’s a journey, and my responsibility is to keep watch, to make sure I keep it under control and do everything I can to do that.” A middle-aged woman with hairy cell leukemia emphasized that she quit her career as teacher and worked full-time on her cancer, asking herself every day “how am I going to get healthy?”

The notion of vulnerability reflected in these comments embraces a reframing of power and control. What could have happened is that, by taking responsibility for causing cancer, the participant was also claiming the power to overcome the disease. The power and authority gained by appropriating responsibility allowed patients to move into the future with the new reality of having blood cancer. This represents a constructive reframing of the blood cancer experience into something reflecting personal control over reframing disease process into something familiar versus a supernatural phenomenon. Referencing religion, or

spirituality, this study showed that notions about the spirit, soul, and other concepts did not come up in conversation with the participants unless specifically mentioned by the researcher (myself). For an existentially important issue such as identity, many researchers have assumed that spirituality would play a key role (see chapter 4). However, notions of spirit, soul, Supreme Being, afterlife, and the like did not arise naturally in the interviews and it wasn't until questions around belief systems were asked that these subjects were referenced, often very briefly. About half of the participants claimed to be religious, attending church regularly, but none of these folks referenced their religious beliefs or made claims about their identity in ways that were different from the so-called non-religious participants unless specifically asked to comment. This was surprising to me, as I (wrongfully) assumed from research in Phase One that blood cancer patients (and indeed, all patients) would entwine religion or spirituality with their sense of self, identity, and personhood. What I did find upon analysis of the data was that whatever the participant started with was what they came out with: namely, if they expressed (for example) that they were spiritual when they received their diagnosis, they were still spiritual when I interviewed them. In each case I specifically asked if the person was more or less spiritual/religious because of their cancer diagnosis, and each participant responded negatively. What did arise from the data was that the values they had as a spiritual and/or religious person impacted on how they reacted to their diagnosis. One person noted, "I'm religious in my own way. I haven't started going to church or whatever." Another stated, "So my family is a spiritual family. Like, extended family on both sides of my family, my mom's side a little bit more than my dad's, we've always attended church, so through this, we definitely had people there supporting us, bringing my parents food, and praying for me. So we had that going on." An older woman with CML (chronic myeloid leukemia) noted, "I've always been spiritual. I'm not practicing. If I was to choose a religion, it's Christianity, but I would just say that, no, I just have not changed in my views." Another gentleman who had always been religious noted that this had not changed with his cancer diagnosis, and his church was able to support him: "...when I got sick and then I let the church know what was going on and that sort of thing, and they—a marvelous group of people there that—you know, for support and all sort of thing. So one thing they did for me is they made me a prayer shawl, which I take with me everywhere." Thus, this dataset suggested that people with haematological cancers maintained their sense of spirituality (or

religiosity) at about the same level and manner as before their diagnosis. It was this belief system that helped them frame the disease in a meaningful way, provided support network (or not), and gave them a reference point from which to work out questions around mortality. The self-proclaimed *identity* of these patients as being spiritual, Christian, atheist, etc. did not change with a blood cancer diagnosis.

One of the most significant observations around a reconstructed self was that patients had to be outside of active treatment to want to reflect on identity and their experience of self with blood cancer. The flyers for recruitment were circulated to the acute in-patient unit at Vancouver General Hospital (L/BMT), to the L/BMT daycare clinic, the BC Cancer Agency daycare clinics, and the Leukemia and Lymphoma Society's newsletter. Despite the active promotion of this study within the in-patient and daycare settings by the healthcare team (physicians, social workers, and nurses), only two patients from daycare clinics were willing to be interviewed and they were more than 1 year out from their initial diagnosis. Many participants (n=12) that came forward had surpassed active treatment (meaning chemotherapy and/or transplantation) and were in remission or palliation. I asked one of the participants towards the end of recruitment to comment on this and she commented that upon diagnosis, "I had to go into sort of survival mode... I was so sick in the beginning, I just had to sort of go into what am I going to do next?" Indeed, active treatment is exhausting and side effects like nausea, vomiting, diarrhea, anemia, and the like amplify the physical suffering. Another gentleman who spent several months after diagnosis in the hospital (acute care) noted:

I thought I would journal a lot, but I didn't. I didn't have—I just didn't have the energy and the motivation to do that part. I don't know if that would have made any difference or not. I was thinking that it would but I just couldn't do it. I would just talk to myself and try and enjoy external things like, wow, it's a beautiful day. I mean, the views up there are amazing, so okay, you're going to walk around six times. So yeah, I guess the more rote kind of things to try and get you through your day. Okay, dinner's at so and so, you need to stay awake till blah, so you need to watch TV or whatever it is.

The daily activities around getting treatment and dealing with the physicality of the cancer seemed, at least from retrospective accounts, to be the major concern during the initial phase after diagnosis. The inability, or unwillingness, to discuss issues of identity and self in active treatment may have been a protective measure to decrease vulnerability. By waiting until the ‘right’ time to talk about existential matters, the participants also expressed the notion of reconstruction in that they had come through the active, acute disease process (origination, deconstruction) and had redefined themselves as a blood cancer patient.

The theme of reconstruction captured the essence of an active, purposeful creation of new self employing pieces of the past (pre-diagnosis) and the present (post-diagnosis). Reconstruction in this study was saturated with various components of control and power, recapturing a sense of safety and personality stability after the assault of a blood cancer diagnosis. Due to the fact that a haematological cancer is never really considered cured, the participants were aware of the fact that at any moment the delicate self each worked so hard to reconstruct could crumble. With every draw of surveillance blood work, each tiny pain or novel bruise, haematological cancer patients were living in perpetual tension of recurrence, being told they were terminal, or having to receive salvage treatment. The subthemes of regaining control and overcoming vulnerability encapsulate anxious tension and suspicion arising from building a new future on a scarred and defective foundation.

Discussion

After extensive consideration of the data collected through face-to-face interviews with a new blood cancer patient cohort, the themes of origination, deconstruction, and reconstruction were used to try to make sense out of the complexity of human identity. These labels, or terms, were carefully chosen for their inherent and social meanings to imperfectly but effectively convey a process of discovery, transformation, and resolution following diagnosis with a potentially fatal blood cancer. While not precisely sequential, the pathway of a dissolving identity and the reconstruction of a new identity based on these experiences of cancer reveal a deeply entwined process with naturally built-in feedback loops between the elements. Within the theme of origination, the patient assumed the self-described ‘mask of sick’ and was transformed against their will into something else. This something else was profoundly influenced by social pressures and expectations around what it meant to be sick,

to have cancer, and to have a blood cancer. Social naivety and ignorance around haematological cancers led to frustration but also to a sense of being unique. Consideration of treatment strategies, usually chemotherapy and perhaps transplantation, emphasized the notion that the blood is systemic and that the treatment must therefore be systemic. These findings consolidated a view of the person who struggled with meaning of self when their physical body had been taken over, literally, with cancer which was in the blood.

Deconstruction occurred for the participants when they had reached some kind of peak or phase in their treatment journey. This theme was meant to capture a notion of disintegration, of dissolving the former self into parts and components which could then be rebuilt into something new that incorporated the cancer diagnosis. A sense of unawareness and lack of knowledge about blood cancers led to research and exploration of what the diagnosis actually was. This process, in turn, resulted oftentimes in the realization that because the impact on the body required abstract understanding, an active imagination was compulsory for even basic comprehension. Further deconstruction occurred as the cancer became part of the self, not the self, and took on meaning and languaging of its own in a pathway of understanding. Deconstruction for the haematology oncology patient was a process of sense-making, of breaking the experience down into parts that could be understood, mulled over, digested.

As the participants moved into the later stages of treatment or remission, these pieces were captured in self-reflective activities that spawned the need for getting back to life and finding that new normal. Reconstruction in this sense captures the process of reframing experience, of rebuilding after being destroyed or damaged that self lost to the word “cancer.” For each of the participants in this study, reconstruction captured a sense of regaining control through various means such as setting goals, focusing on outcomes, and seeking ways to help themselves (through complementary medicine, for example). Patients sought an explanation for their cancer by self-reflecting on their own behaviours, blaming thoughts, indulgences, actions, diet, and other lifestyle vices. Spirituality played a role in vulnerability by providing a source of comfort as well as direction for behaviours, but as stated above, the participants did not readily discuss spiritual matters unless prompted. Additionally, a diagnosis with blood cancer did not pressure any of the subjects to change

their spiritual leanings; those that were spiritual (or religious) remained so, while those who were agnostic or atheist simply incorporated meaning into the cancer experience appropriate to their belief system.

What the findings help us envision ultimately is the gradual move towards prioritizing matters of identity within the health care setting. Methods of dealing with existential crises such as having a blood cancer offer a unique glimpse into some of the delicate steps of a nonlinear process of searching for mechanisms and means to cope with a serious and devastating illness. Contained within the interviews with this new patient cohort were multiple themes present in the modern academic literature around meaning making, spirituality, existential crises, suffering, and other ways of thinking and talking about the multifaceted concept of identity. The patient narratives also demonstrated how medical metaphors were used to discuss physiological process in a way that provided context and understanding. What evolved from this research process was not *the* answer about identity for the haematology oncology patient, but diverse visions that intertwine to compose what we can call identity as a subjective and personal experience for these individuals. Anxiety, fear, depression, and emotional trauma were present, of course, as reflected in the themes described above (and particularly around reconstruction) but they are consequential. Perhaps the person is not, in the early stages of diagnosis and treatment with a haematological cancer, able to speak about identity and self, not because these are unimportant concepts at the time; rather, they evolve and move to the forefront in priority when the person achieves some clinical goal (like remission, 100 days out from transplantation, etc). This is a theme that I will discuss in clinician interviews as part of Phase Two, layer 5 primary data collection to try and understand how and if identity should be a concern of the health care professional in various stages of the cancer journey.

Conclusion

The cohort of haematology oncology patients interviewed in this layer of primary data collection revealed the deeply complex and highly personal nature of their diagnosis. Juxtaposed against the secondary analysis research, identity serves as an informative way to feature different aspects of the modern blood cancer experience. A final step in this layered qualitative research project was to undertake interviews with experienced oncology

clinicians. Rationale for this layer of inquiry highlights the unique and important contribution thoughtful and reflective clinicians can make to research on this patient cohort. The extensive experience represented by clinicians intimately familiar with blood cancer patients provided a different lens from which to view the experience of identity. It is not that the experience of the clinicians is preferable to that of the patients, nor does it represent a view that is more expert or right than those experiencing cancer. Rather, the clinicians may have seen some of what I heard in the broader patient groups. Reflections on what they have seen, heard, and interpreted may assist in the crafting the manner in which I can convey the findings from this research project to the practice environment. This concluding study with experienced clinicians constitutes layer 5 (Phase 2) of this research and is presented in the following chapter 8.

Chapter 8: Haematology Oncology Clinician Interviews (Phase 2, Layer 5)

Introduction

This chapter presents study findings from experienced clinician interviews undertaken as layer 5 in Phase 2 primary research of the haematology oncology patient experience around identity. As a fifth layer of data collection and occurring after the completion of the first four layers of research, I undertook directed interviews with thoughtful interdisciplinary oncology clinicians to generate knowledge and a deeper understanding of the phenomenon of identity as experienced by patients. Experienced oncology clinicians from the disciplines of nursing and social work were asked specific questions arising from the previous four research layers about identity as a social and individual construct, and specifically I asked them to comment on their personal beliefs and observations around the phenomenon of identity as experienced by their patients. The research question for this layer of data collection and analysis was: How can insights of experienced oncology clinicians around issues of identity for haematology oncology patients contribute to an understanding of this phenomenon?

Directed interviews with experienced oncology clinicians were incorporated into this research study as an additional layer of data to supplement and complement the previous layers in a meaningful and unique way by providing another lens on the patient experience of identity. As discussed in chapter 3, rationale for including experienced⁵² oncology clinicians in this study was multifactorial. Foremost, interviewing clinicians as a final step within successive data collection layers strengthen credibility indicators for a study such as this (per Thomas & Magilvy, 2011). Following recommendations set out by Thorne (2008), the inclusion of insights from accounts of thoughtful clinicians in addition to patient reports of subjective experience can also help bolster confidence towards the dependability of the research findings. More importantly, this layer of research honours the perspective and

⁵² I am using the phrasing “experienced clinician” in this chapter, but recognize that within the nursing clinical practice environment the term “senior” is used more frequently. Experienced clinicians (and most particularly nurses) are often referred to as “senior” to designate those with -- loosely speaking -- more than five years of clinical experience. In many cases, “senior” and “junior” are also used in practice to differentiate those who have been on a unit or in a specialty for an extended amount of time (again, this is usually several years). Since this research included interdisciplinary team members, I chose to use “experienced” as an inclusive label.

observations of experienced clinicians by accessing what they have observed working with haematology oncology patients in a variety of settings. It was not my expectation that the clinicians would validate or replicate the patient participant findings. Rather, the intention of this layer of data collection and analysis was to explore how patients self-report identity issues within a clinical context as observed and noted by oncology clinicians. In addition to providing clarity to my evolving thinking, interviewing experienced haematology oncology clinicians challenged and strengthened my own reflections and therefore shaped my thinking with respect to findings that could be drawn from the study as a whole. This layer of primary research with experienced haematology oncology clinicians was also indispensable for creating an engaging and relevant discussion that informed my thinking about the intended audience of this work, so that practice recommendations arising from this study might be both pragmatic and appropriate.

Sample Description

Data collection with experience oncology clinicians occurred after receiving ethics approval from the UBC Office of Research Services (UBC BREB H15-01335), the BC Cancer Agency Research Program, and the Vancouver Coastal Health Authority Research Institute (V15-01335). A purposive sample of six highly experienced haematology oncology nurse clinicians was recruited for this layer of the study. Each of these nurses had at least ten years of experience caring for haematology oncology patients in various care areas, and each was currently working in an oncology setting. I conducted pre-interviews with potential participants to determine both their level of interest in this topic and their overall ability to be reflective on existential matters including identity, and all six nurses who volunteered for the study were included. I also interviewed a haematology oncology social worker (SW) as part of this study due to the participant's deep interest in psychosocial matters, as well as her extensive twenty-five-year career counselling oncology patients. This focused selection of participants allowed me to ask targeted questions that arose from the first four layers of this research project. I believe the sampling was reasonable, informed, and broad enough to reinforce the credibility of this layer of research. See Table 3 for additional demographic qualities of this sampling cohort.

Table 3: Demographic Qualities of the Haematology Oncology Clinician Participants

| | Clinician Cohort (N=7) |
|---|-------------------------------|
| Experience in Haematology Oncology | |
| 10-15 years | 2 |
| 15-20 years | 2 |
| 20 + years | 3 |
| | |
| Mixed Oncology Experience (solid tumour and haematology) | 5 |
| | |
| Haematology Oncology Work Settings (overlap possible) | |
| Counselling (outpatient) | 1 |
| Inpatient (acute) | 6 |
| Day Clinic and outpatients | 3 |
| Social Work | 1 |

Method

Within this experienced clinician cohort, the primary data collection approach consisted of individual interviews. These interviews were digitally recorded. The interviews were semi-structured and based on the interview guides developed after deep foundational analysis of research in Phase 1 (layers 1-3) and particularly driven by analysis and findings of Phase 2 (layer 4) (See Appendix C for the clinician interview guide). Data collection and analysis occurred concurrently, allowing subsequent interviews to be tailored to address specific concepts or issues. Each interview lasted about 60 to 90 minutes. These interviews were then transcribed by a hired professional transcriptionist using a naturalistic transcription technique. As with the previous research layers (Phase 2, layer 4), this technique involves verbatim transcription of the interview to allow a “talk-in interaction” (Hutchby & Wooffit,

1998, p. 13). Transcripts were uploaded both to a continuous MS WORD file and NVivo™ (v.10) software program to allow multiple and diverse opportunities for data analysis. Field notes were written during and immediately following the interview. Ongoing analysis of data gathered from both the clinician and patient interviews constituted reflective journaling. Overall the process of gathering, processing, and analyzing data in this layer of research mirrors academically rigorous qualitative methodology.

Developing the Interview Guides

An interview guide was developed based on the exploratory research of Phase One (layers 1-3) and the patient interviews of Phase Two (layer 4). This semi-structured guide was flexible in that I anticipated the conversation to be primarily driven by data and findings from the patient interviews. Besides asking basic demographic questions about their current employment and experience in oncology (Question #1), additional interview questions asked for details around clinical experiences that might speak to issues of identity as they had observed for patients. Question #5 specifically dealt with observations that the clinician may have made about the use of metaphors, descriptive, nouns, adjectives, or other social labels (such as victim, survivor, etc.) while communicating with patients. For example, I included such questions as: “In your clinical experience, how do patients talk to you about their cancer journey and perceptions of self? What words, metaphors, or descriptive do they use? Does any type of nonverbal communication come to mind here, such as silence, reflective pauses, refusing to make eye contact, wringing hands, etc.”? Clinicians were also asked about their “gut feeling” (intuition) about how patients talk, or don’t talk, about identity issues, including if there could be other factors going on such as existential pursuits of meaning-making or notions that might indicate embodiment, existential, or identity crises. Question #6 stated, “In what ways have patients you have worked with tried to maintain a sense of self during treatment and beyond? In your opinion, what types of things affect the way patients think about themselves?” and leaves room open for discussion about holistic or complementary healing modalities which are, thus far, largely excluded from the research in Phase One (except for the historical inquiry piece, where holistic medicine and spirituality were more openly and socially discussed as parts of reality) but known to exist as indicators of self within the health care setting. Overall, the interview structure followed the interview guide,

but the semi-structured nature of the interviews allowed for additional direct questioning over specific issues that arose as findings or issues within previous research layers.

Data Analysis

The qualitative framework of interpretive description guided an inductive analysis process. Constant comparative analysis was employed to analyze and code data by applying generalized themes to portions of transcribed text. Constant comparisons were between the data and themes constructed based on the patient interviews, thus creating a comparison between clinician and patient perspectives of patient identity. As data collection and analysis continued, additional exploration of patterns and key concepts was done to achieve more precise thematically-driven coding of the transcribed text. As major themes were identified, reexamination of the transcripts ensured they were grounded in the data. This analytic process was further complemented by rereading the transcripts and listening to the audio moments of key reference points in the interviews. Consecutive analysis of field notes and personal reflections strengthened conclusions and addressed issues of validity and consistency.

As the interviews with experienced clinicians were meant to supplement and expand on the patient data, this aspect of the overall research project did not constitute a stand-alone product derived from inductive data analysis. Rather, the data gathered from directed questioning of clinicians was purposeful in the sense that the line of inquiry was open-ended with subtle framing based on the themes and subthemes arising (primarily) the findings arising from the patient interview data. The stated purpose of interviewing clinicians was to gather their clinical observations and impressions of how haematology oncology patients expressed, struggled with, or engaged with questions about identity as part of their cancer journey. As stated above, the findings from the patient interviews offered guidance for the development of interview questions in terms of general themes and areas of emphasis. During the interviews, I occasionally used stories, themes, and data arising from the previous four layers of research as a way to frame questions and gather more information. In some cases I utilized stories or experiences from my own clinical practice in careful and measured ways meant to stimulate conversation and inspire deeper insights from the participants. Overall, I did not reveal my own research impressions or findings except when I felt it was

appropriate and would not alter the course of our conversation or on the observations reported by the clinicians. My primary goal of speaking with these clinicians was to gather *their* clinical impressions and observations, and so I was very cautious about feeding them information or creating any illusory goal of data validation. The findings from this research are presented below.

Findings

Findings from this study specifically addressed perspectives around the patient experience of having a blood cancer from the perspective of experienced clinicians. Their reflections constituted theorizing and musing about the phenomenon of identity for these patients as well as on the larger vision of what it means to be a cancer patient within the healthcare system. I understand these reflections shared by the clinicians represented subjective and biased (from a healthcare professional perspective) observations of what patients had expressed or conveyed (verbally or nonverbally) about their ongoing, contextual identity experience. The clinician data also contains elements of contemplation around professional training and socialization, which I understand contributed to their interpretation of the patient experience of identity. For example, these haematology oncology clinicians routinely discussed the inferior role that the patients' subjective self takes within the priorities of an organized healthcare environment focused chiefly on the body-proper. Discussions with the seven clinicians interviewed for this layer of primary research allowed me to confirm that identity and associated psychological and physiological factors are prominent features of the larger experience of having a blood cancer, and that these concerns require further attention and research. Aligning with the structure used to organize findings from the patient interviews, the following report of findings is structured around similar themes of origination, deconstruction, and reconstruction. The use of these major themes arising from the patient findings served as a useful way to meaningfully organize and understand the clinician findings, but I never intended to imply a comparison or member-checking between clinician and patient data. I understand the nature of the data extracted from clinicians to be different from the patient data. For their part, patients were trying to convey complex experiential phenomena around identity issues as best they could. My own theorizing about the patient data constituted a baseline through which to engage clinicians in further

theorizing, seeking feedback on thoughts and themes that resonated with their own perceptions.

Origination: Timing is Everything

Within the patient findings, the theme of *origination* referred specifically to that crucial moment when a previously healthy person became a patient with haematological cancer. The subthemes contained within the concept of origination for patients included the creation of a unique identity and the perception of the cancer as systemic and as self. During interviews with the experienced clinicians about these themes, the participants strongly agreed that a haematological cancer diagnosis was life-changing and the consequent crisis in identity played a significant role for patients. Reflecting a different angle on this theme however, the clinicians I spoke with felt that identity was most closely tied to timing in two aspects. Acknowledging the transition from healthy person to cancer patient, the clinicians first emphasized the critical importance of the stage of life at diagnosis. Additionally, the clinicians accentuated that patients could go through the origination process several times depending on phase of the patient within their disease experience and along the cancer care trajectory.

A number of the clinicians theorized that life stage (and thus age) at diagnosis had an important impact on a person's identity.⁵³ As one experienced clinician noted, "timing for a blood cancer patient is everything." By this she was referring to the age at which the patient was diagnosed and the importance that age and place in life has on the identity – or complexity of identity – expressed by the individual. In adult patients, because family, work and community roles play an important part in identity, the disruption of these added a layer to the existential complexity of having haematological cancer. In addition, this nurse was referring to the aspect of time that follows the cancer trajectory, namely that period starting at diagnosis and extending through the rest of the person's lifetime. Many of the clinicians associated social identity with demographics, social roles, and employment, all of which alter, change, and mutate over the course of life. There seemed to be an assumption among the clinician's that the most difficult time for receiving a cancer diagnosis was in early and

⁵³ This harkens back to work by Hubbard, Kidd, and Kearney (2010) as well as Cho and Park (2015) whose articles emphasized the importance of life stage in a cancer diagnosis. See chapter 4.

middle adulthood, when development of that social identity with assuming roles as worker, adult, and potentially parent are added. Thus, the clinicians in this study described identity and existential crises as more of an issue for adults than it would be for children, “because they have a lot more to lose.” One experienced BMT nurse noted that, “younger folks... just don’t have the roles and responsibilities that older people do. Like they aren’t mothers or fathers, they don’t have an identity based on a job or career that they worked hard to get.” When asked to extrapolate on how identity might be different for a younger person this nurse said, “from my experience, for younger people identity is about who I am in the now and really is about what other people think about them versus what they think about themselves which is how older people think.” The social worker commented on the impact of cancer to identity being similar to retirement saying, “all of a sudden your role changes in ways that were unexpected. You walk away from the life that you knew before, which was based on your work role, and you enter into a new role of a non-worker, or an altered worker.” This is not to say that the clinicians downplayed the importance of identity for any particular age group – each acknowledged the importance of age in relation to identity, but overall the data demonstrated a deep concern for age as a context in which cancer occurs and around which identity is created – and recreated. It is hard to tell how much of the clinician’s own age or life experience played into this. A natural passage of time allows for the accumulation of multiple identity markers on the part of both patient and clinician, and perhaps the clinicians were more sensitive to these adult patients because they are all age compatriots. Age was definitely an important component of concern within the patient interviews, but I believe arising from my privileged perspective of being able to look across the demographic spectrum and thus compare individuals. Older patient participants tended to have families, spouses, children, and more socioeconomic concerns, but it is difficult to extrapolate rationale conclusions from this in a way that would honour the life experience of each person, young or old.

A second aspect of timing expressed by the clinicians related to the cycling through the stage of origination many times through the course of a cancer care journey. Having been made aware of this aspect in my discussions with patients, I undertook purposeful sampling of clinicians in this layer of research as a thoughtful attempt to speak to clinicians with demonstrated expertise at all stages of care: acute care (inpatient hospital nursing staff),

daycare/clinic (nurse navigators and clinic nurses), and post-treatment phases (organizations, clinic nurses). Several clinicians noticed that, in patients they had worked with, focus and priorities seemed to shift depending on how acutely ill they were and the particular treatment or post-treatment phase they were in. One of the nurse participants commented that, “I think a lot of the patients that I’m right now seeing don’t even have the possibility of thinking about life after their disease because they are fighting it in the now.” Those clinicians working in acute care were aware of identity concerns but acknowledged that the preservation and treatment of the corporeal body took priority. Physical suffering and dealing with acute body issues seemed to echo the experience of the patients as well. The clinicians agreed that during the entire period from diagnosis to starting some type of treatment, the imperative for self-preservation typically required the full attention of the patient. As discussed in the previous chapter, during the patient participant recruitment stage I had found it very difficult to find volunteers who were less than one year out from their initial diagnosis, despite several attempts by myself and other health care professionals to reach out to these individuals through face-to-face requests. During the fifth layer of research, I asked each of the clinicians to comment on this and all agreed it was probably because the experience was “too raw.” A clinician working in acute care noted that, “they are not really focusing on identity in the early weeks of treatment. People are really focused on getting the chemotherapy they need to survive.” Another nurse working in HSCT described the all-too-common experience of a new leukemic patient by saying:

When you have leukemia, you have to address issues immediately. You don’t have much time to think about it. And right from the get go the treatments are, you know, affecting your quality of life significantly. And relapse is also, I think, much more common. So your time—and under, in remission is, you know -- there’s not as much hope, you know, in terms of [cure]. So you are bombarded, you know? From the time you’re diagnosed, whether you’re going to make it or not, it’s—within one or two years -- you’re going to have many treatments which will significantly change your life. You’re very likely not going to be able to go back to work, you know. And when you don’t have those vital blood cells, you know, you are prone to infection, you are prone to bleed. Like, it has a life-threatening component that is a little bit more

vicious than a solid tumour where things are also difficult, but occur in a longer timespan most of the time.

Still another clinician noted that, “while they are having an identity crisis, probably most people are not actually aware it is even happening. They are just trying to get by day-to-day.” Another participant elaborated, saying “people are sick and tired in these early stages, and they have no energy for self-reflection and to wonder ‘who am I now?’”

The clinicians I talked with who saw the patients post-acute phase and in the longer-term stages of disease seemed more likely to emphasize psychosocial concerns and reflect on the identity crises experienced by patients. In fact, those clinicians working with patients several months or years post-treatment tended to be highly supportive of identity as a fundamental priority for the patient who they saw as deeply concerned about their new identity. One clinician noted, “The farther out from diagnosis someone is, the more likely we can take our minds away from saving their life and instead focus on saving their souls.”⁵⁴ This journey of the self was also described within the patient interviews, whereby persons with chronic diseases (such as CLL) and those who had achieved remission had identity issues at top of mind. Thus, in many instances, it seems apparent that the diagnosis of a blood cancer means an immediate cessation of the former identity and immediate search for a new identity, both occurring in the name of self-preservation. There is an irony to this, that the person must cease the self in order to continue the self. This cessation represents the passage of time, namely, marking that there was a time before diagnosis (and thus a self-identity) and that there is a time post-diagnosis that requires a new identity. According to clinician impressions, the person is not really able to reflect on this transition, however, until some point after diagnosis.

Thus, as I have considered it here, the notion of time in relation to the haematology cancer patient journey covered aspects of not only age and associated social identity labels, but also of timing and pacing along the disease trajectory. The perceptions of these clinicians caring for haematology oncology patients resonated with many of the insights that arose from the patient interview data and observations. The clinician data often affirmed patient

⁵⁴ This seems a good example to me of how Cartesian dualism is engrained in our common everyday language and in the way that some medical experiences are narrated.

findings, but also elaborated the context of these findings from an outsider's perspective around issues of time and life stage in a way that expanded understanding about the patient experience of identity. The resulting data is not the lived experience of identity per se, but rather a sort of emic (from within the social group, in this case, healthcare) and etic (an observer perspective, in this case, as observing patients) dialectic that arises as result of being close to, and directly involved in, the cancer care journey of so many patients.

Deconstruction: A New Full-Time Job

The theme of *deconstruction* identified from the patient interview data captured the essential breakdown of the whole person into components after receiving their blood cancer diagnosis. The process of deconstruction seemed to be an unintentional destruction of the pre-blood cancer identity in a way that fashioned groundwork for a budding new identity based on the changing circumstances. Subthemes within the overarching theme of deconstruction included social unawareness about blood cancers, the abstractification of the self as a means of understanding, and ultimate personification of the cancer into something that would be understood and bargained with. The clinicians in this study discussed identity in traditional demographic and socioeconomic terms, prioritizing employment and career, and described the real shift in identity occurred the person (man, woman, mother, father, accountant, doctor) suffered various degrees of loss while moving towards becoming a homogenous *patient*. There existed some support for classic sociological theorizing that, in the context of an acute affliction, people are expected to enact a so-called "sick role" (per Parsons, 1951; Parsons, 1975). The deconstruction process that patients went through, when reflected on by clinician participants, tended to emphasize this taking-on of a patient role as part of a patient identity, and the key ingredient of this was the loss of employment and associated title. Within these interviews there was an unspoken understanding of what it meant to be a "patient," sociological-based in that this label conveyed a sense of socially-accepted behaviours expected for the role by both the biomedical community and the society-at-large. Emphasis on this patient role was around physiological limitations brought on by disease and treatment, with minimal emphasis on the psychological (emotional or mental) experience of the patient.

The experienced clinicians interviewed agreed that the journey for a haematology oncology patient must be complex and intensely difficult, both physically and psychologically. This was due to not only the treatments, which always included chemotherapy and sometimes biotherapies, but also because of the abstract and multifaceted nature of blood cancers. A BMT nurse told me, “I fight for people who have blood cancer, you know? I fight for their journey, and I want their journey to be human. And there is so much—the treatments are very—are not that—they’re extremely difficult, so there’s a lot of work to do.” A social worker with decades of experience working with this patient population noted that:

The journey was harder and more horrible than they thought it would be. I think they compare themselves with people they would see who had solid tumour cancers, you know, and they’d go to the Cancer Agency, walk out, and they would lose their hair, and you know, that was kind of the pattern that they saw. Whereas with blood cancer, it’s far more—you’re so dependent on the medical system.

When asked to extrapolate on their observations about the patient experience, several clinicians described that they believed being a patient meant a deep sense of loss. Many of the clinicians described patients as being at the mercy of the medical system and this translated into the individual - previously autonomous – being almost forced to rely on, and comply with, agents of the system for survival.⁵⁵ Patients with blood cancers are provided copious amounts of handouts, booklets, and one-on-one education. Part of preventative care (to avoid remission) or prophylactic care (to avoid getting ill) includes long lists of should do’s-and-don’ts. Current patient care protocols propose that patients shouldn’t eat certain foods (like sushi), shouldn’t be in crowds, shouldn’t be around construction sites, shouldn’t enjoy fresh flowers, shouldn’t be with pets, and shouldn’t be around children. They shouldn’t smoke, shouldn’t drink alcohol, shouldn’t eat at restaurant buffets, and shouldn’t garden or play in soil. The results of these rules mean, in many cases, that everyday activities, hobbies, and vocations are directly impacted. As well vacation and travel plans are limited by the

⁵⁵ The paternalistic nature of the healthcare system, as represented in the stories and beliefs of most of the clinicians, provided a shockingly honest portrayal of how clinicians view the system they work in. The findings as outlined in this section provide data drawn from the clinician interviews about the patient experience, and I will address some of the key things learned about the *clinicians* themselves in the “Discussion” section.

availability of blood products or proximity to an advanced medical facility. Part of the new role in the medical system, called “patient” (or “client” in private healthcare), meant abandoning aspects of self-control and autonomy. One clinician noted that becoming a blood cancer patient was like, “joining a church.” Another said, “getting a blood cancer is like getting a new full-time job.” A senior oncology clinician described her attempts to honour the importance of work in modern identities when she spoke to patients in the hospital and day clinic settings. She stated:

I have said to people, ‘This is your new job. You need to go to your appointments, you need—this is a full-time job. You need to see it as such,’ and that—maybe to give them a sense of still committing to be part of a consortium, you know?

Social emphasis on roles and contributing to society was reflected in these statements, with the clinician assumption being that if the patient could metaphorically fit back into the idea of a social world of alleged employment (“new job”) and work (“keeping appointments”), their feelings of comfort related to their identity status might improve. In many ways, the clinicians might have been pre-empting identity changes that they knew would occur. While the job of being a patient was unpaid and is consumer work (consuming services) as opposed to provider work (providing a service), it seemed to affirm a traditional way of thinking about having something to do, to focus on, to put one’s energy into that was productive (even if only for the self). The idea of a “new job” also contains an underlying assumption of a work ethic, whereby in order to be successful (i.e. healed, treated) the person would have to be punctual, reliable, organized, and demonstrate diligent attention to detail.

The data from these expert clinician interviews reflected a functionalist standpoint through conveying a sense of loss of identity through disease and being unable to continue fulfilling social roles (worker, mother, etc.) but there was also a parallel new identity assumed by becoming patient, or taking on the institutionalized character of their role within the healthcare system. This was not quite the case for patients who tended to see themselves as fulfilling similar roles, albeit in a different capacity. One nurse stated, “my identity is linked to what I do, even for me, you know, in the activities I do. And all of that becomes impossible, and yes, I believe that of all cancer, blood cancer is so intense that yes, there is a shift from having a very strong life, because often they did, to being a leukemic patient. I

believe that it's a very abrupt example of loss of identity." The observation made by many of the clinicians was that this shift or transformation was not one that was desirable, but rather was the unfortunate and inevitable result of being diagnosed with a haematological blood cancer. The social worker participant noted:

I think the loss of their roles was one of the things that people found the hardest, so people who were affected in a way where they couldn't continue their function. So you know, an elderly European man who was, I guess, a hard physical worker, and he couldn't do those things, so he would phone and he would say, 'I feel useless. I feel useless.' You know? And mothers who couldn't care for their children, and those loss of roles.

A very experienced haematology oncology nurse noted, "I think that, personally, identity is crucial, first of all, but I think that we are removing their identity. So it's not only something they do to themselves or they become a different person, but it's also something that I think we do, in the sense that they can't work anymore." Another acute care clinician said:

So what are they left with? So they're sitting in a bed. They can't be a good—they can't be a good employee, they can't be a good mother, they can't be, you know, a good sprinter if they like, or they can't jog or they can't make their art if they love arts. You know, like, we're depriving them of—it's not us, but there's this inability to be the way you normally— You know, if all of a sudden, all you are is—it's yourself and you inhabit your whoever you are, like, it's not—it's not anymore what you do, it's who you are.

That "who you are" described here was the stripped-down person, the self devoid of the social labels around the action of *doing*. This sentiment echoed loudly throughout these interviews – that the ability to do (whatever) was deeply entwined with the "who you are" as a person. Patient identity forced the individual to stop *doing* what they had done before, and to start *doing* something else. Another nurse rationalized this transformation as a social role characterized by what the person was *not* or *no longer*:

I think honestly it's the treatment that—and the side effects that—somehow, if your identity is placed into what you do versus, you know, who you are, you know, if everything that you are, you manifest in what you do, it's a lot more difficult to face than if you—if you have a sense of who you are besides all the things that you do, besides being a super good employee, besides being a super good mom, you know, besides all these roles that you—now you can just be.

To “just be” was described as the role of the patient, and contained within are notions of losing control and passivity. To “just be” within the medical system meant to be a patient, one who did not make a fuss, who did not make demands, and who was compliant with care. The same nurse reflected on the role as patient by relating her approach to patients in acute care. She told them, “‘right now I have to do vitals,’ ‘right now I have to give you blood.’ And all they're left with is how they interact with the personnel... But within the health care model this personal choice isn't going to work. They have to give up control over the smallest things in order to receive care. They have to be a patient.” Instead of being proactive, purposeful actors within the social world, the clinicians generally portrayed patients as passive receivers of care. This was also reflected in a subversive thread noted in many of the clinician interviews which seemed to merge disease with diagnosis, in a sense that bringing on a diagnosis (associated with the medical system) was similar (if not identical) to taking on a disease.

Finally, social naivety, abstractification and personification were major subthemes under deconstruction within the patient data findings (Chapter 7). The clinicians were in consensus about a generalized lack of social understanding around haematological cancers and really seemed to focus their discussions and interventions with patients and their families around education about the abstract nature of blood cancers. For example, one clinician explained that her experience led her to believe that understanding the tiniest details of the specific cancer was a way she could help people understand what was happening to them. She said:

It's very important for me to somehow talk about the cancer cells like they were somebody who took a different route, like those cells are not kind of evolving as they

should. I bring it to the cellular level to help people understand it. They're not carrying a monster, they just—you know, they're just—there's something [in the cells] that is working differently.

A keen sense of clinician identity radiates from this statement, reminding that identities are relational. The intersections of identities (patient and clinician) influence each other, as do the roles of being the *helper* and the *helped*. Another nurse agreed saying, “yeah, it's really abstract, and the systemic nature of it, that's hard for them to figure out.” She later noted that patients will acknowledge, “‘It's everywhere,’ and then you're going, now, okay, this is a systemic kind of illness...They think that it's everywhere, so it's hard to conceptualize.” An experienced HSCT nurse felt that the focus on the abstract, unseen cells took the pressure off the person and instead put it on where the problem was: “the cells themselves, and their DNA.” The theme of deconstruction as experienced by patients seemed to be perceived by the clinicians as necessary process of disempowerment whereby accepting an identity as *patient* carried with it an associated loss of control over autonomy. To combat this, the efforts of clinicians to re-empower patients occurred mostly through education about the pathophysiology of their disease. The deep sense of the systemic nature of blood cancers was present in this data, but this was acknowledged through an emphasis on using abstractification of the cancer at the cellular level. The clinicians in this study seemed to believe that conveying knowledge focused on the unique cellular dysfunction experienced by the patients was an important and successful device that would alleviate fear and anxiety.

The clinicians confirmed the intimate and highly personal nature of the communication and interaction between patients and clinicians within the healthcare setting. Clinicians not only administered care and treatment, but each described a personal and professional responsibility to help the patient make sense of their experience. While patients discussed this sense-making in terms of more existential languaging, the clinicians used physiological processes and descriptions (like cellular actions) to reinscribe an organic body process that could be understandable to patients. The education of the clinicians seemed to accept the subtheme found in patient interviews of general lack of understanding around blood cancers. This simple language of cells going wrong, and focusing on cells instead of the person, reflected a goal of trying to help people understand what was happening to them

in the most basic of ways accepting that they probably had very little pre-existing knowledge. This process also reflected a socialization into the medical system of which social loss (of a job, primarily) was a necessary consequence of them being sick. When asked to reflect on this point, the clinicians expressed that identity was a concern, but not major concern, during acute illness. From the clinician perspective, the central challenge to identity occurs in the acute phase, but for the patients, emphasis on identity was more when the acute phase had past and their role of being/doing sickness was replaced with a need to become a new person. It was not until the acceptance of illness and completing this acute illness phase that the patient entered into the next phase of reconstruction, when emphasis on “doing” illness could be replaced with “being” a new person through finding a new normal. The theme of reconstruction as reflected on by the clinicians interviewed follows.

Reconstruction: Finding that New Normal

The final theme drawn from the patient findings was that of *reconstruction*, the process whereby patients started to rebuild notions of self and identity that had been challenged by a blood cancer diagnosis. Reconstruction refers to rebuilding something that has been destroyed, a work in progress with transitions both forwards and backwards. In this case, reconstruction work references issues around existential well-being and identity. It also addresses the need to move on and find a way to survive in what both patients and experienced clinicians referred to as “the new normal.” Within the findings from the patient data, reconstruction was closely associated with regaining control and overcoming vulnerabilities. Most of the clinicians had worked with patients outside the acute and clinic treatment environment and were able to comment on this stage in the cancer care journey. All of the clinicians were able to reference their experiences with patients whose disease had relapsed and who had reentered active treatment. A nurse in acute care theorized that remission offered people a chance to address their identity in a way that was not possible during treatment. She described a woman she knew who told her, “oh, my god, I’m under remission, and I have time to think about it, and understand, like, maybe my smoking habits were not the best, and maybe now I’m going to make the most of all the things I’ve always wanted to do, and, like, reflect on it.” Clinicians described the post-treatment stage, which was either remission or palliation, as a time when people began searching for a new normal

that would incorporate the sense of new identity gained from their blood cancer experience. The clinicians generally felt this was difficult because survivors of a haematological cancer live with a long list of prohibited activities as well as a persisting concern that they will be sick again. One experienced nurse said, “at any moment the bone marrow could revolt and they will be catapulted back into fighting for their life again. I call this living with extreme anxiety.” The social worker participant explained, “the bigger picture for so many people with cancer is living with uncertainty.” She rationalized that, “I think it throws every single person for a loop, making them reexamine their life and their priorities and that sort of thing.” The anxiety of remission or palliative phase of illness became part of a normalization process, and thus strategies to deal with this anxiety (or fear) were a focus for clinician conversations around how patients attempted to rebuild their identity.

The subthemes inductively derived from the patient data around regaining control and overcoming vulnerabilities seemed to resonate with the clinicians as accurate reflections of what they commonly observed in the clinical context. While patients tended to focus on the emotional logistics of creating new identities post-diagnosis, the experienced clinicians I spoke with pragmatically described a rebuilding of identity in terms of patient education and action. For example, the social worker interviewed in this study emphasized the importance of support groups and finding others with the same diagnosis as critical in the creation of a new identity. The nurses emphasized the importance of patients in following medical advice about travel warnings and the need to attend regularly scheduled appointments with the health care team for surveillance blood work. This reflected continued emphasis on the “new job” requirements of maintaining a healthy work ethic for the sake of perpetually relying on the medical system for care.

Perhaps one of the most telling aspects of the clinician interviews with respect to their view of patient identity in this stage arose when they reflected on the language choices associated with referencing persons with blood cancers once they were outside the acute phase of treatment. Within this data, as evident from the patient data as well, clinicians expressed general disagreement over the use of the word “survivor.” A majority of the clinicians noted that, in their experience, patients generally disliked being identified with this

title. The social worker explained that she was constantly at odds with patients over what term to use for people who were in remission or palliation:

So what I would say, whenever it was grammatically possible, was, ‘the person who’s had a cancer diagnosis.’ And then often I would be saying ‘patient.’ And I think—yeah, I mean, I do say ‘survivor’ because—but I would argue with the head office who’d say to people’s questions, like, ‘Are you a patient or a survivor?’ And I’d say to them, ‘You know what? Everyone has a different definition of what that means.’ It doesn’t mean on the day of your fifth anniversary of having, you know, gotten rid of cancer that you shift into being a survivor. And my survivor definition would be that of from the day of diagnosis, for the rest of your life. So you know, I would constantly have that conversation. But then it comes down to, how do you fit something into this tiny little space, or use a term, you know, that is palatable to some people or understandable?

Thus most of the clinicians found themselves using ‘survivor’ and ‘survivorship’ as ways to identify patients, but admitted that the patients were generally uncomfortable with this label. The notion of labelling oneself was a major topic of conversation around overcoming vulnerabilities and regaining control as a blood cancer patient tried to reconstruct an identity. Ultimately despite probing questions around this topic, the clinicians offered diverse labels or terms that seemed to be more appropriate in capturing this aspect of the patient experience. Suggestions included “person with cancer,” “health-seeker,” and simply, “cancer patient.” All agreed that the identifying label of the patient should be determined by the patient to honour their highly personalized and unique process of reconciling existential concerns with a practical need to re-identity. One nurse said, “I call them what they want to be called, and refer to their journey how they want me to refer to it. Most don’t want survivor.” One of the more seasoned nurses working in HSCT reflected on how language played out in the context of an ambulatory daycare setting:

I don’t recall the word survivor. By the time they were in daycare, they were still not out of the woods, right? I think that that whole five-year survival kind of was always sticking in people’s minds. Yeah. I don’t recall the word survival. It was more, ‘I’m

in remission. I've got to stay in remission. Remission is the goal. Stay in remission.' You know, that the cancer wasn't going to come back. So suppressing, pushing it away, keeping it away. It was more that keep the monster in the closet and don't let it out, and keep the lock and key on it so it never comes out.

From the perspective of these clinicians, survivorship in the ordinary sense in which it is used in cancer care did not quite capture the complexity of what haematology oncology patients encounter in the phase of identity reconstruction. Rather than having come through something, or having completed something, their survivorship instead implies a continuation of disease that will be infinite in the sense that the cancer could always come back. The examples and narratives provided by the clinicians about their experiences with blood cancer patients therefore conveyed more of a sense of reconstruction as remission, as a pause in blood cancer, rather than implying a definitive ending.

Discussion

As the fifth and final layer of my research, interviews with thoughtful haematology oncology clinicians explored emerging themes and concerns that arose from analysis of the patient data and provided another angle on the patient experience of identity. The capacity and willingness of clinicians to reflect on patterns of identity as experienced across the many patients they had worked with further promoted the development of findings from earlier layers of research. Findings from the patient interview data provided the structure and rationale for how the clinician interviews were undertaken, and subsequently provided the framework around which the clinician data was reflected on and analyzed. The shared themes of origination, deconstruction, and reconstruction seemed to resonate with clinicians as a way to organize and understand identity struggles experienced by the blood cancer patient. These themes also capitalized on the cancer care journey, which was a major point of emphasis in the clinician interviews when it came to identity concerns.

Issues of time and life course were prominent in the perception of clinicians with respect to matters of identity for their patients in the acute phase of the illness. Research with both clinicians and patients suggested that identity concerns develop (to some extent) within the acute stages of illness and then morph and transform as the person moves through the

cancer care trajectory. The clinicians heavily emphasized labels pertaining to employment and stage in life, perceiving that patients were most affected by changes in their ability to work and by changes to their ability to contribute to society. Context to this emphasis may stem from the dominant social values within Western capitalist and neoliberal societies which tend to prioritize employment as the basis for adult personal identity. When someone is acutely ill, they may not be able to work, and this is certainly true for a blood cancer patient. Key elements of identity are then adversely affected in ways that may not be addressed until some kind of recovery. In many acute illnesses, the individual is often able to return to work after they become better. Concerns over identity are short-lived, and resolved by picking up where one left off with sometimes minor disruptions in identity roles. Haematology oncology patients face inevitable disruption of their former identity because even when their acutely ill phase has ended and treatment has resulted in remission, many are not able to fully resume their previous lifestyle, pacing, or employment. In cases where treatment was not successful, patients remain fully engaged with the healthcare system as they begin to navigate the realities stemming from salvage or palliative treatment. Because of the nature of blood cancers being “for life,” a person in remission may also have to change their behaviours or employment due to the long list of excluded practices (mentioned previously) or due to enduring effects of the treatment on their functional health status.

Through emphasizing the hegemonic idea of work (employment) as lost, the clinicians could then turn this around to help normalize the acute phase of the blood cancer experience by calling it “your new job.” This cheerful reframing of usefulness through employment aligned as well with the overarching paternalist and functionalist idea of the patient (or sick) role (per Parsons). It wasn’t that the blood cancer patient lost their job, but rather that they gained a new job which embraced a new world vision. As discussed above, the new job had responsibilities, deadlines, and a hierarchy of command (albeit one could not be fired from this new job without terminal consequences). The notion of a patient role, or even of a sick role, as referenced directly and indirectly within the clinician data, suggests a sociological understanding that could be attributed to training and theoretical backgrounding by disciplines (in this case, nursing and social work). Sick role identity theory is most commonly attributed to the work of Talcott Parsons in the 1970s, who described the distinct relationship between the individual who “agreed” to work towards recovery of their state of

illness (biological) and the related social role of alleged patient interaction with “the therapeutic agent” [the social system] (1975, p. 258). Parsons believed the role of the therapeutic agent “should be the recovery of the sick person” (p. 258). Much of the description Parsons introduced in his work around the asymmetrical relationship between the healthcare provider (in his case, the physician) and the patient was sociological and hierarchical, placing significant emphasis on power and responsibility. There seems a parallel between the clinician reports and Parson’s description of sick role identity and the adherence to this identity, although the details of what this relationship would be are hard to pinpoint. For example, Parsons discusses the vow of clinicians (again, in this case physicians) to treat and protect the patient from harm by motivating the patient to “recover” (p. 269) so as to reenter the capitalist economy (1951, p.437). This is what the clinicians did when they reframed the illness as a patient’s new job and thus allowing them to feel useful again within this same economy (as a consumer rather than provider, but in the same economic system nonetheless). Similarly, Parsons reflected on the proper role of the sick person as choosing to be passive to receive treatment (1964, p. 270). Within the context of the healthcare system, the notion of sick role and its associated behaviours assigned to both clinicians and patients seems a useful way to describe the dynamics of the acute care environment. Since this particular layer of research sought to investigate what clinicians thought about the patient experience of identity as they had experienced it through clinical practice, it might make sense that their training and aspects of disciplinary theoretical grounding would seep into interpretations and interventions. This would also explain an absence of similar languaging in the patient interviews.

Parsons has been challenged repeatedly over the years, and within nursing the idea of a sick role has existed in form as both theory and within practice with uncomfortable points of contention (Burnham, 2014; Cockerham, 2014). This could be because, while the sociological aspects of this theory are useful to describe the complex hierarchical relationships inherent within the healthcare system, notions of the biological aspects are largely absent. Health education is a reductionist component of the biomedical model which views the mind and body as separate and promotes an illness perspective (thus the “sick” role) (Allan, 2016; Whitehead, 2003). For all intents and purposes, the goal of the clinicians embraced health education which Whitehead defines as the process of encouraging

individuals to enact behavioural changes through “directly influencing their values, beliefs, and attitude systems” (2004, p. 313). Allan (2016) discussed the notion that one *becomes* a patient, and by doing so relinquishes their biological self to the system. Yet it is the biological self that the clinicians utilized as an additional way to help blood cancer patients normalize their experience. The clinicians (and particularly the nursing clinicians) in this study used education around the biological aspects of haematology cancer in a way that seemed to empower many patients and ultimately provided them a basis on which to (re)build a new identity.

Analysis of the research literature in chapter 4 revealed a strong emphasis on temporality as a critical component of the cancer experience. Indeed, each of the proceeding layers of research highlighted time as critical to our understanding of how the blood cancer patient experiences their disease. The primary research layers (4 and 5) further accentuated the importance of time to the patient experience but revealed multiple complicated modes such as age, knowledge, and movement along a cancer journey trajectory. Upon entering the medical system, patients relinquish a certain amount of autonomy in exchange for care (see for example, Joseph-Williams, Edwards, & Elwyn, 2014; Oxelmark, Ulin, Chaboyer, Bucknall, & Ringdal, 2017). Patients may regain this power (or control) as they move along the treatment timeline and pass certain checkpoints and are allowed more choice, autonomy, and thus more power over the self. For example, when haematology oncology patients reach certain treatment-based goals (such as 100 days post allogeneic transplant) they may regain a certain level of power and more control over their destiny and are deemed in remission. To be in remission as a blood cancer patient is considered by the medical oncology community a success that deserves and allows a new identity, one in which the fight for life is essentially over (but not forgotten). Normalization is, after all, the goal of re-identifying with the self and signals some measure of adaptation (at least psychologically) to the original blood cancer diagnosis. Some aspect of reacquiring autonomy follows when the patient has gained the ability to mimic the biological language used by clinicians in understanding their disease process as an organic, cellular process. In this process of finding a new self, the incorporation of certain goals, phrases, and languaging in the patient interviews echoed that of clinician self-reported patient education narratives. To clarify, patients tend to pick up the language of their new culture (the medical system) as they move along in the cancer care trajectory. This

is a language that is primarily biomedical and physiological in nature. The ability to speak the language of the healthcare providers was important for the patient journey, and after interviewing the clinicians I wondered how much of what the patients told me could be attributed to the clinicians they had worked with. Therefore, patient identity within this context was co-created and relational in the sense that the social microcosm of the healthcare system provided a novel framework within which persons could become patients (a new identity) and could be acclimated to the language appropriate for this new identity. For patients further along the care trajectory (as all of the participants in this study were), the influence of clinicians within the healthcare milieu on a ‘blood cancer identity’ is unquestionable. By imparting constructs like “a new job” and educating about the biological, cellular nature of the disease, clinicians seemed to be helping the patients accommodate their new role. Whether this initiation process is intentional or an unintended consequence of nursing training remains unknown.

Within the clinician interviews, many of the themes and subthemes that arose from the patient participant interviews were echoed, elucidated, and elaborated on. I believe the compilation of perspectives has provided a deeper understanding of identity as an important component in the haematological cancer patient experience, and has allowed access to variable angles of the lived experience. Discussions with these clinicians also genuinely reinforced the notion of control, disempowerment, and empowerment roles, and social expectations as critical concepts for persons who agree (albeit reluctantly) to be patients, including the development of some ‘new’ expertise. Within healthcare there exists an explicit society replete with explicit hierarchy, morality, and values. Adopting Sontag’s metaphor around the kingdom of the sick, this final set of findings has reinforced notions that to enter this kingdom is to adopt a new world order, one dependent on timing (proximity to diagnosis) as well as identity (pre and post-diagnosis). What was highlighted from the data of these interviews, beyond recounting clinical observations made about the blood cancer patient experience, was the theoretical background and underlying assumptions of the clinicians themselves.

Conclusion

This chapter concludes the collection and analysis of data about the haematology cancer patient experience of identity as gathered from a variety of sources. A firm and expansive foundation was developed in Phase One (layers 1-3) of this study. Phase 2 (layers 4 and 5) research focused exclusively on primary data collection with haematology oncology patients and haematology oncology clinicians. The experience of identity for the haematology oncology patient is complex and deeply personal in a way that is incredibly important to the care and outcomes for these patients. As an existential topic that is outside the dominant biomedical orientation of priorities, identity is ranked low in the hierarchy of care, if noticed at all. The interviews with both patients and clinicians have clearly demonstrated that identity is an important component of the blood cancer patient experience, in ways that have not previously been addressed in the clinical literature.

The next chapter will provide a summarizing discussion of both Phases of research, including reviewing findings from both secondary and primary research. The purpose of this upcoming ninth chapter is to offer a thoughtful integration of the findings to form a meaningful narrative about identity for haematology oncology patients within a nursing context.

Chapter 9: Discussion

It is not
that I aim to
discover new landscapes
or relive past experiences
Rather,
I strive
to develop
fresh eyes.
(Perry, 1998, p. 22)

Introduction

In her work with terminally ill cancer patients, Perry (1998) penned several poems that sought to describe various elements of the cancer experience. In the above quote, the cancer experience is captured as time-based and related to the goal of finding a new normal that would signal a new identity. This process was reflected in the current research project and described in findings from patient and clinician interviews as a fairly linear process flowing from diagnosis and extending into remission and beyond. In this chapter, I will integrate and discuss the key findings of this study gathered from each of the five layers of research. The overarching research question guiding this study was, how are identity experiences described and elucidated by adult haematological cancer patients? This qualitative research project has reflected on the question of identity for adult haematology oncology patients by utilizing a multi-layered research process. A layered research method was chosen as the best and most comprehensive approach for this project due to the complex nature of identity. Phase One (layers 1 to 3) of this research was comprised of an integrative literature review, a historical inquiry, and a secondary analysis of an existing database. Phase Two (layers 4 and 5) research was composed of primary data collection and subsequent analysis with a new patient cohort and with experienced haematology oncology clinicians. During this study, each preceding layer laid a foundation for the next and proceeding layers of inquiry. The sequencing of layers was carefully considered in order to encourage

thoughtful consideration of data and findings in a way that would inform the next layer of research. Secondary research was undertaken in a way that created a sound foundation for primary research. The methodology constituted a logical expansion of research findings in a way that generated new knowledge and simultaneously inspired the following research inquiry. Taken as a whole, this layered research method generated a highly detailed study on the experience of identity by haematology oncology patients.

This chapter represents the integration of the key findings from each of the research layers for the purpose of capturing some aspects of the complexity of identity as a component of the haematology oncology experience. I will first briefly discuss linkages between the five research layers as a basis for launching a broader discussion on two major themes that have emerged from this study. A final chapter will discuss strengths and limitations of this study as well as implications for clinical practice.

Review of Layered Findings

Identity is arguably one of the most important elements of the human experience, and yet its complex and personalized nature make it strikingly difficult to fully grasp. Identity remains an important topic for secular and philosophical writings in multiple disciplines including psychology, sociology, and medical anthropology. As the integrative literature review revealed, the exploration of identity as a component of the patient experience by the nursing profession is both relatively recent and rare. This dissertation has applied a definition of identity as that which specifically what makes a thing a thing, namely the conditions that make a thing or person what it is. Identity can be imbued with concerns around ‘who am I’ and ‘who am I becoming’ in the healthcare environment and have implications for practical application both from an existential and pragmatic perspective. For this reason, five distinct yet overlapping layers of data collection and analysis formed the basis for this research project in order to answer questions about identity for the adult blood cancer patient.

Phase One constituted secondary research that aimed to capture historical and modern social labelling as well as indicators suggesting a unique identity experienced by the blood cancer patient. Findings from the integrative literature review (layer 1) highlighted six broad themes from the literature that constituted the essence of identity inquiry as it related to blood cancer patients. These included a diverse definition of identity, predetermined identity labels

with a focus on survivorship, the temporal nature of identity, identity reconstruction, physiology as identity, and generalized *cancer*. The historical review (layer 2) further extrapolated on this idea of an overarching cancer experience and discussed how the social notions and understanding of cancer, and secondarily blood cancers, arose over time. This was complemented by a discussion of the similarly modern concern around identity and the self and how we came to think about identity from both social and philosophical viewpoints. These two layers fostered a strong sense of sociocultural definitions around identity and how to talk about identity so that by the time layer 3 (secondary analysis of a preexisting database) research commenced I had a very good idea of how identity might be talked about and recognized within secondary data. I developed four key ideas from this layer of research to describe how haematology cancer patients seemed to be talking about issues around identity within the secondary data. These were the self with cancer (ontological), the abstract self (experiential), the suffering self (experiential) and the disconnected self (social). Identity tags such as *patient* and *survivor* that took precedence in chapter 4 (integrative literature review) dominated this data. The modern association of cancer with military languaging further amplified aspects of patient and survivor in relation to fighting, battling, and other terms of aggression. The findings of each layer had individually and collectively constituted new knowledge in a way that was both complex and challenging. In concert, they allowed me to further sharpen the focus on what could be gleaned from listening to the experiential accounts and deeply personal interpretations of this phenomenon by patients and clinicians. It was from this Phase One analysis that key ideas around the abstractification and systemic nature of blood cancers arose, as patients with these cancers tended to describe their experiences differently and simultaneously referred to themselves and their disease differently than the solid tumour patient sampling. Time and memory were important themes as somehow inscribed within the essence of identity, but at this stage I was not sure how these concepts would be incorporated into my research.

After completing the Phase One research, the concept of identity felt so complex and multifaceted that I had to take some time to ponder the process and methodological grounding behind my intentions for primary interviews with patients and experienced clinicians. The importance of identity on every facet of the human experience – both within and outside a cancer journey -- was clear to me. It was in this spirit that I undertook Phase

Two research commencing with primary interviews with blood cancer patients (layer 4). The findings arising from these primary interviews included the overarching themes of origination, deconstruction, and reconstruction, which honoured the importance of a temporal component as a way to understand the patient experience of identity. Themes found in modern academic literature were present in some form or another within the patient interviews including meaning making, spiritual concerns, suffering, depression, anxiety, and emotional trauma. Yet the patients spoke to me about more than what these singular concepts offered. Instead I was overwhelmed by a vision of an identity process intimately coupled with the actual cancer care trajectory. I was also impressed with the sense of confusion and neediness conveyed by these patients, which I came to understand as arising from a lack of social cues around what a blood cancer patient was supposed to be like. Most patients talked about their self-image when referencing identity, and told me in great detail that the popular image of “cancer” was not good enough. Instead, the patient participants spoke about their cancer as cellular, as an abstraction that required imagination to understand, and of the systemic nature of their disease. Within this data existed a notion of blood as spirit, as energy, as permeating the entire body in a way that escaped a geographic place, and this reality set the blood cancer patients apart from other cancers in a way that capitalized on their uniqueness. As a final research layer, my discussions with experienced oncology clinicians (layer 5) focused on themes of normalization and social ignorance about blood cancers. It was clear that the observations of clinicians did not quite match the reported experience of the patients. For example, the clinicians described that employment and not being able to work was a major identity issue for patients, but my interviews with patients didn’t echo the same level of concern. Tied to nursing practice, clinicians emphasized the need for the patient to quickly and efficiently reconstruct a new identity based on being a forever blood cancer patient. It was really an issue of getting people back to “normal,” which the patients also emphasized but in a way that lacked the pragmatic task-like structure conveyed by clinicians. Finally, I was very moved by the frustration clinicians expressed over social ignorance around blood cancers which they felt deeply affected these patients by limiting their ability to self-express according to a pre-established social model. Yet, the clinicians did offer some biological explanations, recasting the blood cancer as a cancer of cells and hence affecting the entire body. This biological and pathophysiological account seemed to

empower patients, resonating with their efforts to find a new identity, and ultimately came through in the way patients talked about their cancer. Having captured the highlights of what each layer of this study has uncovered, I now turn to a more integrated consideration of what has been learned about the phenomenon of identity as experienced by this patient population.

Discussion: Finding Identity as a Haematology Cancer Patient

When I began this research project, my focus was exclusively on identity as a stand-alone psychosocial phenomenon, and my belief was that struggles with identity after a blood cancer diagnosis were paramount for the patient. I took for granted the simple colloquial definition of identity as the qualities that make something that thing, and applied this to the multilayered research approach in this study. While a quick fix, the complexity of identity in both definition and application created hurdles which had to be overcome in unique ways in order to complete each layer of research. Lawler said about identity that “more or less everyone knows more or less what it means, and yet its precise definition proves slippery” (2014, p. 1). This certainly proved to be true in the sense that everyone has an idea of identity, but when asked to elaborate more on what identity means in specific contexts, understanding is blurred. Elias (1994/1939) described identity as taken for granted as a personal concept bounded and self-contained within an individual. Within this study identity was both superficial and outside the self/body, assuming the socially-prescribed form of self-labelling (for example, victim, survivor, patient) while embracing a more intimate and personal quality as a descriptor for the way someone talked about themselves as a person with blood cancer (as suffering, abstract, disconnected, unique). Within this study I explored various layers and aspects of identity in relation to cancer within the academic literature, the historical record, and with modern cancer patients and clinicians. Discussed in chapter 5, self-identity has grown since the 1960’s to be a paramount issue for modern folks (Giddens, 1991; Martin & Barresi, 2006). Through the course of this study and while reflecting between research layers, I began to appreciate that there are multiple aspects of the human experience that people understand, in some way, as having to do with identity. Although this study reveals identity as an important phenomenon informing our understanding of what haematology cancer patients go through, a simplistic definition of “identity” seems not to be helpful. This research has instead offered a more complex and multi-dimensional vision of what identity might entail.

The overarching conclusion I have reached through my analysis is that haematology cancer patients see themselves as both having and not having cancer, in that their disease is something that is both similar and dissimilar, both analogous and distinct. They see themselves as a cancer patient, but not only a cancer patient. They experience something that is beyond a generalized cancer identity. They do not, however, see themselves ONLY as cancer patients, but there exists a tension around having cancer but not identifying with being seen as a cancer patient. To clarify, the haematology cancer patients whose voices are represented within the multiple layers of this study both embraced and rejected social labelling around writ-large cancer. The perspectives of experienced clinicians offered a similar insight, each confirming that haematology cancer patients were identified with cancer expectations and labelling but they were also somehow different and special in a way that reflected the unique biological and physiological processes of their disease. I believe that haematology cancer patients ultimately crave a distinct identity framework outside traditional social languaging around cancer because of their cancer's distinctive quality, presentation, and care trajectory. The resulting distinct identity framework is comprised of interlocking components that embrace contrary aspects of disidentity and identity. Three key themes arising from this multilevel research that constitute elements of a distinct blood cancer-identity framework include the embodied nature of cancer, disidentifying with solid tumour cancers, and fashioning a cellular-based cancer identity.

The Embodied Nature of Cancer

The integrated literature review and historical inquiry chapters discussed the development of cancer and blood cancers as social, political, biomedical, and cultural phenomena throughout history and into our contemporary time. As learned from this research, the notion of cancer as anything but solid tumour is very recent and totally dependent on highly advanced technological interventions. For example, the historical literature is rich in references to solid tumours and the arising medical interventions were specific to dealing with these physical manifestations of cancer. The tumours could be excised or leeches applied to them. More importantly, tumours could also be seen and felt. Oftentimes the tumours were associated with specific organs (deemed the primary tumour site) such as breast, uterus, muscle tissue, lungs, and so on. The technology

that allowed for the discovery of blood cancers also allowed for a more precise ability of medical professionals to diagnose the exact type of cells within a tumour and thus gave more credence to the importance of physical body location. Our contemporary medicine provides evidence of original tumour site even when metastases are spread diffusely in the body. Therefore, the cellular nature of cancer diagnostics has been bolstered by the ability of the medical diagnostic system to prioritize the cells that make up the primary tumour, and those cells signify the original organ. When a patient receives a cancer diagnosis in our modern clinics, the oncologist names the primary tumour site: breast, prostate, melanoma (skin), etc. The metastases are called “metastases” and are thereby associated with a primary site. The entire diagnostic process is highly organic and focused on physical body place, i.e. that place where the original cancer cell developed. Solid tumour cancer is highly embodied in this sense, since the tumour site becomes the physical manifestation of the disease. It is a body (tumour) within the *body*.

Research on cancer embodiment by Waskul and van der Riet (2002) emphasized embodiment as the merged experience of body as object with body as subject “within situated social interaction” (p.510). Cancer experienced as embodied robs patients of a “natural” relationship with their body that was previously built on “trust” (p. 510). This attitude of distrust and betrayal was highlighted in Sontag’s *Illness as a Metaphor* (1978), which detailed the similarities and differences between tuberculosis and cancer. Sontag’s own biographical experience with breast cancer was taken up in *AIDS and its Metaphors* (1990) where she claimed cancer (or AIDs) is a type of personal identity producing guilt, fear, suffering, and stigma (called “spoiled identity” by Goffman, 1963). Her subsequent location of cancer as embodied through place in contrast to AIDs which she likened to leukemia confirmed the importance of location as a sociocultural element of cancer (Sontag, 1990, p.107). In fact, the documentary film *The Face of Cancer* highlights women with breast cancer as the true social and media “face” of cancer, and pities these women whose only desire is to be seen as “a beautiful valiant warrior” (Carter, 2017). Academic work on cancer embodiment has suggested that embodiment of cancer (or any disease) is ahistorical and a new identity applies to self-identity in the present (Prouty, Ward-Smith, & Hutto, 2006). Extrapolating further, the new self-identity of the cancer patient in the moment is directly created by the influence of sociocultural factors at the moment. While notions of

cancer personality have fallen out of favour in the last twenty years, our current social thinking about cancer remains focused on solid tumour cancers as evident within each of the five layers of this study. Several themes arising in data analysis included a general social ignorance about blood cancers, as well as the participants own confirmation that discussing their disease was very difficult due to an inability to talk accepted organ-based cancer language. This cancer language often includes a place (breast, prostate) and surgery (excision) with occasional references to radiation and chemotherapy. Chemotherapy or biotherapies (including monoclonal antibodies) are the go-to, absolutely-only treatment for a blood cancer while solid tumour cancer patients are only offered these treatments in specific incidences. Therefore, social interaction of the body-as-subject enclosing tumour-as-object lies within a core social understanding of what cancer is.

There has been some academic research into what it means, socially (within Western society) to have cancer. I already discussed the association of cancer with death and terror. Sontag similarly emphasized the cultural association of cancer with death: “in the popular imagination, cancer equals death” (1990, p.6). In a systematic review of the literature on social perceptions of cancer, Flanagan and Holmes (2000) detailed that social norms around cancer associate it with fear, dread, and stigma within both lay and academic literatures. Recent research by Moser et al. (2014) sought to tease out some of these cultural themes. Their conclusions highlighted the social association of cancer with death and fatalism. This confirms other recent research on social perceptions towards cancer including a large five-stage study on death accessibility and cancer stigma by Arndt, Cook, and Goldenberg (2007) who concluded that cancer is widely associated with terror. Within the literature, cancer was generalized and homogenized down to meaning (or prioritizing) solid tumour cancers. Thus, within a sociocultural context, embodied cancer is most popularly associated with solid tumour cancers, and to embody cancer (i.e., to physically represent cancer) is to represent what cancer is associated with: terror, stigma, and death. To identify as someone with cancer has complex meaning associated with it, and taking on this identity is to take on the socially-prescribed meaning. Therefore, a logical conclusion might be that to have cancer is to be identified as death or being close to death. A cancer identity, both historically and in a modern context, can be terrifying, but to have cancer that is more abstract and mystifying than solid tumour cancer is, as expressed by the patient participants in this study,

simultaneously dispiriting and empowering. Yet in this study, the patient participants acknowledged death as an aspect of their cancer experience but did not elaborate on this to the point of identifying themselves as dead or dying. Within the context of the terror and potential finality of a blood cancer diagnosis was more a reflection on the strength of social bonds with family and friends, and patients often would transform conversation around death into concern over what their absence would do to those around them. This confirmed for me the importance of role, namely, that acknowledgement of cancer as death was accepted within a context of how this would affect others in a social network.

Beyond the existential questioning of “who am I” and “why am I here,” identity studies focus on the interplay between essence of self and society through the embodied interaction of three dimensional components: ontological, social, and experiential (Barresi & Martin, 2011). Writing on the creation and maintenance of social identities, Bauman (2004) argues that identity is inherently fluid and insecure and that theoretical concern with identity stems from a corresponding social concern with identity. Identity tends to be relatively stable until it is challenged by any number of things, including illness. Asbring (2001) discusses the impact chronic illness has on identity, noting that for ongoing illnesses (such as fibromyalgia) identity transformation is partial yet enduring as the illness will never be resolved. Since a blood cancer is never really cured the potential for a return of cancer is ever-present. It is eternally embodied in the sense that the biomedical term “remission” refers to the insidiousness of disease that is in hiding, kept at bay until that moment when the cells could become malignant again. This perpetual embodiment embraces a notion of disease embodiment that integrates past, present, and future into the singular experience of blood cancer. Most patient participants in this research were in remission and were able to convey a changed identity that contained both positive and negative elements. The component of temporality, defined as being in a trajectory of illness at a particular point in history, plays into the notion of transformation in the sense that the patient was transformed along a trajectory of their disease. My interviews with patients described both good and bad things occurring as their identity was transforming. For example, while they might have been a self-defined work-a-holic before, grappling with a blood cancer helped them to see how their future self should deemphasize work in place of family. I have several examples of research participants who told me they were grateful for their cancer *because* of the impact it had on

their identity. Namely, they didn't work as much, they focused more on family, they simplified their material existence, or they got to know themselves better. By stripping old identity away, a new identity based on embodiment of the blood cancer was possible. Because they did not embody cancer in the way others in society expected, haematology oncology patients were able to have more choice about how they embodied their cancer experience. Chapter 7 detailed how they would situationally *choose* to keep their diagnosis hidden (or not), indicating an ability to choose an embodiment strategy.

Disidentifying with Solid Tumour Cancers

Both primary and secondary research in this study indicated a strong desire of haematology cancer patients to disidentify and distance themselves from an overlying generalized cancer identity. While aspects of this identity were accurate, it was clear from my interviews with blood cancer patients that there existed clear motivation and justification to develop a cancer identity that was more appropriate for what they were experiencing.

Solid tumours are described specifically by the corporeal location (and associated body cells) responsible for cancer: breast cancer, prostate cancer, thyroid cancer, lung cancer, gastrointestinal cancer, and so on. Regardless of metastases, which may diffuse the actual location of cancer activity within the body, each of these titles simply and clearly makes the statement about a definable *where* in relation to cancer. Identity of cancer is the name of an organ, and subsequent identity cues and links arise from the sociocultural associations with this organ. One remains a breast cancer patient, even in the context of metastatic disease. Breast cancer patients are usually women (identity label) and young (identity label).⁵⁶ Social norms and values tell how to think about the solid tumour cancer patient because of this relationship to physical body place. These norms and values also provide guidance to the patient in how they are supposed to act, to think, and to look as a member of a specific identity group. As discussed in Phase One research, being with-cancer and cancer-free are labels wrought with military languaging and metaphors as a Western sociocultural response

⁵⁶ I am not saying that all breast cancer patients are young women. What I am trying to reflect is the overlying sociocultural norm of assuming that a breast cancer patient will be a younger woman. We see this tendency reflected in the marketing and messaging around breast cancer. For example, much of the stock imagery is of groups of young women, often dressed in fitness wear. Also the color pink, used for breast cancer awareness, is associated in chromotherapy with children and femininity. See a copious literature on this topic including more recently McDonnell, Jonason, & Christoffersen, 2017; McGannon, Berry, Rodgers, & Spence, 2016.

to a solid tumour cancer, which is (generally) to encourage people to fight, to battle, and to do what it takes to win (cure) (see Halperin, 2017). The imagery conjured is that of a socially-familiar body place (breast, prostate, lung) that transforms into the battlefield which is attacked through surgery, radiation, and chemotherapy.

Embodiment has been discussed in this research project as associated with the whole person (systemic). Ontologically speaking, the body is solid: the tumour is solid. The popular notion that solid tumour cancers are embodied does not exclude blood cancers; rather, it is socially acceptable to discuss cancer as the overarching physical manifestation to describe a malignant solid tumour. This cancer is thus visible, concrete, and tangible. Embodiment as a concept has both physical (seen) and internal (invisible) elements. Several participants in this present study specifically remarked on their ability to appear what they called “normal,” attributing normal to the illusion of wellness and health. Unlike many solid tumour cancer patients who undergo surgical removal, blood cancer patients lack physical skin markers such as scars or deformations. Therefore, arising from my primary research with a cohort of blood cancer patients was the idea of invisible embodiment of cancer, whereby patients described identity in terms and concepts associated with embodiment but did so in a way that reflected a more psychological state of embodiment versus a physical, corporeal embodiment. And employing more of a mentally-formed identity for cancer is appropriate for liquid cancers ultimately composed of tiny cells.

Yet in the case of solid tumour cancers, the cancer itself does not (realistically) extend throughout the body but is self-contained in both a tissue-sense and through language. Social labels of “breast cancer” or “prostate cancer” locate and map cancer to one physical albeit anatomical space. If the person becomes the embodiment of cancer, or embodies cancer, there exists some hope and comfort in excising the tumour as a way to remove the cancer from the person. Harkening back to historic imagery from the Renaissance and early modern period, medical literature focused heavily on graphic drawings of surgical procedures to remove tumours from bodies. The idea of cutting-out cancer still dominates our social understanding of the disease. During my interviews with the haematology cancer patients, participants would often explain how hard it was for them to tell family and friends that their blood cancer (or liquid cancer) could not just be cut-out or irradiated. When asked to clarify, patients would describe their blood cancers as being “everywhere,” “pervasive,” “systemic,”

“constant,” that they were “covered in it.” The blood cancer was through “the whole body” and several participants accused it of being “invisible.” Blood cancers are not neat, tidy packages easily contained within tissue vessels or geographically-specific languaging. For example, *acute promyelocytic leukemia* tells the layperson nothing, and tells the medical professional that disease lies in specific white blood cells of which there could be thousands. *Non-Hodgkin’s lymphoma* may signal the layperson to think of enlarged lymph nodes but tell the medical professional that a specific white blood cell is diseased, again of which there could be thousands. Haematology cancers are not enclosed, they are not geographical or physical but rather they are fluid and are everywhere. One of the clinicians I interviewed said that identity studies were important for blood cancer patients because in reality the patient is becoming the cancer, literally and figuratively. Unlike with solid tumour cancers, the transient nature of blood cells means they are moving around the entire body and touching every organ and every tissue. They permeate our precious organs like the brain and the heart, historic centers of being, self, psyche, feelings, emotion. The person with blood cancer can truly embody the cancer experience, poignantly described by one participant as, “it’s my whole body.”

Captured in the complexity of a whole-body cancer is this repeating discourse around cells and the cellular nature of blood cancers. As the patients struggled to find identity within a generalized cancer framework, based on solid tumour organ labels, the blood cancer patients knew that their labels were cellular: myelocytic, lymphocytic, leukemia, lymphoma.⁵⁷ Patients participating in this study actively engaged in abstractifying their cancer into cell types in order to construct a meaningful understanding of what was happening inside their body. In several instances, imagined narratives around cells allowed participants to further deconstruct their specific disease into language that personified their unique experience. As I stated earlier, I believe the purpose of this was to create meaning from invisible cells in a similar way that clustered cells (i.e. organs) were named and had meaning. By acknowledging these invisible cells as part of the self, the cancer (disease of these cells) assumed a distinctive personal identity. The clinicians interviewed in this study

⁵⁷ The haematology cancers are all named according to the blood cell type that is malignant. For example, Acute Myeloid Leukemia (AML) has eight subtypes named for the immature myeloid cells which can develop into leukemia, including non-lymphocytic white blood cells, red blood cells, or platelets. These subtypes thus include myeloblastic, promyelocytic, myelomonocytic, monocytic, erythroid, and megakaryocytic.

echoed and fostered this distinctive personal identity framework by providing the information (via education) about the cells, disease, and associated treatment processes within the healthcare system. Ultimately this study captured a circular process of people struggling to create identity in dialogue with those who had the knowledge to push this identity formation along. In this final thematic section, I will discuss my impressions of what it is like for haematology cancer patients to create, and live with, a cellular identity.

Fashioning a Cellular-Based Cancer Identity

Cancer is corporeal; it is real; it is contained within the boundaries of the body proper and is thus embodied in a realistic sense. Accepting that we lack a social standard of what it means and looks like to have blood cancer, the patient participants in my research were really searching for a way of expressing what their cancer meant for them. Findings from this study indicated that throughout history and into modern times there has existed a socially accepted way for cancer patients *to be*. This sense of being includes physical appearance, body image, behaviours, social expectations, and labels. The historical inquiry chapter detailed issues of fear and terror, of likening cancer with death, of metaphors about being attacked or invaded, and conveyed the isolative social stigma attached to having cancer. Self-identity has been long-defined by labels such as “survivor,” “victim,” “patient” but these have been applied within the context of organ-based cancer. Contained within these labels are socially-acceptable and expected behaviours such as fighting cancer, battling cancer, beating cancer, succumbing/losing to cancer. It is socially acceptable to talk about the cancer experience as a journey, trajectory, a living-with, and a path. To identify publicly as someone with cancer is to enter a socially-constructed socially-accepted mode of what that means culturally. All the patients I interviewed talked in the same general terms about cancer and used the same conceptual labels to reference it. They did not, nor could not, self-identify with cancer in any other way than what was presented to them as expected socially. Yet there was uneasiness with self-description as being a “cancer patient.” They embodied cancer but were not the textbook perfect embodiment of cancer because there was something wrong with this description, something innately felt and acknowledged by both cancer patients and clinicians. It is this tension, this awkwardness in accepting a cancer-identity writ large, that seems to encompass the lived experience of having a blood cancer.

Our modern culture associates the self and identity as being contained within the body proper. Van de Vall (2009) pointed out that skin forms the only boundary between the self and the other. This is how it is possible to say the self is an embodied self. Per Descartes, the self exists only as the entity that is the specific body and the specific soul. The blood cancer patient becomes the Other, both in terms of generalized cancer and in relation to society. The outward appearance of this self through translation of the interior condition on the exterior surface (i.e. the skin) is one of the ways in which a person signals to society that they are well (normal) or unwell (abnormal). Most of the blood cancer patients I spoke with described the desire, and intermittent ability, to camouflage their illness in a social context in which they did not know how to act or in which they did not want to act in a way that was expected. This observation arose from an understanding that to have cancer is to enter a new realm of social expectations around what that means and what it should look like. A certain image of cancer is accepted within our culture but, as gleaned from my Phase One research, there is currently no widely-accepted way someone with a blood cancer is supposed to *be*. As identity is triggered by outward social cues, the lack of social feedback to the blood cancer patient about how they are supposed to *be* in the world manifests tension and anxiety around identity of an embodied self with a confusing type of cancer that permeates every aspect of the physical body. This confusing identification seemed to be strongest in the initial, acute phase of disease. As discussed, blood cancers are described through a title that is more abstract, microscopic, cellular, and systemic: multiple myeloma, leukemia, or lymphoma. Expanded titles are even more nonrepresentational: acute promyelocytic leukemia, non-Hodgkin's lymphoma, myelodysplastic syndrome. These titles tell an informed individual or healthcare provider about the cellular dysfunction causing the cancer, but at initial glance these titles do little to expand on knowledge around a particular blood cancer. These titles do not provide a physical body place that holds the cancer, but rather convey the sense of systemic and whole-body. "Leukemia" might signal an association with white blood cells, but does little to say *which ones* or *where*; rather, the leukemia conveys a total-body condition. The lack of a clearly delineated physical boundary as provided by a tumour site creates tension for the blood cancer patient because it mandates a different context of the idea of what it means to embody cancer. It also muddies the water about where to fight the cancer, and obfuscates a notion of winning since a blood cancer is not generally spoken of in terms

of cure. Take, for example, the social mandate of the Canadian Cancer Society or the American Cancer Society which aim to cure cancer. For the haematology cancer patient, cure is not entirely possible, so it would be more appropriate to speak about remission. Yet these patients are lumped together in “a race for the cure.”⁵⁸

If the cancer patient has a solid tumour cancer, or a *place* cancer, to be socially visible is to have eyes move to the organ of primary involvement: prostate (between the legs), breast (chest), lung (chest), brain (head). For haematology cancers, the space which comes under society’s gaze is the body, and the body is personhood expressed. This made participants in this study very uncomfortable, and several wanted to explicitly locate their cancer. A patient with NHL acknowledged that the cancer was “technically” located throughout her entire body, in her mind she located it only as a mass in her lungs. This gave her a place to talk about (“I have a mass in my lungs”) and she was able to fixate her energy on this physical location – exactly echoing the languaging and purpose of solid tumour patients (as evidenced in Phase One research). It is a personal conundrum if your body is personhood expressed socially, and if your body is filled with cancer. The Canadian Association of Psychosocial Oncology (CAPO) has a campaign called “I am more than cancer.” By making this statement, CAPO promotes an overarching social assumption that the cancer patient equates the I/self with cancer, thereby reflecting the notion of cancer embodiment (i.e. the person/self as the embodiment of cancer/disease). My present study on haematology cancer patients cannot confirm the validity of this statement for the blood cancer patient cohort. It might very well be the case for solid tumour patients, which was certainly suggested (at least peripherally) in my secondary analysis of the cancer patient database. Within my primary research with blood cancer patients, participants were careful to delineate between the cancer and their body and self. I will elaborate on this further. The participants in my study, along with the clinicians who described their experiences working with the haematology cancer subgroup, described a sense of anxiety and unassuredness around naming the self as cancer. Yet to me, particularly at the beginning of this study, it seemed painfully obvious that if

⁵⁸ I am not ranking diseases here, but rather pointing out that dominant social (and economic) languaging is solid-tumour based. I also recognize that most cancers are solid tumour cancers and that haematology cancers are still relatively rare. According to the Canadian Cancer Society (2017), half of all newly diagnosed cancers each year consist of prostate, breast, lung, and liver. In 2017, Non-Hodgkin’s Lymphoma constituted the most common blood cancer diagnosis and constituted 4.5% of new cancer diagnoses in men and 3.6% of new cancer diagnoses in women.

blood permeates the body and the blood is filled with cancer, then the body is filled with cancer. I assumed that the experience of having a blood cancer would reflect an embodied cancer-as-self. Instead, most patient participants expressed acceptance of the following premises:

1. I have a blood cancer.
2. Blood is imbued with life (or soul or spirit or energy) and is composed of cells.
3. Blood cells exist everywhere in my body. They are systemic.

It is difficult to find a singular logical relationship between these three premises that would lead to the deduction that the patient is the embodiment (noun/person) of cancer. I interpret these premises as something like a triptych, in which three angles considered together allow us to appreciate the depth and complexity of the phenomenon. Lacking a socially accepted identity of blood cancer, participants were unable to link their *self*-identity to that of *being* their blood cancer even though it was (literally) coursing through their body. This suggested that these patients accepted their disease as in the physical body (embodied) and systemic, but there was some disconnect in accepting that it was them or that they represented the disease (embodiment). Thus, one of the major conclusions I reached in this study was that the haematology cancer patient experience seems to embrace aspects of a dichotomous identity: a self-identity that is shaped by the condition of the corporeal body but is also quite separate from the corporeal body. Blood cancer patients may be the true embodiment of cancer, but they seem disembodied in the sense that they divest their identity from the body because, I believe, of the lack of a physical location upon which to assign the cancer. Therefore, the blood cancer patients might not relate to the statement “I am cancer” or “I am more than cancer” because of the disconnect between the body/self/cancer that occurs.

The notion of biographical disruption (Bury 1982) lends itself to explaining the notion that the blood cancer diagnosis is a “new job” as promoted by the clinicians. Bury explained that the onset of an illness that will be chronic (as certainly is the case with blood cancers), throws a person into crisis as they are forced to engage in deep (and largely undesired) self-reflection in order to navigate the new cultural system represented by the social entity called *medicine*. The result is that the individual story is disrupted by the medical reality (and medical system) through three key points: a disruption in taken-for-granted behaviours, a disruption in self-concept, and a disruption in the mobilization of

resources. Efforts then are towards navigating this disruption and seeking a way to re-establish a new identity (which was characterized by the theme of reconstruction in this study). The affected person (i.e. patient) seeks to re-establish a recognizable biography; however but this is a conflicted and difficult process. Bury (1982) considered the chronic illness sufferer to be caught in a conflict between lay and medical knowledge, leaning towards one or the other depending on the exacerbation of their symptoms. This explanation may be useful in understanding why it was difficult for me to recruit patients who were in the phase of acute illness. I wondered if it was only when patients were beyond that medicalized phase that they would be sufficiently intrigued by issues of identity and a new reality that they would be inclined to participate in a study with that focus.

Some people joined an established cancer community upon receiving a diagnosis. The participants in this research told me of going to generalized cancer meetings composed of an array of cancer patients, and within this context they felt considerably out of place. They described being a part of the cancer writ large community because they had cancer, but each had a sense of alienation from what that meant within a larger context. Several described being different, and not being able to relate to those *other* cancer patients. In each case the participants never accepted the definition of cancer *as self*. Rather, they described the unique situation of having a blood cancer in acknowledging that it was systemic (“it’s my whole body,” or “I was covered in it”). Within this context, the cancer was self (cells) that became non-self (something else) when the self-cells converted to cancer, and this non-self (cancer) permeated the entire body (systemic) but was somehow *not* self. Therefore, when the patient participants were asked about how they talked about their experience and their disease, they would provide a specific diagnosis: “I have leukemia,” “I have hairy cell leukemia,” “I have CML.” Not one said, “I have cancer,” nor did they say “I am cancer” (per CAPO, for example) despite acknowledging the systemic nature of their disease as being the whole self (and particularly in contrast to a localized solid tumour cancer). The widespread use of “patient” by both participants and clinicians as identity label signified both the absence of health and captured elements of expectations around how society should think about them. Identifying as “patient” prioritized social expectations about behaviours, appearances, and priorities. The use of “patient” over every other label choice (as discussed in chapter 4 and

including victim, survivor, person living with cancer, member of a cancer community, etc.) acknowledged that significant transition between being well and being sick.

Embracing a “patient” identity over other identity label options is important in several ways. First, being a patient signals a loss of autonomy and an initiation into the healthcare system. There exists copious research in the literature on the patient (or sick) role, health belief model, and related health behaviours (for example, Becker, 1978; Bowling, 2014; Conner & Norman, 2017; Heid, Knobloch, Schulz, & Safdar, 2016; Jones, Smith, & Llewellyn, 2014). The idea of a sick role as established by Parsons (1951;1964;1975; Varul, 2010) has been challenged several times by movements such as health promotion, but it still goes far to describe the expectations that exist between the health care provider (and system) and the ill person (patient, or in private health care systems, client or consumer).⁵⁹ Within the confines of this research, it seems the greatest confusion for participants was when they first entered into the healthcare system and took on (to various degrees) a role as ambiguous patient. Then, as they received and sought out information and education both about writ large cancer and their specific blood cancer, the notion of patient was advanced and transformed into a more distinctive, specialized patient identity (i.e. I am a mantle cell lymphoma patient, or I am a CLL patient). Through this process of knowledge gathering, reidentification seemed to occur multiple times as the participants pushed past identifying as only “patient” or even “cancer patient.” The sick role allowed a patient to be passive, a way of being that seemed preferred by many patients despite an overarching social language of proactivity and personal responsibility (Thorne et al., 2005, p. 895).

Labelling and the acceptance or rejection of a label has some relationship with spoiled identity, which in turn is related to (but not identical to) stigma. Per Goffman in *Stigma (1963)*, a spoiled identity occurs when someone is no longer considered one of the “normals” by society. This can occur for a variety of reasons, and of course the literature and this study support the notion that someone who is sick (with cancer or any other disease) is no longer “normal” in the classic sense, and therefore suffers from some degree of stigma. This notion was captured by the dual kingdoms promoted by Sontag (1978) of healthy and

⁵⁹ Parsons “sick role” model has been supplanted, for the most part, by health behavior models such as the health belief model as social and medical emphasis as increasingly focused on self-action by the ill-person. See Burnham, 2014.

sick whereby health was “normal” and sick was “not normal” (i.e. stigma).⁶⁰ A spoiled identity, then, occurs when a person is no longer normal (read as stigmatized) for whatever reason, and their previous identity is temporarily or permanently invalid. Stigma within the framework championed by Goffman can occur on a spectrum, and thus in the case of the blood cancer patient the participants expressed cancer as stigmatizing because it was both known (“cancer”) *and* unknown (“blood cancer”). This sense of binary stigmatization, and associated spoiled identity, produced the environment in which the patients in this study sought to cope with stigmatization in a way that would give them both power and social re-acceptance (although they acknowledged that their previous sense of identity might never be regained).

Threaded throughout the layers of this research is the theme of uniqueness upheld by blood cancer patients. As expected as an outcome of any major life upheaval, the participants in this research focused on a movement towards (ultimately) reconstruction and finding that new normal as quickly as possible. The phrasing “cancer journey” was used universally to represent the purposeful plan laid out by the healthcare system which involved specific treatments, scheduling, behavioural expectations, and checkpoints. My interviews with patients contained details of their intense self-education about their blood cancer, which I took to be a longing to find that new identity (beyond patient, or cancer patient, or blood cancer patient). Reflecting on these interviews, it seemed that an individual could only start grappling with a new self after forming a mental construct of what their *specific* disease actually meant. In chapter 7, I discussed how most blood cancer patients I interviewed emphasized how unique they were according to their specific diagnosis. They absolutely could not comfortably relate with other patients also under the umbrella cancer or even a “blood cancer.” Perhaps our understanding of haematology cancers as new diseases only detected through advanced, modern diagnostic technologies with the ability to hone cancer down to a genetic level further bolsters the sense of being unique. This deeply important search was also noted by some of the expert clinicians I interviewed, and the social worker noted her frustration about never being able to find patients the “right” support group or “right” patient buddy. The overarching label “blood cancer,” or leukemia or lymphoma or

⁶⁰ Notions of physical appearance are particularly important here. See Goffman (1963) and his writings on outward bodily signs characterizing and triggering stigma.

MDS were not specific enough for most patients seeking support. They complained about wanting more: more specificity, more commonality, and more likeness to self. I believe this intense focus on finding someone intimately similar was a response to unease about being unable to identify with the larger cancer community. If they could just find that other person with Philadelphia positive acute lymphoblastic leukemia, then they would know how to *be* and be truly understood. One gentleman told me, “if someone doesn’t have my same lymphoma [diffuse large B-cell], they can’t possibly identify with my experience.” Another participant told me that she endlessly searched blog posts searching for others with the same lymphoma so that she could find out how to act, how to think, and what to hope for. This intense sense of being special, and of needing to find others who were similarly special, seemed to signify a desire to find community but also identity. If identity is a social phenomenon, an outward expression of an embodied self-situated within society, then the blood cancer patients in this research were seeking a community of those they could relate to in order to *co-create and enact a new identity defined specifically by their haematology cancer*. As participants dealt mentally and emotionally with their blood cancer diagnosis, focus on self-identity represented less an exploration of the self as a person and instead seemed part of an effort to re-identify the self in relation to a new social and medical context and a new autobiography. For the participants in this study, being a cancer patient wasn’t good enough and didn’t really describe their identity. That identity was placed on them by society and the biomedical system contained some elements that made sense, but overall the labelling and expectations for a cancer patient didn’t make sense for haematology cancer patients. Instead, through knowledge-gathering about their specific disease, and through embracing the cellular abstract nature of their condition, patients were able to form a new identity for themselves. The process of identity recreation (origination, deconstruction, reconstruction) detailed in patient interviews signified checkpoints along this journey of self-discovery and emphasized the fluctuating and transitory quality of self-identity.

Summary

This research has offered a new way in which to view the identity experiences for the haematology cancer patient. **The main conclusion I have reached is that haematology cancer patients convey a sense of multiple identities arising from being both a cancer**

patient and as somebody beyond a writ large cancer patient. This beyond-cancer identity is based on their specific blood cancer diagnosis down to a cellular and genetic level. The voices of the haematology cancer patients represented in the multiple layers of this study both embraced and rejected the hegemonic social labelling used by dominant discourses around cancer including the popular notion of “survivor.” Primary research with experienced oncology clinicians confirmed that haematology cancer patients generally identified with cancer expectations, behaviours, and labelling but they were also different and special. Overall this research has shown a purposeful process by which haematology cancer patients create a distinct blood cancer-identity framework. Three key elements of this process include the embodied nature of cancer, disidentifying with solid tumour cancers, and fashioning a cellular-based cancer identity. In our encounters with haematological cancer patients, those who provide care might be better informed by a framework of understanding that allows for alternatives to the current constraints associated with biomedical and sociocultural cancer expressions or language.

A final concluding chapter presents reflections on the strengths and limitations of this research project. I will also discuss more specific implications this work has for nursing practice, as well as thoughts on future research questions and projects.

Chapter 10: Strengths and Limitations, Future Research, Implications, and Conclusion

Introduction

The journey undertaken in this research project to explore multiple angles and meanings of identity for adult haematology cancer patients has been complex and comprehensive. In this concluding chapter, I reflect on some of the strengths and limitations of this study as a whole. I also consider some implications the study findings have on our understanding of the phenomenon of identity and embodiment as these important issues pertain to the unique population of haematology cancer patients.

Reflections on Strengths and Limitations

The multi-layered approach to qualitative research undertaken in this dissertation provided a comprehensive analysis of identity as an important phenomenon experienced by haematological cancer patients. The new knowledge generated from this research has significant multidisciplinary implications particularly around improving the psychosocial well-being of patients. The greatest strength of this qualitative study was in the interviews collected from both patient and clinician participants. In total, 21 people provided in-depth discussion, experiences, and observations on this phenomenon. The intensity of information and data collected was quite substantial and expansive in content, allowing for a textured and deep analysis of the data in a way that really benefited an existential and subjective phenomenon such as identity. As discussed in chapter 3 (on methodology), the sample size I aimed for in this project was based on a notion of sample adequacy (Morse et al., 2002). The sample of patients I was able to recruit included a wide range of haematology oncology disease types as well as an impressive range of demographic characteristics. Likewise, the sample of participants recruited as experienced oncology clinicians included very thoughtful and richly qualified individuals who each felt passionately about the importance of having a conversation on identity issues for this patient population.

Beyond being able to gather data from two robust samples of participants, the comprehensive overlying structure of a five-layered research process proved significantly effective for revealing nuances and assembling an inclusive picture of identity as a core concern of blood cancer patients. Identity is not an easy phenomenon to study, especially in

the clinical setting and for an applied discipline such as nursing. In keeping with the identity's nature as being both theoretical and practical, identity studies are highly multifarious. Like blood cancers themselves, our social understanding and acknowledgement of identity as an important component to both person-hood and patient-hood are relatively recent conceptual inventions couched in sociological understandings. Split into two distinct phases of inquiry, the five diverse and unique research layers I utilized in this qualitative study allowed for a comprehensive and thoughtful means of generating new knowledge around this complex phenomenon. Each of the five layers of inquiry individually signify a significant piece to the identity puzzle, but a richer understanding emerged from coalescing all of these visions and angles into a greater whole. Although complete representation of identity and its full complexity remains elusive (and perhaps is ultimately unattainable), these five angles of vision have uncovered worthy insights into how we can better understand the workings of identity concerns within a healthcare context, and more specifically, around how these issues can affect our work with blood cancer patients in the applied practice context.

Perhaps the main limitation to this study was unforeseeable when this project was first designed. Having been a practitioner for many years, I formulated the overarching research question based on my clinical experience working in acute and critical care environments with oncology patients (both solid tumour and haematological cancer patients). In the context of bedside practice, conversations occur that are intriguing, thoughtful, and critical to the in-the-moment aspect of nursing care. Within my own practice I had been struck by the deeper philosophical explorations of blood cancer patients as they were in the acute care (hospital) environment. They would speak about their sense of self, identity, and how they personified the cancer *at that moment*. As their nurse, I was in a privileged position of being able to hear these stories from a perspective of being a coordinator of care. The research question in this study was therefore created assuming that similar conversations could occur with patients along the entire spectrum of cancer care, from diagnosis through acute care and day clinics and beyond. However, what I learned through this study was that the research context matters greatly when patients are reflecting on their experience. While patients are in an acute phase of their illness, either when newly diagnosed or experiencing complications or coming out of remission or awaiting stem cell transplantation, they may have many ideas to share that would add valuable insight to our understanding of identity

within the most acute and life-threatening phases. At least within the confines of this study, patients who were acutely ill could not see their way into entering a research relationship as a means by which to share these experiences. Within the boundaries of the ethics requirements, I put great effort into recruiting patients in the acute care or immediate care phase of their disease including having other health care practitioners advocate the importance of joining the study. Ultimately, however, I found it impossible to recruit patients willing to engage in the study who were more recently acutely ill and receiving treatment in a hospital setting. This impediment was confirmed during my discussions with the clinicians who lamented that patients seemed unlikely to engage in formal research projects on psychosocial topics (including identity) while they were in the midst of active treatment.

While a minor grievance, this indicates to me that identity may be a major concern for haematology blood cancer patients at the moment of care. They told me that it was in my (retrospective) interviews. They tell me that it is when I am working with them in the context of the acute care nurse-patient relationship while they are being actively treated. What I conclude from this is that identity, like other existential issues, is an imperative concern for haematology cancer patients arising from the moment of diagnosis. The ability, or desire, to discuss such a personal and subjective concern with others depends on a wide variety of factors including roles, timing, hierarchy, and personalities, to name a few.

Both the patient and clinician participants expressed the potential inability of someone who is acutely ill to discuss identity in ways that made sense or had meaning for them. This could be especially true immediately following a diagnosis. For the sake of this study, I have to agree in the sense that I could not, wearing a researcher's cap, talk to people about their identity issues until after they had come to resolution about what had happened or was happening to them. It was at that point, which seemed to be around a year out of their last major treatment episode, patients wanted to participate in the study. While in the role as primary care nurse, I am granted access people's deeper and more private thoughts in a way that reflects the inherent intimacy of deeply relational practice. As a researcher, this ability (magical, in a sense) was absolutely more difficult and awkward, more forced in the sense that our conversation had structure, organization, purpose, and time restraints. The spontaneous nature of a late night musing on identity that erupts from an introspective and reflective patient, bored with television and trapped in a negative pressure unit, was not the

same as engaging in a prearranged interview. The quality of information gathered from the participants in this study was expansive, reflective, thoughtful, and extremely important in developing our knowledge around identity. This data reflected a retrospective, longitudinal view of the patient experience versus the immediate, in-the-now experience of receiving treatment, and it is impossible to say (ultimately) how or if the component of timing really made that much of a difference for informing the overall research question.

This experience taught me about the incredible responsibility gifted to the floor nurse of the willingness and openness some people have to explore profoundly personal topics in the sterile and impersonal context of the acute care environment. The bedside nurse exists in a coveted position of seeing people at their best and worst, and of having the ability to make lasting and deep impacts through thoughtful conversation. This organic relationship forged during difficult and trying times highlights the importance of having a nurse's perspective in studies of patient phenomena beyond just that of identity. It also has convinced me that identity research, and subsequently some manner of psychosocial investigations, are uniquely informed by the theoretical and disciplinal lens of nursing.

Implications for Future Research

Nursing research around psychosocial and biological aspects of disease is important for both advancing the profession and as a critical means of improving patient care (Dilworth, Higgins, Parker, Kelly, & Turner, 2014). Emphasis on the psychological, emotional, physiological, and mental health of patients represents a non-pharmacological intervention that can improve quality of life and potentially enrich outcomes. The importance of psychosocial research for nurses working with haematology cancer patients is paramount, as these patients constitute one of the most challenging populations both in terms of the severity of the disease and complexity of treatments. Furthermore, once someone is diagnosed with a blood cancer they enter into a relationship with the healthcare system that will, literally, last their lifetime through ongoing surveillance. In many cases, over time the blood cancer patient may leave remission and need to reinitiate treatment, and disease may advance to the point of needing palliative and end-of-life care. The relationships forged between the haematology cancer patient and members of the healthcare team require an approach that demands praxis with regards to both psychosocial and physiological elements.

This study was developed with the intention to explore the concept of identity and embodiment as components of a growing body of research on the patient experience of cancer. As presented in the general and integrative literature reviews, nursing as a discipline has generally avoided in-depth research with patient subpopulations on identity (expressly). There is a deep-rooted emphasis of nursing theory and practice on psychosocial concerns, but somehow identity and embodiment for cancer patients has (largely) been undertaken by other disciplines such as sociology, medical sociology, social anthropology, or psychology. It is my hope that this study promotes the importance of identity as an issue of concern within the realm of nursing practice, and subject to appropriate and thoughtful nursing interventions.

More specifically, this study has demonstrated the importance of research that addresses the experiences and needs of specific cancer subgroups. The idea of a generalized cancer patient permeates most of the research literature, as evidenced by studies that combine the multitude of cancer diagnoses into one homogenous “cancer” experience. That is not to deny the existence of a commonality of knowledge, concerns, or issues that cancer patients face in light of dealing with a malignant disease. As has been discussed in multiple contexts within this study, cancer as a biological disease and social conception is imbued with multiple cultural meanings, expectations, and perceptions. Chatoo and Ahmad recognized this when they noted “there is no way of living and dealing with cancer outside the meaning ascribed to the illness within a particular culture” (2004, p.20). As the biomedical model shifts towards fine-tuning boundaries and variations between cancer types, it makes sense that other research models follow suit to focus more on specific physiological, psychological, and cultural attributes unique to each diagnosis. This study has confirmed haematological cancers as being unique, distinct, and different enough to warrant specialized research studies. Taking this further, prospective research could focus more precisely on the experience of specific blood cancer subtypes. Specifically, if similar research on identity, embodiment, and other existential concerns was undertaken with distinct blood cancer populations – say acute leukemia patients or chronic leukemia patients or non-Hodgkin’s lymphoma patients – the findings could be compared in a way that might lead to a greater understanding of both similarities and differences. This in turn would motivate theoretical and evidence-based knowledge geared towards honing and improving cancer-specific care interventions.

It is important to acknowledge the exceptional nature of a blood cancer diagnosis both biomedically and within the greater sociocultural milieu. A focus on generalized (combined) cancer blurs all individual cancer diagnoses into one homogenous entity called “cancer.” As the historical inquiry research indicated, our modern understanding of cancer is based on layered social understandings that are hundreds of years old and which focus almost exclusively on the experience of someone with solid tumour cancer. This is not surprising – even today, blood cancers are relatively rare when compared to occurrences of solid tumour cancers. What this study has indicated is the importance of discovering, developing and promoting appropriate sociocultural mores, symbolism, and languaging that better reflect our modern physiological understanding of haematology cancers. The impression provided by this study is that both patients and clinicians are unsystematically moving in this direction, but more research is needed to corroborate this finding.

Finally, studies such as this reflect a growing sensitivity within nursing that acknowledges the diversity and complexity present within the broader patient experience. Acknowledging the importance of studying populations and in generating substantive data, we are also living in a time when catering to individuality and the personal self has become a principal component in providing authentic and appropriate care. Regarding haematology cancer patients, future research studies could be longitudinally based, seeking feedback about experiences at specific points along the care trajectory. Sociocultural studies seeking subjective experiences centered on gender, ethnicity, or class identity might also be beneficial in the sense of understanding patterns and implications blood cancers have on specific groupings of individuals. Studies characterized by intersectionality, namely research which aims to analyze the interaction of multiple, complex identity categories, would be another angle through which valuable insights into the patient experience might arise. Seeking critical understanding around intersections of oppression and privilege, intersectionality research could expand knowledge around how haematology cancer patients experience social location through concepts such as ageism, sexism, classism, or ethnocentrism (per Hulko, 2004 in studies with dementia patients). These additional studies could potentially be focused on other angles of identity and embodiment with an aim of providing better, and more directive, patient care.

Implications for Nursing Practice

The nurse creates and nurtures an intimate bond with the patient and family through a constant presence and hands-on care. She or he gets to know the patient and family better than any other healthcare provider, learning their wishes, fears, capabilities, and challenges. It's the nurse in whom the patient confides in the middle of the night and to whom the patient's loved ones often turn for information, support, and solace (Fitzpatrick, 2015, p.2).

This study has highlighted an interlaced relationship between psychological and biological factors with regards to nursing practice. Psychosocial care of the oncology patient is a growing concern of several disciplines, and nursing is only recently beginning to acknowledge the role that nurses have in providing this care (Manhedran, 2014; Nicholas, 2016; Regan, Levesque, Lambert, & Kelly, 2015; Stanton, Rowland, & Ganz, 2015). Within nursing theory there exists the concept of moral responsibility. Morality is based on the existence of a self: a self-aware being who has the ability to consider questions around agency, freedom, and responsibility. Thomas Reid once noted that personal identity, "forms the foundation of all rights and obligations and of all accountableness" (Reid, 1785, p. 112). The focus of nursing on the unique individual is one which embraces all aspects of personhood in order to give appropriate care: physiological, spiritual, emotional, and mental. Within nursing theory, identity exists as a subcategory under self-concept. Nursing research on self-concept by Drench and colleagues (2011) affirmed the role self-concept and delineated associated terms such as self-esteem, identity, body image, and self-perception have on self-management of chronic disorders and healthier lifestyle choices. Therefore, probing questions around identity for patients is not only appropriate, but necessary, in nursing practice.

Identity as the phenomenon of interest in this study is not necessarily amenable to nursing interventions in a traditional or clinical sense. Rather, I believe this research signals many constructive implications about how nurses and other healthcare practitioners might be better prepared to support blood cancer patients through a complex treatment trajectory which potentially encompasses multiple stages including diagnosis, treatment, palliation, and remission. Of primary concern for nurses in practice is recognizing and acknowledging the person-as-patient. This corresponds to the idea of "being known," whereby patients seek various degrees of human connection with a caregiver, who in this case is a cancer care

provider. Thorne and colleagues (2005) explored this notion as an element arising from effective and ineffective communication scenarios depicted from a cancer patient perspective. These authors concluded that improvements to the healthcare communication environment can exist through affirming a patient's uniqueness within an overbearing and homogenizing cancer care system (p.894). This deep longing to be seen as unique and special was expressed in the present study explicitly during the patient interviews in which participants specifically sought out diagnostic or genetic indicators to set themselves apart from other cancer patients. The individual didn't want to be known as just another blood cancer patient, but as a *mantle cell* lymphoma patient or as a *hairy cell* leukemia patient. In this sense, nursing practice that seeks out and embraces specific details and knowledge around a precise pathophysiological diagnosis allows for a person to "be known" in a way that positively impacts care. Good nursing practice makes an effort to integrate identity concerns as impactful to the transformative nature of identity work that accompanies a person's cancer journey.

Nurses use communication as a means to assess, understand, and assist patients throughout their care journey, and understanding how patients might be communicating their experience of identity is an important component towards improving patient care. Not understanding what is said during a conversation, or misinterpreting a statement or label, or even ignoring key cues about identity concerns, could inadvertently complicate the patient experience. Within the communication environment, healthcare providers may better serve the patient by listening to concerns and thoughtfully reflecting back important themes that seem bothersome. This could include inviting patients to discuss topics such as a loss of employment (and therefore the loss of an identity label as "worker") or the inability to care for family members in the same way (such as experiencing the loss of identity as "parent"). Simple, genuine acknowledgement of a forced identity shift resulting from a blood cancer diagnosis may ease some of the concern, fear, and anxiety over what the person is going through.

As is also implied within these findings, the need for patients to receive information about the pathophysiology and clinical pathology of their specific disease represents a way in which identity is both created and reinforced. Speaking to the precise location of chromosomes (for example, "I am a Philadelphia positive acute lymphocytic leukemia

patient”) or being able to generate mental imagery about abstract cellular types (T-cells, B-cells, etc.) provided patient participants in this study a means through which to assemble and claim a new self-identity. Although still a diseased self, nonetheless by the identity reconstruction phase precise biological facts and knowledge cued personal identity nuances. Patient education has long been considered an essential component of standard care provided by nurses (Bastable & Gonzalez, 2017). The clinician interviewed for this study related how they, instinctively or through training or a combination of both, taught haematology cancer patients about their disease in a way that focused on stem cell functions, blood cell types, lab work values, medical terminology, pathological processes, and treatment specifics. Ultimately the stated intention was to intervene through knowledge translation (the knowledge of cancer as translated from professional to layperson) to effect patient knowledge and subsequent health behaviours.

Orr called illness an “educational opportunity,” (1990, p. 47) and within this study the knowledge conveyed by the healthcare team around a diagnosis was distressing (i.e. the fact of having cancer) but also liberating in the sense that patients eventually used this knowledge to reconstruct identity and a sense of self within a greater sociocultural context. The present study has highlighted a need for increased sensitivity in the care environment around supporting individual choices when and where appropriate as important interventions supporting any identity concerns experienced by the patient. This could include a personalization of space while in care, which would allow the individual to maintain a sense of independent self while engaging with the medical environment. Forms of self-expression that remind the patient of what is personally important, such as allowing pictures or art to be displayed, may promote a sense of normalcy in a way that might be comforting. Allowing the patient to wear personal clothing or to decide matters of body image and physical appearance (both in and out of hospital or clinic setting) promotes self-expression in forms that are harmonious with safe and respectful care. These interventions can also encourage a new sense of identity as a blood cancer patient as the person explores what it will be like to live with changes related to certain facets of their diagnosis. For example, participants in this study reported increased levels of fatigue due to both treatment and disease. This forced many to explore creative ways to conserve energy, which included strategies such as abandoning or changing make-up routines, choosing a different style of haircut, or finding a

less cumbersome wardrobe. This image projected into the social world constitutes an important reflection of identity and may be an important factor in rebuilding a new normal and bolstering self-esteem.

This study brings into question the usefulness of terms like *patient*, *client*, and *survivor* within a healthcare context. Through etching away at the various dimensions associated with identity (ontological, social, and experiential), these labels seem to deflate identity from being person-based and person-centered to something less-than-person in order to receive care. By receiving one of these labels, the person has been challenged in a way that reflects loss of former self and a new identity with admittance as a component of the healthcare system. These labels signify loss of identity due to illness. Since our social emphasis is on ways people contribute to society through employment, volunteering, or familial roles, utilizing the idea of the “new full-time job” could be a means to encourage the patient to rethink identity around issues of *doing* and *being*. For example, one clinician proposed to call the patient a “health seeker,” a proactive, positive, and optimistic label. Another clinician suggested calling patients “a person living with a blood cancer” instead of “cancer patient.” What this study suggested to me, however, was that the healthcare provider should step back to grant the patient the ability to create their own identity which they will then directly, or indirectly, communicate about. One of the major conclusions of this work was that the blood cancer patient is both a cancer patient and something else, something that is unique based on their specific diagnosis. During communication exchanges, members of the healthcare team might listen for cues in languaging around self, carefully reflecting back similar words or themes. For example, if someone talks about themselves as a person with hairy cell leukemia, the healthcare provider could resist the urge to call them a “leukemia patient” or simply, “blood cancer patient,” and instead acknowledge them as a “hairy cell leukemia patient.” Similarly, to recognize the importance placed by the patient on identity (and uniqueness) as well as “being known “to caregivers, nurses (and other healthcare providers) would benefit by addressing patients specifically by the name of their choosing. Asking and remembering the response to, “what would you like me to call you?” is a simple, yet shockingly effective strategy in removing the patient from the immediate cancer-focused

environment by acknowledging an identity (name) that is beyond cancer or being a cancer patient.⁶¹

Finally, this study has strongly supported the expressed desire of patients to link with others in their diagnosis peer group as a means of self-reflection, consolation, and comfort. Developing relationships with others sharing similar experiences also allows patients to take cues and signals about next steps in identity formation around the blood cancer diagnosis. A possible implication for the healthcare provider could include proactively trying to link patients with similar diagnoses beyond the broad solid tumour versus blood cancer subgroupings. The literature is replete with examples of how to create, and foster, peer support mechanisms for cancer patients (such as Medeiros et al., 2015; Meyer, Coroiu, & Korner, 2015; Niela-Vilén, Axelin, Salanterä, & Melender, 2014; Zhang et al., 2017). For example, several organizations hold meetings that are for cancer patients as a whole (like the Canadian Cancer Society, or the American Cancer Society) that offer details on topics like nutrition, exercise and chemotherapy side effects that might affect large numbers of varied cancer patients. Other organizations offer support groups for haematology cancer patients (for example, the Leukemia and Lymphoma Association). Nurses, social workers, and physicians are in the exclusive position to have intimate knowledge about patients and their contemporaries in a way that highlights specific pathophysiological components of a diagnosis. As discussed, these components such as genetic typing or specific cellular abnormality seem to be important to patients trying to grasp at a new, unique identity. By linking specific patients through personal introductions, support meeting invites, online forums, disease-specific blogs, and website recommendations, the healthcare team can facilitate a cooperative network and collaborative environment in which to socialize and make interpersonal connections.

This research study has highlighted the importance of co-embracing existential and biological aspects of blood cancers as emphasized by patients describing their illness experience. Using a lens of identity, this section has presented some implications arising from this research on how nurses and other healthcare practitioners might better support haematology cancer patients through a difficult and complex diagnosis.

⁶¹ After all, Bertrand Russell said that one's name is the only thing that remains constant over time in regards to personal identity. See Sainsbury, 2005.

Concluding Thoughts

Cancer patients struggle with existential and psychosocial concerns from the moment they are diagnosed. Identity is an overarching concept through which other expressions of selfhood are contained and conveyed. In this dissertation, identity has been broadly defined as the condition or character as to who or what a person is. This dissertation has explored issues of identity as experienced by adult haematology oncology patients through a five-layered qualitative research process driven by methodological framework provided by interpretive description. The results from this research recognize the profound nature of identity as a complex and multifaceted concept reflecting many dimensions including ontological, social, and experiential. Primary research with blood cancer patients has suggested that origination, deconstruction, and reconstruction were processes by which an old patient identity was grieved, dissolved, and rebuilt into a new identity of the self with blood cancer.

The research also showed that blood cancer patients are conflicted in their identity between being a cancer patient and also being somebody unique. This difference was expressed by both patients and clinicians as a special way of being which personified elements specific to the blood cancer experience. I have discussed at length issues of embodiment and the paradox of body location for blood cancer patients struggling to conform to modern sociocultural ideals and expectations around how cancer patients should enact and embody that role. The experience of a haematology cancer patient is highly personalized and distinct, and yet this research has demonstrated several areas where social labelling is more descriptive of the generalized cancer experience to the detriment of the haematological cancer patient. The participants in this study described a strong desire to associate with others sharing their distinct diagnosis, reflecting what seems like an innate and deep-seated urge to co-create a new identity that could honour the unique experience of being a blood cancer patient. As healthcare professionals, our aim to customize support for patients through their illness trajectory requires effective and thoughtful communication that is respectfully sensitized to identity concerns.

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Appendix A: Criteria for Inclusion/Exclusion for Primary Data Collection

New Patient Cohort Interviews (N = 10?)

Criteria for inclusion as a participant in the recruitment of a new cohort of haematology oncology patients for Phase Two of this study include the following:

1. Patients diagnosed with haematological cancers such as leukemia, including but not limited to the many forms of both acute and chronic disease (for example, APL, AML, CLL, CML, CMML, and MDS) and lymphoma (NHL and HL). Patients with multiple myeloma, MDS, or aplastic anemia may be invited to participate if sampling strategies are not sufficiently productive for the main group of haematological cancers.
2. Patients who are 18 years old or older.
3. Patients who consent to be interviewed in person on at least one occasion.
4. Patients who are at any stage in their disease trajectory.
5. Patients who have the ability to speak and understand English.
6. Patients who have the cognitive ability and desire to reflect upon their cancer experience.
7. Patients who live in British Columbia or the Yukon and who have received treatment or are being treated by provincial agencies the BC Cancer Agency (BCCA) or the Leukemia/Bone Marrow Transplant Program of BC (L/BMT).
8. Patients who do not live in BC or the Yukon permanently but who are temporarily in BC to receive treatment will also be considered eligible for this study. This includes, for example, Ontario-based patients living in BC for the purpose of double cord transplantation (dUCB).

Criteria for exclusion as participants from the *Phase Two* portion of this research study include:

1. Patients who are, or who become too sick or debilitated, to participate in interviews.

2. Patients who may have signs of mental illness, dementia (temporary or permanent), or other neurological conditions that might deem them unable to give independent informed consent.

3. Patients who have cancer comorbidities. This would include patients diagnosed with leukemia in addition to a current solid tumour cancer diagnosis (such as breast cancer). This does not eliminate patients who had a previous solid tumour cancer diagnosis, go into remission (or cure), and then develop a secondary cancer type. For example, many breast cancer survivors are cured and develop a haematological cancer several years after their original cancer diagnosis. If such patients became available within the recruitment pool, they could add an important dimension to the analysis.

Appendix B: Sample Questions for Initial Interview (Participant Interview)

Interviewee # _____

Project Title:

Exploring Issues of Identity in Adult Haematological Oncology Patients

Project Researcher:

Jennifer Stephens, MA, PhD(c), RN, OCN

PhD Candidate, University of British Columbia School of Nursing

Preamble: Thank you for meeting with me. The purpose of this interview is to explore and reflect on how a diagnosis of haematological cancer has impacted your vision of yourself. I am very interested in how your concepts around your body and self-identity have changed and appreciate thoughts on what affect this has on how you function and relate to the world.

Interviewer note: Participants should be gently encouraged to delve into deeper meanings through phenomenological interview technique of asking “what do you mean?”

Potential Interview questions:

1. Tell me about yourself. [Demographical: family component, career, retirement, pets, lifestyle choices, religious background, social background, geographical history, schooling]
2. How was your cancer diagnosed? What kind of cancer do you have and where are you in terms of treatment? [NOTE: How specific will they be about using the disease name versus “cancer” versus something else?]
3. What does it mean to have a blood cancer? Have you heard of [patient’s cancer type] before and in what context?

4. For some cancers, such as prostate or breast, people have an identifiable body part to locate their cancer in. In a haematological cancer such as yours, it isn't quite like that. How has it been for you to have a form of cancer that is not located in a specific body part?
5. In your cancer experience, has having cancer had any influence on how you think or feel about yourself? In what way? Would you say your sense of yourself has changed in any way as a result of having this kind of cancer? [NOTE: Will they use the term "cancer" or will they reference it by its disease name, such as lymphoma?]
6. What do you think about your cancer journey so far? How would you describe the changes you have noticed in how you feel about yourself? [NOTE: Are they talking about their cancer in terms of self ("I," "me,") or are they using group terms ("we," "us")? Ask for clarification around any group references.]
7. How do you talk about [cancer type] to other people? Is it difficult for you to describe what it is like to have this type of cancer in comparison to other cancers? What kinds of questions do people ask you about [cancer type]? What do you tell them, and do you think your responses have changed over your cancer journey?
8. Since your cancer diagnosis, have you changed your mind about major philosophical or lifestyle choices such as purpose of life, goals, spirituality, religion, values? Please elaborate on these changes and how you came to them. [NOTE: For example, this could include if the patient has become religious or changed religions, if they lived one way before the diagnosis and then changed to another way (such as unhealthy versus healthy or omnivorous versus vegetarian).]
9. Is there anything else you want me to know about you and your cancer journey, specifically in reference to your sense of self?
10. Why did you choose to be a part of this study?

Appendix C: Sample Questions for Initial Interview (Clinician Interview)

Interviewee # _____

Project Title:

Exploring Issues of Identity in Adult Haematological Oncology Patients

Project Researcher:

Jennifer Stephens, MA, PhD(c), RN, OCN

PhD Candidate, University of British Columbia School of Nursing

Preamble: Thank you for meeting with me. The purpose of this interview is to explore and reflect on a diagnosis of haematological cancer and how it can affect someone. I am very interested to hear your personal stories about working with haematological cancer patients, specifically how they talk about themselves and how their identity concerns may or may not impact care and communication with the health care team.

Interviewer note: Participants should be gently encouraged to delve into deeper meanings through phenomenological interview technique of asking “what do you mean?”

NOTE: These questions will be impacted by the data collection and analysis produced from the patient interviews (phase two, level four) of this dissertation research. The below questions will be modified in order to elicit insight and reflections in order to both validate and expand on information and knowledge gleaned from the patient interviews.

Potential Interview questions:

1. Tell me about yourself and about your role as an oncology clinician and your expertise in haematological cancers. What is your training and work experience? How did you come to work in oncology?

2. Can you describe what it means to have a blood cancer? How do you tell patients about haematological cancer? What words or metaphors or stories do you use to describe this cancer? Is this different or similar to the way you talk about solid tumour cancers? In what ways?

3. From your experiences working with haematological cancer patients, can you describe how your patients talk about themselves and use labels to describe their experience? Do they tend to talk in terms of themselves (“I,” “me”) or do they bring others into the experience by making it a group (“we,” “us)?)

4. Can you reflect on ways in which you may have noticed a patient’s self-identity being affected by their cancer diagnosis? Have you seen people change over the course of hospitalization, clinic visits, or after specific treatments? In what ways? What is your personal take on these changes and why they may have occurred?

5. In your clinical experience, how do patients talk to you about their cancer journey and perceptions of self? What words, metaphors, or descriptive do they use? Does any type of nonverbal communication come to mind here, such as silence, reflective pauses, refusing to make eye contact, wringing hands, etc.?

6. In what ways have patients you have worked with tried to maintain a sense of self during treatment and beyond? In your opinion, what types of things affect the way patients think about themselves? (NOTE: This could include personality traits, external influences such as stress, horoscope signs, and a host of other factors.)

7. Is there anything else you want to share with me about your experience working with haematological cancer patients in relation to their identity and sense of self?

Appendix D: Information and Consent Form (Patient Participant)

Title of Study: Exploring Identity in Adult Haematological Oncology Patients

I. Study Team

Principal Investigator:

Sally Thorne, PhD, RN, FAAN, FCAHS

Professor, School of Nursing, University of British Columbia, Vancouver, BC

Phone: 604-822-7482

Principal Researcher:

Jennifer Stephens, BA, BSN, MA, PhD(c), RN, OCN

Doctoral Candidate, School of Nursing, University of British Columbia, Vancouver, BC

Phone: 778-230-4027

II. Sponsor

This study is not being sponsored or funded by any funding agencies.

III. Invitation and Study Purpose

You are being asked to participate in a nursing research project conducted through the University of British Columbia. In order to participate, we require that you give your signed authorization after reading a brief explanation of the project. Please read this description and discuss any questions or concerns with the Principal Researcher (PR). If you decide to participate in the project, please sign the last page of this form.

We are interested in learning more about how the experience of having haematological cancer may influence the way people feel about themselves, their bodies, and their lives. It has been suggested that having haematological cancers may be somewhat different from having more site-specific cancers in terms of the challenges people face around identifying as persons with cancer, interpreting what it means to be living with this kind of condition, and

communicating about these aspects of their experience with family and friends as well as members of the health care team. The goal of this project is to increase our understanding of identity experiences for persons with haematological cancer so that the health care team can become better informed in its sensitivity to complex experiences, supportive care planning and meaningful communication with patients.

IV. Study Procedures

What happens if you say, “Yes, I want to be in this study?”

An initial face-to-face interview will be conducted at a time and place that works best for you. This interview would last approximately 45 to 60 minutes. In this interview, the Principal Researcher will ask you about your experience as a haematology oncology patient and explore your perceptions of what it means for someone to have blood cancers. A subsequent follow-up interview may be requested approximately one to three months after the initial interview in order to clarify our understanding and to ask you to elaborate on ideas you may have raised in the first interview. This interview would last approximately 30 to 60 minutes. The total time commitment for participation in this study is estimated to be a maximum of 2-3 hours, including time needed to review and sign this consent form.

The Principal Researcher will digitally record the interview and transcribe the recording into text.

V. Study Results

This study is part of a larger research project within a doctoral program at the UBC School of Nursing. When complete, the results of this study will be reported in a doctoral dissertation, which is a public document. The findings arising from this study may also be published in journal articles and books.

All participants who request updates will be provided a digital copy of the research synopsis once analysis has been completed, including reference to any papers that are published in relation to this study. If you are interested in receiving this material, please include your mailing address and/or email when signing this consent form.

VI. Potential Risks of the Study

We do not think that this study could harm you in any way. Due to the nature of the topic under study, some of the questions asked may seem personal or sensitive. Should any concerns arise as a result of the interview that lead you to feel you wish counselling services, a list of counselling resources will be provided.

VII. Potential Benefits of the Study

It may be helpful for you to participate in this study in order to gain further personal insight into your feelings and experiences around your kind of cancer. Others may benefit from what we learn in this study, and patient care changes may result from these new understandings.

VIII. Confidentiality

Your privacy will be respected. All interview data and the identity of the interviewees will be kept strictly confidential.

The interview transcripts will not include any names or identifying features (such as personal information) that could identify individuals, and all documents will be identified only by code number and kept in a locked file cabinet. Your name or any identifying information about you will not be included in any written reports or presentations of the completed study.

The recordings will be stored at a secure location within the UBC School of Nursing for five years before they are permanently deleted. Transcripts of the interviews will be kept in electronic format on a password-protected computer with access limited to the Project Researchers for a minimum of ten years in order to allow for potential secondary analysis of the data in relation to associated or related themes.

IX. Payment

There is no payment for the time you take to be in this study.

X. Contact for Information about the Study

If you have further questions or concerns about this study, please contact the Principal Researcher at 778-230-4027 or jennifer.stephens@alumni.ubc.ca

XI. Contact for Complaints

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

XII. Participant Consent

This is a voluntary study, and taking part in it is entirely up to you. You have the right to refuse to participate in this study. If you agree to participate in an interview, you can refuse to answer any question at any time without giving a reason. You are able to withdraw from this study at any time. Refusing to answer questions or withdrawing from the study at any point will not compromise you in any way.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

Signature of Participant

Printed Name of the Participant

Date

Mailing Address (optional)

Email (optional)

Appendix E: Information and Consent Form (Clinician Participant)

Title of Study: Exploring Identity in Adult Haematological Oncology Patients

I. Study Team

Principal Investigator:

Sally Thorne, PhD, RN, FAAN, FCAHS

Professor, School of Nursing, University of British Columbia, Vancouver, BC

Phone: 604-822-7482

Principal Researcher:

Jennifer Stephens, BA, BSN, MA, PhD(c), RN, OCN

Doctoral Candidate, School of Nursing, University of British Columbia, Vancouver, BC

Phone: 778-230-4027

II. Sponsor

This study is not being sponsored or funded by any funding agencies.

III. Invitation and Study Purpose

You are being asked to participate in a nursing research project conducted through the University of British Columbia. In order to participate, we require that you give your signed authorization after reading a brief explanation of the project. Please read this description and discuss any questions or concerns with the Principal Researcher (PR). If you decide to participate in the project, please sign the last page of this form.

We are exploring the relationship between a diagnosis of haematological cancer in adults and self-identity. This includes how cancer patients envision themselves, and how their concept of body and self has changed post-diagnosis. We are also seeking clarification around

potential influence that a new-found cancer identity has on these patients including how they relate to the health care system, family, and friends.

An important aspect of this research is to obtain input from experienced clinicians who have worked extensively with haematological cancer patients. As one such clinician, we would like to hear your perspectives on care trajectory issues such as decision making, information interpretation, sense-making, and sustaining emotional support systems. The goal of this project is to use the information gleaned to inform health care providers about how they can improve care planning and therapeutic communication between the patient, their friends and family, and the healthcare team.

IV. Study Procedures

What happens if you say, “Yes, I want to be in this study?”

An initial interview will be conducted in a format that works best for you, either over the phone or face-to-face, at a convenient time and location. This interview would last approximately 45 to 60 minutes. In this interview, the Principal Researcher will ask you about your experience working with haematology oncology patients, and explore your perceptions around what it means for someone to have blood cancers.

The Principal Researcher will digitally record the interview and transcribe the recording into text, which will be anonymized and used for analysis of findings.

V. Study Results

This study is part of a larger research project within a doctoral program at the UBC School of Nursing. When complete, the results of this study will be reported in a doctoral dissertation which is a public document. The findings arising from this study may also be published in journal articles and books.

All participants who request updates will be provided a digital copy of the research synopsis once analysis has been completed, including reference to any papers that are published in relation to this study. If you are interested in receiving this material, please include your mailing address and/or email when signing this consent form.

VI. Potential Risks of the Study

We do not think that participation in this study can cause harm in any way. . Due to the nature of the study, some of the questions we ask may seem personal or sensitive. Should you wish to avail yourself of counselling services as a result of any issues arising from the interview, a list of counselling resources will be provided.

VII. Potential Benefits of the Study

It may be helpful for you to participate in this study in order to gain further personal insight into your feelings and experiences around haematological cancers. Others may benefit from what we learn in this study, and patient care changes may result from new understandings.

VIII. Confidentiality

All interview data and the identity of the interviewees will be kept strictly confidential.

The interview transcripts will not include any names or identifying features (such as personal information) that could identify individuals, and all documents will be identified only by code number and kept in a locked file cabinet. Names and any potentially identifying material will not appear in any written reports or presentations of the completed study.

The recordings will be stored at a secure location within the UBC School of Nursing for five years before they are permanently deleted. Transcripts of the interviews will be kept in electronic format on a password-protected computer with access limited to the Project Researchers for a minimum of ten years in order to allow for potential secondary analysis of the data in relation to associated or related themes.

IX. Payment

There is no payment for the time you take to be in this study.

X. Contact for Information about the Study

If you have further questions or concerns about this study, please contact the Principal Researcher at 778-230-4027 or jennifer.stephens@alumni.ubc.ca

XI. Contact for Complaints

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

XII. Participant Consent

This is a voluntary study, and taking part in it study is entirely up to you. You have the right to refuse to participate in this study. If you agree to participate in an interview, you can refuse to answer any question at any time without giving a reason. You are able to withdraw from this study at any time. Refusing to answer questions or withdrawing from the study at any point will not compromise you in any way.

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

Signature of Participant

Printed Name of the Participant

Date

Mailing Address (optional)

Email (optional)

Appendix F: Research Articles Used in the Critical Integrative Literature Review

RELEVANT INTEGRATIVE LITERATURE REVIEWS (N=1)

| Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodological Questions or Survey Material | Disease Type (and subtype) |
|--|---------|--|-------------------|---|-------------------------------|---|--|---|-------------------------------|
| 1 Henoch, I., & Danielson, E. (2009). Existential concerns among patients with cancer and interventions to meet them: An integrative literature review. <i>Psycho-Oncology</i> , 18(3), 225-236. doi:10.1002/pon.1424 | Sweden | Integrative literature review of 109 articles on qualitative (60) and quantitative studies 5 were mixed | Systematic review | Research question: explore existential concerns among patients with cancer with respect to components, related concepts and targets of Interventions. | Health sciences Ethics | Existential aspects of a cancer diagnosis include meaning making, faith and belief, love, belonging, forgiveness, meaning and purpose, hope, guidance in life, harmony. | Qualitative studies generally showed two themes: a struggle to maintain self-identity, and threats to self-identity. - Quantitative studies attempted to describe relationships between existential concerns and other concepts - No interventions that were application to everyday clinical practice could be found in the literature. - Gaps in research that were identified: 1) Gaps in research on existential concerns in patients with cancer include the need to clarify the concept; 2) how patients' existential well-being may best be supported by health-care professionals in everyday practice; 3) effects of existential interventions on physical symptoms; 4) stability of results of interventions | | Cancer (general) |

QUALITATIVE RESEARCH (N=21)

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologic al Questions or Survey Material | Disease Type (and subtype) |
|---|--|---------------------------|--|---|---|-----------------|--|---|--|--|
| 1 | Mathieson, C. M., & Stam, H. J. (1995). Renegotiating identity: cancer narratives. <i>Sociology Of Health & Illness</i> , 17(3), 283-306. doi:10.1111/1467-9566.ep10933316 | Tom Baker Center, Alberta | 37 people aged 26-77 Varying stages of disease and treatment (including active, inactive, palliative) | Qualitative Semi-structured interviews Purposive sampling Inductive Open-ended questions | Narrative Analysis Grounded theory | Psychology | Preliminary categories to transformed categories to delimited theories (p.293) | Living with cancer is identity-altering - CONCLUSIONS: Identity work is disrupted feeling of fit, renegotiating identity, and biographical work - Illness is a threat to identity | Questions were developed from pre-research done by the authors. See list of questions | 2 of the 37 were lymphoma patients. 35 were solid tumour patients |
| 2 | Waskul, D. D., & van der Riet, P. (2002). The Abject Embodiment of Cancer Patients: Dignity, Selfhood, and the Grotesque Body. <i>Symbolic Interaction</i> , 25(4), 487-513. | Australia | Palliative care unit 4 months spent on the unit as a volunteer talking to people and offering massage therapy 72 personal interviews with 18 people Ages 38-77 Many had secondary cancers and were dying | Qualitative Interviews Unstructured and nonstandardized No preexisting questions Informal conversational structure Use of basic questions to start conversations Unrestricted open-ended discussions Interviews were 20 min to 60 min long | Symbolic Interactionism | Social Sciences | Really looks at the relationship between the person and their physical body. - Cancer is consistently described as "it." Cancer is contained within person but is an alien intruder (not of the self) | Embodiment is a verb. - Embodiment is the fluid, emergent, negotiated process of being - Abject embodiment - everything that can go wrong - Types: 1) diseased body 2) grotesque body 3) painful body - Person's own body fluids are a threat to self and others. Medical science further objectifies the person as being overtaken by something foreign. - Re: SCT patient said that she was disgusted by her own stem cells because they had to be injected through a medical procedure. see note 4 | 1) how does your body feel? 2) tell me about your experience with cancer | Breast (50%) Bowel NHL Lung Renal |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|---|--|---------|--|--------------|---|------------|--|--|---|---|
| 3 | Skott, C. (2002). Expressive metaphors in cancer narratives. <i>Cancer Nursing</i> , 25(3), 230-235. | Sweden | Cancer unit | Qualitative | Ethnography Audiotaping conversations | Nursing | Metaphors found in cancer (such as eating) often are also an example of personification. Metaphors of cancer and militarization also emphasize the personification of cancer. | Preoccupation with the cancer/body leaves no room for consideration of the self -- Illness experience is a narrative. - Patients express fear of losing their self and of dying. - Interactions with our physical environment and with other people within our culture form what is real for us and induce how we perceive the world and act upon those perceptions. P231 | | NHL Hodgkins Lymphoma Sarcoma Melanoma Breast |
| 4 | Persson, L., & Hallberg, I. (2004). Lived experience of survivors of leukemia or malignant lymphoma. <i>Cancer Nursing</i> , 27(4), 303-313. | Sweden | N = 18 Longitudinal (getting ill, treatment, survivorship) Had to have been treated with chemotherapy Have to be currently in remission Interviews between 60-150 minutes and in the participants home | Qualitative | Narrative studies Phenomenological hermeneutic (Norberg and Lindberg) Lived experience Step-wise analysis (naive reading, structural analysis aimed at explaining the texts, interpretation of the texts as a whole) | Nursing | The pro and con of this study is the use of time as a variable in the interviews. Each theme is divided into three sections based on time (initial, treatment, remission). This is distracting from what would be actually happening, and implies that time plays a critical role in the interpretation of the lived experience. The way the material is presented, however, is not convincing enough to show the differences between the themes on the aspect of time. - This study almost emphasizes the importance of personality. | THEMES: 1) believed in life, fought for it, came through stronger - disease turned out to be a very positive experience - average age 40 - N=5 2) life went on, adapted - N=6 - average age 68.2 - understood the threat but did not worry about it - life goes on 3) life was over, felt out of control and lost hope in life - N=7 - average age 61 - negative self-image during the entire trajectory of treatment and remission. - scared of the future - bitter about life - did not find a way to live with their changed identity (not accepting being a "survivor" and what that meant) - Emphasis on social support systems and the role they play in patient identity making. Those with less support had less to identify with and less identity support when faced with disease. | - what does it mean to be a survivor? - Preface: "I would like you to please narrate your experience of falling ill, being in treatment, and recovering. You can start the story where you want. You are free to talk about it in whatever way you choose. I'll go back and ask you more specific questions in the areas where I want to know more." - | Leukemia Lymphoma |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|---|--|---------|---|---|---|--|--|---|---|---|
| 5 | Lugton, J. (1997). The nature of social support as experienced by women treated for breast cancer. <i>Journal Of Advanced Nursing</i> , 25(6), 1184-1191. | UK | Stage 1: 29 women visiting a health unit plus 18 interviews over the phone of people who were at home Stage 2: 35 women - | Qualitative - 12 open-ended questions - Interviews were done via health workers (and not with the researcher) | Grounded Theory Social contact analysis Discourse analysis Discourse comprehension | Nursing | There is no clear rationale or definition for identity. Within the context it is used in this article, multiple assumptions are made around the use of the term. This causes a confusion over social identity, personal identity, etc. | 6 crises to their identities as a result of the breast cancer experience: Future uncertainty, healthy identity, autonomy, being normal/overcoming stigma, normal sexuality, normal relationships - Goal of patients was to maintain identity in the face of cancer -- Nurses should support patient social and informal social networks. | | Breast |
| 6 | Mesquita, M. R., Moreira, M. C., & Maliski, S. L. (2011). "But I'm (became) different": cancer generates reprioritizations in masculine identity. <i>Cancer Nursing</i> , 34(2), 150-157. doi:10.1097/NCC.0b013e3181f5568d | Brazil | 12 men during a chemotherapy session Adult to geriatric Portuguese and then translated to English Actively receiving chemo | Qualitative Semi-structured interviews | Gender studies Thematic analysis | Nursing | | Themes: 1) life before cancer - macho 2) CA Tx - time to reprioritize 3) reprioritization of values - becoming different versus returning to macho 4) glimpse of post-cancer life | 1) What thoughts crossed your mind when you found out you had cancer? 2) What changes have happened in your life since then? 3) What have been your greatest needs in dealing with this situation? 4) What could nurses do to help? 5) Is there anything you want to tell me? - Movement of the patient away from reputational attributes to relational attributes. | Colorectal Lung Parotid Gastric NHL |
| 7 | Anderson-Shaw, L., Baslet, G., & Villano, J. L. (2010). Brain Neoplasm and the Potential Impact on Self-Identity. <i>AJOB Neuroscience</i> , 1(3), 3-7. doi:10.1080/21507740.2010.485122 | USA | Case studies of 3 brain cancer patients | Qualitative Clinical interactions | Case studies Qualitative | Neuro-oncology Ethics Psychiatry Medicine | Is self-awareness a better way to describe the phenomenon at hand? - | Lots of quality of life indicators, but nothing really addresses the issues of self-identity. - Assessment of self has important impact on clinicians, patients, and loved ones | | Brain |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|--|---------|--|--|---|----------------------------------|---|---|--|-----------------------------------|
| 8 | Bokhour, B. G., Powel, L. L., & Clark, J. A. (2007). No less a man: Reconstructing identity after prostate cancer. <i>Communication & Medicine (De Gruyter)</i> , 4(1), 99- 109. doi:10.1515/CAM.2 007.010 | USA | Part of a larger study of men just diagnosed with prostate cancer | Qualitative In-depth interviews based on focus group involvement 90 minutes Semi- structured | Discursive narrative analysis Sociolinguistic narrative approach Analysis of linguistic structures Identified instances of identity claims | Public health Medicine | Maintain the continuity of identities in the face of identity dilemmas | Understanding the cancer challenges identity is not enough. We must also help men by exploring ways in which they can rely on other valued identities as a way to move forward and cope | 1) Tell me what it was like when you were first diagnosed with cancer 2) what is it like to live with prostate cancer? | Prostate |
| 9 | Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. <i>Social Science & Medicine</i> , 67(1), 79- 87. doi:10.1016/j.socsci med.2008.03.036 | USA | 39 women who recently completed treatment (within 3-18 months of the interview) | Qualitative In-depth interviews Recruitment d/t small city and personal referrals Flexible interview guide Honorarium of \$25 | Grounded theory Deductive and inductive Data coded as "survivor identity" or "no survivor identity" | Population studies | Perpetuation of "survivor" as an accepted theme of identity. - Discussion of having too much of a public identity. - -- There is a nuance of understanding when identity is generalized down to a single term. Some women were uncomfortable with this term. Others used it but held very different meanings. | Survivor is a cancer identity ("new"). - This survivor identity can help patients frame their cancer experience OR The survivor identity is a framework for "craftwork," whereby women consciously construct their lives and the meaning of cancer. | Asking about life before, during, and after treatment. - What does the word "survivor" mean to you? - | Breast |
| 10 | Reynolds, F., & Prior, S. (2006). The role of art- making in identity maintenance: Case studies of people living with cancer. <i>European Journal Of Cancer Care</i> , 15(4), 333-341. doi:10.1111/j.1365- 2354.2006.00663.x | UK | 3 people | Qualitative Taking up of art as a leisure activity Case studies | Narrative psychology IPA – interpretive phenomenologic al analysis Thematic analysis | Nursing | (Crossley 2000) the self has a consistency over time, unity, coherence. | People might not just need psycho-social support, but they may also need meaningful activities that support their identity. - People used art as reflection but did not reject their pre-cancer life or self. -- Identity loss and reconstruction are key things experienced by those with chronic illness - People with cancer maintain a positive identity through using art - Art helped establish a familiar identity in the face of cancer identity. | Grand tour question (can you tell me about yourself) - How has your health and day to day life been affected by your illness? - When did your interest in visual arts begin? - In what ways does visual art help you manage your life? | Stomach Lung breast |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|--|-----------|--------------------------|---|---|--------------------------|--|--|--|----------------------------------|
| 11 | Hubbard, G., Kidd, L., & Kearney, N. (2010). Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first year following diagnosis. <i>Health (London, England: 1997)</i> , 14(2), 131-146. doi:10.1177/1363459309353294 | UK | 18 people | Qualitative Longitudinal for a total of 3 interviews in a year Semi-structured interviews in the persons home 1-2 hours each | Constant comparative analysis PART 1 and biographical disruption as Part 2 analysis | Nursing Sociology | Physical, social, emotional disruption as well as evidence of threats to identity. - Not all people experience a threat to identity. - Identity threat is not necessarily d/t acute versus chronic disease | Explore the first year of living with diagnosis. - Saying that it is a biographical disruption is not accurate. Cancer is an assault on personal identity. -- Stoma changes sexual identity -- Stage of life and timing of illness determine how much of a disruption cancer has. People who are older or who have had a hard life often experience cancer in a different way. - Biographical disruption is context specific - Not all may experience cancer as a threat to their identity. - Call for biographically informed care. - Pre/post disease identities – does someone want to retain who they are or take on a new identity? | Describing experience in each of the domain: dx, tx, symptoms, information given, finances, psycho-social, leisure, existential concerns | Colorectal |
| 12 | Fisher, C., & O'Connor, M. (2012). 'Motherhood' in the context of living with breast cancer. <i>Cancer Nursing</i> , 35(2), 157-163 7p. doi:10.1097/ncc.0b013e31821cadde | Australia | 8 women | Qualitative social constructivist paradigm - Multiple case research approach - | Biographical disruption as described by Bury - Interviews, continual immersion in the literature, and analysis were conducted simultaneously and informed each other. | Nursing | Four themes, "diagnosis and disruption," "maintaining normality," "continuing the mothering role," and "experiencing survivorship," reflect women's experiences of identity reconstruction in the context of living with breast cancer. -- Identity and self-concept -- Health care providers need to acknowledge the different roles/identities that patients may have. | A breast cancer diagnosis precipitates complex changes in a woman's identity as a mother. A woman's postdiagnosis identity invariably integrates a changed prediagnosis identity and that of "breast cancer patient" and "survivor." The relationship between the 3 is dynamic and in constant tension. - . Young mothers living with breast cancer should also be offered assistance about what, if, and when to tell children about their cancer and help to incorporate this communication into their role as mothers. | | breast |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|---|-----------|---|--|---|------------|---|--|---|----------------------------------|
| 13 | Gibson, A. F., D'Cruz, L., Janda, M., Beesley, V. L., Neale, R. E., & Rowlands, I. J. (2015). Beyond survivorship? A discursive analysis of how people with pancreatic cancer negotiate identity transitions in their health. <i>Journal Of Health Psychology</i> . doi: 10.1177/1359105315592050 | Australia | 19 people 6 were interviewed at home and 14 were interviewed via Skype | Qualitative state-wide, case-control study -- conducted individual and semi-structured interviews until the topic had been investigated in such depth that additional interviews did not appear to produce new information. | discursive perspective - thematic discourse analysis - Coding - Critical realist | psychology | We examined both the physical reality of participants' experiences of cancer (materiality) and how they understood and spoke about their illness (the discursive construction and articulation of having cancer). - Movement of the last decades to personal responsibility. - Participants drew on neoliberal discourses of individual responsibility, optimism and survivorship to construct their identities. They engaged in a complex, on-going negotiation of their identities over the course of their illness, collaborating with family and doctors, thus demonstrating that identity construction is fluid and responsive to people's social and relational contexts. | We identified two discursive themes relevant to this analysis, which captured the transitions participants experienced following a diagnosis of pancreatic cancer. The first theme, 'moving from healthy to ill', involved participants' talk about their diagnosis and the links between their health and identity, including the rapid transition from being well to 'ill' and the associated physical and psychological symptoms and lifestyle modifications. The second theme, 'moving from active treatment to end-of-life care', illustrated another transition that participants faced when weighing up the decision to (dis)continue active treatment, thereby working to achieve reasonable quality of life and a 'good death'. | The interviews began with a general question: 'Can you tell your story of how you were diagnosed with pancreatic cancer?' Subsequent questions explored interactions with health professionals, experiences of treatment and people's access to emotional, social and physical support. | pancreatic |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|---|---------|--|--------------|---|------------|---|--|--|----------------------------------|
| 14 | Clarke, C., Mccorry, N., & Dempster, M. (2011). The role of identity in adjustment among survivors of oesophageal cancer. <i>Journal Of Health Psychology, 16</i> (1), 99-108 10p. doi:10.1177/1359105310368448 | UK | 10 people open-ended non-directive questions with minimal probes. | Qualitative | Interpretive phenomenological analysis (IPA is a phenomenological approach which involves a detailed examination of the person's experience and is focused on understanding the individual's personal perception of their experience and thoughts, while acknowledging that the participant's perceptions are elicited through a dynamic, interactive process, and interpreted by the researcher) | psychology | The desire to be viewed and known as an individual and not just a tumour or slab of meat (devoid of personality) was manifest for our participants particularly at the early stages of their illness experience— p103 -- My future started. If somebody asks to me—what age are you? Eh, physically I'm 63, mentally I'm maybe 23, but in reality, you know, I was born in 1994 [time of cancer diagnosis and surgery]. It's like a re-birth you know, a whole new life."p.104 - role erosion and renegotiation (Bellizzi & Blank, 2007; Gillies & Johnston, 2004; McCorry, Dempster, Clarke, & Doyle, 2009), bodily disruption (Mathieson & Stam, 1995; Wainwright et al., 2007), personal growth (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2008), unique characteristics of peer support (Edelman, Craig, & Kidman, 2000; Fawzy, Fawzy, Arndt, & Pasnau, 1995; McCorry et al., 2009) and biographical work, such as that described in detail by Mathieson and Stam (1995). | all encompassing a dimension or sense of 'change' from the pre-cancer state, and appearing to represent myriad challenges to the self-concept. - Identity is also concerned with differentiation from others, and our participants stressed the value of personal aspects of relationships with medical staff. - Cancer can threaten the continuity in one's identity, and personal narratives are transformed to incorporate the experiences of illness. Participants often distinguished between their old pre-cancer self and their new identity, - There were also many reports of personal growth as a result of the cancer experience, and positive results of having coped with its challenges. | | esophageal |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|---|---------|---|---|---|-------------------------|--|--|---|---|
| 15 | Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. <i>The Sociological Quarterly</i> , 36(4), 657-680. doi:10.1111/j.1533-8525.1995.tb00459.x | US | 55 adults 16 followed longitudinally Persona accounts provided collateral data | Qualitative Constructivist Grounded theory | Symbolic interactionist 115 interviews Stage analysis per Kubler Ross | sociology | Illness provides opportunity to find new meaning on the relationship between body and self. - illness may actually help people to find a greater sense of themselves (per conclusion). Provides clearer focus on life, purpose, and what is important. - By coping with chronic illness, the strange becomes the familiar. | THEMES: 1) experiencing an altered body - body is altered, alien - betrayal - separation of body from illness (separate illness from self-concept) (objectification) - having suffered enough (victimization) 2) changes to bodily appearance - identity changes require a change in the physical appearance 3) changing identity goals - changes to the function of the body can result in changes to identity goals. This includes both getting better and getting worse. - people may not change identity goals until they are forced to do so. - identity trade-offs much be negotiated based on social needs including finances, jobs 4) surrendering to the sick body - anchoring of body feelings in the self - labelling past attempts to deny illness identity as being phoney or ill-advised - surrendering the desire to recover - self unity with the sick body - surrender allows for new integration of body and self | Not specified | Chronic illnesses including cancer but also including chronic fatigue syndrome, cardiac disease, diabetes, emphysema, MS, rheumatoid diseases, asthma Number of cancer patients or the type of cancers not specified |
| 16 | Barker, K. (2002). Self-help literature and the making of an illness identity: The case of fibromyalgia syndrome (FMS). <i>Social Problems</i> , 49(3), 279-300. doi:10.1525/sp.2002.49.3.279 | USA | Review of 5 best-selling books on FMS used to form foundation of interviews with 6 female FMS sufferers Ages 28-55 | Qualitative | Ethnography narrative analysis structured interviews | Sociology, anthropology | The influence of accepted ways to have a disease as portrayed by the media (including organizational and pharmaceutical advertising and educational materials) demonstrates how the idea that these things play a role in identity-formation that is socially acceptable. Outliers would feel both personal and social pressure to "fit in." | Public narratives of diseases such as FMS help create a coherent and cohesive illness identity. These materials help to take what could be variant experiences and organize them (via media) into a coherent social voice about what it means to suffer from disease. This group illness identity helps reduce self-doubt and alienation for sufferers. - The creation of an illness identity occurs in each disease and can be considered part of the medicalization process. | How do you relate to these self-help books? What is useful to you? In what ways does your experience with FMS identity with the experiences of others described in these books? | Fibromyalgia |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|---|---------|--------------------------------------|--|--|-------------------|---|--|--|----------------------------------|
| 17 | Krieger, J. L., Palmer-Wackerly, A. L., Krok-Schoen, J. L., Dailey, P. M., Wojno, J. C., Schoenberg, N., & ... Dignan, M. (2015). Caregiver Perceptions of Their Influence on Cancer Treatment Decision Making. <i>Journal Of Language & Social Psychology, 34</i> (6), 640-656. doi:10.1177/0261927X15587556 | USA | N = 58 caregivers | Qualitative in-depth semi-structured interviews | Communication Theory of Identity (CTI) - Family DECIDE typology (determinants of clinical decision making) | Social psychology | p. 641 – "Identity can be broadly conceptualized as the categories individuals use to define who they are and to locate themselves in relation to others (Owens, 2003). Identity is subsumed within the broader and more historically examined concept of "self." The self is distinguished from identity in that it is primarily born out of self-reflection, whereas identity is viewed as a socially constructed categorization tool by which individuals group themselves and present themselves to others (Owens, 2003). Unlike other identity theories that view communication as a product or outcome of identity, the CTI is unique in that communication is viewed as identity (Hecht, 1993; Hecht et al., 2005)." | Illness framed as a personal identity issue – caregivers would say that it was the patient's body so they could make their own decisions about treatment. (personal identity) - For relational identity, illness was a part of the relationship between the caregiver and patient. They would talk about the situation in terms of "we" while still attributing the final decision making to the patient ("their body") - Notion of co-ownership of disease was important. Both partners owned the disease and outcomes, even though only one was suffering from the cancer. - Illness identity gaps can be defined as a conflict between 2 identities. The first identified in this study was a personal-relational gap (whereby the patient and caregiver perceived different identity models) and enacted relational identity whereby the patient perceived decision-making as personal and the caregiver perceived decision-making as communal. These gaps are defined in terms of intergroup rather than interpersonal processes. | | Cancer (General) |
| 18 | Mesquita, M., Moreira, M., & Maliski, S., (2011). 'But I'm (became) different': cancer generates reprioritizations in masculine identity. <i>Cancer Nursing, 34</i> (2), 150-157. doi: 10.1097/NCC.0b013e3181f5568d | Brazil | 12 men during a chemotherapy session | Qualitative Cross-sectional Descriptive | Thematic analysis Medical chart analysis Questions derived from the literature and clinical experience | Nursing | Seems that men in this study were highly pragmatic about coming to terms with their diagnosis. | Cancer was examined from a temporal perspective with themes based on the stage of treatment: life before cancer ('macho'), the cancer treatment (time to reprioritize), reprioritizations of values (becoming different – return to life as normal as it could be), and glimpse of post-cancer life. - Men usually can reprioritize their values and identity during cancer treatments to maintain a sense of identity. | 1) What thoughts crossed your mind when you found out you had cancer? 2) What changes have happened in your life since then? 3) What have been your greatest needs in dealing with this situation? 4) What do you believe nurses could do to help? 5) Is there anything else you want to tell or ask me? | Prostate |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodological Questions or Survey Material | Disease Type (and subtype) |
|----|---|---------|--|--------------|---|------------|---|--|--|---|
| 19 | Asbring, P. (2001). Chronic illness -- a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. <i>Journal Of Advanced Nursing</i> , 34(3), 312-319 8p. doi:10.1046/j.1365-2648.2001.01767.x | Sweden | Women only N = 25 Between 32-65 Interviews done in the participants choice location, like home or place of work 25 was considered a saturation point for data collection | Qualitative | Grounded theory Symbolic interactionism Retrospective reflections by participants | Nursing | Assumption that the theory of biographical disruptions is correct, and working from this as a basic premise. - Again, temporality is a key feature with the women at various points in their disease trajectory. | Underlying assumption: people with chronic illness suffer identity loss. - Recognition that most illness identity work is within medical sociology. - Adheres to concept of biographical disruption caused by illness. - Findings: 1) earlier identity partially lost. - New identity was described in terms of otherness. - identity loss in relation to work and social life - withdrawal for several reasons including to avoid expectations from others. - sense of alienation - disruption of relationships 2) coming to terms with a new identity - reorganize life - rely on other people - illness gains included reexamining life - identity belonging to a healthy life was lost - Every participant featured some aspect of negativity along a spectrum. | An interview resulted in a primary analysis, which then guided additional interviews. - Details of questions or interviewing methods not given. | Chronic fatigue syndrome and fibromyalgia |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|--|---------|--|--------------|--|------------|---|--|--|----------------------------------|
| 20 | Fife, B. (1994). The conceptualization of meaning in illness. <i>Social Science & Medicine</i> , 38(2), 309-316. | USA | 38 adult at various stages of the cancer trajectory Caucasian | Qualitative | Symbolic interactionism Open-ended questions Open coding procedure | Nursing | Chart of how the construction of self-meanings and the construction of contextual meanings interplays to the reformulation of identity. | <p>Self-meaning is defined as the implication of illness on personal identity. This was aligned versus contextual meaning, defined as implications of illness on one's life.</p> <p>-</p> <p>Three specific changes to self-meaning: 1) loss of personal control 2) threats to self-esteem or self-worth 3) changes in body image.</p> <p>-</p> <p>The self who has to live with cancer influences ongoing evaluation of the social environment and the roles they must assume. Likewise, the social world now responds to the individual who now has a new dimension added to their identity – that of a 'cancer patient.'</p> <p>Persons who felt their identity had been compromised by cancer tended to feel stigmatized and withdraw socially. Those who with more social ties tried to continue into the future with minimal interruption to their previous goals.</p> <p>-</p> <p>Clinical application is going to have to be personalized, to find out the person's definition of meaning and what is important to them.</p> | <p>1) How has cancer affected your relationships with family and friends? 2) How has your illness affected the way you think about yourself? 3) What have been the most difficult aspects of having cancer? 4) Have there been any positive things for you about the illness experience?</p> | Cancer (" a variety of cancers") |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|----|---|---------|--|--------------|---|-------------|--|--|--|---|
| 21 | Hamilton, H. (1998). Reported speech and survivor identity in on-line bone marrow transplantation narratives. <i>Journal of Sociolinguistics</i> , 2(1), 53-67. | USA | Analysis of 61 narratives posted to the website SupportBMT | Qualitative | Narrative analysis Linguistical analysis | Linguistics | Of note here is the use of two predetermined identity models: survivor and victim. It is unclear where the researcher got the framework for this discussion from, perhaps taking it for granted and thus applying it to the lens while doing the narrative analysis. The distinction between the patient relationship with doctor versus nurse is of note. This does confirm a communication difference between the two in what the patient is able and willing to say to either. | Research focused on the differences between direct and indirect speech as found in the narratives of the blog postings. Author hypothesizes that the language choice of the blog contributors demonstrates how the patient assumes either a survivor or a victim identity. Survivor identity can be seen when the reports are of poor doctor behavior or utterances. In these cases, the patients have survived not only the disease but less-than-ideal doctors. The author associates a survivor mentality with being more positive in general. There is also an interesting note that communication is different from patient-doctor than patient-nurse. P. 66. The researcher attributes this to the different spheres of practice, as well as the role of the doctor in prognosis and prescribing treatment options. | | Patients and family members of patients who have undergone BMT (usually haematological cancers) Health care providers who posted about BMT patients or experiences |

QUANTITATIVE RESEARCH (N=5)

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologic al Questions or Survey Material | Disease Type (and subtype) |
|---|---|---------|--|--|--|-------------------|--|---|---|--|
| 1 | Park, C. L., Zlateva, I., & Blank, T. O. (2009). Self-identity After Cancer: "Survivor", "Victim", "Patient", and "Person with Cancer". <i>JGIM: Journal of General Internal Medicine</i> , 24:430-435. doi:10.1007/s11606-009-0993-x | USA | 168 young to middle aged adults (18-55) who previously had cancer (1-3 years prior) SURVIVORS | Quantitative Cross-sectional questionnaire based study Time 1 Time 2 (1 year later) | Predetermined categories Psychological Well-Being scale and FACIT-sp And COPE | Psychology | With the predetermined identities based on labels, and the questionnaire format, deeper descriptive understanding is not possible | 4 post-cancer identities: 1) patient (58%) 2) person who has had cancer (81%) 3) victim (18%) 4) survivor (83%) - Identity is defined as a label a person puts on themself. -- Identity impacts well-being and communication with HCP | "When you think about yourself in relation to your cancer, how much does each of these phrases describe you? (see identities) (rated 1-5) | Breast Prostate Colorectal Lymph nodes Cervix/uterus |
| 2 | Zlateva, I., Park, C. L., & Blank, T. O. (2009). Self-Identities After Cancer: Predictors and Determinants of Adjustment. American Psychological Association 2009 Convention Presentation, 1-3. doi:10.1037/e601212009-001 | USA | Young to middle-aged adults N=167 Diagnosed 1-3 years prior to taking the survey | Quantitative | Survey | Health psychology | Conference presentation, but perpetuates predetermined identity categories. These questionnaires don't have space for additional identities, leaving one to ask if these are the only 4 identity categories available to a person post-cancer diagnosis? | This article reflects a smaller study as a part of a greater program of research. - Predetermined categories by the researchers" 1) victim (associated with poorer adjustment to post-cancer changes, as well as worse psychological well-being) 2) patient (neutral identity, usually occurring closer to the time of treatment) 3) person who has had cancer 4) survivor (holds some advantages in terms of psychological well-being) - Study suggested that participants who had cancer adopt multiple labels to reflect their experience. | Several quantitative measures via surveys including: measures of identity (adapted from Harwood & Sparks, 2003), psychological functioning [Psychological Well-Being subscales of autonomy, positive relations with others, purpose, environmental mastery, personal growth, and self-acceptance. (Ryff, 1981) and Spiritual Well-Being (faith and meaning/peace subscales of the FACIT-Sp; Cella et al., 19xx)], recurrence and risk appraisals (Mullens et al., 2004), coping (subscales from the COPE (Carver et al., 1989) assessing problem-focused, emotion-focused, meaning-focused, and avoidant coping), and adjustment [(life satisfaction (SWB; Diener et al., 1985); mental and physical health-related quality of life (HRQOL) (SF-36; Ware, 1993); PANAS positive and negative affect (Watson et al., 1993); intrusions (subscale from IES; Horowitz et al., 1991); and post-traumatic growth (BFS; Helgeson et al., 2001)] | Cancer (general) |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi cal Questions or Survey Material | Disease Type (and subtype) |
|---|--|---------|---|--------------|--|---|--|---|---|----------------------------------|
| 3 | Bellizzi, K. M., & Blank, T. O. (2007). Cancer-related identity and positive affect in survivors of prostate cancer. <i>Journal Of Cancer Survivorship: Research And Practice</i> , 1(1), 44-48. doi:10.1007/s11764-007-0005-2 | USA | 490 prostate cancer survivors 1-8 years after diagnosis | Quantitative | cross-sectional study design -- Identity theory, derived from symbolic interactionism, suggests that one's self concept is socially constructed and reflects one's interactions with others and society. | Human development, family studies, Survivorship (NCI) | | years after treatment many prostate survivors feel little need to form a significant part of their identity around their cancer experience -- The most frequently reported cancer-related identity was "someone who has had PCa" (57%). The least reported self view was "victim" (1%). Twenty-six percent of men self-identified as "survivors" while 6% thought of themselves as "cancer conquerors." Only 9% self-identified as a "patient." - People who identified with survivor had higher levels of positive affect than those who identified with survivor. | | prostate |
| 4 | Beanlands, H. J., Lipton, J. H., McCay, E. A., Schimmer, A. D., Elliott, M. E., Messner, H. A., & Devins, G. M. (2003). Self-concept as a 'BMT patient', illness intrusiveness, and engulfment in allogeneic bone marrow transplant recipients. <i>Journal Of Psychosomatic Research</i> , 55(5), 419-425. doi:10.1016/S0022-3999(03)00509-9 | Canada | 90 BMT allogeneic outpatients | Quantitative | illness Intrusiveness Ratings Scale, Modified Engulfment Scale, and a semantic differential measure of self-concept | MD | Self becomes lost in the disease in some cases, particularly those allo patients who have to undergo extreme treatments and long regimens. These patients are never cancer free, but are in remission if things go well. -- These authors are using self-concept over self-identity. Define self-concept as "is a complex construct, including instrumental, esteem, social, achievement, and other dimensions [19,20], any or all of which may be vulnerable to the physical, psychological, and social stressors imposed by chronic life-threatening disease." p.420 | Self-concept:a crisis of identity threatens self-identity whereby the former self may never be regained. - New cancer self - ENGULFMENT. The disease and treatment become the self-concept. Dominate the self entirely. Not only is it accepting the actual disease, but it is accepting the meanings and role ascribed to this disease.p.423 - Illness and the role of patient become the new self-identity - Illness INTRUSIVENESS is magnified when patients feel engulfed, depressed, helpless. | Self-reported scales. Have to rate on a scale if they are a BMT patient..... myself as I am now.... | BMT patients |

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologi- cal Questions or Survey Material | Disease Type (and subtype) |
|---|---|---------|--|------------------------------|--------|------------|---|--|---|--|
| 5 | Cho, D., & Park, C. (2015). Cancer-related identities in people diagnosed during late adolescence and early adulthood. <i>British Journal of Health Psychology</i> , 20(3), 594-612. doi:10.1111/bjhp.12110 | USA | N=120 for time 1 and N= 84 for time 2 (one year later) | Quantitative Longitudinal | | Psychology | Authors use the usual 4 identities (victim, survivor, person with cancer, patient) and added conqueror as a cancer identity and member of a cancer community. | Identity labels can affect people in their post-cancer adjustment. - Younger folks tend to use the terms "survivor" and "member of cancer community" whereas older adults just use "survivor." - The term "survivor" is contested and used in different forms and contexts. The authors suggest that a more appropriate definition be created and universalized so that confusion about being a survivor is buffered. Some sources claim it is anyone after diagnoses, while these authors advocate that it should be reserved for those who have passed a certain milestone (such as 6 years as embraced by Khan, Rose, & Evans, 2012). | COPE survey, people answering on Likert scale | Multiple: breast, lymphoma (27), thyroid, testicular, gynecologic, leukemia/blood (7), brain, colon, kidney, other |

MIXED METHODS RESEARCH (N=2)

| | Reference | Country | Subjects/ Demographic | Study Design | Method | Discipline | Discussion and Notes | Themes and Findings | Methodologic al Questions or Survey Material | Disease Type (and subtype) |
|---|--|---------|---|---|---|---------------|---|--|---|---|
| 1 | Shahar, G., & Lerman, S. F. (2013). The personification of chronic physical illness: Its role in adjustment and implications for psychotherapy integration. <i>Journal Of Psychotherapy Integration, 23</i> (1), 49-58. doi:10.1037/a0030272 | Israel | Literature review plus own research in their "program" that included unspecified patients (beyond these specific disease types) | MIXED Qualitative (narrative) Quantitative (pain personification questionnaire) | Narrative analysis Literature review Survey statistical results | Psychotherapy | Not necessarily a proper research study, but instead details interesting ideas about a host of studies (including literature reviews) and reference to the author's other articles. | Proposing the term ILLNESS PERSONIFICATION to describe how people live under, and outside chronic illness. = ILL-PERF = an individual's tendency to ascribe human attributes to the stressful condition (e.g., chronic illness), qualities particularly relevant to his or her self and identity p. 50 -- Humans tend to anthropomorphize experiences, including illness. They often will assign the illness with a human-position, and then identify themselves in relation to this (i.e. attacker vs victim). - Cognitive behavioral therapy can be used to address negative personifications of disease | | Chronic physical pain Systemic lupus erythematosus (Lupus) |
| 2 | Sparks, L., & Mittapalli, K. (2004). To know or not to know: The case of communication by and with older adult Russians diagnosed with cancer. <i>Journal Of Cross-Cultural Gerontology, 19</i> (4), 383-403. doi:10.1023/B:JCCG.0000044690.45414.f7 | USA | | Mixed methods with interviews and survey/document data | Intergroup approach | communication | Culture and age are major factors in the cancer diagnosis. | Identification as one who is ill, identification as one who has been diagnosed with cancer, and identification as one who is labelled a cancer survivor should all be considered. -- 3 levels of identity: first argued that the identities that were traditionally at the center of intergroup research need attention (identification with large social groups such as OLDER RUSSIANS AND CANCER 387 cultures/nationalities, sex groups, age groups, etc.). Second, it is suggested that we need to discuss identities associated with health-related behaviours. As Harwood and Sparks (2003) point out, the most obvious of these is identification as a smoker, but there are others, including some with more positive undertones (e.g., identification as a mountain climber). Third, attention must be given to identities that are unique to those who have cancer. Identification as one who is ill, identification as one who has been diagnosed with cancer, and identification as one who is labelled a cancer survivor should all be considered. | | Mixed CA diagnoses |