St. Stephen’s College

A Field Guide to Sanctuary:

Women’s Experiences of Personal Sanctuary Contextualised Within Chronic Health Conditions

by

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Abstract

This analytic autoethnography draws on a passage from Celtic philosopher John O'Donohue to consider women's experience of personal sanctuary within the context of chronic health conditions. Guided by the question: 'what is your experience of sanctuary and how does that relate to your experience of your chronic health condition' and informed heavily by social work theory and practice, this dissertation engages a range of research methodologies and methods, including Critical Reflection on Practice and Response Art (from art therapy) in conjunction with participant interviews. Through the constant comparative method, the data revealed that within this context, sanctuary comprises elements (spirituality, nature, creativity, and purposeful occupation), as well as qualities (transgressiveness, nourishingness, and fluidity). This research not only revealed the structure of sanctuary, it assisted the author to understand sanctuary as her personal ministry and fundamental to her social work practice, as well as clarifying the spiritual practices leading to her experience of sanctuary. This dissertation concludes with many plans for future study, including the possibility of this type of sanctuary as a social work practice framework.

Keywords: analytic autoethnography, chronic illness, cræft, sanctuary, spirituality

Dedication

Love is absolutely vital for a human life. For love alone can awaken what is divine within you. In love, you grow and come home to your self [sic]. When you learn to love and to let your self be loved, you come home to the hearth of your own spirit. You are warm and sheltered. (O'Donohue, 1997)

This work is dedicated, with love, to Jason and to Leif for their enduring support.

This work is also dedicated to the memory of my Grandmothers.

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A work of this magnitude may have only one name attributed to it but in truth, it is the work of multitudes.

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List of Abbreviations

BCASW - BC Association of Social Workers

BSW - Bachelor of Social Work

CASW- Canadian Association of Social Workers

CASWE - Canadian Association of Social Work Education

CBT - cognitive behavioural therapy

CDT - Critical Disability Theory

CSR - Critical Self-Reflection

CRoP - Critical Reflection on Practice

CCM - constant comparative method

DMin - Doctorate of Ministry

ISRP - Individual Self-Reflective Practice

NASW - National Association of Social Workers

NMT - Neurosequential Model of Therapeutics

STEM - Science, Technology, Engineering, and Maths fields of study

Glossary of Terms

60s Scoop -a term used to denote the mass abduction of First Nations children beginning in the early 1950s and accelerating into the 60s.

Ableism - defaulting to non-disabled as the ideal or norm; prejudice against those with disabilities

Anti-oppressive practice (AOP) - an emancipatory social work practice situating the individual within their social context and supporting them to overcome structural patterns of the society that perpetuate inequalities

Cræftivism/Craftivism -craft used for activist purposes

Celtic spirituality - spiritual practices with a connection to the regions of the Celtic League

chronic illness/condition- an incurable physical health condition that impedes functioning and requires ongoing attention

Decolonize- actively resisting colonial power and structures; privileges Indigenous history and ways of knowing.

Folklore- the study of human creativity within specific cultural and social contexts; how that expression is linked to identity, and the informal transmission of such information

Gaeltacht - districts within Ireland officially recognised as having Irish/Gaeilge as the primary language

Gaeilge - Irish language

Identity first language - language that sees disability as part of a person's identity, e.g. disabled person; often used in the blind, deaf, and autism communities where their disability is seen as part of their whole self; controversial within the disability community

Intersectional - a framework for understanding the way social and political identities combine to create types of discrimination and privilege (Crenshaw, 1989)

Intersex - a generic term describing a variety of conditions wherein a person is born with a reproductive/sexual anatomy outside the typical definitions of female or male

Microaggression - common, everyday slights or comments relating to various types of discrimination

Ministry- within the St. Stephen's College context includes service to both the human and non-human global community.

Narrative textiles - textiles as text also call story cloth

Othering - perceiving individuals or groups as part of an 'out-group'; often accompanied by discrimination

Person First Language- identification of a person before their diagnosis, e.g. person with lupus; controversial in the disability community

Problem-saturated stories - a way of relating a story that privileges the problem elements and neglects or minimises the values, skills, choices, strength, etc. of the person experiencing the problem

Residential School System - a Canada-wide school system established by the government and administered by churches that forcibly separated Indigenous children from their families and community ostensibly to educate them. This school system made explicit the

aim to assimilate the Indigenous children and has been found, repeatedly, to have been a vehicle for abuse of children.

Sanctuary - in this context a sense of personal peace or security that may, at times, have a physical manifestation.

Spirituality- a sense of connection to something greater than the Self.

Transreligious - active engagement with multiple faith paths simultaneously

Vernacular religion - religion/faith practices as they are enacted

Way opening - a Quaker term indicating a revealed path forward, similar to the notion of Calling

Chapter 1: Foundation

> There is a place in the soul that neither time nor space nor no created thing can touch. What it means is that your identity is not equivalent to your biography and that there is a place in you where you have never been wounded, where there is still a sureness in you, where there's a seamlessness in you, and where there is a confidence and tranquillity in you. And I think the intention of prayer and spirituality and love is now and again to visit that inner kind of sanctuary. (O'Donohue & Tippett, 2008)

Spirituality has been part of the human experience since time immemorial. Whether informally through personal, even secular rituals, or formally, as part of faith institutions, humans have a longing to connect with something greater than their own ego (Palmer, 2014, 2015). This passage from O'Donohue, a Celtic author, captures that sentiment, that sense of wholeness and equanimity that spirituality connects us to. While there is no doubt that we are living in a secular age (Taylor, 2007) I do not believe it necessarily follows that we are also living in an a-spiritual one. We see the importance of this connection in the ways people of all walks of life came together to memorialise George Floyd, to demand the overhaul of justice systems, the school strike for climate, and the calls for action on Canada's shameful history of residential schools. We see it too in campaigns to knit caps and shawls for chemotherapy patients and premature babies.

We see it in memorial quilts, and impromptu art installations. We see it in online communities where people existing on the margins finally feel that sense of togetherness. We see it in mainstream celebration of LGBTQ+ Pride and gender fluid folx challenging visible gender stereotypes. We see it in the way we draw strength from each other and build strength within ourselves as these types of communities, connections, and ritual help us access our personal, inner sanctuary.

Although I have long been aware of the importance of this personal sanctuary and have always considered myself a justice oriented social worker, for most of my career I failed to recognise the role spirituality plays in justice-oriented work. I shied away from spiritual discussions and, although trained in the biopsychosocial spiritual model, I had perceived that spiritually oriented work was outside of my scope of practice. It was not until my own health care crisis that I recognised the importance of spirituality.

While it is improbable that I will ever be grateful to have lupus, I am grateful for the new awareness I have gained as a result of these circumstances. After more than 20 years of front-line social work experience, I finally recognised that spirituality-oriented social work, in particular helping individuals access this inner sanctuary, is my ministry. Beyond that, not only is it fundamental to my practice, it is also fundamental to my personal well-being. I believe that my struggle to come to this awareness resulted from a combination of factors ranging from the absence of substantive spiritually oriented training during my social work education to my own changing interests. I have come to recognise the way that spirituality, in a variety of forms, has been part of people's lives throughout history and across all cultures. Now how do social workers integrate this

knowledge into our practices? After all, a social work truism is that we 'meet the person where they are at', but do we when we exclude working in the realm of spirituality? Given this, I believe that the field of social work would benefit from learning more about the reasons for including a spiritual framework in practice, in this case specifically framed within the concept of sanctuary. As social work reconsiders its colonial roots and consequently reconsiders itself as a profession, explicitly integrating a spiritual lens to practice may contribute to more inclusive and participatory models of intervention. However, to be effective, we must consider these ideas academically, even formalising them, understanding them first for ourselves as practitioners and from there, understanding the broader meaning.

The purpose of this dissertation research was to immerse myself in this idea of sanctuary (my ministry), to understand what sanctuary means for me, how it guides and supports me, and where it informs my practice. To do so, I chose to use analytic autoethnography to explore my experience of sanctuary, privileging the areas where the lupus experience and sanctuary overlap. Included in my query, and informed by the experience leading to my awareness, was the intent to clarify what sanctuary comprises, with specific attention paid to the intersections of sanctuary and spirituality as well as sanctuary and creativity.

While my research goal was personal understanding, I also recognise the value of drawing on other perspectives to clarify and illuminate one's perspective. Further, I hoped to generate a theory of sanctuary to both articulate the experience of sanctuary and provide a foundational understanding with social work practice applications. Analytic

autoethnography as my core methodology foregrounded my experience and drew on the data shared through interviews with community members who volunteered to participate.

In this chapter, I articulate the foundation that informed the research direction and development of the methodology and questions. I offer a consideration of social work's history and intersection with religion and spirituality. I then explain my decision to undertake the Doctorate of Ministry and what that means for me personally and as a social worker. From there I articulate influential aspects of the lupus experience. The chapter closes with a discussion of the research questions and dissertation structure.

Social Work

At present, although there is a notable increase in the social work literature discussing religion and spirituality (Béres, 2017; Canadian Society for Spirituality & Social Work, 2021; Crisp, 2017; Gardner, 2020; Gokani & Smith, 2019) there is still an uneasiness in bringing these fields together. Gokani and Smith (2019) highlight two primary reasons for this in Canadian social work. The first is the adoption of the medical model as a means of legitimising the profession. The second area of concern resides in the difficulty in extracting spirituality from religion in common discourse, and that the "relationship between religion and social work is uneasy and has been for some time" (Gokani & Smith, 2019, p. 73). Gokani and Smith expand on this through a discussion of the religious roots of social work that resulted in social work's participation in the Residential School System and the '60s Scoop'. After all, "[the] white social worker, following on the heels of the missionary, the priest, and the Indian agent, was convinced

that the only hope for the salvation of the Indian people lay in the removal of their children" (Fournier & Crey, 1997 in Sinclair, 2007, p. 67). Gokani and Smith echo this asserting that "[b]oth the RSS and 60s scoop were implementations of policies of assimilation, in which both religious groups and social workers share blame" (p. 73). As Gokani and Smith suggest, I do believe that interplay of religion and social work practice has compromised social work's relationship with spirituality.

While a full discussion of the history of social work and decolonizing social work practice is beyond the scope of this dissertation (please see Gray et al, 2016, for more), the integration of spirituality into social work practice cannot be discussed without acknowledging social work's colonial history and its entanglement with religious institutions. To do so, I briefly acknowledge the history of the profession in Canada here, including its history as an agent of social control, whether through removing Indigenous children from their homes or supporting the moralising policies that delineated the deserving from the undeserving poor, for example. I offer this brief historical context as a background for the discussion of the renewed interest in spiritually oriented social work found in the literature review (Chapter 2).

The first Canadian social work type organisation, the Society for the Protection of Women and Children, was created in 1881 in Toronto. At that time social work was largely informal, administered by either religious institutions (such as the Catholic Church and Jewish charities), or through charities such as the Society for the Prevention of Cruelty to Animals, and Children's Aid Societies organised by communities (Jennissen & Lundy, 2011). Much of the children's aid work done initially was informed by the

social gospel movement, a movement that flourished in English Canada from 1890 to 1939 and "promoted a progressive Christian response to social problems" (Jennissen & Lundy, 2011, p. 5). Other organisations provided housing, advocated for mother's allowances (only for those deemed worthy and competent), and a range of other supportive services from food and clothing charities to free libraries. However, there were challenges to quality service provision as many of "those delivering relief often lacked … adequate knowledge and skills" (Jennissen & Lundy, 2011, p. 10).

Jennissen and Lundy (2011) argue that just as the emerging industrial capitalist economy created social problems of a scale not seen before, it also created conditions conducive to establishing social work as a profession. Given the increased demand for social work and emboldened by the success at professionalising in the USA and UK, Canadian social work proponents "took this opportunity to define and develop the work that they were doing" (p. 22). On September 1, 1926, the Constitution of the Canadian Association of Social Workers was approved with the aim of promoting professional standards, encouraging proper and adequate preparation and training, and cultivating an informed public opinion which was to recognise the professional and technical nature of social work (CASW Constitution 1926 Article II: 3 in Jennissen & Lundy, 2011). The profession has continued to grow from there.

So, what does it mean to be a social worker now? Like so many of the concepts in this document, social work can be a challenging profession to define. Labath and Ondrušková (2019) "consider social work to be a highly contextualised activity, varying considerably in different contexts of practice" (p. 19). While social work, from practice to

theory, can now be discussed internationally through web-based training and conferences, international journals and textbooks, and even practice discussion groups, the reality is that in practice, social work remains regional and national, influenced by the culture, law, policy, and traditions of its locales (Payne & Reith-Hall, 2019).

Within the Canadian context, social work education encourages focus on the "person within their environment" recognising "the importance of family, community, culture, legal, social, spiritual, and economic influences that impact the well-being of individuals, families, groups, and communities" (CASW, 2021, n.p.). The Canadian Association of Social Workers (CASW) (2021) further instructs that social workers ground their practice in a strengths-based perspective and that social workers view "individuals, families, and communities as resourceful, resilient, and having capacity" (n.p.). Further social work practice is to be informed by "[p]rinciples of respect for the inherent dignity and worth of persons, the pursuit of social justice, and culturally responsive practice that applies an anti-oppressive lens to all areas of practice and is grounded in ethics, values, and humility" (n.p.).

Although the Canadian Association for Social Work Education (CASWE) has comprehensive standards of accreditation for schools of social work, each school retains its particular focus. This results in each school having a different scholarly emphasis in their programme. While some programmes are seen as more clinical, with a strong emphasis on counselling skills for example, other schools emphasise social justice action and anti-oppressive practice (AOP). While my integrated practice professor incorporated a strong clinical lens to our education my programme emphasised anti-oppressive

practice and strengths-based social work (e.g., Saleeby, 1996, 2001). Although it was challenging to understand the importance of theory at the time, I now recognise that "[h]ow social workers make decisions and choose to engage with clients is influenced by the theories that they are exposed to and choose to embed in their practice" (Manion, 2019, p. 383). Exposure to a range of theories allows social workers to draw on a multitude of theoretical perspectives, allowing us to "weave them into an eclectic framework at the individual or institutional level" (Manion, 2019, p. 384). While this wide-ranging approach has caused some challenges for implementing a cohesive theoretical framework, barriers and challenges can also be the birthplace of creativity and innovation (Manion, 2019).

What I now reflect on through the sanctuary research is that while my education thoroughly acknowledged our colonial past, offered instruction in anti-oppressive, strengths-based practice, and held space for the potential of transformation, instruction integrating a spiritual lens into practice was not part of that so what limit did that place on the potential for creativity and innovation in practice? I now wonder if that colonial history, so deeply entangled with Christianity coupled with the desire to legitimise the profession through adopting a scientific or positivistic lens on practice (Gokani & Smith, 2019) has been a factor in steering our work away from any discussions to do with faith, spirituality, and religion. However, after years of practice, I now have to ask, how does a social worker 'meet the person where they are at' (a key social work phrase) without meeting the whole person, which includes their spiritual self, especially if they are in a spiritual crisis?

Social work's current contention with its colonial history and considerations of how to move forward and decolonize, offers a rich opportunity to consider and reconsider its roots, foundations, and purpose (e.g. BCASW; CSAWE Standards for Accreditation; McConnell, 2018). This reckoning offers a needed opportunity to reinvent our profession, returning to what has been useful and helpful, rejecting the problematic, and bringing in new, perhaps less considered aspects of practice, such as spiritually-oriented practice. Much as with our training in decolonisation, anti-ableism, and anti-oppressive/intersectional practice, spiritually oriented social work, especially one rooted in critical spirituality (discussed in the next chapter) provides the social worker with a frame of reference to serve the whole person.

Through this dissertation, I have begun this exploration for myself and ideally, laid a foundation that will support further academic investigations in the context of sanctuary as a spiritually oriented social work practice. While I discuss the current literature considering spirituality and social work in detail in the next chapter, here I highlight two practice frameworks that, in retrospect, offered me an antidote to the significantly positivist approach that dominated social work education at the time of my training. Both narrative therapy (NT) and the Neurosequential Model of Therapeutics (NMT) made space for what I consider to be if not spiritual then spirituality-adjacent practice. For example, rather than relying on 'clinician as expert' both of these models emphasised the importance of mutuality in the therapeutic relationship, honoured other ways of knowing, and supported a process rather than being focused on the outcome. Given their importance to both the direction of this research and the results, I first expand on

narrative therapy, followed by an explanation of the NMT which then leads into an explanation of the doctorate of ministry programme that guides this research.

Narrative Therapy

As I reflected on the influences that contributed to conceptualising and framing this research, it was no surprise to recognise the importance of narrative therapy within those given that the philosophies underscoring narrative therapy (NT) resonated with me from my first exposure. What was more surprising was how NT also intersects with the interests that brought me to study folklore. In my experience, even without immersive training in NT, I find it invites me to be curious about experiences, both my own and others, in a way that other frameworks do not. I appreciate how it de-centres the 'therapist as expert' instead embracing a collaborative process between the practitioner and the person (or people), congruent with anti-oppressive practice (AOP) (Béres, 2014). Concomitant with this, NT privileges insider knowledge and lived experience, without diminishing the expert knowledge while also keeping the practitioner's potential to cause harm through reifying dominant structures in the course of 'helping' in plain view (Béres, 2014; Payne, 2011).

Given its influence on my practice and therefore the research, I briefly summarise NT here. Beginning with the origins and philosophical underpinnings, I then continue with the core elements of NT, especially those that directly informed the research. I conclude this section with a discussion of the way Béres (2014) makes explicit the connection between spirituality and NT. Drawing on similar definitions to those found in

this document, coupled with her amplification of White's 'little sacraments', she identifies the way that NT helps people identify that which makes life meaningful, even worth living. For a full treatment of the topic please see Béres (2014), Duvall and Béres (2011), White and Epston (1990), Madigan (2019), Payne (2011), and White (2011).

Narrative Therapy's (NT) Origins and Philosophy, in brief

In an epistolary dialogue with White, two years after White's death, Epston (in White, 2011) recounts how "in Foucault's intellectual company" (p. 18) White was able to "reflect on and critique the cultural history of the psychotherapies and their very practices [sic]". Epston indicates that this was the ground in which the way of "thinking otherwise" about psychotherapy took root and was nourished. While other philosophers, such as Derrida and Deleuze clearly informed the development of NT, for Epston it seemed almost as though "Foucault was addressing [White] directly at times" (p. 19). Epston hypothesises it was through Foucault's work that White was able not only find the means and fortitude to reflect on his practices but to take it one step further and reinvent them.

Rooted in postmodern philosophy and social constructionism, NT is the only therapeutic intervention conceived by social workers (Béres, 2014). Integral to their postmodern approach and congruent with social work's aims is the recognition of the implicit and explicit role of power and structure in society. White and Epston (1990) articulate how those structures also contribute to 'truths' about society that in turn, reinforce social controls influencing most aspects of a person's life. They speak to the

way that ‘truths’ are often constructed or produced in the operation of power, resulting in the docility of people and contributing to the perception of an ‘objective reality’. Further, within a Western context, those ‘truths’ often contribute to norms that laud what White (2007) calls the ‘encapsulated self’ which values self- sufficiency and ‘bootstrapping’, seeing challenges and barriers as personal failings rather than systemic issues that reinforce social structures and controls.

Within ‘the system’ (e.g. health care or child and family services) I feel we often acquiesce to the positivist perception of the ‘encapsulated self’ and ‘objective reality’. Our dysfunction-oriented lens contributes to pathologizing or problematising the person, focusing on the problems and often reinforcing oppressive social structures. Adopting a dysfunction-oriented stance can contribute to reinforcing a problem-saturated storyline for the person which, in turn, makes it much more difficult to uncover other possible and preferred storylines.

This is one of the many reasons White and Epston (1990) amplify the importance of a social justice practice that reflects on these power dynamics and how they shape lives. As part of this, the NT posture privileges and celebrates informal and insider knowledge, rather than expertise and invites curiosity from all participants (Béres, 2014). Perhaps most importantly, the NT approach reminds the practitioner that when we begin drawing conclusions about the person’s experience, perhaps seeing them as ‘resistant’, ‘lacking motivation’, or being a ‘concrete thinker’, this is a reminder to both reflect on the stance we are adopting and recognise these challenges as facets of the person’s experiences ranging from a sense of being mired to the various social factors at play in

their experience (Béres, 2014; White, 2007). NT's rejection of a focus on dysfunction offers room for the complexity of lived experience, contexts (especially those around power), and honouring the areas of exception (e.g. where the problem has not been the problem, where there have been successes and even unexplored opportunities). Within the scope of NT, these are all considered as part of engaging curiosity, exploring multiple storylines, and re-authoring.

The Importance of Curiosity

Integral to my research is the NT stance of curiosity. Within this stance I see the values of privileging insider knowledge, de-centring expertise, and openness to other possible storylines coupled with openness to leaving the storyline to stand as it is. Essential to me is NT's emphasis away from problem-saturated stories, making room for the innumerable events that make up a person's life; including events that are seemingly unimportant and so, are never shared (Béres, 2014). This was a critical orientation for this research as I suspected that sanctuary existed but was something not discussed, certainly not in my experience of health care or in the way I framed it. It seemed especially important in light of the way the experience of chronic illness can become a problem-saturated story. In the language of NT, I wanted to explore all of the side storylines that may not seem important in the face of a massive challenge like chronic illness but, in fact, are essential to the person's sense of self.

While the ethos of NT has informed the research, this is not a NT study. As such, core elements such as re-authoring, conversation maps, and definitional ceremonies have

not been included. One link that I believe is essential between NT and my research is illustrated by Béres (2014) who picked up on White's thread of 'little sacraments of daily existence', drawn from Malouf's work. Béres notes that within the 'little sacraments of daily existence' White "reminds us to be open to those little events in people's lives that can evoke a sense of the significant or of the sacred" (p. 116). While this certainly felt like a possible aspect of sanctuary, even more interesting to me was Béres' ability to connect this concept back to Celtic spirituality. This conjunction significantly influenced this research, as discussed in the next chapter.

In this section, I have clarified just how thoroughly NT influenced this research. I wanted to end with an excerpt that I believe captures the general tone of NT. When Payne (2011), who was writing a text on NT, asked White what he felt should be included in the text White replies 'I would hope to hear your own voice, your own discoveries of this work, the ways in which this work has resonated in your own life and the ways in which your life has contributed to your participation in this work' (p. 3). This is entirely congruent with the ethos of narrative therapy as well as the intent with which I embrace all aspects of social work, including this research.

Neurosequential Model of Therapeutics

> Communication, after all, is about getting some idea, concept, or story from your cortex to another person's cortex. From the smart part of your brain to the smart part of their brain. The problem is that we don't communicate directly from cortex to cortex. We have to go through the lower parts of the brain. All the rational thoughts

> from our cortex have to get through the emotional filters of the lower brain… Along the way, there are many opportunities for the meaning of any communication to be distilled, distorted, magnified, minimized [sic], or lost. (Perry & Winfrey, 2021, p. 274)

Fundamental to my social work practice are the principles of the Neurosequential Model of Therapeutics (NMT). While all of my social work experiences have contributed to my research direction and focus, it was the specific and unique perspective of NMT that led me to start thinking differently about how we support people in stressful circumstances. Although I did not complete my NMT certification until 2015, the principles, especially the NMT-specific relevant interventions informed by the five Rs: relational, repetitive, relevant, rewarding, and rhythmic (Perry, 2006, 2014, 2020) have informed my work since I first learned of it in the early 2000s.

NMT is not a treatment modality so much as a developmentally sensitive, neurobiologically informed clinical framework for organising interventions and informing clinical decision making that focuses on emotional/nervous system dysregulation (Mason et al, 2020; Perry, 2006, 2020). Rather than applying a pre-set treatment framework, the NMT trained clinician considers the particular needs of the client, as established by the NMT specific assessment followed by assessing how those specific needs can be met by using established interventions (Perry, 2006, 2014, 2020, 2021). Those interventions are largely drawn from nervous-system sensitive engagements such as eco-therapies and expressive arts therapies as well as other activities such as yoga

or tai chi. As the clinician sees evidence of nervous system regulation, insight-oriented and verbal interventions that tend to rely on the prefrontal cortex can be integrated.

While my NMT training focused on assessing children and youth, the interventions were often family focused and it was to those moments I turned when, as a hospital social worker, I would find myself supporting a patient (and/or family) with a difficult diagnosis. At the bedside, I would support the patient (and others) to draw on their pre-existing nervous system soothing activities or to find and develop new ones. And it was to these that I unconsciously turned when faced with my own medical crisis. I began to spend more time walking in the woods with my dogs, creating textiles, baking, and sweeping the floor. These patterned, repetitive, soothing activities took on a spiritual tone for me. As I reflect back to those experiences and what led me to the programme through which I write this dissertation, I recognise that my experiences with NMT were fundamental to my decision. Within that framework and training, I came to see that interventions might look very different if we viewed health crises and how we support people from a different vantage. With this desire to engage differently with the patients I was supporting, I began to look at programmes that would support my aims.

While both NMT and narrative therapy (NT) are considered practice techniques, what this research has demonstrated is how both have become an orientation or way of seeing the world for me. The core elements of both of these philosophies informed the research intention, from my desire to move away from a problem-saturated story of chronic illness to the use of creative practices as part of my methodology (see Chapter 3). And while neither narrative therapy nor NMT are overtly spiritual, they both approach

interactions with a sense of 'connection to' which grew into an essential aspect of my practice and would become the definition of spirituality guiding this research.

Ministry

Had I been asked ten or 15 years ago; I would not have predicted that I would take on doctoral studies in a theology school leading to a Doctorate of Ministry. For years I considered various PhD programmes, largely in social work as well as further afield but without a clear sense of academic direction. With my return to medical social work and in conjunction with my own health care crisis, I saw a need to address what I felt was a concern in health care: namely, that I was supporting people who, by dint of a medical crisis, were likewise experiencing a spiritual crisis but I was doing so without formalised training. In order to provide ethical practice, I had engaged in continuing professional development with psychotherapists known for their 'soul work' such as Moore, Hollis, and Estes. I also trained in spiritually oriented expressive therapies, feeling that there may be some answers, or at least information for me there; though I remained unable to adequately operationalise it beyond knowing that most formal art therapy programmes were not what I was seeking either. I craved a formal immersion in spiritually oriented service work that, at the time, I did not believe I could obtain from a social work programme. I must acknowledge that since then, I have learned that there are Canadian social work programmes, theorists, and professors who are working to integrate spirituality into practice and their work has directly informed this dissertation.

After many years of attending the same textile retreat with the same group of women,

one of my fellow participants pointed me in the direction of St. Stephen's College with the comment that she thought it was exactly what I was describing when we talked about our future goals. I went to the website, surprised that anyone would think me, with my loose association with the Quaker faith and something I might describe as an eco-spiritual orientation, a suitable candidate for a theology programme. I continued my search for a doctoral programme but kept returning to the St. Stephen's College website. I noted the use of inclusive language, space made for theists and non-theists alike, and a general feeling that was much closer to the open relationship with the Divine I felt through my eco-spiritual Quaker orientation and nothing like the church structures I had grown up in. Further, the College also offers programmes embracing spiritually oriented art therapy and while I had only a passing interest in applying for such a programme, it was the combinations of all of these things that prompted me to apply to St. Stephen's College.

Of course, when applying for a theology programme, one must be prepared to speak about one's ministry. St. Stephen's College (SSC) welcomes a range of people from both traditional and non-traditional ministry contexts, provided that they see an inherent, self-described, spiritual dimension in their work (St. Stephen's College, 2019). Their definition of ministry is equally broad. Students are encouraged to articulate their vision and practice ministry in the manner with which they identify; ministry includes the self-reflective awareness of the nurturing quality of service to the human community and earth (St. Stephen's College, Definition of Ministry, 2019). As such the programme accepts applicants from a range of backgrounds perhaps not generally associated with ministry.

At the time of my application, I drew heavily on the O'Donohue passage provided at the beginning of this chapter and which guided this dissertation but had not yet uncovered the language to describe it as my ministry. In my application I believe I spoke of being in service to people in a spiritual crisis brought on through a medical crisis, seeing the need to offer spiritually oriented social work, and not knowing how to do that. I spoke about how people sometimes used creative or naturally informed practices to cope with these situations and how I saw this as somehow spiritual but needed to formalise my understanding about it. I concluded with a passage from Archbishop Tutu articulating the tenets of ubuntu, which summed up my aims, to be with another in their humanity.

Although I did not know then that I had lupus, I did speak about my own brain tumour journey and how the experience of months in limbo coupled with the relief of not having a brain tumour urged me to want to understand my experience and how it might help others. I also knew there were actions and even informal rituals that had been helpful (such as walks in the forest, the garden, work with textiles) and that to me they felt creative and spiritual, they embodied the feeling of sanctuary. I wanted to be more intentional and skilful with my understanding of those actions for myself. I also sought to understand if these were actions that felt that way to me but would not to another.

As I contemplated the applications I had sent out to various doctoral programmes, wondering whether those programmes would allow me to answer the questions that led me to apply, I began to feel pulled in a particular direction. I reconsidered and rescinded those applications, one by one, until only SSC remained. I knew that my work was ministry, as SCC broadly defined it, and in order to continue on my path, I needed a

programme that would further my understanding of both my ministry and myself as a spiritually oriented social worker. What I could not know then was that in the midst of my doctoral programme, my symptoms would flare up again, resulting in a lupus diagnosis. While this brought with it a great deal of clarity about my health history and a treatment direction, it was also accompanied by a change of understanding and direction. In the service of clarity, I will briefly articulate the experience of lupus before continuing to my research question.

Lupus

Systemic Lupus Erythematosus (SLE), aka Lupus, is often called the Disease with a Thousand Faces as a result of its ability to mimic most other diseases. While there are some classic symptoms in some patients (e.g., butterfly rash, joint pain, fatigue, specific lab results), its mimicry means that it often takes years to positively identify the disease as lupus; six years on average according to the Lupus Foundation of America (2020). The disease largely attacks women of childbearing age, roughly 90% of lupus sufferers are biologically women, disproportionately attacking women of colour at a rate of 2-3X that of white women. And, in women of colour, it tends to manifest younger and with more challenging symptoms. It is also in the top 20 leading causes of death, and again, women of colour represent the highest risk category. The United States Centers for Disease Control and Prevention (2021) reports that while there is no known 'cause' for lupus, it is believed to stem from a combination of environment (e.g., stress), genetics, and hormonal factors. It is a challenging disease that leaves in its wake a pattern of atypical disease manifestations, frustrated health care professionals, and often an exhausted, emotionally

worn-out patient.

In my case, lupus may have first appeared in young adulthood when I had unexplained joint swelling and a rash (though not the typical butterfly rash). I went on to develop atypical Crohn's disease with atypical, and at times, severe environmental allergies. All of my symptoms would ebb and flow with neither rhyme nor reason and close to but never truly matching the expected trajectory. In middle adulthood, I developed brain tumour-like symptoms that caused months of agony but resolved with clarity that there was no brain tumour. The diagnosis at the time was 'autoimmune neurological manifestation secondary to Crohn's disease': another atypical presentation. Fortunately, my family doctor continued to monitor me closely and eventually, between her work and my rheumatologist, lupus was diagnosed and treatment initiated.

Having offered general information relating to lupus and my experience of it, I now discuss the research question and how I decided to focus my research on the idea of personal sanctuary.

Research Question

Long before my lupus diagnosis, I had heard, but never forgotten, the O'Donohue interview in which I first heard the quote provided at the beginning of this chapter. The word sanctuary in that particular context and conceptualisation, has held a longstanding, particular resonance for me. It guided me through the dark days before the clarity of the lupus diagnosis, when it looked as though my symptoms were the result of a brain tumour. Other times, I have witnessed moments and participated in conversations that

had the feeling of sanctuary but without the ability to articulate the concept beyond sharing the above passage.

As a person who has felt their identity altered by their chronic illness, at times I have felt this kind of sanctuary and at other times felt it's lack. Understanding the depth of this passage felt important to me personally. However, equally important to me was the importance of understanding how it might inform my social work practice/ministry. To that end, I proposed an analytic autoethnography focused on exploring the experience of personal sanctuary contextualised within the experience of chronic illness. I sought to understand what I meant when I used the term 'sanctuary' and how this understanding would contribute to my social work practice. Finally, the question that guided the research with the participants was: what is your experience of sanctuary and how does that relate to your experience of your chronic health condition?

The process of analytic autoethnography foregrounds the researcher's experience while drawing on the voices of interviewees to add depth and other perspectives (Anderson, 2006). As the goal of autoethnography generally is to situate the personal experience in social context, the use of other voices will assist me in preventing a myopic view. Further 'because story can be told not only as personal but also as representative of a larger, collective experience, [the alignment of the self to the world] makes it possible for stories to have meanings beyond their contexts (Shuman, 2010, p. 71) In this respect, while this research is not specifically practice based, autoethnography's aims of linking personal experience with broader understanding of social phenomenon supports this research as an informant to my social work practice. I will discuss the particular

methodological approach further in Chapter 3.

Dissertation Structure

My intent in undertaking this investigation was to understand sanctuary for myself but to develop that understanding in light of others' perspectives. Although I felt certain that sanctuary was a spiritual practice for me, I wanted to explore that further. Additionally, I wondered if research participants would feel the same. Likewise, I was aware that I had felt what I called sanctuary when engaged creatively but wondered if the same would hold true for the research participants. I hoped that asking these questions would allow me to understand what experiences were specifically true for me and what might be more widely true. I further sought to generate a preliminary theory about sanctuary. It was for these reasons that I opted to engage in analytical autoethnography, which I discuss fully in Chapter 3.

Following this chapter, the introduction to this study, I will engage in the literature review focused on key concepts relevant to the research questions. I begin Chapter 2 with O'Donohue's work including other places within his work that have echoes of sanctuary. I also reflect on his engagement with Celtic spirituality, and briefly summarise the debates in that field. Chapter 2 continues with an attempt to clarify and define spirituality as a concept. Following that, I move specifically to spiritually oriented social work, including Gardner's (2017) critical spirituality. Additionally, I touch on the similar idea of 'soul work' from the field of psychotherapy, a concept that supported the research direction. I then look briefly at creativity generally, followed by a narrower focus on

spiritually oriented creativity, namely the core influences for the research question about creativity. I conclude this chapter with a discussion of disability, focused on critical disability theory.

In Chapter 3, I outline my methodological approach beginning with the cohering concept of crystallisation in research. I then discuss the overarching methodology, analytic autoethnography. A discussion of my personal critically self-reflective practices (CSR) as well as Critical Reflection on Practice (CRoP) follows. CRoP provides the internal guidance for engaging in the personally reflective aspects of the research and includes both creative and spiritual orientations. I continue with a discussion of research-creation, specifically response art, which further supports the CRoP process and the broader methodological perspective.

I continue Chapter 3 by articulating the way I approached the data analysis, drawn from Charmaz's (2006a, 2014) constructivist grounded theory. In keeping with Charmaz's orientation, I apply the constant comparative method (CCM) throughout the research period. In this section I articulate both method and rationale. Following this I offer an explanation of the research process and participants as well as outline the data collection procedures and ethical considerations.

In Chapter 4 I review the participant findings and their relationship to the research questions. At the opening of the chapter, I explain my use of the findings to provide the structure for that chapter. My personal findings and reflections follow in the second half of the chapter where I also include my reflections on the data, excerpts from my journals,

and response art.

In Chapter 5, while I recognise that knowledge is an ever-evolving concept and an idea such as understanding my relationship with sanctuary is work that will never be concluded, I offer a discussion of the findings along with the new learning gained in this research process, areas of growth, and insights as they stand currently. I further engage in a discussion of the findings and how they may inform my practice moving forward, linking them to pre-existing literature as appropriate. I conclude this chapter with recommendations for future research and a summary of possible implications for practice.

I conclude the dissertation with Chapter 6. In this chapter I summarise the circumstances and questions that led to the research focus as well as reviewing the research questions. I then summarise the key findings along with the highlights of the research, and recommendations for future research and practice.

Conclusion

I began this chapter with a quote from John O'Donohue that guided the research and one that I feel captures the essence of personal sanctuary for me. The importance of O'Donohue's work and with that, Celtic Spirituality, in my life and my social work practice cannot be emphasised enough. Hence, foregrounding it here. Perhaps because of its deep integration with my life and my worldview, even where not specifically visible, it has guided and informed every facet of my academic path and this study.

I will speak about the specifics of both O'Donohue's work and Celtic spirituality in the forthcoming chapters; however, it was essential that Chapter 1 provide a

foundation beyond O'Donohue's work and Celtic spirituality to revel breadth of other experiences that also contributed to this dissertation. In so doing, I have identified myself as a social worker and articulated key aspects of my practice that inform this research. With this I have outlined the history of (largely Canadian) social work including its difficult past and problematic history with faith practices as well as disclosing my desire to integrate a spiritual lens to my social work practice. My hope was that this would clarify how that brought me to the Doctor of Ministry programme at St. Stephen's College. As part of this, I also articulated my lupus experience and how all of these different factors coalesced into a desire to understand this type of personal sanctuary as my ministry. This chapter also reveals my research aims, including my core research question, and the outline of the dissertation structure.

Within this chapter I have reflected upon the diverse experiences in my life that coalesced in such a way as to inform, guide, and direct this research. I have indicated the gaps in the literature with regards to spiritually oriented social work practice, especially linked to creativity and in the experience of chronic health concerns, and the need to address it. In the next chapter, I explore those gaps and the literature further. I explore O'Donohue's work and Celtic spirituality in depth. This leads into a discussion of spirituality (broadly) and the relevant spirituality-oriented social work literature. From there I engage with the first person chronic illness narratives that most closely pertain to my research goals. One other important area I have not yet discussed, is that of folklore, and I will also discuss that in the next chapter.

Chapter 2: Literature Review

In this chapter I discuss the literature that informed the research questions and design, excluding that which applies directly to the methodology (found in the next chapter) or the literature investigated to fully understand what arose within the findings (found in Chapter 5). I begin with a thorough discussion of O'Donohue's theology, focusing on his perspective on Celtic spirituality. This discussion is augmented by my folkloric training, specifically vernacular religion. I discuss Primiano's concept of vernacular religion at length later in this chapter so will just briefly summarise that it supports O'Donohue's articulation of Celtic spirituality as vernacular religion and honours the experience of religion (or spirituality) as it is lived.

Following the specific discussion of O'Donohue and his work, I shift the view slightly to the broader concept of soul work. Here I begin again with writing from O'Donohue before moving on to the other scholars whose texts supported my orientation to this research and guided the research focus, before the various elements became clear to me. That section is followed by a discussion of spiritually oriented social work which clarified my professional position and assisted me in further understanding the utility of the research. I conclude this review with a discussion of the first person, chronic illness literature that supported the methodological choice.

O'Donohue

> At the heart of Celtic spirituality is the fire, force, and tenderness of the Celtic imagination. All spirituality derives from the quality and power of the imagination. The beauty of Celtic spirituality is the imagination behind it, which had no boundaries. The essence of a thing or person was never confined in any prison of definition or image. Celtic spirituality is an invitation to a wonderful freedom. The recovery and awakening of the invisible world is as wild and free as the immeasurable riches of the earth. (O'Donohue, 2000, p. 345)

The late John O'Donohue spent much of his life in rural County Clare, Ireland, the region of his birth. He first attended university in pursuit of a Bachelor of Arts in English Literature, Philosophy and Theology. From there he completed an MA and was ordained into the priesthood in 1982. Continuing his examination of the world and the nature of being, his queries took him to the University of Tübingen in Germany leading to the award of a PhD in Philosophical Theology, focused on the work of Hegel, in 1990. Following the award of his doctorate, O'Donohue returned to Ireland where he resumed his work as a priest. The John O'Donohue (Cahill, 2022) website, maintained in memoriam by his family, notes that it was after this that he came to marry the folklore of his native land and Hegelian thought. This then led to his post-doctoral work focusing on the writing of Meister Eckhart as well as the popular works for which he is now known (e.g. *Anam Cara, Beauty, Eternal Echoes*, etc).

Celticness

O'Donohue's history is more than an interesting anecdote. He continually contextualises his work in his upbringing; including the influence of his family, living in the Gaeltacht, the landscape of the Burren region, and the way the lore and history of the region were woven together with his experiences of Catholicism and philosophy. His sense of Celticness originated in these roots. In spite of heated academic debates around the term Celtic at that time (e.g. Meek, 2001), especially in the context of Celtic spirituality, it does not appear that O'Donohue shied away from explicitly naming Celtic ideas. In fact, O'Donohue, who employs Celtic terminology prolifically throughout his work, may have intentionally sought to position his work in such a way as to neatly sidestep those conflicts. For example, he contextualises his first major publication, *Anam Cara: A Book of Celtic Wisdom* (1997) as

> a phenomenology of friendship in a lyrical-speculative form. It takes its inspiration from the implied and lyrical metaphysics of Celtic spirituality. Rather than being a piecemeal analysis of Celtic data, it attempts a somewhat broader reflection, an inner conversation with the Celtic imagination, endeavoring [sic] to thematize its implied philosophy and spirituality of friendship. (p. 29)

O'Donohue provides further illustrations of the sources of his inspiration by infusing his work with Gaeilge (Irish), referencing local lore, and drawing on ancient prayers such as Immram Curaig Máile Dúin (The Voyage of Mail Duin's Currach 8th c CE, found in

Beauty, 2005) and the equally ancient St. Patrick's Breastplate (in *Anam Cara*). The use of ancient poems coupled with the oral history, local lore, and visible traditions all around him informed O'Donohue's Celtic perceptions. Indeed, O'Donohue lived in one of the most arguably Celtic regions of Ireland where language, and alongside lore and tradition, have been preserved, though not without struggle. Ó Giolláin (2007) describes the West as "the most picturesque and most folkloric"; it was first identified a century ago as "the repository of traditional rural and Catholic values, as a reservoir of Irishness" (p. 3).

Within O'Donohue's reverence for local tradition and honour for his deep roots, I read echoes of the Irish government's ongoing efforts to preserve the Irish Republic's lore. Shortly after the Republic gained independence, there was official recognition of the loss of culture through English colonisation. In 1927, the then Gaelic League founded the Folklore of Ireland Society which, along with the Irish Folklore Institute, evolved into the Irish Folklore Commission (IFC) in 1935. Attached to the Department of Education, the IFC coordinated an organised and thorough collection of lore from all over the Republic. They used the well-established framework from the Scandinavian countries and relied on native speakers to ensure those without English, who were seen as most likely to know the old lore, were recorded (Lysaght, 1998; Ó Giolláin, 2017). Ó Súilleabháin, the then head of the IFC developed field manuals to ensure consistency in the data collection (Lysaght, 1998; Ó Giolláin, 2017). These early ethnographers even trained school children to assist in the capture and cataloguing of a rapidly disappearing oral history. Those documents are now found in the University College Dublin folklore archives.

Authenticity and the Celtic Debate

The relevance of this in relation to O'Donohue's work is to touch on the authenticity debates around the idea of 'Celticness' which naturally arises in the context of his work. I will very briefly draw on the work of Hutton, a revered historian with an archaeological background and whose area of expertise encompasses the culture of the British Isles and who summarises the history succinctly. Even the use of the term 'Celt' to describe any facet of culture beyond the Celtic languages became a source of academic controversy in the late 1980s (Hutton, 2011, 2014, 2017; Sims-Williams, 2020). Through the 1990s, the term Late Pre-Roman Age was used to describe the period of migration to what had been thought of as the Celtic lands (Hutton, 2014). Cunliffe, an archaeologist who had 'established himself during the late twentieth century as the leading expert on the British Iron Age' (Hutton, 2014, p. 169) and who had been firmly outspoken against the historic image of 'the Celt', Celtic migrations, invasions, or culture began to reconsider the data. Synchronistically, an American linguist J.T. Koch was likewise reconsidering what was believed to be known about 'the Celts'. In 2010 they jointly proposed a new model of the 'Celt' that avoided the historic problems (Hutton, 2014).

Cunliffe and Koch's model suggests that rather than a migration from Europe to the British Isle/Ireland as has traditionally been theorised, there possibly existed an indigenous, sea-faring population in the Celtic lands that travelled eastward. And that on their voyages, they brought not only language but culture. Within their framework, a foundational Celtic language that served as the lingua franca "called into being by maritime communication in the fourth millennium" (Cunliffe, 2013, p. 246) and spread

outward from there. During the shattering of the late Bronze Age trading system, this lingua franca was likewise fragmented into regional dialects that then evolved (Hutton, 2011, 2014, 2017). Given the importance of the Atlantic as a vehicle for transmission, Cunliffe (2013, 2017) even proposes, perhaps tongue in cheek, the term Atlantean as "a device for enabl[ing] us to think of a likely scenario for language growth freed from the prejudice and preconceptions that encumber the word 'Celtic'. But we could simply substitute 'Celtic' for 'Atlantean'" (p. 246). (For a full discussion of their model, please see Cunliffe 2012, 2107, 2018; Koch & Cunliffe, 2012, 2013, 2016; Hutton 2013.)

While this establishes the use of the term Celt, it does not clarify the presence, or absence, of a dedicated Celtic Christian church or formal Celtic spiritual practices. In her article 'Celtic spirituality: exploring the fascination across time and place' Béres (2017) notes that "in the early mediaeval period (the period in which we find the first descriptions of what is called Celtic spirituality), religious and spiritual practices were far more likely to be fundamentally local, without any overarching religious unity" (p. 101). Hutton (1996, 1999) concurs, noting the breadth in regional practices in spite of the congruence provided by overarching significant holidays. This is, as Béres states, an argument against the notion of a Celtic spirituality separate and distinct from other local spiritual practices in Britain and Ireland at the time.

It is also noted that there were particular Celtic overtones to certain Christian practices in Ireland and Britain. And as Béres notes, faith institutions were entangled with the social, political, and royal spheres so much so that when King Oswald, a Northumbrian influenced by Celtic spirituality "married a Queen who had been raised in

the south of England and influenced by the Roman Church, the royal couple began to experience challenges in their differing faith practices particularly in relation to the date for celebrating Easter, and so a gathering was organised at Whitby in 664" (Béres, 2017, p. 101). The Synod at Whitby heralded a formal change in the official practices, which included an attempt at quashing Celtic and/or regional practices. For example, McIntosh (2013) who states that "[w]hatever was the precise form of the Celtic church it came under challenge at the Synod of Whitby in 664 and, later, with the replacement of Gaelic liturgies by Roman ones" (p. 95).

However, in spite of the formal decree, the reality is that the actual practices retained their local and regional flavour (please see Béres, 2012, 2017; Bradley, 2013; Hutton, 1996, 1999, 2011, 2017; McIntosh, 2013). This convergence of the official and the actual or lived experience of religion is captured by Primiano's 1995 paper. He coined the term vernacular religion to do "justice to the variety of manifestations and perspectives found within past and present human religiosity. It also provides a methodological tool for studying the conjunction of religion, folklore, and folklife studies" (p. 42). Primiano further contextualises the use of vernacular in the etymology and history of the term, arguing the

> need to do justice to the experiential component of people's religious lives can only be satisfied by a term which specifically addresses the 'personal' and 'private'. Equally significant is the relationship of vernacular to the 'arts' manifested in the creativity and artistry expressed by the human drive to interpret religious experience. The omnipresent action of personal religious interpretation involves various

> negotiations of belief and practice including but not limited to, original invention, unintentional innovation, and intentional adaptation. This human artistry is as meaningful as the creation, performance, and communication of any number of folklore genres which have interested folklore and folklife scholars for generations. (p. 44)

Vernacular Religion

Vernacular religion is a concept to honour the real experience of religion (including spiritual, or informal, practices) acknowledging that personal, cultural, or regional variations in faith practices (e.g. Bowman & Valk, 2015) does not render them illegitimate. Indeed, through this work Primiano offers an antidote to the continual reification of certain types of faith/wisdom practices and expressions that, in turn, dismissed or denigrated others. This cycle saw certain practices as legitimate and others as less, which then would be reflected in the literature, further entrenching these perspectives and reinforcing categories of legitimate/not legitimate or authentic/official versus folk religion. Bendix (1997) argues something similar in her challenge to reflect on what is considered authentic versus inauthentic knowledge. How often does the hegemonic gaze reinforce its own primacy, leaving us with the perception of certain practices, beliefs, and even communities as 'lesser'?

In keeping with the idea of vernacular religion, I note that in spite of the arguments that there is no evidence for a formal Celtic Church or even Celtic spirituality (e.g. Meek, 2001; Márkus, 1997, etc) there is an extensively documented, vernacular

Celtic faith tradition (e.g. Béres, 2012, 2017; Bowman, 1993a, 1993b, 1995, 2003, 2007, 2014; Dillon & Doohan, n.d; Hutton, 1996, 1999, 2011, 2017; MacFarlane, 2007; Ó Giolláin, 2004, 2017; Zuchelli, 2016). Excellent examples can be found in the scholarship around the prevalence of the Celtic supernatural interwoven into Catholicism as reflected by vernacular language (Magan, 2020), seasonal celebrations (e.g. Muller in Ó Giolláin, 2004), or lore (e.g. Aldhouse-Green, 2015). One of the clearest examples of shifting perceptions and certainly culturally toned spiritual practices is found in the discussion of sacred trees (Dillon & Doohan, n.d; Lucas, 1963; Zuchelli, 2016). Where it was once believed that sacred trees (bile, pronounced 'billa') were seen to be sacred as a result of growing in a church yard, it is now known that many of these trees pre-dated the presence of those churches. Folklorists now believe that the church sites were often chosen because they were already sacred, not that the site became sacred as a result of the church's location (Dillon & Doohan, n.d.; Lucas, 1963; Zuchelli, 2016).

The importance of addressing Celtic spirituality and vernacular religion is not only to establish the validity of O'Donohue's work in this context. I am also conscious that within the research, I asked the participants to share very intimate details about their own spiritual experiences, as well as disclosing some of my own. I note that at times in scholarship, experiences that are not congruent with a particular official structure and certain those that are the result of a transreligious (Thatamanil, 2016) or a 'spiritual but not religious' (SBNR) path can be dismissed or even derided (e.g. Blake, 2010). In this discussion, I hope to have established that just as I take O'Donohue's experience of Celtic spirituality as he reported it, so too do I accept the experiences of the participants

as they reported them. It is my hope that establishing an academically respectful framework for vernacular religion will not only thwart any debate about the use of O'Donohue's Celtic spirituality or the legitimacy of any private or SBNR practices recorded in this research (e.g. in the Findings chapter). Therefore, for the rest of this section and through the rest of the document, I acknowledge all discussions of spirituality, including O'Donohue's framing of Celtic spirituality, as valid and in no need of further authentication.

O'Donohue's Celtic Theology

Within the core elements of O'Donohue's Celtic spirituality, he notes that one of the "amazing recognitions of Celtic spirituality and wisdom is the sisterhood of nature and the soul" (O'Donohue & Quin, 2018, p. 197). This connection began with the creation of the Self, called our clay body by O'Donohue, for example he says "[f]ashioned from the earth, we are souls in clay form" (O'Donohue, 1997, p. 33). The clay body keeps us connected to every aspect of nature, from the cycles of the sun and moon to the seasons which also relates to his belief that the clay body is the origin of the inner voice of our true self. The true self extends to those we might call our Anam Cara, those heart friends who O'Donohue felt shared some of the same primordial clay as ourselves. And when Anam Caras find each other, even if our human minds do not remember or understand the connection, our clay bodies do (O'Donohue, 1997). A further discussion about the importance of relationship in Celtic spirituality follows.

According to O’Donohue, our clay bodies also connect us to creativity, another fundamental component of Celtic spirituality. He (1997) says that “[t]his tension between clay and mind is the source of all creativity. It is the tension in us between the ancient and the new, the known and the unknown. Only the imagination is native to this rhythm”. He likens this tension to the perfect tension of the violin string; with the perfect tension, “the violin can endure massive force and produce the most powerful and tender music” (p. 172).

All of the themes in O’Donohue’s Celtic theology return to nature. And perhaps it is no surprise that nature should be so present in his ideas of Celtic spirituality. Themes of the natural world prevail throughout the Celtic lore and myths (e.g. Aldhouse-Green, 2015) that informed his theology. Even more immediately, O’Donohue continually contextualises Celticness in the landscape of the Burren, a region that defies the ‘Emerald Isle’ stereotype. Indeed, during the devastation of Ireland, it was claimed that Ludlow, one of Cromwell’s generals, said the Burren was ‘a savage land, yielding neither water enough to drown a man, nor tree to hang him, nor soil enough to bury’ (Miller, 2015). O’Donohue (with Tippett, 2008) describes it as “a bare limestone landscape” and that he thought that “the forms of the limestone are so abstract and aesthetic… it is as if they were all laid down by some wild, surrealistic kind of deity” (n.p.).

Indeed, the great swathes of grey stone appear folded and refolded, laying horizontally along the landscape, with vegetation struggling to grow amidst those folds. Images from the Burren region [1], show a landscape that looks much like the experience of

chronic illness feels; amidst areas of sometimes overwhelming struggle, there are places that nurture growth. Of interest to me is the statement by the Burren Park official website (Burren Park, 2021), reporting the presence of a multitude of plants co-existing in ways not found elsewhere, or, those like heather that require an acid soil and yet, thrive in the limestone rock scape that should not support them.

In the On Being (2008) interview, from which the sanctuary passage was excerpted, Tippett asks about the prominence of the word 'landscape' in his work noting how he frequently related landscape back to how human beings know themselves and move through the world.

O'Donohue replies that:

> I think it makes a huge difference, when you wake in the morning and come out of your house, whether you believe you are walking into dead geographical location, which is used to get to a destination, or whether you are emerging out into a landscape that is just as much, if not more, alive as you, but in a totally different form, and if you go towards it with an open heart and a real, watchful reverence, that you will be absolutely amazed at what it will reveal to you.

He continues with:

> And I think that that was one of the recognitions of the Celtic imagination — that landscape wasn't just matter, but that it was actually alive. What amazes me about

landscape — landscape recalls you into a mindful mode of stillness, solitude, and silence, where you can truly receive time.

The notion of Celtic spirituality, for O'Donohue, is impossible to disentangle from the natural world. He speaks to this connection of self, landscape, and Celtic spirituality throughout his texts.

In *Anam Cara* (p. 92), he ties our selfhood to place

> Landscape is the ultimate *where* [italics mine]; and in landscape the house that we call home is our intimate place. The home is decorated and personalized [sic]; it takes on the soul of the person who lives there and becomes the mirror of the spirit. Yet in the deepest sense, the body is the most intimate place. Your body is your clay home; your body is the only home that you have in this universe. It is in and through your body that your soul becomes visible and real for you. Your body is the home of your soul on earth.

Given the intent of this research, the idea of accepting the body, even flawed, as the home of your soul on earth is both obvious and challenging. I believe that O'Donohue understood this difficulty, the darkness that can come with suffering. He speaks to it throughout his work, for example, in *Anam Cara* stating:

> We are lonely and lost in our hungry transparency. We desperately need a new and gentle light where the soul can shelter and reveal its ancient belonging. We need a

> light that has retained its kinship with the darkness. For we are sons and daughters of the darkness and of the light. (p. 36-7)

I further articulate the manner in which O'Donohue addresses the challenges of suffering and illness in the discussion section of this dissertation. I will state here however that as part of that, that Celtic spirituality is a spirituality of balance with a non-dualist view that translates to life and death as well. O'Donohue indicates this balance through statements such as "[t]he human body has come out of this underworld. Consequently, in your body, clay is finding a form and shape that it never found before. Just as it is an immense privilege for your clay to have come up into the light, it is also a great responsibility" (p. 168). In *Anam Cara* he (1997) expands on the idea of the Celtic underworld, explaining that

> the Celtic idea that the underworld is not a dark world but a world of spirit is very beautiful. There is an old belief in Ireland that the Tuatha Dé Dannan, the tribe of Celts banished from the surface of Ireland, now inhabit the underworld beneath the land. (p. 166; see also Aldhouse-Green, 2015)

This acceptance of the other is part of the non-dualist mindset that O'Donohue says typifies the Celtic orientation. The Celts rejected the "dualism that separates the visible from the invisible, time from eternity, the human from the divine" (O'Donohue, 1997, p. 25). O'Donohue (1997) states that rather than living in a taxonomically ordered world of separate spheres, the "Celtic imagination articulates the inner friendship that embraces Nature, divinity, underworld, and human world as one" (p. 25). In his (1997)

conceptualisation of Celtic theology the tradition of light, brightness, and goodness is balanced with an equally powerful tradition grounded in the strong sense of the threat and terror of suffering. Indeed, O'Donohue speaks about honouring suffering, acknowledging "the solitude of suffering, when you go through darkness that is lonely, intense, and terrible. Words become powerless to express your pain" (p. 171).

Beyond acute or explicit loss and suffering, O'Donohue also saw a generalised suffering in the world, something akin to Durkheim's ennui. O'Donohue observes this in people's disconnection from their true self/clay body and all that represents to him. He saw this malaise in society as the vehicle that drives people to seek out spiritual medicine for their existential woes, in particular, Celtic spirituality, and all that it represents. He felt that to find a "new and gentle light where the soul can shelter" could allow people to have a sense of ancient belonging, something from which too many people in the modern age feel disconnected. O'Donohue argues that a great contributor to this suffering was the lack of relational depth in most peoples' lives.

For O'Donohue (1997) this type of relational richness typifies the Celtic mindset and though it can feel disruptive and awkward to the modern mind, "it gradually refines your sensibility and transforms your way of being in the world" (p. 54). O'Donohue sees this type of depth in relating as an antidote for many of the modern relationship ills from greed to alienation. We are seeking this type of connection, not realising that there are rich Western traditions that offer it. While many of us are attending yoga classes and learning the importance and history of bowing to honour the other and to say 'namaste'

O'Donohue illustrates that there is a similar sentiment in the Celtic tradition; it persists in Gaeilge (Irish language) today. For example, he (1997) says:

> in the Gaelic language, there is a refined sense of the sacredness that the approach to another person should embody. The word hello does not exist in Gaelic. The way that you encounter someone is through blessing. You say, Dia Dhuit, God be with you. They respond, Dia is Muire dhuit, God and Mary be with you. When you are leaving a person, you say, Go gcumhdaí Dia thu, May God come to your assistance or Go gcoinne Dia thú, May God keep you. The ritual of encounter is framed at the beginning and at the end with blessing. (p .57)

This type of ritual occurs throughout the Celtic mindset, not just in greetings and leave takings. The significance is just as profound as understanding why Buddhists or yogis bow to one another. All of these types of rituals remind us of our duty of hospitality in welcoming the stranger.

No doubt as a result of these influences, O'Donohue's work unapologetically engages the mythic imagination, taking the reader through time and space to places where there is only connection, integration, and sanctuary, he does so clearly oriented and grounded in his own Catholic faith with a deeply Celtic cultural overlay. This is not to say he had no quarrel with the Catholic Church. Indeed, he famously said that the best decision he ever made was to become an ordained priest and the second best was to leave the priesthood (Covington & O'Donohue, 2007). He felt that the Catholic Church needed

to make peace with Eros and reconcile its "pathological fear of the feminine" (Covington & O'Donohue, 2007, n.p.). However, he has also been criticised for his statements that "New Age writing cherry-picks the attractive bits from the ancient traditions and makes collages of them" (Covington & O'Donohue, 2007, n.p.). His concern was not in the cherry picking so much as the excision of the ascetic dimension and lack of rigorous thinking in too many movements that seek to offer immediate solutions rather than delving the depth of the questions. Indeed he urged those interested to consider a modern conversation with Celtic spirituality that is critical and reflective; "otherwise Celtic spirituality is in danger of becoming another fashionable and exotic spiritual program in our sensate, driven culture" (O'Donohue, 1997, p. 241). In this way, Celtic spirituality directly connects with the critically reflective practice found in social work as well as soul work, both of which are discussed in the next chapter.

Soul Work

> When you truly listen to the voice of your soul, you awaken your kinship with the eternal urgency that longs to lead you home. The deepest call to a creative life comes from within your own interiority. It may be awakened or occasioned by a person or situation outside you, yet the surest voice arises from your own secret depth. (O'Donohue, 2000, p. 227)

In this section of the literature review I explore the idea of soul work, inspired by O'Donohue's work as well as its use in psychotherapy (e.g. Moore), particularly spirituality-oriented psychotherapy, I focus on those concepts relevant to the research.

Given O'Donohue's influence on the research, I begin with his work to lay the foundation and follow that with a brief, broad summary drawn from some of the notables in popular psychotherapeutic writing. I then balance this with some of the critiques of psychotherapy's use of folkloric material (especially myth and lore) by folklorists. I refocus more specifically on the literature that specifically influenced my research direction.

Soul work speaks to a way of being that moves beyond the intellectual to something I would say is deeper. For me it relates to Palmer's (2014) definition of spirituality, that ineffable sense of being connected to something greater than our own ego and how we support, nurture, and enhance that connection. I believe this is often a fundamental, but absent, component of 'the helping professions' as they are collectively known. I address the lack specifically in social work, in the next section.

Indeed, about psychotherapy O'Donohue says if you need it, get it (O'Donohue, 2007) even as he wondered how much of the need for psychotherapy resulted from missing the spiritual aspects of our lives. He captures the essence of needing something more than a strictly cognitive, a-spiritual approach to healing our spiritual wounds, arguing that the "cuts at the core of your identity cannot be healed by the world or medicine, nor by the externals of religion or psychology. It is only by letting in the divine light to bathe these wounds that healing will come" (O'Donohue, 2000, p. 424). He continues with a commentary on the loneliness of postmodern culture and that our loneliness rose up from our frantic attempts to avoid suffering and pain. This, in turn, drives people to "calm their inner turbulence by all manner of therapy and spirituality"

(O'Donohue, 2000, p. 365), seeking refuge in programmes "as if [they] offered final resolution" (p. 365). But these programmes, O'Donohue (2000) says, have no real substance to them, there is "no earth beneath the seductive surface (p. 365)". This returns us to his cautions about generic, not critically reflective spirituality. O'Donohue (with Quinn, 2018) says:

> [w]hen people get into trouble psychologically, it is often because something comes upon them that frightens them, or paralyzes [sic] them, so that they cannot move, work or function. It is something they would never have anticipated in themselves. This sudden confrontation with unexpected otherness becomes crippling. (p. 167)

He (O'Donohue & Quinn, 2018) continues by addressing what happens when that something is illness, enumerating the way in which the appearance of illness can feel like a contradiction with the self we believe we know. This sense of contradiction can present a larger challenge than the illness itself. He reminds us though that in reality, our selves are "a bundle of contradictions. Normally we are not aware of our internal, contradictory nature because there is so much of ourselves that we keep completely hidden" (O'Donohue & Quinn, 2018, p. 168-9). In this he sees the revelation of the contradiction not as a problematic tension of opposites but an opposition that "has come alive with great tension and energy" (p. 169) though acknowledges this "can be a frightening time in a person's life". During this time we feel vulnerable as the previously held image of ourself falls away but for O'Donohue, there is richness for the soul in this tension as well. He advocates for embracing a broader perspective than being married to the dualism of

our ill/not ill state. He says that “[u]sually, the way we settle and compromise with ourselves is by choosing one side over the other side, and we settle for that reductionism until something awakens the other side, and then the two of them are engaged” (p. 169). O’Donohue urges us to companion ourselves, seeing the changes, even the illness itself as an interesting time. However, within that he does not minimise the impact of illness, the pain, the fear, or the awfulness.

It is the type of hope O’Donohue expresses that sparked the interest that led to my research question. I wondered not so much about post-traumatic growth, or something similar, but rather if the burden of a chronic health challenge presents the possibility to know ourselves differently. In the context of the O’Donohue (2008) passage, I wondered if sanctuary is an aspect of what might best be called the soul, if it is always there with us, but silently, unbeknownst to us, even implicitly. And through certain circumstances, of which I suspected chronic health conditions are one, we become aware of it. This is not to minimise the experience of suffering; indeed, it is awful. Yet, when it is inevitable and inescapable, is there any usefulness in focusing all of our energy on fighting it? Are we better served by opening to the potential that suffering forces us to consider? In this regard, I see a connection with narrative therapy which distinguishes between problem saturated storylines and other possible storylines (for more about narrative therapy, please see Chapter 1).

In the O’Donohue passage that guides this dissertation, he speaks of spirituality as a means of accessing sanctuary. Initially, I would have said sanctuary is spirituality but as I contemplated that passage and the literature in preparation for the research, I recognised

the difference. The clue for me was in his (1997) statement that “spirituality is the act of transfiguration” (p. 109). I began to recognise spirituality as the engagement, the acts, and the processes that lead us to sanctuary, which I suspect is a metaphorical location, though for some it may have physical representations that our spiritual actions help us move towards.

Although O’Donohue ties identity and spirituality to landscape, it is the interior process that are fundamental to our spirituality for him. In fact, he (1997) explicitly cautions against longing for a Divinity ‘out there’, urging us to move closer to our own soul allowing “the presence of the divine [to be] completely here, close with us” (p. 112). He later says “you do not have to go away outside yourself to come into real conversation with your soul and with the mysteries of the spiritual world. The eternal is at home—within you” (p. 154). He reiterates the Eckhart concept that led to the passage guiding this work. In this framing O’Donohue (with Quinn, 2018) says “[t]here is a place in the soul—what Eckhart called ‘the uncreated place within you’—that no darkness, shadow, suffering or separation can ever touch. If, therefore, you want to bring God alive within you, it is to that place that you must begin to journey” (p. 57). This also informed the inclusion of the clarifying question about the relationship between spirituality and sanctuary.

Soul Work and Psychotherapy

While I draw heavily on O’Donohue for my understanding of soul work, I must now acknowledge the influence of modern psychotherapy on the concept. All of the

authors to be discussed were academics who now write for a popular audience and who advocate for spiritually oriented psychotherapy congruent with what we see in the literature (e.g. Sperry & Shafranske, 2005; Sperry, 2018 or the meta-analysis of Captari, et al, 2018). These works offered me a sense of direction about the research until I found the spiritually oriented social work literature (which follows).

These terms, spiritual, soul, and psyche have many common usages as well as rich spiritual and linguistic histories, perhaps especially so when considered in relation to psychotherapy. For example, in *Modern Man in Search of a Soul* Jung says (1933, 2011):

[i]n Arabic, wind is rīh, and rūh is soul, spirit. There is a quite similar connection with the Greek psyche, which is related to psycho, to breathe, psychos, cool, psychros, cold, and phusa, bellows. These affinities show clearly how in Latin, Greek and Arabic the names given to the soul are related to the notion of moving air, the 'cold breath of the spirit'. (p. 209-210)

As psychotherapists rightly proclaim, soul is intimately connected to psyche, from whence comes the root word of many of the helping professions. Hollis (2006) makes this connection explicit in the introduction to *Finding Meaning in the Second Half of Life* where he says the word soul:

> has been banished by most of modern psychology and psychiatry, even though the word psyche, which lies at the heart of psychology, psychiatry, psychopathology, psychopharmacology, and psychotherapy, is the Greek word for soul. Almost as egregious, the soul has been sentimentalized by much so-called New Age thinking, or

> imprisoned in fearful, defensive dogma by religious fundamentalists. Yet I will risk using the words soul and psyche interchangeably in this book, for in each of us, the Self* is in service to the soul; which is to say, the directive, purposeful energies that govern our lives are themselves in service to meaning, though a transcendent meaning that often has little to do with our narrow frame of conscious understanding. (p. 5)

Likewise, Moore (2016, p. 9) says that if you were to read about these concepts in Greek

> you would see that the word used for soul is psyche, the word found in our words psychology, psychiatry, and psychotherapy. Imagine if we restored the original sense of soul to those fields, how we might deepen them and make the necessary connections between psychology and spirituality.

Indeed, where O'Donohue approaches these discussions from the predominantly spiritual side with a glancing nod to psychotherapy, others, like Jung, embrace the spiritual, including the mythic and mythopoetic, from the psychotherapeutic vantage. While there are certainly others integrating spirituality and psychotherapy, I have drawn heavily from those trained in Jungian or 'depth' concepts, primarily Blackie, Estes, Hillman, Hollis, and Moore.

Hillman (with Moore, 2008), a student of Jung's, focused his work on the concept of archetypes which, of necessity, draws heavily on soul work. Indeed, his work became a field of psychology known as Archetypal Psychology which centres the importance of the

soul in therapy. The threads of Hillman's soul-oriented work were picked up by his friend and colleague, Moore. In his preface, Moore (2008) states that Hillman "reserves the words psychology and psychological to refer to a genuine sensitivity to the soul. Psychoanalysis, therefore, is itself not always psychological" (p. 3). Further, for Hillman the soul "eludes reductionistic definition" and expresses all of the mystery contained in our lived realities (p. 5). Beyond that though, soul "connects psychology to religion, love, death, and destiny" (p. 5) and suggests the depth of the work. Similarly, in what is arguably his best-known work, *Care of the Soul* Moore (2018) also pleads for counselling and psychotherapy to include 'soul work'. Moore also advises people to seek the potential in their suffering, to embrace a curiosity about it, asking what is being revealed by the experience of suffering, to partner with the person in a process of exploration.

Hollis, another Jungian psychotherapist, highlights the importance of soul work, especially when one is suffering. Acknowledging that while we often feel victimised by our suffering and cannot imagine that anything positive could come of it, we "may [also] grudgingly admit that even the suffering enlarged us, and made us more richly human" (Hollis, 2006, p. 4). And like the others, he did not minimise the pain of suffering, acknowledging that "[f]or those in the midst of such suffering, talk of enlargement seems gratuitous, or insensitive" (p. 4). He (2018) likewise says "[o]nly through suffering, coming to consciousness, and being humbled, can one start anew" (p. 93). While this concept has been difficult for me to come to terms with, it also resonates with me, and certainly informed the rationale for the autoethnographic portion of the research, which I discuss in detail in the next chapter.

While it is arguable that men likely have been overrepresented in that literature, women also have been part of the psychotherapy community since its earliest days (e.g. Woodman, 1985; von Franz, 2001). Of those women, most influential in the context of this research was the work of Estes's (1995) text *Women Who Run with the Wolves* (Wolves) and Blackie's (2019) *If Women Rose Rooted.* I begin with Estes' work and with that, draw upon some of the critiques of psychotherapist's use of myth and folkloric concepts. From there I continue with Blackie's and their particular relevance to this work, in spite of the understandable critiques.

In step with the Riot Grrrl movement of the early 1990s, Estes' work provided a pivotal influence at a time of transition for GenX women. Her thesis centres the general and specific types of suffering experienced by (Western) women in the modern age. It can be argued, this work served as a call to action in keeping with the themes of the second wave of feminism. Her work drew on her personal history informed by cultural and mythological elements.

Folklore's Critique of Myth in Psychotherapy

The integration of myth as part of psychotherapy relies a great deal on folklore which began with Jung's work but remains an essential part of the practice today (e.g. Hillman, Moore, Hollis, Estes). However, the lack of rigour has long drawn criticism from the academic folklore community and must be noted. Given my background in folklore, I must briefly address those concerns before returning to the topic of soul work.

La Barre (1948), a folklorist, wrote that Jung's studies in folklore are methodologically reprehensible "for they are based upon a demonstrably false psychology" (p. 383). He further states that "Jung would deductively range over all time and space with the dreambook of absolute archetypical [sic] symbology, and rediscover eternally only what is in the book" (p. 384). Although Toelken (1996) offered a more favourable opinion regarding the integration of folklore and myth to psychotherapy, he agreed with La Barre's sentiments generally stating that

> [d]espite the rich possibilities in this area, however, few psychologists and psychiatrists have taken the trouble to get acquainted with the dynamism and variation in folklore, so they have tended to use single versions of a tale (and at that, something found in print in a standard collection of children's stories) rather than study the whole range of articulation found in all extant versions of a tale type. (p. 413)

He took particular aim at Estes' application of Bluebeard arguing that her application was "a highly unlikely occurrence in folklore" (p. 413).

The views from the folkloric community are not universally disparaging however. Propp (1958/1968) noted that an aspect of the evolution of tales is in the telling. Bendix (1997) argues that we need to consider the gaze of the viewer when conducting folkloric analysis and differentiating the authentic from the inauthentic. Popławska (2018) noted the thematic use that allows us to reconsider our attitude to myths, legends and folktales and appreciate their value as meaning-bearing cultural artefacts (p. 15).

Dundes in particular was considered a promoter of 'psychoanalytic folklore', advocating for "a modern folkloristic approach that focuses on symbolic patterning in cross-cultural variants while questioning for the purposes of explanation the particular symbols and specific projections that are culturally relative" (Bronner, 2017). Dundes (1987/2017) himself states that "[a]s a folklorist, I have come to believe that no piece of folklore continues to be transmitted unless it means something - even if neither the speaker nor the audience can articulate what that meaning might be" (p. vi). This plea to attend to the meaning within folklore carried throughout his work (e.g. Dundes, 1976). He (1976) argues that:

> [t]he fantastic dimensions of folklore have been consistently disregarded by folklorists and members of other disciplines studying folkloristic data. These scholars prefer instead to concentrate upon collection, classification, storage (in archives), comparison, and endless searching for the oldest cognate versions of a particular piece of folklore. The history of folklore scholarship is by and large a series of attempts to dehumanise folklore (p. 1501-02).

Dundes (1976) continues his argument with a clarification that he means dehumanise literally; to extract the 'folk' from folklore, distilling the products of folklore to quantifiable, decontextualised categories. Those categories allow folklorists to "effectively forget about the fact that folklore is used as a means of traditional communication between humans" (p. 1502). And perhaps this is where the work of those like Estes becomes invaluable to women seeking an understanding of themselves, especially during an epoch in which women were reclaiming power, declaring that the

‘personal is political’ but with few templates to follow. These works (re)build that template for women by reflecting historic themes. They push back against the narratives that centred the dominant gaze and left no room for the lore of others. Estes (1995) argues that “instruction found in story reassures us that the path has not run out, but still leads women deeper, and more deeply still, into their own knowing. The tracks we all are following are those of the wild and innate instinctual Self” (p. 12). Estes, and later Blackie, amplify the threads of women’s stories within the larger body of lore. In the aforementioned Estes version of Bluebeard, she has reframed the trope of the disobedient wife as the curious woman who learns to set boundaries. Perhaps not considered an authentic retelling, it is also perhaps an important one for women wishing to break free from another, more constricting narrative.

Estes (1995) shared the numerous ways women do and have always pushed back against the dehumanising, soul constricting narratives; feeding their souls in ‘unauthorised ways’ often through creative practices such as painting and writing as well as strong relationships and connection with nature. She argues that addressing these needs is essential to women’s health and healing though “[t]raditional psychology is often spare or entirely silent about deeper issues important to women" (p. 12). It is her care for the souls of women that compelled her to write Wolves and further, “has driven [her] work on the Wild Woman archetype for over two decades” (p. 12). She feels the conventional treatments only serve to “[carve] her into a more acceptable form as defined by an unconscious culture” (p. 12) or to bend her “into a more intellectually acceptable

shape by those who claim to be the sole bearers of consciousness" (p. 12). Her work then, is soul work but focused specifically on the souls of women.

When I considered her work in relation to the reason for my research, I wondered if, given the social constructs of gender, there is something about chronic illness/conditions that perhaps amplifies the need to claim/reclaim the Wild Woman energy for women. This curiosity informed the rationale to constrict the research participants to women only. It was the connections Estes draws, in conjunction with the work of those like O'Donohue and Fox (2002), that prompted me to include research questions relating to creativity. Estes continually links the Wild Woman archetype to creative expression, whether through dance, art, story, domestic arts, or birth. For her, creativity is integral to the needs of the soul and while exile from the soul wounds creativity, exile from creativity likewise wounds the soul. From her work I wondered if creativity was both a medicine to soothe us when we were not in relationship with sanctuary as well as a vehicle to help us access sanctuary. Like Estes, others have asked these questions, seeking to engage creativity as a kind of soul work. For example, Allen (1995, 2005), and Fish (2006, 2012) embrace arts-based soul work and were instrumental to the research design. As their work informed the methodology, it is reviewed in the next chapter.

Blackie, the final author in this context of soul work, writes primarily for women, drawing on women's myths and creativity in her work. A former neuropsychologist who now writes for the popular market, Blackie describes herself as a mythologist, depth psychologist, and writer. She weaves experiences and knowledge drawn from her doctoral and post-doctoral work in neuroscience/psychology together with her further

studies in Celtic studies and creative writing. Her work shares many qualities with Estes, both in acknowledging the particular enculturation of women and how it has generally informed women's experiences as well as drawing heavily on myth and lore. In Blackie's case, and appealing to me, is her use of Celtic mythology in particular. She also addresses the way that marginalised voices have been impacted by the collection of lore and rather than adhering to the conventional myths she also seeks threads of women's empowerment to amplify within the tales.

Blackie (2019) argues that "[t]he stories we tell about the creation of the Earth and the origins of humankind show us how our culture views the world, our place in it, and our relationships with the other living things which inhabit it" (p. 20). For Blackie, like Estes, reclaiming the old tales of women who had power, agency, and intellect is a way women can develop a counter-narrative that strengthens them, rather than diminishing them. She acknowledges the ways that Celtic myths, in particular, were recorded by Christian monks (in most cases) and how this particular lens then coloured the transmission of these stories from then on. And again, like Estes, she corrects this by noting the threads of strength and power, amplifying those in her own retellings rather than adhering to the commonly repeated narratives.

While I had a sense of these texts as formative to my research, I wondered about their scholarly relevance. In considering their work in the context of women's experiences of disability I recognised a thread connecting their experiences, especially the feelings of being silenced and experiences of microaggressions with the premises espoused by both Blackie and Estes. The congruences with modern fairy-tale studies, with their emphases

on the genre's socio-political and sociohistorical context, supports much of what Blackie and Estes claim. Haase (2000), a professor emeritus of German with a specialisation in folk and fairy tales, credits an exchange between Lurie and Lieberman during the early 1970s as the "advent of modern fairy-tale studies" (p. 16). Within that field "[q]uestions about canonization and the male-dominated fairy-tale tradition would lead to the discovery and recovery of alternative fairy-tale narratives and to the identification of the woman's voice in fairy-tale production, from the earliest documented references to the present" (Haase, 2000, p. 16).

Haase (e.g. 2000, 2004, 2010, 2019) is but one of many highlighting the very contextualised lens through which tales and lore have been gathered (e.g. Jorgensen, 2019; Khan, 2019; Michaelis-Jena, 1971; Neikirk, 2009; Ó Giolláin, 2007, 2017). Haase (2004) challenges Gottschall's claims that the influence that occurs when relying on "samples… collected, edited, translated, and in some cases retold by Westerners, usually males, between 1860 and 1930" (p. 21 Gottschall in Haase, 2004) can somehow be mitigated by the population gathering them. Haase draws on Naithani who "convincingly demonstrates the complex and sometimes hidden intercultural process by which colonial collections of Indian folklore and folktales were gathered, edited, and translated" (p. 22). In the Irish context, relevant to the work of Blackie (2019) as well as O'Donohue, not only has lore collection been gendered but now considered "a product of its time" (Ó Giolláin, 2017, p. 141) with the Irish Folklore Commission preoccupied with "pastness, with the countryside, with Irish-speaking districts, [and] with male informants".

Of interest to me is how much of my mental health training exists along much the same lines as these authors relate with regards to the collection of lore. The system is organised in a paternalistic structure with the therapist as the expert (e.g. making a diagnosis, sometimes with little input from the person), a strictly reinforced hierarchy (therapist and client rather than people in partnership as well as the hierarchy that exists in the Western medical model), and focused on curing or symptoms management. Unlike what I have identified in the realm of soul work, in that paradigm, there was little room to ask what might be being revealed by these symptoms, what the person's experience of the symptoms were, or even to embrace their story about their experience and what their priorities for treatment were. My struggle with that system led me to seek out other ways of being with people such as those articulated by the psychotherapists in this section. Although not so explicitly in the realm of soul work, another influence was narrative therapy, as previously discussed.

Those experiences also led me to this dissertation topic. While elements in my mainstream mental health system training that aided me in coping, they were unequal to the task of truly supporting me in the existential and spiritual crisis that accompanied my health crisis. What I needed, especially during the months of waiting to learn whether I had a brain tumour or not, was not someone to try to help me 'change my thoughts to change my feelings', to paraphrase from one of the many Cognitive-Behavioural Therapy (CBT) trainings I attended. What I needed was a place to just be, to feel safe to process the grief, fear, anxiety, and symptoms without setting a goal focused on improving my mood. I needed someone to support me to uncover what I needed to see, what potential

there might be for me in this experience, and to just be wholly present alongside me in a way my loved ones could not. My personal experience, alongside years of professional experience, reinforced the importance of soul work for me.

This is a summation of the idea of soul work as it influenced the initial research direction. It is from making the connections between O'Donohue's work to looking more broadly at Celtic spirituality and soul work that I found the body of literature focusing on spiritually oriented social work. The relevant texts will comprise the next section of this literature review.

Spiritually Oriented Social Work

As previously discussed, my readings in Celtic spirituality were largely situated in academic folklore and were informed by Primiano's (1995) vernacular religion or 'religion as it is lived'. While this orientation relieved me of the need to validate the 'authenticity' of the practices, my scholarship sought to understand the range of perspectives in this discussion and included researchers from a variety of disciplines including archaeological (e.g. Cunliffe), historical (e.g. Hutton), folkloric (e.g. Bowman), and theological (e.g. Low). These studies eventually led me to a collection of articles by Béres, a social worker, professor, and researcher. In addition to matching my interest in Celtic spirituality her writing (e.g. 2012a, 2012b, 2017a, 2017b, 2018) validated my interest in spiritually oriented social work. Most relevant to this dissertation, these works provided a much needed introduction to the world of spiritually informed social work practice. This portion of the literature review will centre the texts that flowed from my

exposure to Béres work which then directly informed my research direction and questions.

As I have already addressed the fraught history of spirituality in social work, I will not expand on that further. Instead, I begin this section by considering the work of modern theorists who have provided a foundation integrating spirituality with social work practice. While each of the texts have similar threads, each has distinct foci and purpose, and informed this research in different ways. These texts include a range of themes that I will consider here including conceptualising and contextualising spirituality, spiritual diversity, and applications for practice. Critical reflection also formed a significant contribution by these texts but is addressed in the next chapter.

Conceptualising and Contextualising Spirituality

In keeping with the previously discussed distance between social work and spirituality, Bullis (1996) began his text with "[s]pirituality and social work practice might seem like strange bedfellows. They have been estranged for so long that it might have seemed that they have been long divorced with irreconcilable differences" (p. 1). Bullis offers his text as a roadmap for social workers seeking to integrate a spiritual lens to their work and a thorough explanation of its importance in a well-rounded practice. He further shifts the conversation away from religion or a specific spiritual lens towards a broader conversation, including an acknowledgement of the importance of a cross-cultural spiritual lens when that too, would have been cutting edge.

Bullis's definition of spirituality is similar to Palmer's (2014), previously mentioned in the document. Bullis offers spirituality as "the relationship of the human person to something or someone who transcends themselves" (p. 2). This is also similar to Canda's (1988) early definition: "spirituality as concerned with the human quest for personal meaning and mutually fulfilling relationships among people, the nonhuman environment, and, for some, God" (p. 243). Bullis noted that in his definition the terms someone and something are left intentionally broad and vague to make space for all persons' perspective and experiences. And for Bullis, part of that breadth also includes the integration of the mythic. He acknowledges the long history between humans and story, as well as ritual, coupling that with the shift in consciousness and understanding that happens with the integration of imagery and symbolism. He argues that as one of the benefits of a spiritually informed social work practice. This appealed to me personally as it reflected the way I have sought to marry social work and folklore.

Bullis (1996) references Spencer's definition of the religious as "one who holds beliefs about 'the affirmative nature of the Universe and man's duty to do something in addition to advancing his own ends'" (p. 2). He further draws on Joseph's (p. 2) assertion of religion as "'the external expression of faith… comprised of [sic] beliefs, ethical codes, and worship practices". In distinguishing between religion and spirituality, Bullis draws attention to the identity built around religion, its forms of beliefs, rituals, dogmas, and creeds, and, as part of that, the denominational identity. He functionally identifies spirituality as a largely inward process and religion as a largely outward process.

Canda and Furman (2019) position religion and spirituality differently. They begin their discussion of the definitions by contextualising them in the fields they considered to enhance their understanding (e.g. religious studies and anthropology). They acknowledge the variations on the themes of both spirituality and religion along with the challenge of trying to create a definition that is both sufficiently open yet with an appropriately clear structure. They express that the lack of consensus and clarity within the definitions is not a problem for them as "it is better to develop an open working definition, which takes into account previous scholarly work and invites continued dialogue and debate" (p. 64). From here they advocate for clarity of working definitions rather than the rigidity and certitude of final definitions. They acknowledge the history of social workers including ideas of spirituality from the early days of the profession but likewise acknowledge that those ideas were grounded in the Judeo-Christian framework that dominated much of the Western world at the time.

In their continued review of the history, they articulate the shift that occurred in the 60s and 70s, when "prominent scholars advocated for a return of professional attention to spirituality" (p. 65). This attention went beyond the historic Judea-Christian lens to include "existentialist, humanist, Zen Buddhist, and shamanistic perspectives… in the effort to define spirituality in an inclusive manner" (p. 65). People also began to consider outward expressions of spirituality that occurred outside of formal organisations and institutions. No doubt inspired by the changing landscape of social work practice, in the 80s Canda undertook "a study of the diverse definitions of spirituality presented in American social work publications at that time" (p. 65) which included interviews with

the 18 most prominent authors "to cull more detailed personal insights central values and concepts about spirituality and social work" (p. 65-66). The participants represented a range of beliefs and spiritual values including atheist, Christian, existentialist, Jewish, shamanistic, and Zen Buddhist perspectives. In some cases, they held multiple beliefs or spiritual identities.

From the data, Canda (in Canda & Furman, 2019) built an early conceptualisation of spirituality that eventually evolved into the definition they use in the text. For Canda and Furman "spirituality refers to a universal and fundamental human quality involving the search for a sense of meaning, purpose, morality, well-being, and profundity in relationships with ourselves, others, and ultimate reality, however understood" (p. 59). They argue that spirituality can exist both within and without religion. Religion is "an institutionalized (i.e. systematic) pattern of values, beliefs, symbols, behaviors [sic], and experiences that are oriented toward spiritual concerns, shared by a community, and transmitted over time in traditions" (p. 60). They position spirituality as a way of being rather than distilling it to practices or cognitive processes.

In *Critical Spirituality* (2016), Gardner built a similar narrative to the aforementioned texts. With her philosophical and theoretical orientations clarified, Gardner engaged critical spirituality as practice with a discussion of the need to balance the "acceptance of diversity with not accepting spirituality that is abusive or denies diversity in others" (p. 61). She further enumerates the tension that can happen between the "individual's desire for expression and the community's desire for unity" (p. 61). Gardner articulates the importance of engaging in deep personal reflection to ensure self-understanding and the

self as a spiritual person, before engaging in any spiritual practice with others. For Gardner, as spirituality is not fixed, self-reflection must likewise be an ongoing practice. Both Gardner's practice and theory rely heavily on the integration of critical reflection, which as I stated previously, is discussed in detail in the next chapter.

The final core text that informed my understanding of spiritually focused social work is Béres's (2017) *Practicing Spirituality.* This text, to which Béres contributed as well as edited, differed from the previous text in the inclusion of other, allied, disciplines. Béres also argues the importance of including spirituality in social work practice, linking it explicitly to the biopsychosocial model of practice. Drawing on the work of Cook et al (2009) psychiatrists in the United Kingdom, she references Cook's definition of spirituality (in Cook et al, 2009) which asserts that spirituality is of ultimate importance to people "providing them with a sense of meaning and purpose in life" (p. 1). As such, there is no justification for a practitioner to completely disregard it which in turn, requires the practitioner to have the skill to engage in spiritually oriented practice, just as they are trained in other assessments.

Perhaps most importantly, in this text each contributor explored their own ideas of spirituality and how it fits with their practice. Among the contributions, Fook draws on Sheldrake's understanding of spirituality as "a stance of attending to 'life as a whole'" (p. 27). Sheldrake (2013), in his *Spirituality: A Brief History* ties this to the idea of a holistic life, which has connections to the holy and the sacred. He links this etymologically to the root words in Old English (hālig) and ancient Greek (holos). He further links this to the religious origins of spirituality and the current understanding of "the numinous

(sometimes embodied in nature or in the arts), the undefined depths of human existence, or to the boundless mysteries of the cosmos" (p. 3). Sheldrake further links the concept to the personal search for meaning, including a sense of purpose and direction. These elements certainly do add up to a sense of 'life-as-a-whole' but without the challenges that join modern discussions and debates about religion.

One of the unique, yet resonant conceptualisations of spirituality was in Pulliam's chapter in Béres (2017). Pulliam identifies as a woman of African and Native American roots who has engaged with a variety of spiritual traditions. She identifies the fluidity within her spiritual practices that she feels is reflected in Lorde's attestation that "[t]here are no new ideas still waiting in the wings to save us as women, as human. There are only old and forgotten ones, new combinations, extrapolation and recognitions from within ourselves, along with the renewed courage to try them out" (Lorde in Pulliam, p. 50).

For me this captured something about spirituality 'emanating from my intuition'. While I worried about the overwhelming whiteness in my dissertation, I also recognised that the vast majority of my history is rooted in 'Celtic' traditions and the importance of that for my practice. I realised that while my roots share an origin with colonisation, embracing my roots can also be a tool that allows me to know myself on a deep level and can support my own decolonising practice. I had long sought alternatives to this but always felt like an interloper, an outsider, and, at times, an appropriator. What I finally understood was the importance of not fleeing the complexity in my history, but facing it. When we can embrace that complexity, we banish our anxieties about 'the Other' which in turn, empowers us to participate in lifting 'the Other' up. When considering the

literature that informed the research direction, this particular chapter represents a turning point for me as it highlighted the importance of this work, of developing a deep, critical spirituality that embraces complexity, diversity, and carries through to practice.

This is an essential quality of spirituality and a sentiment that underscored the need for this dissertation. O'Donohue, as well as the previously mentioned authors, say much the same thing; for spirituality to be a true spirituality it must have a robustness to it. This depth is what comes through in Mila's chapter 'Mana Moana' (in Béres, 2017b). Like many who write about spirituality, she writes of the interconnectedness of all things from her Pasifika orientation. This connection from the Pasifika lens makes no room for the question: what is spiritual? Instead, the question is: what is not spiritual? And perhaps that question is the better one to ask. After all, rather than spirituality justifying itself, perhaps there is a need to justify what moves away from the spiritual.

Rumbold (2017) states something similar, that he conceives of spirituality as both our experiences of and our stance toward the world (p. 167), and is expressed through all of our relationships (with the animate, the inanimate, and the numinous). He perceives spirituality as expressed through the "various aspects of our existence" (p. 167) and wove all of those aspects together. He expressed spirituality as an aspect of life that cannot be extracted from other aspects and because of this, it can act as a disruptor, deconstructing our analyses and resisting any containment within a tidy intellectual frame. His chapter brought to mind this offering from Gardner, "[o]ne of the ironies of writing about spirituality is that it means putting into words something that by its nature defies

definition" (Gardner, 2011, p. 19) though the importance of being able to communicate about it requires that we at least make the effort.

Spiritual Diversity

All of the aforementioned texts address the need to look beyond the Western/Judeo-Christian perspective. While Bullis's text would have been ground-breaking at the time, it must now be read advisedly. His enthusiasm for embracing practices from other traditions is both laudable and, from the current vantage, at times problematic. In keeping with his openness to a range of perspectives, Bullis makes many of the same points as those discussed in the soul work section though he offered a caution about leaning too heavily on psychoanalytic theory, referencing the work of Susan Spencer.

Bullis articulated the long history of 'healers' and their portrayal in myth, hymn, and lore, from a range of traditions and cultures from Norse mythology to First Nations practices and Tantra. He linked these traditions back to social work practice, articulating the relationship between spirituality and personal/social healing. He restates social work's commitment to value the whole individual, which must include valuing the person's spirituality. He argues that each social worker must do so in an intentional way, by reflecting on their own spiritual orientation, and selecting a model to support them in their work; he emphasises the importance of refraining from relying on default or habit. In support of this, he offered a comparison of the medical and spiritual models, contextualising them in the relevant jurisprudence (of that time). He also reminds us of the importance of myth and ritual in spiritually oriented work, and emphasises the

importance of myth as spiritual truths and ritual as initiatory processes. With this, he connected the spiritually oriented social worker with the psychopomp, one who supports the client in their spiritual adventure and transformation.

While there is no question that Bullis's text would have been ground-breaking when first published, aspects now feel to me like cultural appropriation or simply concerning. For example, he offered a discussion of the use of shamanic techniques, including the employment of ecstatic trance in practice. While he cautioned the interested social worker to engage in these practices "with the same care and grace that should accompany involvement in any professional episode involving spirituality" (p. 134), I think more caution is needed. While a retrospective consideration of these suggestions might be met with concern, what I do appreciate is the challenging, ground breaking, and thorough treatment of spirituality within this text. In particular, I respect Bullis's attempt to challenge the hegemonic cultural and spiritual structure in service to all social work clients.

While Canda and Furman's (2010) text promised a wide-ranging consideration of spiritually oriented social work, they opened the first chapter with a quote from the Bible, which gave me pause. For a text titled *Spiritual Diversity in Social Work*, this felt like a signal contrary to the promise of the title. And then they say:

> spirituality is the heart of helping. It is the heart of empathy and care, the pulse of compassion, the vital flow of practice wisdom, and the driving energy of service. Social workers know that our professional roles, theories, and skills become rote,

> empty, tiresome, and finally lifeless without this heart, by whatever names we call it. We also know that many of the people we serve draw upon spirituality, by whatever names they call it, to help them thrive, to succeed at challenges, and to infuse the resources and relationships we assist them with to have meaning beyond mere survival value. (p. 3)

This felt welcoming to all and consistent with my research aims and goals. I appreciated the statement "by whatever names we call it". I further appreciated the discussion about the history and recent reconsideration of spiritually informed social work in the text. They then state that their aim is to represent "the state of the art of spiritually sensitive social work that is respectful and competent in response to the diverse forms of spirituality that is expressed in clients' lives and communities" (p. 4).

Canda and Furman build on a previous edition of the text, including revisiting and re-administering their previously conducted survey with social workers in practice. While they draw on their own study conducted with the support of the National Association of Social Workers (NASW), they marry those data with data obtained in collaboration with colleagues in the United Kingdom, New Zealand, and Norway. Their goal was both to present an academic consideration of spirituality and social work as well as to reflect what is actually happening in practice. Throughout the introduction they offer implicit and explicit reassurances of the intent to provide breadth within the work. For example, they state that "[a]t the outset, please be assured (or forewarned, depending on your viewpoint) that this book does **not** advocate for a religious sectarian view of spirituality or social work" (p. 5). They operationalise spirituality as being "*a universal quality of*

human beings and their cultures related to the quest for meaning, purpose, morality, transcendence, well-being, and profound relationships with ourselves, others, and ultimate reality" (italics in text, p. 5).

They then reference Canda's 2008 paper

> spiritually sensitive practice is attuned to the highest goals, deepest meanings, and most practical requirements of clients. It seeks to nurture persons' full potentials through relationships based on respectful, empathic, knowledgeable, and skilful regard for their spiritual perspectives, whether religious or non- religious. It promotes peace and justice for all people and all beings (Canda, 2008, in Canda and Furman, 2019, p. 5)

Their explicit inclusion of atheism alongside the other traditions indicates a truly diverse lens on spirituality. Within the text they discuss the reality that while there is a growing group of those who consider themselves atheist, spirituality is a generally universal human experience. Other research such as the Pew study supports this perspective (Lipka, 2019). While atheists may not describe themselves as spiritual (though some do), they do espouse beliefs that fit well within non-religious views of spirituality, such as acknowledging the importance of connection with both human and non-human life.

As part of their Guiding Principles, Canda and Furman engage with the debate around absolutism and relativism which must be addressed within the context of spiritual diversity. What I found most useful about this, especially in light of this research, Canda

and Furman's read of Wilber. Wilber's statement that an extreme postmodern position claims that no one perspective is superior to another which in turn is a "self-contradiction in that it claims itself to be better than absolutism and other perspectives" (in Canda & Furman, 2019, p. 13). Of course, alongside this is also the problematic statement that there is no absolute truth, which is equally self-contradictory. More than simply theoretical exercises, these are essential considerations for social workers given that our work deals in truths, values, and perspective taking with our clients. And these must be weighed against our legislated authority, the rights of others, and safety considerations.

Canda and Furman argue in favour of value clarity for the social worker, open communication, and ongoing self-reflective practices as an antidote to absolutism. In the context of this research, I see this as a key rationale for the inclusion of vernacular religion. It too posits that there is no absolute view of 'official' faith or religion, rather, it leaves space for conversations about each person's lived experience of their practices. While this may be challenging to scholars of specific faith orientations, this way of engaging with faith practices leaves more room for discussion and diversity.

In both of their texts, Gardner and Béres also discuss the importance of diversity in spirituality, representing it through a range of contributor voices. The perspectives offer a glimpse of the self-reflective practices that assist those practitioners in the integration of a spiritual lens to practice. They ground their practices in both social work theory and wider philosophical and even broadly theological considerations. Perhaps most impactful for me were the acts of reclaiming and re-imagining represented in

Practicing Spirituality, such as the previously discussed practice of Pulliam. This type of internal diversity in practice is something that I believe social workers must be open to provide a truly spiritually oriented practice. Perhaps now more than ever, especially for those of us who are not Indigenous living in North America, and who may have a mix of ancestries and origins, there can be a reclaiming of traditions and practices that creates a personal sort of faith or wisdom tradition bricolage. While there are a great many critiques of those who identify as 'spiritual but not religious' or who do not claim a rigid adherence to a proscribed tradition, when one reads Béres (2017) edition, for example, there can be no mistaking the depth of work that is part of creating your own faith-based bricolage.

Social Work Application

While understanding social work theory and our relationship with it is important, social work is a field of practice and application. All of these texts are aware of this and articulate strategies for integrating a spiritual lens within social work. Bullis (1996, p. 7), for example, argues that the rationales for including spirituality in social work can be summarised as the shared goal of promoting the healing of personal and community strife, violence, and ignorance. Social work and spirituality can contribute to each other's effectiveness through different insights that can support transformation.

Bullis continues with more general methods for integrating a spiritual lens to social work, drawing on established social work practices with his instruction on the creation of spiritual genograms and maps. From there he branched into expressive interventions

including the creation of spiritual body art and masks. He included instructions for exploring spiritual themes in dreams as well, though a social worker might want to engage in these practices advisedly.

Before discussing how social workers can integrate spirituality into practice, Canda and Furman (2010, 2019) first engaged with the debate around the inclusion of spirituality to social work practice. They thoroughly enumerated the range of supporting and opposing views they collected in their research, providing a lens for both those who have the desire to implement spirituality into practice and those with concerns. Throughout the text they highlighted the importance of self-reflection to understand one's own position, including positions where there is a desire to remove any notions of spirituality from practice. The exclusion of spirituality from practice can be seen as a superior or 'more' professional orientation but Canda and Furman (like Gardner and those in Béres) challenge this perspective seeing it as too often driven by the social worker's comfort level or policy, rather than the person's needs and preferences.

Throughout these texts exists general unanimity as the exclusion of a spiritual lens by the social worker as incongruent with the idea of "supporting the whole person-in-the-environment" (2019, p. 6). Building on this, Canda and Furman argue the fundamentals of including spirituality as part of a comprehensive and ethical social work practice but implemented with intentionality and a critical stance, bringing it into alignment with Gardner's 'critical spirituality'. They draw on cross-cultural expressions not only demonstrating the importance of a broad lens to define spirituality but also modelling respect for a range of practices and orientations. They noted that although there were

significant differences in the beliefs of their research participants (ranging from atheist to shamanic) the common themes all fit under the broad definitions of spirituality as all agreed that "each human has inherent dignity and worth and deserves unconditional positive regard" (p. 50). The research participants, from all backgrounds, further agreed that humans must extend care and responsibility to the non-human world for a variety of reasons, including our inter-dependence on it, the sacredness of it, or its existence as an expression of the creativity of the Divine. Further, the participants expressed agreement that social work should include efforts in support of well-being as well as social justice. Ultimately, drawing on materials from their research coupled with other literature, Canda and Furman argue that social work, with its belief in the power of transformation, is in its best sense, a spiritual vocation.

Canda and Furman's work revealed that even those who have some hesitation about the general inclusion of spirituality into social work practice do see some specific areas of practice where it is generally an appropriate topic. No surprise to me given my social work practice, terminal illness topped that list, with 86.1% of participants agreeing spirituality was an appropriate topic. Second to terminal illness, though related, both religion and spirituality were deemed appropriate when working with those who are bereaved. My sense of this, both in the readings and in my practice, is that at times there is an implicit permission to include spirituality in practice, even within rigid structures like health care that generally tend to exclude spirituality from practice. This would likely not surprise any social worker practising in these areas. As Rumbold (2017) says, "[s]piritual care was, from the beginning, an aspect of hospice care" (p. 173).

Of course, one must consider more than simply their practice area before deciding to engage in spiritually oriented practice. Within the literature a key determination in the inclusion of a spiritual lens was ensuring value clarity. I read this as a facet of critically self-reflective practice. To this Canda and Furman add the additional step of making one's value positions explicit with both colleagues and clients as part of a commitment to transparency and ongoing dialogue that ultimately contributes to our growth. It is also a fundamental aspect of informed consent. They caution that this must be appropriate self-disclosure, another fundamental aspect of social work practice. I determine whether a disclosure is appropriate by starting with the question: whose needs are being served here?

Concomitant with value clarity is a reflection on ones' own self-awareness and spiritual practice. Integrating a spiritual aspect to social work practice is not, as Gardner argues, a technical skill or technique. She referenced Topper who discussed spiritual care as a way of being, as "an intentional attitude that respects and cherishes a person as a spirited organism with spiritual needs" (Topper in Gardner, 2016). Béres also noted that the integration of a spiritual lens within practice is about more than simply applying another professional framework. As she (2017a) says, we live in a fast-paced world and one that seems to be leaving people feeling disenchanted, even hollow. In response it seems that people are seeking other ways of finding meaning, including accessing a range of wisdom traditions and spiritual expressions; social workers are no exception to this. The integration of the spiritual lens may benefit practice, of course but it may also benefit

each practitioner as well, so long as it is engaged critically, respecting each individual, and supporting them to engage in their own meaning-making explorations.

Gardner offers case examples of applied critical spirituality and self-reflective practices that can be used to guide the practitioner. She includes in that, a discussion of the importance of ritual which, while often conflated with religion, has applications in spiritual and secular frameworks as well. The experiences of applying a spiritual lens are discussed in the interviews Gardner conducted with a range of practitioners. The transcripts offered not only an additional depth to the previous theoretical discussion, they also offered a glimpse of how practitioners integrate spirituality into their practice, as well as their own spiritual explorations.

Béres (2017) *Practicing Spirituality* offers a similar glimpse of a range of practice experiences. Unlike the other texts, the experience of practice, theory, and personal reflections are commingled in each chapter, which represents each author's view. Béres opens the text with a grounding in the literature, reflections on integrating spirituality as a topic in the direct social work practice courses she teaches, and reflections on the experiences that led her to her particular worldview, which includes spirituality as a core aspect of the biopsychosocial model.

Rather than offering a codified set of suggestions for inclusion, each chapter offers a practitioner's perspective on how and why they have a spiritually informed practice. The openness with which they share their process of integration offers a challenge to the reader to do the same. Perhaps most importantly is the integration of a robust critically

reflective practice as part of each chapter. This models the process even as it reveals what is usually concealed: the practitioner's internal or private process. In so doing, the practitioner supports the reader to likewise engage not just for the betterment of practice but also, as Gardener states, to engage with “that which gives life meaning, in a way that connects the inner sense of meaning with a sense of something greater" (Gardner, 2016, p. 40).

With this I have summarised the literature and concepts from the study of spirituality and social work relevant to this dissertation. These readings not only influenced the research direction, they have also contributed to my practice. These readings directly informed the way I considered the research around disability/chronic illness and first-person narratives, which I will now review and discuss.

First-Person Narratives

In this final section of the literature review I begin with my position vis a vis the first-person narratives that informed my view and direction. While I appreciate the enthusiasm of those, like Wong (2020), Ellingson (2017), and Deal (2003) to claim their full identity (inclusive of their disabilities) and to claim ‘crip space’, it is an enthusiasm I do not share for myself. Although the community would claim me (e.g. Samuels in Wong, 2020) my engagement with the community is a reluctant one. This is in part due to the invisible nature of my disability which requires me to share more of myself than I might want to gain access/be seen as a member. It is also because I do not embrace my disability as part of myself. At best, we have an uneasy truce, some of the time; and I

would be rid of it in a heartbeat, given the opportunity. This is not a universal view in the disability community and one, I worry, might be seen as problematic. This, necessarily, complicated my review of the literature as well as validating the inclusion of the autoethnographic focus of the research.

An additional complication that informed my review of the literature is that I share Minich's (2016) concerns that elements of the disability movement are hampered by the lack of clarity in defining disability. Concomitant with that is the hierarchy of disability evolving within and without the community and the problematic aspects of that. I note a deep conflict within myself about that hierarchy. I understand the need for disability to be a self-applied label and that it should be the person, rather than systems or theories, who determines to what extent they are disabled. Contrary to this, I also work in a system with finite resources and do find myself thinking about the theoretical ('if we could meet every need, this is what I would do') versus the actual ('we cannot meet every need so how do we meet the most needs possible in the most ethical way and within our constraints?').

The final challenge was determining from which perspective to view the literature. Given the breadth of literature with disability as a theme and the narrow research focus, I quickly realised I would need to constrain myself to only that which matched the research aims. After a brief survey of the wide-ranging literature, I realised that my focus needed to be on women's experiences, ideally from first person accounts and from those who have invisible disabilities. While there are those (e.g. Reynolds,

1997, 2000, 2017) whose articles include an abundance of direct quotes from participants, those experiences remain filtered through the researchers'/recorders' lenses. While there is certainly use in this vantage in this context, it felt as though the primary literature needed to match my research focus. After all, as Richards (2008) says "[t]he voice that is heard most often in medical narratives of various sorts is the voice of the distant expert, and this voice can be quite pernicious" (p. 1720). Additionally, there is an abundance of literature centring different types of illnesses and conditions but I found myself questioning the parallels of (for example) cancer experiences and lupus; cancer, for example, has a different symbolic charge and social understanding than does lupus (e.g. Richards). Richards (2008) says that "for those of us who do experience or have experienced chronic health problems, each disease is a different country, with different languages and customs, different laws, different international relations with the healthy" (p. 1718). This has been my lived experience both as a chronic illness haver and as a healthcare professional.

For that reason, while I focused on first person accounts, I further narrowed my focus to accounts of invisible, chronic illnesses, privileging the experiences of people who have an uncontroversial condition, such as lupus, multiple sclerosis (MS), thyrotoxicosis, renal disease. What I have observed and what the literature confirmed is that it seems that there is a marked difference in experience for those with diagnoses of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) as opposed to a lupus diagnosis. I have a diagnosis that led to effective treatment, a close relationship with a rheumatologist, and it is a diagnosis that almost any health care provider would

understand and have compassion for. A diagnosis of (CFS/ME) however results in a range of reactions from complete scepticism about the existence of the syndrome to compassion and understanding (e.g. Hillenbrand, 2003; Samuels in Wong 2020). That difference is very worthy of consideration but not in keeping with the aims of this research.

The First Autoethnographic Narrative

The first autoethnographic narrative about lupus that I encountered was Ferdinand's (2016) 'It's like a black woman's Charlie Brown moment: An autoethnography of being diagnosed with lupus'. In addition to offering a rare, lupus-centred, first-person narrative, Ferdinand's article highlights the importance of focusing on literature from similar experiences, especially given the autoethnographic focus of the research. There is much in Ferdinand's account that feels remarkably similar to my own, not the least of which is the conflicted relief and fear at realising there is something tangible, medical happening to explain your symptoms and experience., and that those conflicting feelings are compounded by the sensation of fatalism and despair that comes with a life sent off its trajectory.

While there was much in Ferdinand's account that resonated for me, there were equal amounts that did not. For example, while I worried about assuming 'patient' status and the dehumanising that can come with the title patient, I did not ever worry about anyone making a negative assumption about me because of the colour of my skin. I did not sit in an appointment with a rheumatologist who "lament[ed] me with his opinions

and conjectures about affirmative action and the need to repeal it" (Ferdinand, 2016, p. 8) or who voiced "his hope and desire that I "earned" my education and hope it was not "given to me through special programs" as was the case for Ferdinand. With her story, I began to understand just how much representation mattered. This was only reinforced by the correspondence I would later have with the author.

With that knowledge, I sought out other first person, lupus centred narratives and quickly realised that while there are those who have endeavoured to represent the experiences of women with lupus (e.g. Auerbach et al, 2013; Beckerman & Auerbach, 2013; Mendelson, 2009; Richardson-Kline, 2013) I found few women with lupus writing about their first person experiences (e.g. Palmer, 2017). This knowledge coupled with Ferdinand's narrative and Richard's assertions highlighted the importance of this dissertation. Could I provide a resource for the next person seeking a first-person narrative about the lupus experience? Even more, with my focus on sanctuary, might it serve as a sort of field guide for that person? Might this offer a way to ideally understand and find some peace within the experience? Although I centre the experience of sanctuary rather than lupus, there is no avoiding at least some discussion of the lupus experience. The dearth of information, coupled with Ferdinand's encouragement, motivated me through my reluctance to expose myself in this research.

Ferdinand's and Richard's narratives also helped me understand how other narratives seen as critical to the field of disability studies, such as the work of sociologists Frank (1997) and Charmaz (1993) felt important to have read and yet less relevant to this

work. While both are arguably seminal texts informing the modern understanding of illness, both presented problematic issues for me. With Charmaz, it was simply the experience, as with Reynolds, of being seen through another's lens. Richards (2008) noted that much of the writing on disability has othered those who have disabled bodies. Othering "means turning a person into an object of some sort, such as a stereotype or even an object of study" (Richards, 2008, p. 1717). It creates a division between "the disabled" (or "the patient") and the expert. Indeed, no matter how well-intentioned, as Richards noted "[t]hose whom we study are never quite on the same level as we are. And they are always 'not us'" (p. 1717).

Difficulties With Some First Person Narratives

My encounter with Frank's (1997) text was much more challenging. On the one hand, his first-person narrative advocating for dealing with the experience of the chronic illnesses/conditions through the medium of story appealed to me wholly. It was a premise I wanted to embrace. I felt it matched my research aims and, even though he is a sociologist rather than a therapist, there was something in his work that matched narrative therapy as a vehicle for working through the experience of chronic illness. But for Frank, it seems as though the storyteller and their woundedness are one. While I appreciate the need to embrace the woundedness as Sparkes (1996) also articulates, I felt that Frank had perhaps advocated for what felt like an over-identification with the disease/condition. This sat as a counternarrative to my attempts to embrace a narrative therapy approach to the problem of lupus. Of note, within the narrative therapy perspective there is the tenet

that the problem is the problem, the person is not the problem. And although Frank's work felt as though it should offer something similar to the idea of narrative therapy's storylines (such as an illness storyline versus preferred storyline), whether it was his intention or not, within his context it seemed that I am my illness. For him, this may have felt empowering; for me, it felt that I am inescapably my problem, which is entirely disempowering.

Within this I found notable similarities to the aforementioned discourse on women's narratives in myth and folklore. This was also reflected in Whitaker's (2019) critique of addictions treatment in *Quit Like a Woman,* where she questions the relevance of hierarchical structures that comprise most addictions treatment, especially for populations who routinely experience systemic disempowerment. Although Whitaker writes for the popular market, her position is echoed by those like Ettorre (e.g. 2006, 2012, 2018) who notes that the gendered, classed, and racialised power differentials structuring women's lives must be acknowledged, otherwise, what we want to know about women's specific addiction treatment needs remain unaddressed. So too with Jiméneza et al (2014) who focus on the myriad gender differences in addictions treatment ranging from social perceptions to structural barriers, including job loss and childcare stresses.

Though I acknowledge this may have been my reading of the text rather than his intention, Frank (1997) states that "[h]er *story* was not just *about* illness. The *story* was told *through* a wounded body. The stories that ill people tell come out of their bodies" (p.

2). While I very much appreciate what seems to be an attempt at re-storying and embracing this new self rather than denying the illness experience, for me, there is far too much weight given to the self-as-ill throughout his text. For example, he says:

> [t]he alternative to this frustration is to reduce the body to being the mere topic of the *story* and thus to deny the *story's* primary condition: the teller has or has had a disease. That the teller's diseased body shapes the illness *story* should be self- evident primary condition: the teller has or has had a disease. That the teller's diseased body shapes the illness *story* should be self- evident. (p. 2)

I recognise that in the context of the day, the idea of illness and the conversations around it were vastly different than they are now and that this change is due to texts like Frank's (and Charmaz, 1993). As I contemplated further literature in the shadow of my reaction to Frank's work and the purpose of the research, I returned to Ferdinand's observation that "most illness narratives feature stories of survival; they offer a therapeutic escape in an effort to create a healed and whole self, a way of restoring a fragmented body. My story is not so much a story of healing, but a story of being" (p. 4). This resonated for me, in spite of our differences. While Ferdinand (2016) understandably contextualises her experience within the frames of race and gender, noting that at times, those experiences are "more poignant than the illness itself" (p. 4) she also noted that her work was not a celebration of triumph over the disease so much as "a story of being". The idea of a story of being, rather than of triumph, felt consistent with my research aims.

Differences in Experience

With the opening of Ettorre's (2006) 'Making Sense of My Illness Journey from Thyrotoxicosis to Health: an Autoethnography', I understood Ferdinand's concern about other illness narratives. Ettorre says "I have just suffered for two years from thyrotoxicosis" (p. 154). While I appreciated Ettorre's deep honesty and the example of marrying the personal with the theoretical, I cannot envision a world in which I could say that I had suffered lupus, in the past tense. Where Ettorre's work spoke to me was in her call to action. Like Ferdinand, as well as Richards, Ettorre called for "multiple embodied forms of health and illness representations, replete with uncertainties" (p. 156) through "actively engaging with anxiety, despair, disgust and agony as well as triumph, hope, joy and pleasure" (p. 156). These narratives "grapple not only with the intricate, interior language of wounding, despair and moral pain but also the victory of living an illness" (p. 156). While I understand Ferdinand's concern about the notion of victory, what I appreciate about Ettorre's position is that she follows this with a discussion of these works as offering an anti-narrative that "frustrates closure" (p. 157) and gives "voice to the structured silence of embodied illness experiences" (p. 157).

Although I appreciate Ettorre agreement with Frank's (1997) notion that through these narratives we can transform the challenges and struggle into a positive, even victorious experience I hope this may be the case for me but am not yet convinced. I currently identify as being in a truce with lupus, or taking peace with it, but I would not claim that I accept lupus and I certainly have no sense of the experience being positive or

victorious. To that end, Ettorre also argues that the author must engage in a self-reflective process to protect against unwittingly romanticising a preferred reality. This is one of the advantages, she argues, in engaging in autoethnography, which demands self-reflection in the process. I discuss the relevant aspects of autoethnography in the next chapter.

Conclusion

Although this is not a dissertation of Celtic spirituality, nor of O'Donohue's work per se, the reality is that these concepts underscored everything from the spark that generated my interest in this research to the actual structure of the research. Further, my understanding of personal sanctuary is contextualised by O'Donohue's work and the associated spiritual concepts. As such I began this chapter with a discussion of O'Donohue's relevant work which naturally led to the discussion of Celtic spirituality. Following that, I expanded on the idea of 'soul work' and how it guided my intent before I encountered the body of spiritually informed social work literature, which I reviewed next. I concluded the chapter with the relevant first person, chronic illness literature. It was my experience of this literature that directly informed my decision to undertake this research using the analytic autoethnographic method. The discussion of this method and the supporting methodologies begins in the next chapter.

One of the fundamental challenges of the literature review is determining what literature is relevant and appropriate for inclusion and what is interesting but must be left out. In this chapter, I have discussed the literature most relevant to the research focus as well as that which directly informed the research question. This literature also informed

decisions about methodology and the development of the semi-structured interview which is discussed in the next chapter. I will note that the literature review does not include the literature I investigated in response to the findings. I have incorporated that in the discussion of the findings found in Chapter 5, since it did not influence the development or structure of this research, but rather emerged from the data.

Chapter 3: Methodology and Research Framework

I liken the idea of methodology to the roots of a tree; they are essential not just to nourish the tree but for providing the necessary structure that keeps the tree upright. They are anchoring, the very definition of grounded, and yet, when we look at a tree, I suspect few of us give the roots much thought unless they call to our attention. I would say this is also often the case with research and methodology. And yet, like the roots of a tree, there is no research without it.

For me to achieve my research goals, the tree was a perfect analogy. My aims required an arboreous methodology that would marry strength and stability with flexibility and growth. The methodology needed to be scholarly but still creative, self-reflective, generative, and offering professional utility. I also needed a methodology that would encourage me to foreground my experience while remaining academic, rather than autobiographical. And ideally, a means to contextualise my data with other experiences to broaden my understanding and to keep the research self-reflective without becoming myopic.

As my social work experience informed the research goals, I hoped to generate a foundational theory that might, one day, grow into a broader, practice supporting theory. Further to this, a fundamental aspect of my social work training is in critical self-reflection (discussed in depth further in this chapter). Given that I suspected my ideas of sanctuary informed my actions from personal coping strategies to my social work

practice but could not clearly articulate how, I felt obligated to consider these experiences through a critical lens.

These aims, goals, preferences, and desires led me to the overarching structure of analytical autoethnography. I discuss the rationale for this at length in the next section but here I will simply summarise, stating that I wanted to both critically reflect on my experience and knew that my personal reflections would have much more depth if they were grounded in the experiences of similar others. I wanted to create a document that was scholarly and generated a theory more than being a narrative of my experience. While I have seen the merit of more evocative or narrative styles of autoethnography, it was not the right fit for me in this context.

Having established analytic autoethnography as the primary methodology, I considered how I could further ensure my fidelity to the process, develop deep personal understanding, and accurately report on that. I knew that I would need a framework to help me formally process what was arising through the interviews as well as to offer me a formal method of self- reflection. With that in mind, I employed two self-reflective processes; my own informal process and the much more formal, Critical Reflection on Practice (CRoP).

Recognising the effectiveness of expressive elements in my personal self-reflective practice (as well as my social work practice generally), I looked to the world of research-creation and from there, expressive therapies to augment my self-reflective practice. This led me to integrate response art as a supplement to the self-reflective structure. The self-

reflective practices and response art married well with the integration of Charmaz's constant comparison method (CCM) as my framework for data analysis. Applying CCM meant the data analysis occurred in conjunction with data collection and could therefore allow me to be responsive to the emerging data during the research period. I tied all of these separate facets together through the unifying structure of Ellingson's Crystallization Theory, and it is with that that I will open the methodology discussion.

Study design/crystallisation

Upon realising my research question, I likewise recognised that my research did not fit within a conventional framework with a single methodological process. Lockyer (2008) notes that the origin of qualitative methodologies "are located in the work of early ethnographers during the 17th century" (p. 706) with the Western, colonial, usual male researcher endeavouring to understand 'the other'. However, "the second half of the 20th century saw an increase in the amount and strength of criticisms directed toward positivism" (p. 710) dovetailing with calls for "methodological pluralism" championed by researchers, such as Tashakkori and Teddlie (in Lockyer, 2008, p. 710). Qualitative methodologies often follow a path toward new understanding and knowledge and within that there remain innumerable options to consider. Additionally, the ways in which the data is collected and used differs based on the researcher's orientations and research motives. Even before my research question had been fully articulated, the spiritual orientation of the question felt creative to me and so it followed that the methodology would need to be as well. I also knew that there must be a self-reflective component and ideally, a way to bring in outside voices.

Interdisciplinarity and boundary-riding

I encountered Horsfall and Higgs' (2011) discussion of interdisciplinarity or boundary-riding as I pondered the question of how to achieve my goals. Boundary-riding traverses "research territories, crossing discipline and personal/professional boundaries, having an ability to imagine transformation in personal and social practices, being curious about the unfamiliar, and being open to exploring new territory and learning along the way" (p. 45). Horsfall and Higgs emphasise the label of boundary-riding must not be a justification for haphazard research; rather engaging in boundary-riding should be intentional, yielding a better rounded and deeper result. Ultimately, within the concept of boundary-riding there is an element of moral agency and transformative practice inherent to the research. For those concerned about stepping outside of convention in this manner, Horsfall and Higgs remind the reader that the use of 'I' in research and autoethnography was once considered a transgressive act as well.

While their work did not offer a clear map forward, it did inspire me to persist. Fortunately, I encountered Ellingson and Ellis's (2008) discussion of the negotiation that occurred during Ellis's supervision of Ellingson's dissertation, including her boundary-spanning methodological approach. This caught my interest. In reference to the comment about boundary-spanning, Ellis reported that she "thought about how insistent [Ellingson] had been in her dissertation on including everything but 'the kitchen sink'" (p. 446). Even more important for me was the next line: "[s]he wanted to engage in crystallization and approach the oncology team she studied from a variety of perspectives".

Their discussion took me to Ellingson's relevant texts (e.g. 2008, 2009, 2013, 2014). I worked my way back to the genesis of the crystallisation idea, Richardson and St. Pierre's (2005) chapter 'Writing: A Method of Inquiry' where they explore the crystal as a structure to guide qualitative research; using that image to encourage researchers to consider a multitude of perspectives from a range of vantages. Crystallisation, Richardson and St. Pierre say, "provides us with a deepened, complex, and thoroughly partial understanding of the topic" (p. 963). Picking up the threads from Richardson and St. Pierre, Ellingson (2008) advocates strongly for boundary-riding research. While she outlined a suggested framework, she likewise urged that it be seen as inspiration rather than a rigid structure, offering her work as a map as a structure that:

> combines multiple forms of analysis and multiple genres of representation into a coherent text or series of related texts, building a rich and openly partial account of a phenomenon that problematizes its own construction, high- lights researchers' vulnerabilities and positionality, makes claims about socially constructed meanings, and reveals the indeterminacy of knowledge claims even as it makes them. (p. 4)

Like Horsfall and Higgs, Ellingson (2008, 2017) asserts that the ability for researchers to access myriad points along the research continuum provides increased opportunities for richer engagement. She argues that employing this type of breadth throughout the research enriches each facet of the process, resulting in greater richness overall. Further, within the crystallisation model, just as with boundary-riding, one embraces and seeks out a variety of methodologies in an effort to encompass a number of

perspectives along the research continuum (Ellingson, 2017). For example, while art and science may hold each other in tension Ellingson stated that this tension is not necessarily oppositional. Rather, art and science perform the necessary tasks of anchoring the far ends of the research continuum. In this, I was reminded of O'Donohue's suggestions that it is in the liminal places, within the tension of the opposites, that growth occurs.

As a textile artist, the idea of tension as a place of growth spoke to me. In my textile work, perfect tension is essential to the process. Even more so, I had also been reading about narrative textiles and felt that within the social context of textile work, there was another type of tension that I elaborate on in the discussion. Further, the idea of a map to guide the research reminded me that first reproductions of cartographical maps were made by women and stitched on silk (e.g. Tyner, 2018). I envisioned the research quite like those early maps, built from the collected experiences, routes connecting important points, and one's vantage influenced by the point of entry. With this, Ellingson's work offered me a sense of coherence to the structure of my chosen methodologies. It provided me with multiple options for entry and exit points as well as mechanisms for ensuring I could and would work from multiple vantages.

With that image in place to guide me, I was able to turn to the research. I will now discuss each of the methodologies in detail, beginning with analytic autoethnography.

Analytic autoethnography

Once it became clear that an autoethnographic framework would be the most logical way to proceed, I immersed myself in the researcher-as-researched literature. I

considered the extensive body of autoethnographic scholarship, starting with Wall's (2006) 'An Autoethnography on Learning About Autoethnography' and (2008) 'Easier Said than Done: Writing an Autoethnography'. Her perspective matched my aims. She stated that she is "able to learn to think differently about what constitutes knowing. The essence of postmodernism is that many ways of knowing and inquiring are legitimate and that no one way should be privileged" (2006, p. 147). This related to my own feelings about undertaking autoethnography, especially as I felt it would be disingenuous to focus my research with others if I did not understand the meaning of sanctuary for myself.

As with other qualitative methodologies, autoethnography systematically collects data for analysis and interpretation. Also as is common, the term autoethnography refers to the methodology, the process, and the product. Most importantly for this dissertation, while the focus is turned on the self, the purpose is to gain a deeper cultural understanding. As Chang (2008) says "individual stories are framed in the context of the bigger story" (p. 49) and without that contextualization, "self-exposure without profound cultural analysis and interpretation leaves this writing at the level of descriptive autobiography or memoir" (p. 51). Chang (2008) recommends autoethnography as a particularly useful tool for researchers working where self-reflection is integral. Chang highlights the importance of self-reflection throughout the text with statements such as "[w]hether seeing self through others or against others, the study of self-narratives through self-reflection is beneficial to cultural understanding" (p. 34). And "self-reflection can lead to self-transformation through self- understanding" (p. 57).

This very much echoes the motivation behind the inclusion of the self-reflective

processes (the description of which follows) and response art (which also follows). Chang encourages the use of self-reflection and self-observation as fundamental aspects of fieldwork as "self-observation collects factual data of what is happening at the time of research whereas self-reflection gathers introspective data representing your present perspectives" (p. 90). Béres (2018), speaks to the importance of autoethnography as a vehicle "[allowing] for movement back and forth between academic literature and field notes, adding greater richness to the exploration of [an] idea … than would be possible with either a purely academic review or merely a personal account" (p. 4).

Perhaps most notably autoethnographers argue that autoethnography serves as a counterbalance to the dominant paradigms in research (Anderson, 2006a; Chang, 2008; Ellis, Adams, & Bochner, 2011). For me the value of this aspect of autoethnography was immeasurable. It is consistent with the aims of the research, answering a question I had when learning about chronic conditions namely: where are the lived experiences? It is also consistent with my training in social work and folklore, both of which privilege the lived experience. And it offered a mechanism to explore a concept I felt and drew upon in my work but could not wholly articulate.

Criticisms of autoethnography

One of the challenges of autoethnography however, is that it suffers from a range of criticisms. In addition to the usual criticisms applied to qualitative research such as a lack of objectivity, generalisability, and replicability (Chang, 2008; Ellis et al, 2011; Wall, 2006, 2008, 2014, 2016), no doubt some of the field's internal conflict (such as the

debate between evocative and analytic autoethnography) contributes to the specific criticisms. In spite of this, autoethnographers seem united in their belief in the usefulness of the methodology and willing to push back against the detractors (e.g. Anderson, 2006a, 2006b; Chang, 2008; Ellis et al, 2011; Ettorre, 2006; Holt, 2003; Sparkes, 2000; Wall, 2006, 2014). Ultimately, autoethnography serves an important function in articulating an experience bracketed by the literature. I can assert that most of the comfort I have found in the literature came from first person 'illness' accounts such as Ferdinand (2016), Ettorre (2017), Frank (2013), Richards (2008), and Simeus (2016).

To some degree, I envision the work of autoethnography as similar to sharing in a therapy group. One's experience is only one's experience; however, sharing the experience can lead to connection, understanding, and solidarity. The quality of the sharing in a group is moderated by the facilitator whereas in autoethnography, it is moderated by the academic paradigm. Chang (2008) echoes this stating that while transformation of self and others may not always be a conscious aspect of the autoethnography, the personal nature of the stories frequently stirs self-reflection within the listeners. I certainly found this to be the case in my reading of first-person narratives in preparation for this work.

Philosophical guidance dominates writing about autoethnography, although Chang (2008) offers some concrete suggestions. The absence of an explicit, tangible structure no doubt contributes to the challenges to academic acceptance. In addition to concerns about the lack of structure, further critiques of the methodology include concerns that autoethnography lacks rigour, is self-indulgent, is of questionable utility,

and/or is narcissistic (Coffey in Holt, 2003; Wall, 2014, 2016).

Further complaints focus on the perceived lack of clear terminology or cohering structure within the methodology; indeed Chang (2008) reports that the lack of clarity in the methodology has resulted in over 30 terms associated with autoethnography. However rather than seeing this as a failing, Chang states that, reflective of the methodology itself, this simply indicates that autoethnography means different things to different people. Chang ultimately contends that the essential nature of autoethnography is to situate the self within a cultural context and understand the meaning that naturally follows. In so doing, would it not stand to reason that there would have to be almost as many terms and concepts, as well as ways of working within the methodology as people doing it? Without prescribing any particular structure, she urges autoethnographers to foreground "the concept of self as a relational being" (p. 27). She also encourages embracing 'edge-walking' which reads very similar to boundary-riding, an intentional and relational engagement with different cultures, perspectives, and methodologies.

Contrary to the critiques, issues of reliability and validity are essential to autoethnography (Anderson, 2006a; Chang, 2008; Ellis, Adams, & Bochner, 2011; Holt, 2003; Sparkes, 2000; Wall, 2006, 2008, 2014, 2016). Rather than autoethnography pointing to a particular method of ensuring reliability (e.g. triangulation) it is for the reader to determine the veracity of the writer's claims (Ellis et al, 2011). I address some of these concerns through incorporating CRoP (see below) as a fundamental part of the methodology.

The Two Main Paradigms of Autoethnography

At this time, autoethnography is divided into two main paradigms: analytic and evocative (Ellingson & Ellis, 2008). Chang (2008) explains these as occupying the far ends of a spectrum. On the one end are the subjective autoethnographers, such as Ellis and Bochner, advocating an evocative model with a "focus on narrative presentations that open up conversations and evoke emotional responses" (Hunt & Junco, 2006 in Ellis & Ellingson, 2008, p. 445). As is fundamental to all autoethnography, the evocative model seeks to capture the experience of the researcher situated in their social context. Where it diverges from the other end of the spectrum is both in its more narrative presentation style and by intentionally leaving space for the reader to draw their own conclusions.

At the other end of the spectrum are the objective autoethnographers, such as Anderson, seeking a less narrative, more analytic model, hence the name analytic autoethnography. Anderson (2006a) proposes core criteria as facets of the analytic stance including full and visible membership in the research group or setting, the use of informants beyond the self, and a commitment to "an analytic research agenda focused on improving theoretical understandings of broader social phenomena" (p. 375). While Anderson's stance has been criticised by notables in the field (e.g. Ellis & Bochner 2006) as being too closely aligned with realistic ethnography, Anderson (2006b) counters with the assertion that it is the degree to which the researcher is visible that differentiates between autoethnography and ethnography. And indeed, this is the differentiation for me.

The goal of my research matches the aims of analytic autoethnography. Most

notable from the analytic perspective was the desire to arrive at some understanding, or even generate a theory, in relation to my research question and the intent to include a small sample of outward facing data (such as interviews) to compare with the inward facing/autoethnographic data. However, I also understand the importance of not just drawing information from the participants to further my own goals, thus I aim for a collaborative, relational interview process, ideally resulting in information to be shared with the community (Kovach, 2012; Wilson, 2008).

Finally, while I propose a "boundary riding" dissertation with arts-based components, I also feel strongly that my final work should be a scholarly endeavour that includes creative elements rather than a complete immersion in an arts-based or evocative paradigm. The idea of producing a narrative piece that is "akin to the novel or biography" (Ellis & Bochner, 2000, p. 744) that is solely a revelatory, shared experience without a quest for theory generation, understanding, or answers holds no appeal for me in this instance.

Like Wall (2006), I agree with Sparkes' (2000) assertion that autoethnographies "are highly personalised accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding" (n.p.). With that as my intent and the goals of autoethnography as articulated by Chang (2008) and Anderson (2006a) in mind, the framework to achieve those goals unfolded. From the foundation of analytical autoethnography coupled with the guidance of Ellingson's Crystallization Theory I constructed a boundary-riding research structure that would allow me to embrace the academic alongside the creative, as well as honouring the intent that brought

me to this research. To increase the reliability and fidelity, I inserted the critically reflective practices that I will now discuss.

Critical Self Reflection (CSR) and Critical Reflection on Practice (CRoP)

Balancing my informal CSR process with the formal CRoP structure as part of the methodological framework offered a way to intentionally consider all aspects of the research thus ensuring my fidelity to the research goals and model. While my CSR process has been honed since my Bachelor of Social Work (BSW), CRoP offered a much more formal and structured process that uncovered gaps in my CSR as well as offering me an opportunity to become intimately acquainted with it. Although there are variations of critically reflective practices, I focus on the process recently expanded by Fook in partnership with Béres (2020). These alterations match the research aims and include formalising a spiritual component to the process, a time of contemplation between phases 1 and 2, and arts-based aspects to make space for data below the conscious or intellectual mind to emerge (Béres, personal communication, 2020). Because the use of critical reflection varies by discipline and in popular usage, I will first distinguish what I mean by critical reflection followed by a discussion of CSR and CRoP.

Academically we use ‘critical’ to highlight a societal or structural concern. Critical theories argue that societal problems generally have their roots in social, rather than personal, problems and that those problems disproportionately impact certain individuals/groups. Further, critical theories argue that certain groups benefit from those structures and only through the liberation of all groups and subsequent equalisation of

power can any sort of just society exist (Gardner, 2014, 2017; Payne, 2016).

While I would argue all critical theories share a core of universal liberation and are therefore intersectional (Crenshaw, 1989, 1991), specific critical theories highlight the experiences of certain groups. In the context of this research, a critical disability theory (CDT) lens foregrounds the gaze of the research and acknowledges the experiences of structural challenges and barriers resulting from disability. These challenges and barriers also impact interpersonal relationships, such as the experience of microaggressions in interpersonal exchanges (e.g. Olkin et al, 2019). Further, as critical theories speak to structural/social issues, they also highlight how those structural issues have been internalised by the community members. In the context of CDT, an example of internalising can be seen when the disabled person apologises for requiring an accommodation.

In the context of critical reflection, the term critical denotes our consideration of what (and how) structural issues might be at play in the incident being reflected upon in the critically reflective process. Reflection is a word that, in common usage, tends to be synonymous with generally thinking about something; in a philosophical context reflection is a “way of approaching an understanding of one’s life and actions” (Fook, 2007, p. 441). Critical reflection, however, is a particular type of thinking with many different suggestions for practice and concomitant with numerous theories and frameworks to guide the way (Béres & Fook, 2020).

The Foundations of My Critically Reflective Practice

My first explicit exposure to critically reflective practice occurred during the Integrated Practice Course of my BSW. Cheryl, my professor, who taught in addition to maintaining a private practice, instructed our small group in a range of self-reflective techniques informed by Fook's work in conjunction with the expressive and somatically oriented therapies of the day. For example, as part of the self-reflective process she taught, Cheryl emphasised beginning our self-reflection by first checking in with our bodies, noting any indicators of stress. I recall her cue to reflect on: 'what's going on for you right now?'. From there we were instructed to consider what information we had about the situation at hand, what assumptions we might be making, and how these might inform our decision making.

Over the course of the academic year, Cheryl would regularly ask us to 'check in with ourselves'; she used phrases like 'find out what's happening for you' and 'where have you been when you felt these feelings before', which served to remind us that rarely, if ever, is an experience a 'pure' experience, occurring without any influence from our history. She would then encourage journaling to 'have a conversation with ourselves' about those feelings and experiences. Similar to CRoP, she urged us to consider issues of power and language that might be at play. The final step was always to link the reflection back to practice. Like Hunt (in Fook et al, 2016, p. 35) her stated goal was to help us integrate this type of CSR into all facets of our practice rather than having us consider it to be a tool to use once something had gone awry. While at the time these various elements were likely an amalgam of Cheryl's practice experiences coupled with theory

and married with Fook's early work, they now have been formalised within the CRoP. For example, Béres now actively encourages the integration of creative practices as part of the CRoP process (L. Béres, personal communication, 2021) and Botelho (2020) has now written about her integration of body phenomenology as informed by Merleau-Ponty's 'embodied motility'.

Philosophical Foundations of Critical Reflection

Fook (2007) notes that there is an argument claiming an increased need for reflective practice in a range of professions, including social work and that this "crisis revolves around an increased questioning of professional authority and infallibility" (p. 440). She further asserts that part of this move is a response to increase professional accountability. Much as with autoethnography, concerns stem from a lack of formalisation in the process and from there, the multiple ways in which the terms are used. Fook notes that "[t]he terms 'reflective practice' and 'critical reflection' are often used interchangeably" (p. 400). Rooted in Western philosophical traditions and drawing on a range of models including social learning, constructivism, and postmodernism, much of the writing on critical reflection (e.g. Béres & Fook, 2020; Brookfield in Fook et al, 2016; Fook, 2016; Fook & Gardner, 2007) articulates the theoretical foundations that underscore the model developed to facilitate the process of unearthing implicit assumptions. This framework elucidates how we both create and are created by relationships and experiences. From there we further consider their impacts upon us and the often cyclical, or self-reinforcing, nature of those impacts and interactions. To paraphrase Dewey (1933) it is our reflection on experience that teaches us. It is through

our reflections that we connect the experience to our emotions and associations, providing information beyond the mere reaction to the experience.

In addition to Dewey's influence on her work, Fook's scholarship was influenced by Schön who is perhaps the progenitor of modern reflective practice. Schön is credited with alerting "us to the crisis in the professions often represented by the perceived gap between formal theory and actual practice" (in Fook, 2007, p. 441). Schön argues that professionals have become ubiquitous, especially to help people define and solve their problems; however, "[p]rofessionally designed solutions to public problems have had unanticipated consequences, sometimes worse than the problems they were designed to solve" (1984, p. 18-19). Examples of this relating to social work's history were articulated in Chapter 1.

Schön asserts that these problems, as well as the numerous scandals, conflicting opinions, and inconsistencies eroded the public's confidence in professionalism and his work was, in part, a response to that. He further acknowledges the increasing complexity of the systems professionals work in and the difficulties that arise from that complexity. He also addresses the competing interests that exist within professional frameworks that can result in what would appear to an outsider to be errors but are a predictable consequence of those competing interests. He (1984) notes that "[p]ractitioners are frequently embroiled in conflicts of values, goals, purposes, and interests" (p. 44) which has led professionals to speak out about their concerns. While he wrote *The Reflective Practitioner* in the 1980s, many of those pressures remain today.

Schön notes that one of the greatest challenges for professionals was to demonstrate how they know what they know. These other ways of knowing are a fundamental facet of professional competence (Schön, 1984, p. 111; Payne, 2016; Gardner, 2011); however, they can also be the result of confirmation bias. And for that reason, Schön developed a model for structured reflecting. In this, he "stressed similarities of pattern in the various arts of reflective professional practice" (1984, p. 549) while also acknowledging the important differences, for example, the different perspectives held by professionals from diverse fields. With these attributes in mind, he developed constants for reflective practices that served as a framework for others to build from (e.g. Fook, etc).

One common theme uniting the various conceptualisations of critical self-reflection (and associated practices) is the engagement with the story behind the experience and the numerous factors contributing to the meaning-making process (e.g. Fook 2011; Fook & Gardner, 2007; Béres & Fook, 2020; White, 2007). The goal of CSR is neither problem solving nor solution finding so much as understanding our relationship with the story. Story may seem to imply something inaccurate or fictional; however, consider how important story is to the human experience, especially in the realm of understanding. Consider also the way story informs our personal and social development (such as the importance of folktales as teaching tools and oral histories) as well as most aspects of our relationships (White, 2007). In my work, I often see how a familial or personal story, for example, unconsciously informs decision making. A common theme in all of my training and education has been honouring our experience as story generating

beings.

Story and Meaning-Making

In the introduction to their seminal work, *Narrative Means to Therapeutic Ends* (*NM*) White and Epston (1990) share the origins of narrative therapy which are similar to the intent that led the sanctuary research. They begin by highlighting the importance of Foucault's work, especially given his consideration of power. As I reviewed *NM* in preparation for the research, I recognised the same echoes for myself. Learning about Foucault's conceptualisation of power and authority ultimately led me to social work practice and, in hindsight, underscore the intention to enter into this research collaboratively, rather than as the research expert gathering data from the 'other'.

It was probably through White and Epston that I first truly understood the importance of the 'lived experience' as a social worker as well in the context of research (p. 9). White and Epston say "[i]n striving to make sense of life, persons face the task of arranging their experiences of events in sequences across time in such a way as to arrive at a coherent account of themselves and the world around them" (p. 10) which can be considered a story or self-narrative. White and Epston further state that the "success of this storying of experience provides persons with a sense of continuity and meaning in their lives" (p. 10). They continue along this thread arguing that if we accept the importance of the storying process both as an organisational and meaning-making experience, the expression, performance, and enacting of these stories necessarily shapes lives and relationships.

We also know that story-creation is a biologically driven meaning-making exercise that aids us to understand the world and our experiences (Bronner, 2017; Saleeby, 2013; Zak, 2015). To manage this, the brain fills in gaps in the story, often using associations with other memories and experiences to do so (Meena & Kumari, 2018). When we recall a memory, we knit together a story that makes sense to us, unconsciously drawing on pre-existing templates, patterns, and themes, creatively filling in gaps with bits and pieces from other stories and experiences (White & Epston, 1990). Naturally, our human inclination towards confirmation bias means the 're-storying' process will usually reinforce our worldview or preconceptions unless we consciously shift the narrative (Barraza, et al, 2015; White, 2007).

Rather than let the story stand as imagined, CSR processes require that we reflect upon and weigh the story we make up in relation to other experiences and knowledge. This assists us to minimise the unconscious associations that impact perceptions and decision making. From there we can intentionally position ourself in relation to the story and our desired outcome (Fook & Gardner, 2007). To achieve this, CSR draws on the intellect while including other ways of knowing, or tacit/non-quantifiable knowledge which includes intuitive, somatic, and unconscious ways of knowing (Payne, 2018). For me, engaging with these other ways of knowing is best accomplished through engagement with creative processes and time in nature.

CSR as Methodology

I first realised the potential of drawing on CSR as part of a research methodology

following Fook's chapter in Horsfall et al (2011). There Fook notes critical reflection's application and success in facilitating a deepened and complex understanding of practice experience. She then began "to speculate about the research potential of the critical reflection process and whether it might be developed as a research method to allow better formulations of practice experience" (p. 55). In this chapter, she outlines the "preliminary case for developing critical reflection as a research method" (p. 55). This led me to consider what we mean by practice and how my research question was personal yet both informed by and would inform my practice. While Fook clearly means professional practice, she has encouraged the use for self-reflection with personal experiences as well. After all, "the way to untangle complex ideas begins, whenever possible, with the use of personal narrative" (Brookfield, p. 18).

Fook's (2011) assertion of CR's value in research, based on its dialogic, integrative, and transformative qualities fit the intent of the research. The dialogic nature of CR matches the analytic autoethnographic notion of including participant interviews, as well as my desire to analyse the data using Charmaz's constant comparative method (CCM) framework (discussed below). CCM likewise matches the integrative quality of critical reflection. The integrative quality of CSR offers a framework "and process for integrating all aspects of complex experience (emotions, beliefs, values, actions) by articulating its meaning *in context* [italics in original] and representing it by creating relevant language" (Fook, 2011, p. 61). This quality allows the uniqueness of the experience to be preserved, as well as communicated, in the research.

The preservation of the uniqueness contributes to the third quality, that of

transformation. While the stated goal of the research is understanding, within that, there is the implicit hope for personal, professional, and even social transformation. I believe that enriching and clarifying my understanding of sanctuary, especially in the context of lupus, will not only enhance my social work practice, but will also contribute to my personal transformation. I do hope that out of this research I understand, for example, the elements of sanctuary thus allowing me to access them more intentionally. I also hope that the understanding that flows from the research will enable future research that may have larger social goals. And that those goals may also be transformative.

CRoP Structure

As outlined in Béres and Fook (2020) CRoP is a more formal, usually small group process consisting of two stages. Stage 1 involves deconstructing an experience of an incident; stage 2 involves reconstructing, potentially including practice theory development. Those participating are asked to arrive prepared to discuss an incident. The critical incident can be a situation, circumstance, or occurrence, anything the participant would like to learn from and are comfortable sharing in the group. They are asked to reflect on the following:

1) Why did you choose this incident?

2) What is the context of this incident?

3) If they will please share a description of the incident with as little reflection as possible.

During the first stage, the participant is asked questions to help them "reflect and

unearth deeper meaning" (p. 16). These questions are grounded in the five theoretical frameworks outlined by Béres and Fook (2020) which include: reflective practice, reflexivity, post-structural thinking and post-modern narrative practice, critical social theories, and spirituality. Given the significant changes since the first four theoretical frameworks presented in Fook and Gardner (2007), I will focus here on the structure as described by Béres and Fook (2020).

Reflective practice, the first framework, relates back to the previous discussion of Schön's work and articulates the gap between what professionals say they do and what they actually do (Béres & Fook, 2020). This is not necessarily problematic and often relates back to other or implicit ways of knowing however, it is imperative that the professional become aware of their embedded assumptions and practices. Béres and Fook state that the usefulness of this stage is both in improving practice and in beginning the CRoP process with the intent to uncover "embedded or hidden assumptions" (p. 11). According to Béres (personal communication, 2021) this is often where people discover how they have filled a gap left by an explicit theory by creatively drawing upon implicit theories and knowledge.

Reflexivity follows reflective practice. When used in tandem with reflective practice, reflexivity addresses some of the concerns about the blind spots in reflective practice, such as the lack of clarity around values and theoretical weakness (Béres & Fook, 2020). Reflexivity refers to the way in which we understand our social location, the lenses through which we see the world, and how we construct knowledge. Reflexivity in practice helps us understand our implicit biases and how those might inform our

perceptions and actions. This particular framework closely mirrors personal self-reflective practices.

The third theoretical framework is post-structural thinking and postmodern narrative practice. These are two different concepts that dovetail, informing each other and bringing awareness about the incident and how we have framed it. Post-structural thinking informs how we employ language in our worldview and experiences as well as how language functions as an agent of social control. Like narrative therapy, and drawing on that framework, it also counters the positivist view of an objective truth or correct perspective and helps us release implicit binaries (such as good versus bad judgements) to provide space for a richer narrative to develop. This is a key element in the CRoP process as it helps us understand our own framing of the incident and our perceptions. This, in turn, assists us again in seeing our underlying assumptions.

As stated, postmodern narrative practice is informed by narrative therapy and works in conjunction with post-structural thinking by offering a way to understand the story. Each incident is just that: the person's story, a series of circumstances constructed along a theme. As we construct our narratives, we all select the aspects we wish to include and exclude, both by design and as part of our unconscious processes. All of this is information for the CRoP process, which asks why we included certain elements in our narrative and why not others. Additionally, this aspect of the CRoP asks the person to focus on the language they used to articulate the incident.

Meidinger (2020) illustrates the usefulness of NT's influence on the CRoP model.

Given the influence of NT on this research, I do take the time to expand on this relationship; however, I will not revisit all of the elements of NT outlined in Chapter 1. Meidinger begins with a reminder of the importance of centring the learning experience within the NT paradigm, through supporting participant's autonomy and self-discovery rather than focusing "on the group member and their ability to fix the situation" (p. 46). This orientation includes refraining from engaging with, what Fook (2012) calls, the inner victim where, rather than remaining in a curious stance of discovery, the attention is turned to consoling and reassuring.

Meidinger (2020) argues that the stance of narrative therapy, especially its ability to assist "individuals in examining the language, meaning, and impact of problem storylines" while also assisting them to "identify gaps, alternatives, and exceptions to problem narratives" (p. 47) makes NT a natural companion to CRoP. The stance of curiosity and honouring 'insider knowledge' within the NT framework further supports its inclusion in CRoP. Perhaps most important to this stance is, as Meidinger states, that the spirit of curiosity and honouring of insider knowledge ensures that the reflecting practitioner remains the authority figure in the CRoP process. It also supports them to explore the story rather than needing to have the answers or find solutions. Concomitant with this is the importance of externalising conversations that allow the reflecting practitioner or participants to sit with uncomfortable thoughts, to decouple identity from the circumstance being reflected upon, and harkens back to a maxim of NT namely: the problem is the problem, the person is not the problem. Drawing on White (2007) Meidinger articulates the way the internalised labels can become an overarching belief or

identity which, in turn, limits the ability to be curious about them; externalising conversation can offer some relief from this.

This leads to a conversation about the value of including the NT notion of the 'absent but implicit'. While Meidinger (2020) discusses this concept in the context of CRoP, I turn to the deeper discussion offered by Béres (2014), written after attending training with White. During that training White acknowledged the importance of the concept in hindsight as well as the wish that he had emphasised this concept further. His death four months later robbed him of the opportunity to further articulate his thoughts on the topic but, as Béres (2014) notes, close friends and colleagues have done so in his name.

White's notion of 'absent but implicit' was essential to this research as it encourages exploration of the particular words used to describe the situation, the values implied in those words, as well as what is not being said by using certain words rather than others. Engaging with the 'absent but implicit' not only supports the person to read between the lines and develop their own understanding, it also encourages the practitioner's (or researcher's) curiosity about why a certain word is used, what meaning it holds for the person, and what is the implied, but not stated, meaning. To recouple this concept to CSR, in this research context, 'absent but implicit' might mean considering why the word chronic illness was used in the research question rather than disability, what it means to be chronically ill, what does that mean for the participant's views and experiences of health, what values are implied in the use of that label and so on. Béres (2014) links this concept back to the social constructionist roots of NT stating that "[w]hen a person is attempting to describe complex emotions, thoughts and reactions, it becomes even more

important to be cognizant of the multiple and fluid meanings of the words used" (p. 47).

The fourth framework, critical perspectives, has evolved alongside our understanding of social concerns. Critical perspectives draw on the principles of critical social theory which emphasises the "connections between personal experience and the social/political world" (Béres & Fook, 2020, p. 13). Critical perspectives highlight connections between those beliefs that not only encourage a person to act against their own best interest, but reify established power structures, maintaining hegemony and creating, at times, nearly insurmountable barriers for the excluded groups. "Critical perspectives are based on an analysis of how power is created and maintained socially and structurally" (p. 13) and how that, in turn, contributes to the maintenance of social injustices. In deference to the ever evolving understanding the critical perspectives highlighted in this CRoP model encompass intersectionality with practitioners looking to feminist analysis, critical race theory, and critical disability theory to assist in deepening understanding.

The final theoretical framework, one that was not present in the 2007 model, is spirituality. Béres and Fook (2020) note that spirituality in this context encompasses the sense of valuing and honouring what gives people a sense of meaning and purpose" (p. 14) and include spirituality to "identify and articulate those previously hidden values and commitments, which have provided meaning to life" (p. 15). In turn, this engagement may contribute to "making deeper and perhaps transcendent meaning of 'life as a whole'" (p. 15). They assert that personal understanding of deeper, and sometimes transcendent, meaning is required for truly critical reflection.

These five theoretical frameworks guide the questions for CRoP stages one and two. These stages are separated by a break during which the participant has the opportunity to reflect on the process and what has surfaced for them during it. This also offers a chance to step away from the process, which can be a needed break that makes space for other information to surface. During that time the participants are encouraged to engage other ways of knowing by drawing on non-cognitive processes (e.g. Botelho). Examples can include engagement in somatic knowledge (through the body), connecting with nature, and/or participating in creative exercises (Béres, personal communication, 2021). This inclusion of creative and art-based processes led me to include a research-creation element to the methodology, using the principles of response art as a guide. I will discuss this in the next section.

Research-Creation

The Social Sciences and Humanities Research Council (SSHRC) calls research-creation a combination of

creative and academic research practices, and supports the development of knowledge and innovation through artistic expression, scholarly investigation, and experimentation. The creation process is situated within the research activity and produces critically informed work in a variety of media (art forms). Research-creation cannot be limited to the interpretation or analysis of a creator's work, conventional works of technological development, or work that focuses on the creation of curricula. (2021)

Of the many models of arts-based research, research-creation (RC) with its interdisciplinary nature that centres "feminist, queer, decolonial, and critical race interventions while working committedly across practice/theory lines" (Truman, 2019, p. 225) best fit the intention of this research. For Loveless (2019) these 'boundary-riding' elements sharply delineate RC from other arts-based research and matches the use of response art as part of the self-reflective aspect of the methodology. Further, RC privileges creation as a vehicle for understanding. While the process may result in a created product that is neither a requirement nor a focus.

RC is inherently intersectional and self-reflective, having been "tied to interdisciplinary and social justice interventions [within] the university landscape that worked to challenge which research methods and vocalities could be understood as scholarly" (Truman, 2019, p. 226). Loveless further draws on the comparison of the personal voice championed by earlier feminist work in which the assertion "the personal as political" came to life. This ideology has been amplified as an analogue to the current work being done in RC. Springgay (in Truman, 2019) expands on this stating that "[r]esearch-creation is a way of doing theory/thinking that is bodily, experimental, and considers research (knowledge making) as a (speculative) event emerging from a practice, rather than preformed or predetermined" (p. 226).

While RC is a new paradigm (Loveless, 2019), the marriage of creativity and research is not. Higgs et al (2011) offer a thorough overview of this relationship, including a timeline that considers the shift in the research gaze. For example, Loftus et al (2011) remind the reader that in recent history qualitative research too, had to justify its location

within research. Like qualitative research generally, creative and arts-based research approaches do not seek to test, so much as consider and generate theory, provoke consideration, and offer different perspectives (Loftus et al, 2011). Loftus et al remind us that truly useful and forward moving research must be creative, whether implicitly or explicitly so and if this is the case then, why not reveal the creative threads? For this reason, adding creative elements to research, focused on privileging "embodied, cultural and relational knowing, and to represent experiences by including, if not foregrounding, emotions and bodily perceptions" (Loftus et al, 2011, p. 8), appropriately augment my autoethnographic exploration and expression.

Cherry and Higgs (2011) draw from Rittel and Webber (1973) to articulate 'wicked problems', "those that are messy, circular, [and] aggressive" (p. 13). Rittel and Webber (1973) identify ten key elements of 'wicked problems' including a lack of definitive formulation, a lack of clear resolution/end point, and the lack of a means to immediately and ultimately test proposed solutions, which have real world consequences and cannot be tested through trial and error. 'Wicked problems' call into question our fortitude, our commitment, our courage, and our expertise; they are rife with unknowns and potential pitfalls, offering no assurance of future success. When I mused on 'wicked problems' I realised how perfectly the concept applied to my experience of lupus and the proposed research.

Cherry and Higgs applied an arts-based lens to researching 'wicked problems' in health care. This allowed them to approach those problems from oblique perspectives, facilitating the participants' contextualisation of the negative or white space that exists in

between the questions commonly asked by qualitative research, much like the space made between stages one and two of the CRoP process. I feel the need to do the same. My concerns were not with my sleep or my level of exercise, they are with the existential and ‘wicked problems’ that lupus has brought into my life. I did not believe they could be answered by adhering to traditional forms.

Truman (2019) and Loveless (2019) concur with just such an approach, arguing the need for a paradigm shift in research. Drawing on King’s (2003) illustration of how stories shape us, Loveless takes this one step further. She urges those in the academy to consider the story and the shape it takes in the world as well as how we, in the academy, contribute to the story telling and subsequent world shaping. The ‘boundary-riding’ structure of my research allows me to incorporate “ontological, epistemological, ethical, and political attunements” (Truman, 2019, p. 227) in service to creating a different world through creating something coherent and suitable for academic and public consumption. This is what I believe King means when he urges us to privilege different stories. He asserts that if we want to change societies, we need to change the stories we tell (King, 2003). I see this as congruent with the critically reflective elements and narrative therapy as well as the research goals. My experience of critical reflection is that it works best, for me, when I am able to employ a creative, intermediary process that helps me access the unconscious. To that end, I constricted the potentially vast aspect of RC through the method of response art, a technique most often found in the world of art therapy.

Response Art

The RC application best suited to my research falls under the heading of response art. Although usually used as a way of processing a clinical experience, response art assists "art therapists [to] bear difficult material and explore the meaning of our experience" (Fish, 2012, p. 139). About this Allen (2005) says:

> Don't become a witness that is merely a container. You will calcify. The only way to be healthy is to be a vehicle. Witness, reflect, express. These are the three arms of response art. It happens in the process and it happens over time. (p 216)

Although her injunction was written for therapists, I believe it applies well to this type of research. Allen's text led me to Fish's body of work, starting with her 2006 dissertation *Image-based Narrative Inquiry of Response Art in Art Therapy*, intended to "gather, evaluate, and synthesise information leading to a definition and theory of response art" (Fish, 2006, p. 15). She feels that response art focuses "our attention in session and help[s] in the transition from work to personal life, supporting healthy equilibrium as we contend with inevitable personal or darker sides of ourselves that may arise as part of providing therapy" (Fish, 2005, p. 139). To her position I would add its similar usefulness in the practice of research as well.

Fish was not the first to explore this concept, nor is she the only one writing about it presently. Kielo's (1991) seminal work considers the importance of a non-verbal medium to access other ways of knowing, particularly during post-session imagery in art therapy. The participants reported a range of art making and functions that ultimately served them

to enhance empathy, clarify feelings/render acknowledged feelings into form, explore the preconscious and unconscious, differentiate affect, and explore relationships. Moon built on the work of Kielo. For example, his responsive art making (e.g. 1999) is a process by which the therapist creates art in response to the session. Among other purposes, the responsive art making offers the therapist "an expressive outlet for the … powerful feelings that are often stirred up in the clinical context" (Moon, 1999, p. 79).

Visual journaling is a variation on the theme of type of response art "a technique that pairs experiential art activity with reflective thinking" (Deaver & Shiflett, 2011, p. 262). In their study with graduate students, they integrate "artmaking [sic] combined with reflective writing, created in response to life experience" (p. 271). Visual journaling can occur in traditional forms, such as coloured pens in a conventional journal or alternate forms such as stitch journals (e.g. Wellesley-Smith, 2015, 2021). Although art therapy techniques have historically focused on interventions, materials, and techniques largely drawn from the fine arts world, there are those (e.g. Leone, 2021; Moon, 2002) who advocate for the inclusion of craft techniques and materials.

Congruent with RC, response art is process oriented rather than outcome focused; its goal is an experience rather than the creation of an artist's work. Visual journaling, the creative technique employed in this research, has been used by art therapists and people as part of a therapeutic plan, as part of supervision, and as a personally reflective tool (e.g. Deaver & Shiflett, 2011; Fish, 2012). As with response art generally, the premise of visual or art journaling is that it offers a non-cognitive way to process information, thoughts, and feelings. Klorer, in Fish (2012) states that "[i]t helps me articulate the

unthought unknown, that place beyond words where I find myself emotionally tied up. Releasing these feelings into the art helps me to accept my own limitations. The art becomes a container for me" (p. 256). Though the use of the term container sits in opposition with the sentiment from Allen, Klorer's articulation perfectly states my goal in incorporating response art. I expand on the specifics of this in the discussion chapter.

These combined methodologies, analytic autoethnography, CSR and CRoP, and response art have been brought together through the cohering structure of Ellingson's crystallization structure. Together, I believe they match the intent and aims of the research, offering a balance between self-reflective practices and methods of validation. With the methodologies clarified, I will discuss data analysis followed by the strengths and limitations of the research process as a whole, having already addressed the specifics of the methodologies above. This chapter concludes with a discussion of the participants, an outline of the selection and ethics reviews processes, and finally, the interview structure.

Data Collection and Analysis

As with qualitative research generally, autoethnography draws upon conventional sources of data such as field notes, interviews, and personal effects (documents, photos, diaries, etc) (Chang, 2008). Where autoethnography diverges from other qualitative analysis is through the "visibility of the researcher's self, strong reflexivity, relational engagement, personal vulnerability, and open-ended rejection of finality and closure" (Anderson & Glass-Coffin, 2013, p. 58). With this research the data collection included

the above as well as "more fragmented 'autoethnographic vignettes,' revisiting and retelling specific emotionally memorable events" (Anderson & Glass-Coffin, 2013, p. 66) relating to the research question. Within the analytic autoethnographic milieu, they promote the use of both self-interviews as well as interviews of others "to gain deeper understandings of topics and events" (p. 70). The interviews of others used the conventional reflexive, dyadic protocols (question and answer) but "with the added dimension of the interviewer sharing personal experience with the topic" (p. 70) creating a conversational, rather than hierarchical, exchange.

The Analysis

The data was analysed using Charmaz's (2014) version of constant comparative method (CCM) (drawn from grounded theory). Within CCM, the researcher analyses the data alongside the research process. My data analysis began with my pilot project which informed subsequent interviews. Analysing the data as it came in to inform the next steps was most appropriate to the research's aims and purpose, especially the self-reflective components. In keeping with Charmaz's view (2014, 2015; Gibbs & Charmaz, 2015), the interviews were conducted using a semi-structured interview guide that was modified in response to the incoming data. All participants were provided with an interview guide as well as an explanation of the methodology, to contextualise any changes. All participants were advised that they were not obligated to answer any questions and to offer only as much data as they preferred.

Self-reflective processes as outlined above followed each interview. These

assisted my consideration of what had emerged in the interview process, inclusive of what we (researcher and participant) co-created as well as what arose for me individually. The journal entries reflect upon the ways in which self-understanding emerged from my engagement with the subjects and accompanying experiences, or 'the field'. As Anderson and Glass-Coffin (2013) illustrate, 'the field' may involve "experiences with other people or it may not; instead, 'the field' may be the 'state of mind' that one assumes when recording one's own experiences and how one is changed by [them]" (p. 66). 'The field', in this case, included the interviews as well as my self-reflective components, gleaned through arts-based approaches, time in nature, and engaging in digital ethnography. This resulted in what Chang (2013) calls "a big pile of data" (p. 116).

Illustrating the steps required to transform 'a big pile of data' into a "beautifully constructed, compelling autoethnographic text" Chang (2013) first of all cautions that "there is no one-size-fits-all approach" (p. 116). Similar to Charmaz, Chang advises taking "notes on (or 'memo') recurring topics, dominant themes, unusual cases, and notable statements" (p. 116) as well as coding (grouping data according to dominant topics/themes). Chang cautions against moving from themes to categories prematurely lest that colour the ongoing analysis. It can also predispose the researcher to begin looking for categories in subsequent data collection, rather than collecting the data and assessing what emerges.

As the goal of this work is ultimately meaning-making and understanding, in the manner of Anderson (2006a, b), Chang (2008, 2013), and Pace (2012) I aimed for an analysis of the experience more than a pure reflection of it. Pace (2012) articulates the

concern expressed by Ellis and Bochner regarding employing an analytic or grounded theory frame. He then shares Charmaz's rebuttal that within constructivist grounded theory there can only be a claim to having interpreted a reality, rather than making a general statement, for example, about the realities of all people with lupus. The aim of building, rather than testing, a theory marries with the aim of the proposed research. Employing a constructivist grounded theory approach to the data analysis pairs well with both the topic and the methodology.

The Story in the Data/Coding

Like Chang (2008, 2013), Charmaz (Gibbs & Charmaz, 2015), and Pace (2012) and adjacent to narrative therapy approaches, I asked the question 'what is the story of sanctuary in the data?'. To answer that question, I coded the data as it emerged but refrained from assigning strict categories until the data collection period concluded. Consistent with my training and in keeping with Saldaña's (2015) steps, I manually engaged with the data. I transcribed the interviews followed by sorting, re-labelling/grouping, and then coding. Codes were then labelled, grouped, and sorted into categories and subcategories which then led to themes and from there, a theory.

During the first level of coding, copies of the transcripts were made and highlighters used to capture a range of data from gerunds to possible codes and themes (Charmaz, 2014; Glaser & Strauss, 1999). I augmented the process with sticky notes, note pads, and journals available to facilitate memoing. On the transcripts and in the journals/memos, I used a range of colours and images to capture similar concepts. I began

with in vivo codes/gerunds (Gibbs & Charmaz, 2015) as initial themes, recognising that they would likely change as more data coloured the landscape.

Once all interviews were completed, I left the transcripts and focused on my hand written notes. Drawing on response art and Ellingson's (2017) embodiment to assess the goodness of fit, I contemplated the themes that had emerged as well as the memos I had collected. Once I had established themes, I then moved on to categories. I assessed whether the initial categories were reflective of the data followed by reflecting on each element/code within the category. I followed this with weighing each category against each code. Each time a category or theme felt settled, I returned to the range of memos (visual and written) to reconsider and assess. As I worked between themes and codes, I noted an alignment with Harry, Sturges, and Klingner's (2005) use of the term themes to discuss this stage of coding. They:

> find it more explanatory to call Level 3 the 'thematic' level, referring to the underlying message or stories of these categories as 'themes'. It is in seeking the interrelationships between these themes that the researcher begins to build a theory. (p. 5)

This concept of theme felt congruent with what was emerging in the data as well as the importance story has in the research process and my own sense of this as a narrative experience. I expand on this in the Discussion. I also appreciate how explicit it makes the purpose or function of that level of coding; the idea of a theme is something that is likely more broadly understandable than technical coding terms. Most important to me however, was the feeling that there was a 'goodness of fit' in the term. Ellingson's

notion of embodiment and the idea of 'goodness of fit' became essential to the research process. Even as late as beginning the writing of the first draft of the dissertation, there were two aspects of the data that felt 'stuck'. Through continued engagement with the data and the self-reflective processes, I uncovered the areas of 'stuckness'. This resulted in clarifying that there are both elements and qualities to sanctuary, which are discussed at length in the next chapter.

Overall, my research processes come closest to Saldaña's (2015) "participant-inspired rather than a researcher-generated" (p. 74) approach. Although an unconventional research strategy, the combined methodological elements allowed me a perfect balance of both space and structure to explore all of the material. I believe that only through that exploration could clarity be constructed. The data analysis perfectly matched the methodology and the intent of the research. It was through deep engagement with the process and the data, that I was able to generate a theory, which I articulate in the Discussion (Chapter 5).

Limitations and Strengths of the Methodology

Many of the limitations and benefits of this research have been previously discussed, especially with regards to the methodology and applicability. To briefly summarise the core limitations are centred on the subjective nature of the research and sample size. Because of these factors, the results cannot be considered generalisable. However, there is usefulness to this type of research as well. There is merit in the addition of another first-person illness narrative to the literature. There is usefulness in

social workers making their reflective practices explicit, for all of the reasons previously articulated about the importance of self-reflection as well as CRoP in the profession. And finally, I also feel that the addition of outside voices as a vehicle to enhance my personal understanding contributes to a slightly bigger picture overall. This is discussed at length in the next chapter.

Participants and Participation

I began this research with a pilot project upon completion of the University of Alberta ethics review (REB Study ID: Pro00103831). After reviewing the pilot project findings, my Committee granted permission to continue with the full research plan. At that point, I began to advise colleagues and friends of the research. Ultimately, all participants were recruited via word of mouth and all initiated contact with me by email or social media messaging prior to enrolling in the research. In my initial, official introductory email to each participant, I introduced the research topic as well as the origins of my interest including my experience as a medical social worker. I also self-identified as a member of the chronic illness community.

In addition to being provided with all of the research materials including the letter of introduction and semi-structured interview guide (Appendix D), participants were encouraged to ask about my interest and experiences. I also shared that the semi-structured interview guide was simply a guide to keep me on track. In the body of the email, I reiterated that the interviews would be conducted via Zoom and recorded.

With participants who opted to be interviewed, we set a time to meet virtually by

email. At the start of the meeting, I re-confirmed their consent to participate and, as part of that, reminded them that they are in complete control of their participation, that they were in no way obligated to share anything with me, and could end the interview at any time without repercussions. I affirmed that the topic was a challenging one and that I hoped that more than anything, we would have a shared experience guided by the research intention. I reminded them that they were welcome to ask me about my experience and that, if they had any concerns after the fact, I would appreciate it if they shared them with me. I warned them that interviews, from the pilot project onwards, had been exceeding the projected timeframe and that I would be as mindful of the time as they would like.

I began each interview by reading from the semi-structured interview guide, including the excerpt that guides this work. Once the question about personal spirituality was asked, the interviews largely became conversational with both general and specific discussions about spirituality and what it means to be spiritual as well as who has the authority to determine what constitutes a spiritual practice. At intervals I referred back to the interview guide to ensure that the participants were given many opportunities to share any information that felt pressing to them as well as to implicitly remind them of the purpose of the conversation.

Once the interviews hit the 60 minute mark, I drew on my social work practice skills to begin cueing the participants that we were approaching the end of the interview. I indicated my appreciation for their sharing, reminded them that there was a blog where I would report findings and that they were invited to email or text me as well. I asked them

about their experience of the interview, if there was anything that felt uncomfortable for them or any cautions they wanted to share with me about the process. I also asked them if there was anything else they felt should be included in the interviews. I ended with asking if they would be comfortable being contacted for follow up interviews as needed and if they would please contact me with any thoughts or concerns that arose for them after the fact.

The majority of women participating self-identified as white, GenX, and interestingly, able bodied. Although many Black, Brown, and/or Indigenous women considered participating, there were few who completed the interview process. There were participants from the LGBTQ+ community, including one participant who identifies as female and intersex. I believe that the somewhat homogenous population of this research is a topic that must be addressed in all scholarship of this era. It is critical to acknowledge that members of the Black, Brown, Indigenous, LGBTQ+, intersex, and disabled communities may not want to participate in white/abled/formal/academic research because of the numerous injustices perpetrated against them under the guise of 'research' or 'helping'. All researchers must acknowledge the history of forced or coerced experimentation done to these communities (such as the Tuskegee 'Study') or 'nutritional studies' in residential schools (e.g. Kovach, 2012; MacDonald et al, 2014). I feel it is imperative that all people in the academy continue to extend invitations to members of all communities with openness and understanding alongside acknowledging how they and/or their communities have been injured by our formal systems. We need to find a way to include their voices in the academic narrative while respecting their

boundaries and hesitations rather than obligating them to participate. This is an area I think especially compelling given the impact of disability on this research however, it is also a much larger topic that can be fully addressed here.

The nine core interview participants all agreed to an initial interview and follow up as needed. Many of them have provided feedback on the results. All of them understood that information about the research would be posted on a blog[1] and they were invited to offer feedback. They were also invited to contact me directly if there was information they were interested in (such as findings) that were not posted on the blog. And of course, they were invited to contact me with any concerns and given numerous ways to do so.

All participants selected the name they would like to have used in the research. All (Alexis, Allison, Amanda, Bec, Cathy, Lynn, Rebecca, Robbie, and Willow) [appendix with chart] were North Americans, with Canadians representing the majority. All of the participants have advanced education. Most work or have worked as professionals. Some, though not all, had left their professional employment as a result of the chronic condition. The participants reported that they had generally supportive families and faced a range of social challenges. All expressed feeling that participation in the research was an act of service to the disability community. They all hoped they would be contributing to understanding the experience of chronic conditions and ideally, how we can better help others.

[1] https://afieldguidetosanctuary.weebly.com/

Conclusion

In service to transparency, this chapter has revealed the complete framework of this research: from the methodology and my decision-making processes about it to the composition of the participants. Fundamental to this has also been the interplay with the philosophical guidance of these methodologies and my own training. I have also discussed the method of data analysis and philosophical underpinnings that guided it.

I will close this chapter by stating that the dissertation methodology serves as an internal framework for the research; it offers structure but more than that, it also guides how the research is conducted. To use a weaving analogy, the methodology is akin to the weaving draft which explains how to thread the heddles and how to tie up the treadles. Many weaving drafts even offer a ‘drawdown’ to the schematic of the finished cloth. Without the draft, there would be no plan for that finished cloth and yet, no one would say the two are interchangeable.

Chapter 4: Findings

Consistent with analytic autoethnographic methodology, this chapter presents the findings through a reflective, narrative discussion alongside my experience of the research. Here I focus on the participants' data which led me to reconsider Wall's (2016) musing as she wondered whether research including informants is truly autoethnographic or is it a mini-ethnography that "is perhaps more appropriately thought of as accounting for self or locating oneself in the research" (p. 3). With this question in mind as I reviewed the interview data, I wondered whether I had adhered to the structure as intended or whether I was guilty of conducting a mini-ethnography and simply, appropriately, locating myself in the research? Indeed, did the name matter at all?

With that in mind, I recalled Charmaz's (2006b) statement that the symbolic interactionists have long argued that names "are rooted in actions and give rise to specific practices" (p. 396). That is what has happened in this research. This process centred my understanding the elements of sanctuary and how it relates to the experience of lupus. Significantly, it affirmed that even within that centring, the questions I have asked resonated for others. Through this I learned that my experience echoes the experiences of others. Those echoes became critically important to me. After all, the roots of autoethnography encompass self-observation within ethnographic research attending to the social worlds in which autoethnographers participate (Ellis & Bochner, 2000). And so in this, I did achieve an analytic autoethnography.

Further there are those, like Charmaz, who advocate for the inclusion of

informants, even in researcher-centred research. In discussing Murphy's first-person disability narrative, Charmaz (2006b) notes the "honesty and clarity" with which he writes and yet, he falls into the trap of unwittingly reifying the "images of disability that other people with disabilities have struggled to reject" (p. 399). She attributes this to the experience of the autoethnographer failing to move beyond their own experience. Her assertion is that drawing on other voices from the studied world prevents gaffs such as Murphy's. Her caution echoes my experience. The interviews provided me with self-reflective data I could not otherwise obtain.

As I worked through the analysis, I noted that the most illuminating data resulted from the interplay of the interviews and my self-reflective data. In spite of the intention behind the interview questions, unexpectedly the experience of chronic conditions informed much of the data but only peripherally. The bulk of the data revealed a breadth within the importance of sanctuary that had surprisingly little connection to the experience of chronic conditions. As you will read in detail, for Amanda, sanctuary was important to her functioning as an intersex woman but even more so, in leaving the religion of her birth and the process of adopting. Bec identified sanctuary as the key factor enabling her ongoing connection with her daughter through her daughter's brain injury and subsequent struggle with addictions. Willow too identified that she had no sense of sanctuary when she was first diagnosed but that it came later, as she built her inner grove and labyrinth. Without this type of input, I may not have understood that even for me, while the experience of sanctuary has been important to living with lupus, the experience of lupus has been less important to my understanding of sanctuary.

These revelations, which challenged my original conception of the research, may have been unobtainable without the input from the participants and validated the choice of methodology. Likewise, as I consider the process and the data alongside the concerns and critiques of analytic autoethnography I am convinced that I achieved my aims. Participants reported that the personal nature of the interviews resulted in them feeling comfortable to share freely, unlike the formal process they had envisioned. The combination of Critical Reflection on Practice (CRoP), critical self-reflection (CSR), response journaling, and constant comparative method (CCM) resulted in my having personal data to share with the participants; in turn, this resulted in their own self-reflective moments and disclosures during the interviews.

And to that point, I do not assert that the data were there waiting to be 'discovered' (Charmaz, 2006a, 2014, 2015; Gibbs & Charmaz, 2015); they were very much co-constructed through all of the research processes. Using the term 'emerge' to discuss the co-construction, I liken the experience to that of weaving a blanket. To weave a blanket, I need the structure of the loom and to that I add the warp yarn. The structure holds the yarn in perfect tension, this allows the weft yarn to be thrown through. The equipment, yarn, skill, time (and sometimes a pattern) come into relationship; from that engagement emerges a blanket. So too did the co-constructed data emerge from the process.

As an antidote to the aforementioned criticisms of autoethnography, the informants' contributions provided a form of de facto triangulation, especially in

conjunction with constant comparison in the data analysis. Their voices offered a way for me to continually challenge my own internalised story (which also pairs with the CSR processes previously discussed). What I concluded was that while I speak about the findings generally, I situate myself within them. Thus, the generous sharing by the participants provided an essential frame for this research. Their data helped me stay grounded and furthered the contemplation of myself in the social context, which is the goal of autoethnography. And ultimately, the theory I generate is informed by their data while remaining my own theory of sanctuary.

The research process revealed the deep entanglement of the research questions. As such I respond to the research questions conceptually, rather than attempting to address each question discreetly. Begin by answering the question about the relationship between sanctuary and lupus. I then discuss the importance of the O'Donohue passage for me which leads into articulating the elements and qualities of sanctuary. Other questions, such as the echoes of sanctuary in other traditions were beyond the scope of this work and have been included in the discussion of future research.

The bulk of this chapter focuses on deeply understanding the experience of sanctuary, primarily grounded in the data though informed by theory as appropriate. Drawing on participants' voices, I articulate my experiences with the data. Through the discussion of the components of sanctuary, I share the reflective processes that aided my understanding, including images and text. I offer this self-reflection in the spirit of transparency, intended to accurately reflect my process thereby increasing

trustworthiness. I also hope this might provide a template for future researchers seeking this particular iteration of a “mixed methods” or “boundary riding” approach. The resultant findings are shared with an intent of laying a foundation to be further explored in the discussion and recommendations sections.

Ultimately, this research revealed that sanctuary is an experience and a way of being that was shared by all participants. From the data, sanctuary exists outside of formal faith or spiritual orientations but can be consistent with them. Sanctuary is inherently a spiritual practice, even when it is informal, secular, or incidental. It is composed of elements (spirituality, nature, creativity, and purposeful occupation) and qualities (transgressive, fluid, and nourishing) that exist in relation to one another. Some of the elements have subsets or sub-elements that presented challenges to discern. Especially challenging was the realisation that where the O’Donohue passage speaks specifically to an internal type of sanctuary, there were aspects of sanctuary that appeared to be outside of the self. Each of these aspects, including the challenge of determining sanctuary within the self, versus outside of the self, will be discussed in detail in this chapter.

The Findings

This section will link the research question with the data. The question I asked myself was: what is my experience of sanctuary and how does that relate to the experience of lupus? The question that guided the research with the participants was similar: what is your experience of sanctuary and how does that relate to your experience

of your chronic health condition? Within that, I recognised the need to understand what sanctuary comprises to better understand it. As part of the research, I had hoped to look at sanctuary more broadly, such as where similar concepts exist in other cultures and traditions. However, out of a desire to adequately address the topic coupled with institutional constraints, that question will be addressed as a question for future research.

As discussed in the introductory chapter, the idea of sanctuary was drawn from this passage from O'Donohue:

> There is a place in the soul that neither time nor space nor no created thing can touch. What it means is that your identity is not equivalent to your biography and that there is a place in you where you have never been wounded, where there is still a sureness in you, where there's a seamlessness in you, and where there is a confidence and tranquillity in you. And I think the intention of prayer and spirituality and love is now and again to visit that inner kind of sanctuary. (O'Donohue & Tippett, 2008).

Using the question and this O'Donohue passage as a guide, this section will first offer a reflection of my experience of sanctuary and lupus, I will then share the amalgamated findings from the interview and self-reflective data. The exploration of the data includes glimpses of the literature that assisted me to clarify the information in the data. A full exploration of the data and its relationship to the literature follows in Chapter 5.

Sanctuary and Lupus

While it's probable that I have had lupus (as discussed in Chapter 1) since my teenage years, I had never truly experienced the full weight of it until 2018. In keeping with lupus's title as the Disease With 10000 Faces over the years my symptoms had manifested in a variety of ways, resulting in a medical history speckled with diagnoses ranging from queries of rheumatoid arthritis to Crohn's disease. As I had not yet been diagnosed with lupus, the neurologist who ruled out my possible brain tumour hypothesised that my neurological symptoms were the result of an extra-intestinal Crohn's disease manifestation. He warned that they might progress and if so, my family doctor could refer back to him.

It was during the liminal period between the concern about the brain tumour and the neurology appointment that would rule it out that I first became aware of the importance of sanctuary for me. While I had moments of feeling adrift in a tumultuous sea on a dark night, there was always a sense that I clung to something that would keep me afloat, regardless of how rough those seas were. Although I did not know what it was that I clung to, it had a sense of the numinous and perhaps spiritual about it which led me to apply to the Doctorate of Ministry programme. I felt the need to understand it for myself as well as whether a deeper understanding of it might also improve my social work practice.

What I learned through this research was that while I first explicitly understood sanctuary in the context of my health challenges, the existence of sanctuary went much

deeper and had a much broader application than my initial conceptualisation. Early on in the research, I recognised the importance of decoupling sanctuary from my lupus experience if I wanted to truly understand sanctuary. I share examples from the participants further in this chapter. And while my lupus experience is visible in the data, it is very much secondary to the experience of sanctuary.

Assemblage

Fundamental to my understanding of the data was Deleuze and Guattari's (1987) articulation of assemblage. While they do not explicitly state a definition of assemblage, they employ a number of illustrative examples throughout the text. Most compelling for me personally and in keeping with this research, were their metaphors from weaving, basketry, and felt-making to illustrate the idea of assemblage. In those practices, each piece is both whole in and of itself, and is entangled with others to become part of the new whole. The same applies to the findings of this research, which made for some difficulty in distilling the themes/codes. Within this research, each element and quality exist as entities in their own right and as a contribution to the whole.

Perhaps most fascinating to me was that prior to reading about assemblage, I had determined that response art would take the shape of visual journaling, primarily by using stitch doodles on felt. Those pieces of felt could then be transformed into a patchwork representing the whole process. As felt making is a little known textile arts, I was excited to see it represented in Deleuze and Guattari's text. Within the context of assemblage, they see felt as

an entanglement of fibers obtained by fulling (for example, by rolling the block of fibers back and forth). What becomes entangled are the microscales of the fibers. An aggregate of intrication [sic] of this kind is in no way *homogeneous:* it is nevertheless smooth, and contrasts point by point with the space of fabric (it is in principle infinite, open, and unlimited in every direction; it has neither top nor bottom nor center [sic]; it does not assign fixed and mobile elements but rather distributes a continuous variation). (p. 475-6)

Not only did this excerpt feel serendipitous given the importance of textiles to this research, this description also perfectly captures the simultaneous separate and entangled fibres of the elements and qualities of sanctuary. And although there are those who debate the clarity of the term assemblage (e.g. DeLanda, 2006) I found their contextualisation within metaphors coinciding with my own areas of interest such as gardening, basketry, and textiles were sufficient to illustrate it.

While assemblage felt appropriate to the research, there was still a quality missing that I could not name until I recognised the rhizomatic qualities in the data and the results. In *A Thousand Plateaus*, the idea of the rhizome is nearly as prevalent as the idea of assemblage. Deleuze and Guattari (1987) state that “[t]here are no points or positions in a rhizome, such as those found in a structure, tree, or root” (p. 8) as there are no specified entry points or directions of growth.

This was the case with my data. This lack of linear and discrete structure caused me no end of challenges in the data. Drawing on Ellingson’s embodiment, enhanced by Charmaz’s similar urgings to consider the data intuitively (Gibbs and Charmaz, 2015), I

felt that there were nonlinear aspects of the data that felt both like discrete and entangled qualities and elements but I could not see how I would detangle them. It was difficult to reconcile this nonlinearity with my desire to have a very tidy, linear result out of the research and yet, this is how it looked and felt. More than merely tolerating the non-linear, Deleuze and Guattari urge us to consider that

> [t]he middle is by no means an average; on the contrary, it is where things pick up speed. *Between* things does not designate a localizable relation going from one thing to the other and back again, but a perpendicular direction, a transversal movement that sweeps one *and* the other away, a stream without beginning or end that undermines its banks and picks up speed in the middle. (p. 25)

Once I accepted the non-linear qualities of the data, as well as the reality that the "[t]he only way to get outside the dualisms is to be between, to pass between, the intermezzo" (p. 277) understanding and consolidation of the data began.

In addition to the non-linear aspect, the other rhizomatic element within the data was its subterranean quality. The use of the term subterranean acknowledges the way that many of the insights that arose for myself and the participants were just beneath the surface but not obvious to us until we engaged with the research process. Even more exciting, and equally powerful in their similarities to the idea of the rhizome, were the surprising twists in the interviews. These twists felt like fractures breaking off and rather than dying, like the rhizome, they became generative, sending up growth in new and unexpected directions.

Congruent with the rhizomatic assemblage, each section of this research is like a piece of felt with its own distinct stitching and patterns. And yet, these individual pieces of felt also form part of a whole. Attempting to create completely separate categories for each concept resulted in struggle but when I accepted the interconnectedness alongside the separateness, I understood what we had created in the interview. Spirituality, for example, was a thread that wound entirely through the data. Attempting to tease it apart from the other categories felt like an artificial deconstruction. I recognised that each distinct category/theme had echoes of the other in it and all of them were bound together by spirituality. Once I recognised that felting, rather than weaving, was the appropriate textile analogue to represent my experience of engaging with the data and I realised that there was no way to separate the threads of the findings into distinctly pure concepts, the work of understanding the data became much less stressful.

Elements and Qualities of Sanctuary

During the analysis, the sanctuary themes broke into two major groups. The group of elements (constituent parts) consists of spirituality, nature, creativity, and purposeful occupation. The second group, qualities (characteristics), consists of transgressiveness, nourishment, and fluidity. I offer a brief discussion of each in ascending order, representing their prominence in the data. Both the idea of the elements and the elements themselves were extremely prominent in the data. The qualities were much more subtle. I hope to refine these through future study. From the combination of elements and qualities I generated an initial theory about sanctuary, reflective of this data.

I discuss the findings in ascending order of prominence in the data, beginning with the elements; first spirituality and its subcategories. The element of nature follows and from there, the discussions of creativity and purposeful occupation. The qualities of sanctuary follow beginning with the quality of transgressiveness. This is followed by the nourishing quality of sanctuary and finally fluidity and sanctuary. I close this section with a brief summary of these elements and qualities. Their potential application or use, as well as a discussion of theory and follow up can be found in the Discussion chapter.

The most challenging aspects of the findings were the areas of entanglement, where the codes and themes seemed inextricably intertwined. For example, as noted, the element of spirituality was found in every other element. While this was frustrating at first, I came to see spirituality as analogous to warp threads on a loom; they seem to provide a structure for many aspects of sanctuary.

Spirituality was most prominently entangled with nature but visible throughout the data. I have addressed the entanglement of spirituality and nature in the nature section under the heading of Nature Entangled with Spirituality. While this entanglement also occurred in other elements, such as between creativity and purposeful occupation or creativity and spirituality it was never to the same degree as with nature so is noted but not made as explicit as it is in the discussion of the element of nature.

Elements of Sanctuary

In this research, the data revealed four elements of sanctuary. In order of prominence, they were shown to be spirituality, nature, creativity, and purposeful occupation. I will

discuss each in order before continuing with the qualities of sanctuary.

Spirituality

> One of the ironies of writing about spirituality is that it means putting into words something that by its nature defies definition. (Gardner, 2011, p. 19)

As the theme of spirituality was ubiquitous throughout the data, making up the bulk of the findings, it is therefore the most appropriate element with which to begin. Best described as "connection to…" in this context spirituality emerged as foundational to the notion of sanctuary. Running like a thread through every other theme/quality/element, the quality of spirituality caused a great deal of analytical difficulty. This is where the notion of assemblage first demonstrated its utility as I recognised spirituality as both a piece of the assemblage as well in the threads connecting all of the other aspects of sanctuary.

While I do not review the spirituality, soul work, and spiritually oriented social work material here, I do briefly reflect on relevant experiences in my social work education. From there, aided by excerpts from the data, I articulate the primary sub themes of "connection to" the numinous, others/service (including to one's roots), and ritual, as well as touching on the idea of incidental spirituality. I will briefly discuss the connection between spirituality and nature, spirituality and creativity here but focus on that more fully in the nature and creativity sections.

Background

As previously stated, during my social work education spirituality was notable by its absence. However, my MSW clinical internship took place in a child abuse counselling society. In this placement variations on the question ‘why did God let this happen to me/my child?’ arose perhaps more than any other which led to my own questions. Through this I found my prior understanding of faith challenged as I looked for ways to discuss this beyond ‘sometimes people do bad things’.

At that time I had adopted a positivist view of the world, which I felt failed to address much of what I had seen, felt, and experienced. It also encouraged me to deny my own experiences, leaving me without any language to articulate that which could not be quantified. This not only sat poorly with me, it also felt in conflict with the values of social work. As I rejected notions of spirituality, for example, I was not ‘meeting people where they were at’ nor was I respecting their lived realities.

My recognition of the importance of spirituality led me to a great deal of professional development on the matter. I began to read widely on the topic (e.g. Béres, Bullis, Sheldrake). I explored Quaker theology and Buddhism. I took courses from spiritually oriented psychotherapists such as Thomas Moore (2016). I dove into the world of archetypal and analytical psychology. My studies only supported the hypothesis I had hoped to disprove: that spirituality was important in social work/service work. This information coupled with my own health crisis and personal recognition aroused a desire to formally study spirituality and led me to pursue a Doctorate in Ministry. Through the

years of coursework and immersion in the topic, rather than having a clear and concrete answer, I continued to find that the issue articulating what I meant by spirituality remained challenging (Gardner, 2011).

Defining spirituality in the data

As Chapter 2 articulates the spiritually oriented scholarship that informs this research, I will not reiterate that there. However, in spite of the richness in those definitions, none of them adequately reflected the appearance of spirituality in the data. As such, I generated a definition from the data and specific to this research context which is as follows:

> Spirituality in sanctuary is an inherently personal practice that can also be acted on collectively. It provides a sense of personal direction through connection with values, meaning, and purpose. Spirituality is inextricably linked to something greater than ourselves, is intersectional, relational, and at times, numinous.

I will now expand on the subsets of spirituality, beginning with the importance of the numinous, followed by the relationship between spirituality and nature. I then articulate the connection between spirituality and the theme I called 'relationality/roots'. Following that, I discuss incidental spirituality and ritual before ending this section by decoupling spirituality and religion.

Spirituality and the Numinous

Although many of the participants initially declared themselves 'secular and spiritual'

they also related the importance of spirituality to articulate what I categorised under the numinous, a sub-theme of spirituality. This term, derived from the Latin numen, was conceptualised by Rudolf Otto (1959) and first used in publication in 1917, though it is often associated with Jung after his adoption of it. Otto's (1959) intent in coining the term was to capture that which is awe-inspiring but without the cultural overlays associated with words like holy.

The word numinous captured a range of experiences shared in the data. For example Alison, an interview participant who described herself as not inclined to "deliberately do a spiritual thing" or "to contrive a spiritual moment", described an experience that fit the theme numinous as "it's going to make me at peace… it's more like I just go… to the reservoir. I find a weasel skeleton and it's a moment". She continued to speak about the reverence she feels in those moments as well as how different they feel from the structure of her religious upbringing; those moments are imbued with a solemnity and sacredness she could not find in a church. In those moments, she still considers herself an atheist but one who is having a deeply spiritual experience.

Willow, raised in a strict, evangelical Christian background but who is now a (closeted) Druid, articulated numerous experiences of the numinous, usually experienced through a sense of reverence tied to experience and circumstance, such as her first encounter with alternative spiritualities during a Renaissance Faire. She reported that her experiences of the numinous have translated into a deep self-confidence, a sense that there is an inner compass guiding her. Her spiritual practices both reinforce and refine her sense of the spiritual and how the spiritual feeds her sense of self. This is something she

did not feel her prior religious experiences offered her. She distinguishes between religious experience, in which she does have holy, awe-inspiring encounters and spiritual encounters which match the idea of the numinous and have no religious or holy overlay.

Relational Spirituality

It was the data from Bec's interview that first highlighted a sense of service and relationality, as a subset of spirituality. When I asked if she would have the same feeling of sanctuary when helping someone else build a garden her answer was yes as well as no. For her, there would not be the same spiritual connection to place and the earth, though there would be some. In that instance, there would be a sense of sanctuary and spirituality but in the form of service.

Cathy and Robbie also stressed the importance of relationality, especially service, as part of sanctuary. For them, as part of the chronic health condition community, once you have your feet stable under you, you have an obligation to help the next person who might be struggling. Cathy went so far as to suggest that a peer support model might be useful for people who have received a challenging diagnosis. Her lived experience was similar to my experience of looking for literature on lupus. When she was diagnosed with HIV, she did not want a pamphlet from a third party or something generic, she wanted to speak with someone who was also living with the virus. She now provides just that sort of informal support through her doctor's office but she feels it needs to be more accessible and more formalised while remaining grassroots. This is a fundamental aspect of her spiritual identity.

When I asked Willow about such a model, she agreed that it would have been much more useful than anything she was offered at the time of her surprise cancer diagnosis. A chaplain was sent to visit her at the bedside but her lack of connection to his practices rendered the interaction unhelpful. At that time she felt alone and so haunted by the memory of her mother's cancer experience that she could not imagine going through the same. When I asked her what kept her going through that dark time, she told me that she stayed alive for her family. Her act of service was to not take her life because she could not harm her loved ones in that way. She reported that at that time she had no sense of sanctuary or internal reserves and that perhaps having a peer mentor who truly understood her experience might have been useful.

For many of the participants, spirituality and roots or ancestry were an entangled subset of spirituality. For Alexis, it is a notion of connection to all of the women who have made pottery before her. It is also a more specific connection to her grandmothers who garden. So too with Rebecca, who feels strongly connected to the weavers in her family as well as honouring the memory of the weaver who apprenticed her. For Lynn though, the sense of service connects her to her roots in a very deep way.

Lynn, a Black woman born and raised in the southern United States, explained her connection to weaving in a poignant way. While I will discuss the interplay between creativity and sanctuary in the creativity section, there was a deep spiritual connection to her roots that occurred through her creative engagement that must be highlighted here. While Lynn certainly weaves for herself, she also weaves for all of the Black women who loved weaving but had it weaponised through the process of slavery. The passion and

love they may have had for the practice was destroyed through the oppression of being forced to do so under such conditions. Her act of weaving not only liberates her, she feels that it liberates them. She said:

> I'm doing what they did but I'm sort of freeing them because they were dead, they had no choice in what they did. They may have loved weaving but they didn't get to express themselves. They would but they were forced to do what they were told and [my] being able to… I'm being able to free them by being able to put my ideas into the loom. It really is reclaiming.

Incidental spirituality

While Lynn knew this connection to her roots was part of her weaving practice, she had not explicitly linked it to spirituality prior to participating in the research. This type of new awareness occurred during the research for many of the participants (including myself). Many of them articulated 'kind of knowing' that they were spiritually connected with an activity and yet they did not necessarily engage in that activity as an explicit spiritual experience. Alexis and Bec both articulated this in their exploration of their gardening practices among other activities such as pottery (Alexis), hiking (Rebecca), or fly fishing (Bec). For Willow, it was about building a labyrinth once she was physically recovered from her surgeries. While she knew the purpose of the labyrinth would function as a place of sanctuary and home for her spiritual practices, she expressed surprise in the interview as she recognised that the act of building it was also spiritual. She said that as she was building the labyrinth, so too was she repairing herself and

building her “Inner Grove”. She offered photos of the labyrinth to include in this dissertation [Appendix].

There were similar occurrences with all of the interviews, where a practice was discovered to be spiritual but only in hindsight. I have previously encountered a similar phenomenon during my ethnographic work for Dr. Kononenko. In that unpublished study, which was an ethnography considering gardening as a spiritual practice, all of the participants reported that while they have a sense of the spiritual in their gardening, they did not previously consider it a spiritual practice or engage in it to meet a spiritual need. I then termed that phenomenon “incidental spirituality” and think that it fits here as well. There were similar sentiments expressed in the present research with people commenting that they had not previously considered their practices spiritual, even when, like Willow, they were constructing something specifically for a spiritual purpose. Of interest to me is learning about Bailey’s (1990) implicit religion as, at the outset, it appears that the similarities between incidental spirituality and implicit religion are significant.

Ritual

For Willow, the rituals of Druidry are integral to her practice as well as her spiritual identity. In her own words:

> I’m a structured person so I do need a certain amount of structure [like] the set holidays, the set celebrations… you know just how the wheel spins and how each season is different and all of those kinds of things, they're very set.

This set structure has enabled Willow to embrace the Wheel of the Year as a

continual ritual. This offers her guidance alongside ceremony, contributing to the development of her Inner Grove, which has in turn, given her strength when faced with challenges. On a more intimate level, even the receipt of her instructional materials from the Order of Bards, Ovates, and Druids (OBOD) form a ritual for her. She has a set time that she opens them and a way to work through them using candles and incense to set the tone. She then participates in rituals with other OBOD members via Zoom as well as coordinating smaller family ceremonies at home as she is able.

Amanda spoke about the importance of formal ritual within the First Nations community as well as the importance of informal ritual in her home. For her this often takes the form of large family dinners to celebrate an event, or just being together. It is largely informal though at times corresponds with formal holidays. However, while these celebrations may occur on religious holidays, for Amanda, they take on a very different feeling tone than her history of religious celebrations. I discuss her experience, especially her acts of reclaiming spirituality, in the transgressiveness section.

While these examples of ritual were overt, there were few others, though I suspect they are important to spirituality as part of sanctuary. I will address this in the discussion.

Spirituality summary

Although difficult to define, spirituality was by far the most prominent theme in the data. In spite of the visibility of spirituality in the interview questions and O'Donohue's quote, I confess to having been surprised at the strength of its presence, perhaps especially so as most of the participants disclaimed their a-spiritual and even atheistic

orientation at the outset of the interviews. While, as discussed, there are nuances and variations with regards to defining spirituality, within this data it might most simply be framed as "connection with…". In addition to spirituality as its own, overarching, theme, it was also entangled with other themes. For example, within the idea of spirituality were the co-existing themes of ritual, incidental spirituality, relationality, and the numinous. As discussed, spirituality and the theme of nature were both prominent and very much entangled. I began a discussion on that entanglement from the spirituality perspective and will now continue by privileging nature, as a theme, and its entanglement with other themes as well.

Nature

In this research data, nature was often linked with spirituality but was also sufficiently prominent to justify its own category/theme. The element nature encompassed both a spiritual experience that often looked like the numinous as well as examples of tangible, literal engagement with nature. I begin with the discussion of nature as entangled with spirituality followed by a general discussion of the nature related data and the experience of tangible, physical nature.

Nature's Entanglement with Spirituality

Decoupling spirituality and nature proved to be a nearly impossible task. In this section, I will focus on the relationship between spirituality and nature as it emerged in the data. For example, Alexis and Bec both reported experiences of sanctuary in the form of the numinous primarily tied to the experience of gardening; while there is, of course, a

tangible, physical element to gardening as Alexis reported:

> the other day I went out to garden and I think that's definitely one of my spots. I don't know that it's [the] physical place but I put my gumboots on I had my overalls on and I was myself right now. And I was laughing because they're stained, my hair is in a messy bun, it's so not a glamorous look but I felt like my truest self and dirty gumboots and and [it] just feels true. I could just get lost and daydreaming while I'm pulling weeds and puttering around the garden. So I think that's definitely a sanctuary spot.

Alexis further articulated the intersection between the numinous (spirituality) and nature in her description of swimming in the lake near her home. She said "I just feel like there's physical layers that get washed off me" but those physical layers are also "psychically" accumulated; for her the layers that feel physical are absolutely a metaphor for the burdens of life. This, coupled with statements from other participants sparked my awareness of sanctuary 'out there' versus 'sanctuary in here'. I suspect that sanctuary is largely an 'in here' concept but that it can be reflected or even supported by something 'out there', such as Willow's labyrinth. However, as this differentiation was not sufficiently clear in the data to definitively state as a finding, I have included it as an area for future research.

Whether in her garden, swimming in the lake or engaged in connection with clay through the earthy experience of pottery, Alexis reported that these engagements with nature are spiritual practices for her, cleansing and connecting. She felt that in those

practices, she likely gets what others would get from church but without having what she describes as the negatives from church. She was content with the idea of the numinous, to have a way to frame the awe-filled experiences without relying on religious jargon. She "can imagine that somebody who was me thousands of years ago was doing the same thing and that sort of takes me to a really kind of quiet and grounded place where everything totally makes sense."

While Willow expressed the experience of the numinous in many ways, the relationship between spirituality and nature was where it was most common for her. So too with other participants, such as Cathy who reported the need to go into the forest and commune with certain, specific trees. For her, the awe experience is not conventionally holy yet powerful and inextricable from her feeling of connection to nature. Bec also linked nature and spirituality/the numinous explicitly. For her "creating in the garden [is] my own… deep connection [to] Mother Earth". She continued with statements such as "it's the transference of energy" emphasising the connection through being "barefoot in the soil" and "just seeing the whole cycle of it all".

General Experiences of Nature From the Data

There were reports of a 'craving for nature' that would result in time in the garden or a hike and a sense of spiritual fulfilment would follow the activity. Perhaps because the first iteration of nature, as the world 'out there', was so prominent it took a great deal of time to understand or even see the subset of acceptance. That subset is really grounded in the idea of nature 'in here', a sense of internal nature and the self as part of nature. When

I started to think about what it really means to take your cues from nature or believing blossoms will come again, I returned to O'Donohue (and Tippett, 2008) who felt that "the dawn goes up, and the twilight comes, even in the most roughest [sic] inner-city place. And I think that connecting to the elemental can be a way of coming into rhythm with the universe" (n.p.).

The idea of coming into rhythm with the universe connected me back to the data. When participants spoke about the experiences of their conditions codes such as 'emerging from the debatable lands', 'grieving the loss', 'swimming in the symptom pool', 'embracing devout agnosticism', 'facing death', 'finding inner peace', and 'retreating to the cave' emerged. It was when I re-engaged with 'transitioning to acceptance' that I understood what I was seeing. Nature was providing cues to support the process of acceptance, to work with the body as it is, and to understand the health condition as cyclical. I saw a general theme of seasonality, that the body has seasons and whether we want our internal winter to arrive or not, it simply will and the more accepting we can be, the less energy we waste struggling against it. We have ways of keeping it at bay somewhat; I think of the use of medication to minimise symptoms as an analogue for the comforts that protect most of us from the elements. Regardless of our mitigation strategies, hard weather will arrive, if we are fortunate in our location, our housing, and our clothing, it will present less of a burden than it does to those without those comforts. There was a clear link to the embodied, tangible, physical experience of nature as a seasonal force that emerged from the data. While the sense of seasonality, at times, had metaphoric and spiritual codes, the codes relating to tangible experiences of

nature were distinct.

Relating to the idea of tangible nature and the embodied experience is the absence of codes related to a quest for a cure. Some participants spoke of treatments they had considered or used but even that was the barest fraction of the data. There was not a single comment that sanctuary would occur once the experience of their health condition ended. In the absence of a code about cures and remission, I also saw a code of acceptance. This too is linked back to the element of nature. It surprised me to note the absence of a quest for a cure in my own data as well. This broader understanding took me back to Ellingson as I realised that even my use of embodiment in this research links back to nature. It is about trusting my body to offer direction when other ways of knowing are unable to.

Interestingly, Ellingson who is very clear about her distaste for being too close to nature 'out there', also draws on nature metaphors to make sense of challenging circumstances. In response to her late-stage cancer effects she says "I feel like my brain is composting some of my leftover matter, particularly pain" (Ellingson, 2018). Though she is clear that for her composting remains strictly in the realm of the metaphoric. She continues with:

> but perhaps wishing for pain to just go away is misguided; maybe composted pain and suffering provides fertile ground to grow useful insights, gut responses, preferences, creativity, and productivity (2018, n.p.)

Not only did the sentiment resonate deeply for me personally, it also helped me

understand the breadth in the element of nature. There were those whose data (initially) had few codes that linked to nature, indeed there were those who, like Ellingson avoid nature 'out there' but within the research data, there was something that felt similar to what Ellingson is expressing, and that there is a sense of awareness that we ultimately and deeply know we are part of nature. Ellingson says:

> Years ago, black feminist writer (and nature lover) Alice Walker helped me through one of her beautiful essays to understand my alienation from nature as rooted in the patriarchy and its false dualisms between women and men, nature and culture. My former therapist provided another piece of the puzzle when she pointed to the link between my chronic perfectionism and my inability to control the wind, rain, or temperature (2018, n.p.)

One example of the engagement with nature in the data, for those who, like Ellingson, may not prefer or have access to nature 'out there' followed my realisation that in the interviews, pets, in particular dogs were present. My interview with Lynn, for example, began with a discussion of our dogs, including how important they are as companions and sources of comfort, especially in the context of chronic illness. Her interview was not the only one that held these clues. With that, my idea of Nature expanded to include not just pets but animals generally. For some participants, including me, even a momentary engagement with an animal (such as the saw whet owl frequenting my chicken coop) offered a momentary connection with that feeling of sanctuary. That became the code 'the importance of non-human companions' which included feeling connected to wildlife

(e.g. Hanrahan, 2017).

I have alluded to the other example of tangible nature in Alexis's engagement with the clay of her pottery. While certainly this is entangled with creativity, there were codes around engagement with natural materials whether in the garden or like Alexis, with clay, or the wool and cotton preferred by the textile artists, or the wood in Bec's and Cathy's building projects, there was a clear emphasis on the materials as vehicle for connecting with nature. For Amanda, this connection with tangible nature was visible in small ways, such as seeing a deer in the forest outside her office, or selecting foods from a local farm to create a family feast. These codes clarified a different and unexpected dimension of nature.

Through this process, I have come to see the breadth of experiences that link us to the natural world, and contribute to our personal sense of sanctuary. Whether through the experience of nature 'out there' (e.g. in the garden, forest walking, or sitting with a pet) or nature 'in here' (e.g. personal and inward facing processes such as drawing on natural cycles such as seasonality as an analogue for bodily changes), in this data nature is clearly an element of sanctuary. What remains to be uncovered is clarity about the relationship between 'out there' and 'in here' and whether, for example, 'out there' is a manifestation or reflection of 'in here'.

Creativity

Creativity followed nature in frequency of appearance in the data. Like spirituality and nature, there are associated qualities and sub-themes that challenged my notion of

‘creativity’. And just as with spirituality and nature, creativity is generally a difficult concept to define. Naturally, creativity included making things. However, alongside that the data revealed the ideas of problem solving and other intangible sources of creativity. Further it is important to note that while creativity is often conflated with art, in this context it is equally entangled with more practical engagements, such as making a meal. This made decoupling creativity from purposeful occupation very difficult, but as I discuss in the next chapter, while there are areas of overlap there are also some significant differences. This section focuses on creativity as a general concept followed by reflections from the data considering creativity as an act of making as well as of problem solving.

A foundational text highlighting the relationship between creativity and spirituality is May’s (1975/1994) classic *Courage to Create*. He opens with an acknowledgement that the title was inspired by work of the theologian and philosopher Tillich’s text *The Courage to Be*, implicitly and immediately connecting the spiritual and the creative. Fundamental to the text is May’s argument that the interconnectedness of all that creativity is an essential part of expressing our personal sense of being. This is very consistent with this research data.

While May’s work focuses on tangible creativity (e.g. making things) he also argues for a broader applicability. He conceptualises the creative act as an encounter; perhaps with an image or place, or with an idea but ultimately as a “connection to…” which echoes the spirituality data in this research. For May, the materials employed in service to creativity are the language of encounter. May’s definition does not apply to

"hobbies, do-it-yourself movements, Sunday painting, or other forms of filling up leisure time" (p. 68-9) which initially gave me pause, given the types of creativity discussed by the participants as well as my own process. But he continues with a discussion of the depth of engagement the creator has with their creative process, with the absorption and intensity of the experience as well and I recognise his intent. I suspect that his differentiation stems from a sense of commitment and immersion in the process rather than the types of process. This was most definitely reflected in the data.

May's work shares some features with Csikszentmihalyi's (1990), especially regarding the idea of the Flow State. May asserts that there is a depth of engagement and timelessness to the creative process, as does Csikszentmihalyi. Indeed, I wondered if the theme 'creativity' was, in fact, Flow. But after reading Csikszentmihalyi's work, I recognised that while the creative processes in the data met much of the criteria for the Flow State, there were missing components. One such was the requirement that within the Flow State there is a tension felt when the participant is at the edge of their skill level. This ran contrary to this research data. Lynn, for example, enjoys weaving but she does not need to challenge her skill with every new blanket to feel creative or to achieve an enjoyable, even therapeutic, experience of weaving. So too with the gardeners in the study. They were content to simply weed, sometimes finding that the most enjoyable task of their day, offering a sense of satisfaction, even when weeds remained and the job was not complete. This occurred with data compiled under other themes, such as spirituality and with that, ritual or connection. Such as the enjoyment one gets once a feast day meal is finished, dishes are everywhere, and there is contented chatter and banter.

All of the participants noted moments like this which flies in the face of the notion that "the best moments usually occur when a person's body or mind is stretched to its limits in a voluntary effort to accomplish something difficult and worthwhile" (Csikszentmihalyi, 1990, p. 3). A further differentiation between this data and the concept of the Flow state is the Flow-related goal orientation. Overall, while there were similarities between Flow and the data, and there are many studies that do link Flow to creativity, particularly with textiles (e.g. Collier, 2011; Collier & von Károlyi, 2014; Pöllänen, 2015; Reynolds, 2004) there were too many differences to use the concept as a theme in this research. Further, there is now also a growing field of study addressing negative or problematic aspects of Flow (e.g. Botticchio & Vialle, 2009; Partington et al, 2009) which was useful as in this study, the experiences of sanctuary were exclusively positive but the discussions of creativity revealed negative or problematic aspects of creativity that were sanctuary-harming.

Indeed, the data demonstrated that in the context of this research while creativity can be transformative and healing, it can also be consumptive and problematic. Drawing from Gardner's critical spirituality, I wondered if there were two aspects to creativity in the data. On the one hand the data displayed creativity that could have darker or problematic elements as well as critical creativity, the healthy, life-giving creativity rooted in the expression of our true nature and that connects us back to creation. In the data, critical creativity had elements of engagement and timelessness without any requirement of utility or to be socially pleasing. It also required no outward expression. One of the themes within creativity was about thinking around a problem, that is, creative

problem solving. When we are talking about wicked problems, I think creativity in problem-solving must be honoured when it appears. However, while there was a great deal about the positive aspects of creativity, there were many examples of its darker elements. I will begin with those dark experiences of creativity and move onto examples of critical creativity.

As the data showed, those darker sides of creativity can be difficult to see and from there, to act on. For example, in her interview Bec discussed the creativity inherent in running the family butcher shop. Just as with other creative practices for Bec, her creativity begins with planning and problem-solving processes. In her case, it continues through to the making of charcuterie products and considering how to display her wares. Further, for Bec, even the myriad administrative requirements of running a business engaged her creativity. And while creativity is often thought of in a positive light, she reported that she often worked night and day to the detriment of her health and relationships.

In spite of the deeply held value of nurturing relationships with family and friends, the work of the butcher shop often demanded that she missed out on important events. Bec acknowledged that those long periods of intense creative work were deeply spiritual and beneficial to her in a multitude of ways however, even as they increased all of her IgA nephropathy symptoms, from pain to bleeding from her kidneys. And even when the cycles of the butcher shop allowed her time off, that time was often spent recovering. This meant she was still unable to participate in other fulfilling activities such as social engagements, fishing, and horseback riding.

As a result of the COVID-19 pandemic, they decided to close the butcher shop. During the time it lay fallow, Bec noticed that her kidneys were no longer bleeding, her pain had dramatically reduced, and, even with the pandemic related restrictions, she was able to engage in more of the other activities she valued. Mindful of her nephrologist's admonition to decrease the stress in her life, this prompted an evaluation of the relationship between her health and her work. And from there, creativity and health. On the one hand, she expressed feeling like she was "on Cloud 9" after a busy day in the shop. She was able to feel "in the zone" and at the end of the day, able to look back and see all that she had accomplished. She re-opened the shop as soon as pandemic restrictions allowed for it. During the interview she reported that her family and medical team began to be concerned about her health almost immediately after re-opening.

Having heard but ultimately dismissed their concerns, her own awakening came on Mother's Day 2020, when her family urged her to take the day off and enjoy an outing with them. Though she first baulked, her commitment to and love for her family overruled her desire to be in the shop and so she relented only a little reluctantly. As they left the farm and butcher shop behind, she realised she felt like weeping with relief at having a break. She stated that at that point, something in her shifted. She recognised the dark side of her creative passion. She and her husband then began to consider closing the shop permanently, then proceeded to do so.

Not entirely satisfied with the decision, she had a brief reopening, and offered a follow-up report. She stated that she is slowly realising that leaving the shop behind is likely in her best interest. The passion she felt for that work, she reported, was literally

killing her. While she identified creativity as part of sanctuary, this particular iteration of it is not.

While Bec reported that she continues to struggle with her next steps, she also noted that the positive aspects of her creative energy remained. Although she misses the butcher shop, her creative energy has been channelled into substantial gardening projects and creating rustic furniture such as end tables. She acknowledged that she does still push herself too hard or for too long, she can no longer rationalise it as the result of an external deadline as she did with the butcher shop. This is also not to say that the change has brought about a miraculous recovery. While the reduction in one type of stress resulted in benefits to her kidneys, she continues to have challenges with both her health and understanding how to make full use of her critical creativity without returning to her harmful behaviours.

Rebecca, a professional tapestry weaver, did not share Bec's perspective about embracing creativity in the business aspects of her work. She did, however, report a critical engagement with the creativity of weaving. She stated that the O'Donohue passage guiding the research resonated deeply for her. With it she recognised that "there is this sort of creative inner place that is just about me, it's not about the input I'm getting externally". While she acknowledged her inner creative place has not informed her choices as often as she might prefer to date, she has now set a goal, "probably a spiritual goal" to let "that [inner creative place] help me make the decisions instead of what often happens when someone asks and I say yes right because it's someone else's idea and I have to keep them happy."

These are but two examples of creativity's presence in the data. What surprised me was how integrated creativity was with so many of the responses. Whether it was in the area of tangible creativity, problem solving, as a place of sanctuary, or as a way to ground the participants in relationality, creativity in it all of its permutations continually surfaced in the data. And as with spirituality, this made it difficult to decouple from the other data. A further surprise was that creativity can also have a dark side, as Bec's experience illustrates. Like spirituality, the data revealed creativity as both its own element of sanctuary as well as an aspect of other elements. Because of this, it too will continue to be visible in the following sections.

Purposeful occupation

Returning to Willow's aforementioned labyrinth construction offers an excellent example of one of the most tangled intersections in the data. That example, like Alexis's pottery or my own weaving, represents all four elements of sanctuary: spirituality, nature, creativity, and purposeful occupation, however it was its entanglement with creativity that most challenged me. I noted this entanglement in Bec's experiences in her butcher shop, Alexis's pottery and gardening, as well as the data from the various weavers, and Willow's labyrinth. However, when I returned to my own experiences, I felt certain I was missing something. As I reconsidered and returned to the interview data, I caught codes that I had missed; in Cathy's woodlot reclaiming, Robbie's podcasting, Amanda's community suppers, Alison's science articles, and very prominently in my own data, especially in the journals I kept before the official research period which recorded my early experiences of lupus.

Focussing on my own data, I found the first clear example during the autumn/winter following my diagnosis, when the combination of lupus symptoms and hydroxychloroquine side effects incapacitated me. Most days my only achievement was to sweep, make bread and supper. As a result of the combination of fatigue and nausea, every task took many times longer to complete than it would have in the pre-lupus times. I struggled to follow and complete recipes I have made for years. There was little creativity to be found in these tasks I did by rote. And perhaps most importantly, the creative practices (such as textiles) that had previously been integral to my identity were not accessible to me at that time.

During this period, I felt myself, my personhood and identity, slipping away, down an Alice-in-Wonderland-like rabbit hole; something I had seen with patients but never before experienced. In spite of the losses, access to concrete, daily tasks allowed me to feel connected to the ‘real world’ in a way I could not otherwise feel. Where my pre-lupus self might have seen my self-imposed daily obligations of utilitarian cooking and sweeping as acts of domestic drudgery, they functioned as stabilisers. With them my sense of self, and connection, was diminished but not extinguished.

In considering these aspects of the data, I considered the interplay and overlap between creativity and purposeful occupation in particular but recognised that they also had enough distinction between them to be different elements of sanctuary. For example, where creativity can exist as both tangible and intangible experiences, purposeful occupation is generally tangible and may or may not be creative. Indeed, purposeful occupation is the term I am using to articulate largely tangible activities deemed

worthwhile by the maker, that draws on a range of skills and offers an identity sustaining, positive experience. Through my considerations, I recognised that those acts were for some people and at some times, essential for sustaining a sense of sanctuary and yet there was little creative about sweeping a floor or weeding a garden bed. Further, I found purposeful occupation to be a much-needed medicine for the issue of vocation versus Duty which I discuss, along with a further exploration of creativity and purposeful occupation, in the next chapter.

While purposeful occupation can be a solitary activity, it can also overlap with service, as with Amanda's community dinners or Robbie's educational/consciousness raising podcasting. "One of the keywords that I had for myself this year was contribution," said Robbie, "to be adding to equity movements, to be adding to conversations that will hopefully build a more sustaining world for everybody". For me it was about feeding my family, a difficult mental switch for someone who had attempted to decouple herself and her relationship from prescribed gender roles. And yet, I found sanctuary in baking a simple loaf of bread or making a pasta sauce. It is important to disclaim however, that feminised tasks are not the only examples of purposeful occupation. I likewise found it in moving dirt from my livestock pens to my garden beds however, due to the extreme fatigue, that happened with less frequency than the day in/day out experience of sweeping or cooking.

The other fascinating place where this intersection of purposeful occupation and service occurred was in the creation of this research, the recruitment, and participation. Even for those where fatigue and time are significant life challenges, they felt compelled

to participate because they wanted to contribute something that might help another person experiencing these struggles feel seen and supported. This was expressed in every interview. Participation was absolutely an act of service while also being a purposeful occupation. Further, when I consider my motivations for conducting the research, they are much the same. I spent much of my doctoral education studying folklore and had intended to propose a dissertation more directly reflective of this field. Instead, I felt strongly compelled to consider this question in the hope that it might help even one person. The purposeful occupation aspect came as this work offered me a sense of something useful and engaging to occupy myself. Even if reading the literature took hours longer than it would have previously or I spent an entire day struggling to create a single paragraph. This work offered me something purposeful that I deemed worthwhile, that drew on a range of skills, and offered me an identity sustaining, positive experience.

This concludes all of the elements of sanctuary from this data: spirituality, nature, creativity, and purposeful occupation. The role of all of these in sanctuary remained unclear until the concept of assemblage helped me envision how each theme can be both distinct, while also being interconnected. The concept of assemblage further assisted my understanding of the differentiation of the elements and qualities of sanctuary. Having enumerated the elements, I will now report on the qualities of sanctuary as reflected in the data.

Qualities of Sanctuary

There were many parts of the data that I initially called ‘fiddly bits’, unable to make

sense of them. I put them off into their own category initially, unsure about where they would ultimately end up or how to even characterise them beyond being ‘fiddly bits’. In reading the work of others, I understand that this is a common occurrence in research, that some information is just less prominent and yet still worthy of note. Charmaz (Gibbs & Charmaz, 2015) speaks to this, referencing Anselm Strauss who would ask a version of “what is the story here?”. Likewise, I asked myself what the story of sanctuary was in the data. I went back to Ellingson and embodiment. I sat with the data, I walked with the data, and stitched with the data. I realised that I had edited Estes out of the soul work section and she needed to be re-included. And through that process, in conjunction with the previous discussion on the theme of shadow, I recognised transgressiveness as a quality of sanctuary that I had missed. Once that connection had been made, the rest began to fall into place. Where spirituality, nature, creativity, and purposeful occupation were elements of sanctuary, there were qualities to sanctuary as well. The qualities in the data included transgressiveness, nourishingness, and fluidity.

In this section, I outline what it means to be transgressive, which was the most prominent quality found in the data. From there I articulate the data that reflected the quality of nourishment. I conclude with the discussion of fluidity as a quality of sanctuary.

Transgressiveness

The qualities of sanctuary were especially difficult to clarify initially. Drawing on the principles of narrative therapy I asked myself what the story of sanctuary was in the

data that felt important but evaded clarity. With that question in mind, I returned to the data, in particular the transcripts and my memos. I had initially categorised them under 'fiddly bits' but in truth, I saw clear themes of strength, boundaries, and agency. Alongside those were abundant examples articulating the experience of being in a problematic body and transgressing social bounds but Amanda particularly captured the essence of this sentiment. She reported that there is a

> place where I go to where I'm unf*ckwithable is really what it is. That is like taking some ownership over my journey in this body and in this place. What did I come here to learn and what am I doing with my life? And then it's not that I've chosen to have these health concerns or whatever but in a way it does give me strength to be like you know my purpose on this earth is to do the work that I'm doing. And these circumstances have given me that work and so as frustrating or as hard as it is, I feel like it gives me that ownership over my journey so it just doesn't feel like I'm just a ship in the sea. And there's that inner purpose: I'm here for a reason, like these experiences have given me the community, they've given me you know the children that I have, the work that I have, the perspectives that I've had and without these experiences I wouldn't have this.

While the in vivo code, 'unf*ckwithable' felt challenging to me, the interviewee used it with some frequency throughout the interviews, even though it was inconsistent with her language choices otherwise. The term effectively captured the interviewer's willingness to transgress social boundaries to meet the needs of her 'misbehaving' body, the long road of self-acceptance, and the agency she now expressed feeling. Most

importantly, it strongly echoed sentiments expressed by the other participants.

Given my discomfort with the term, I returned to the principles of CRoP, using that format to guide my engagement with the data, especially the consideration of language and my reaction to this code. Drawing on Ellingson, I considered the embodiment of the codes and how they felt. There was something about her idea of embodiment, especially given her focus on bodies that did not conform to the usual standards of 'normal' that had caught me. I reacquainted myself with her discussion about transgressive discourse and how "[b]odies that do not fit in dominant paradigms—queer, disabled, outside gender binaries, mixed race—produce transgressive composing practices and produce bodies-out-of-bounds" (p. 172). I journaled on that excerpt and then left for a walk. Within minutes of leaving my house, I recognised that the stuck category was a quality of sanctuary and that quality was transgressiveness.

This excerpt reinforced my feeling of 'transgressiveness' and perhaps helped me understand that I was dancing around something uncomfortable for me, so I returned to Ellingson. Rather than feeling shame about her missing body part, she embraces it with humour regardless of the comfort of others. And she encourages others to have conversations with her about the experience of disability. For example, in *Embodiment* (2017), she relates the tale of making pizza with Jill who confesses that she "messed up this week" (p. 58). She explains that while driving to lunch with a group, she commented "[i]t's too bad we don't have Laura here with her crip tag, we'd be able to find a space much more easily" (p. 59). And then explains how shocked her fellow riders were. Ellingson says:

> That's my bad—I should have warned you. I like it when you call it a crip tag, because I know that means that you get it, that you think my disability is a part of my identity, not something to pity or ignore or be weird about. So you can use the language. But it's kinda like the n-word that only African Americans can say; only people with disabilities are allowed to use 'crip' that way in public. (p. 59)

Ellingson recognises that while expressing comfort with her disability is transgressive, it is essential to her sense of being a whole person. After all "[i]dentities are constructed within the sticky web of culture by embodied people and embodied communication among them" (Ellingson, 2017, p. 60) which returned me to her statement that it is essential that bodies that do not fit in dominant paradigms must engage in transgressive composing practices. I realised that the other theme/code that fit this category was the in vivo code 'unf*ckwithable' and decided that transgressive was by far the least challenging option.

Amanda's experiences of being a 'body-out-of-bounds' every time she shares space with any group who are not intersex helped me better understand the presence of this quality of sanctuary. For most of her life she is an interloper, she simply cannot avoid transgressing because there are so few spaces where she is in the majority. On being an interloper she said:

> unless I'm in a room with other intersex people. Women have let me in their spaces yes all my life yes. But in that space, in every conversation there is a moment that I will know every single day that this is really not my space. Someone's groaning

> because they're getting their period, someone's hormonal somebody's about to have a period, there’s something [about] birthing babies or all the stuff. There's something every comment, every time I’m with someone I’m reminded again and again and again even though nobody's doing anything against me.

For Bec, being a transgressive parent has been liberating and far more important than transgressiveness with her chronic health condition. She reported that historically, when asked about her daughter (who is brain injured and uses substances) she would dissemble. Now she says proudly “she’s gone back to treatment” or “she’s X months sober”. She acknowledged that this often makes people very uncomfortable yet for her transgressing in this way is an act of honouring her daughter’s journey. It is also an act of social justice in service to all of those who do not have a family member to stand up for them. It was this vignette that helped me understand the need to decouple sanctuary from my lupus experience, due to its much broader applicability.

Data of this nature resulted in codes like ‘cutting the BS’, ‘radical self-acceptance’, ‘rejecting social pressure’, and ‘unf*ckwithable’. These women all expressed the ways in which they managed to push back again or even outright reject social norms and expectations, not just relating to their chronic conditions. I related this back to the idea of boundary-riding in research and quickly realised that transgressive is exactly the right word. Transgressive is what disabled bodies are when they refuse to ‘play nice’ in society; when they do not hide their discomfort or their needs that might exist outside of social norms. When, like Robbie, they are so infuriated by the fact that the world moved to Zoom in response to a pandemic and yet no one thought to turn on

captioning so the deaf community could more completely engage, she went on CBC to raise awareness. At no point did she apologise for either her hearing loss or her desire to be included. Neither did she apologise for drawing attention to the exclusionary nature of what could have been a very inclusionary aspect of the pandemic.

Nourishingness

In spite of its prominence in the data, it was not until the end of our interview, when Robbie stated that the experience had been nourishing, that I recognised it as a potential theme. We spoke about that idea briefly after her comment. Following the interview, I journaled (visual and textile) about it and the word kept surfacing. Nourishing. While I agreed with Robbie's sentiment vis-à-vis the interviews, it quickly became clear that there was more to this idea with regards to the experience of sanctuary. I quickly learned that it was more than just a theme.

As I indicated, this was not the first time that 'nourishing' had come up in relation to the research. I initially noted it as part of the numinous. A journal entry from early November states "experiencing the numinous. I think the core theme is: nourishing activities are required for sanctuary". Shortly after, nourishing became a core feature in my sanctuary-related word doodles. I found it throughout the data. The codes included the phrases: "nourishing to bloom" and "nurturing the mud you have". Once I uncovered nourishing as a quality of sanctuary, I found it all through the interview transcripts. Willow spoke about it in the importance of building her Inner Grove. For Lynn and Rebecca it was about the work of sitting at the loom. For Alexis

it always comes back to the garden analogy of: a garden doesn't grow without manure, it's just not going to. We literally have to have it in there or we don't get the beauty. And if you think about manure, if you throw raw manure on your garden you're just going to burn all your seedlings and they'll be done for. It's got to be well rotted, with a good foundation, and if you don't plant the seeds nothing beautiful will ever come. So there's choices and there's hard work and time. I think that's the other thing, you can't rush it like you'd want to.

Bec illustrated the idea of nourishing through the garden as well as other analogies. She was

> immediately taken back to the lotus yeah or the phoenix. The phoenix doesn't want to go on fire. And not that you need to go through something so destructive, to have your whole entire house of cards burned to the ground and rise as a phoenix, but you do have to get to a place that is… I don't know out of all of that darkness if allowed, it's full of all the right nutrients to build something beautiful. If you're willing to look at it that way.

She returned to the idea of the lotus and how

> you may not have picked that particular mud but if you've got it you've got it so how do you nurture it? Because when you look at that mud it's your own belief in something that will happen or could happen if nurtured enough. So you have to have faith in the unknown and in the ability to transform

These types of examples filled the data from a range of perspectives in every interview. And while there are simple definitions of nourishing, mostly to do with promoting growth or sustaining with nutrition, none of them adequately capture what it truly means in this context. When I consider the concept of it within the data, it has a richer feeling tone than the conventional definitions suggest; something that is more than just sustaining or promoting growth. There is something about stretching, rising to the occasion, meeting a challenge, and tolerating discomfort. That is visible in Bec's phoenix analogy as well as her thoughts about the lotus. Though you would not opt for it and it will not be enjoyable, one must go through the fire to be reborn, or sit in the mud with no guarantee of a blossom.

All of the qualities and elements have the potential to have a dark side, as previously discussed. The creative can close their mind to the logical and linear, and end up with nowhere to live, no family, no friends. The nature lover can escape to the woods and again, turn solitude and contemplation into problematic withdrawal and loneliness. The importance of the nourishing quality is that it keeps all of the other qualities and elements in balance - if it is truly nourishing, it cannot be wrong for you.

Fluidity

There is little to say about the fluid nature of sanctuary that has not already been addressed in the previous sections. As demonstrated through all of the previous elements and qualities, the components of sanctuary ebb and flow just as symptoms come and go. This also brings to mind the idea of the seasons and the garden. We will have spring with

new life and the excitement that brings. Followed by the summer with the hard work of weeding and little reward as the garden is not in full production. And then the harvest of the fall, when there is bounty and, if you live in an agricultural area, a distinct lack of canning supplies in the stores as everyone is busy processing that bounty. And then the world is fallow. There is relief. And by midwinter, there is some sorrow and some longing, some readiness for spring (and growth) to begin all over again.

The codes and themes in the data spoke plainly to this connection. Many codes were grouped under the themes: 'believing blossoms will come again' and 'taking cues from Nature', which led me to believe they were nature specific, and while they are, there is an element to fluidity that also is not. This is how it came to be a quality of sanctuary rather than a subset of nature.

More than that, fluidity emerged as a quality of sanctuary when considering each interview in light of the other interviews. Once the elements had been clarified, I returned to all of the interviews, recognising the repeating elements and categories, but in varying amounts. Fluidity was neither a code nor a theme so much as an indicator of how the components are experienced. In this context, the components must be fluid both in our experience of them and in relation to one another. Fluidity is what allows us to draw on them as we need to, or draw on aspects of them. It allows us to move and stretch in the direction we most need, which makes it fundamental to the idea of being transgressive.

Conclusion

As the findings show, this study revealed that sanctuary, in this context, comprises

elements and qualities. Although the elements (spirituality, nature, creativity, and purposeful occupation) were very much entangled with one another, they were also explicitly clear as specific qualities in the data. Of interest, and surprise to me, aspects of spirituality were present through all of the elements. The qualities of sanctuary were less defined and, ideally, will be a subject of future research. The qualities that were clear in this data included the qualities of transgressiveness, nourishingness, and fluidity.

The participant data illustrated many components of sanctuary not uncovered in the autoethnographic data which validated the methodology. These moments of illumination offered rich insights into the experience of sanctuary as well as its constitution. I discuss this further in the next chapter, as well as what I believe the data indicates, and how the sanctuary data may offer opportunities to inform social work practice.

As the findings emerged, I was reminded of the most captivating aspects of conducting research for me: the inherent creativity in the process. I find this type of co-creating invigorating. Within this, one of the most compelling aspects for me is the interplay between my personal data with the participants data and how this engagement unfolded in relationship to bring about expanded awareness.

As I reflected back on the process of working with the findings and considered how it fit with the literature that brought me to this research process, the importance of O'Donohue's work and Celtic spirituality became clear to me. Although not explicitly stated in the findings, those threads run throughout my engagement with the data. For example, without my background, would the prominence of a particular, and somewhat

unconventional idea of spirituality have emerged as it did? Likewise, would my gaze have settled so completely on the importance of creativity or nature – both crucial elements of Celtic spirituality?

This new awareness brought forward by the results in the data, necessitated a new consideration of the literature. Therefore, rather than returning to the previously reviewed literature (Chapter 2) I re-engaged with the literature. In particular, I focus on the question broadly asking, 'what does this data say it means to experience sanctuary?'; a question I might never have asked if not for my engagement with O'Donohue's work and Celtic spirituality. The discussion in the next chapter explores this question through the experiences of the participants followed by my own autoethnographic exploration, married with the new literature.

Chapter 5: Discussion

This analytic autoethnography sought to understand the experience of personal sanctuary from the perspective of the author and informed by the participants. In addition to this understanding, it held the implicit ideal of informing social work practice through the results. This chapter offers a discussion that first reviews and then reflects upon the findings, marrying those with the relevant literature. I will follow that with my personal reflections including my new learning.

Although the literature discussed in Chapter 2 was essential to the foundations of the research, from conceptualisation to formulation, as a result of the openness of the methodology, true understanding of the data also included engagement with new literature not discussed in the literature review. Rather than revisiting the literature in Chapter 2 this chapter focuses on the interplay of the data with the essential, new literature that supports emergent understandings. Following that I discuss how these understandings may be useful in social work practice and provide recommendations for practice (including future research). The chapter ends with my conclusions including a summation of all of the elements therein.

As previously stated, the participant data, married with the literature reviewed at the initial stages was key to my understanding as well as the development of a theory. Indeed, this can be seen in the analysis where the most illuminating data resulted from the interplay of the interviews and my self-reflective data. Perhaps most importantly was how the data revealed the decoupling of the experience of chronic illness with sanctuary;

without the participant data I might not have realised how true this is for me. To illustrate, for Amanda, sanctuary was important to her functioning as an intersex woman but even more so, in leaving the religion of her birth and the process of adopting. Bec identified sanctuary as the key factor enabling her ongoing connection with her daughter through her daughter's brain injury and subsequent struggle with addictions.

The data also helped me understand that although O'Donohue speaks of an inner sanctuary, in some circumstances there is a need for an external type of sanctuary that then nourishes the internal. For example, Willow identified a lack of internal sanctuary when she was first diagnosed. Through the love of her family and the construction of her labyrinth, her inner grove and internal sanctuary grew. She expressed that without the external, she did not think she would have survived because at that time there was no internal sanctuary for her to access.

These revelations challenged my original conception of the research and may have been unobtainable without the input from the participants, validating the choice of methodology. Likewise, as I consider the process and the data alongside the concerns and critiques of analytic autoethnography I am convinced that I achieved my aims. Participants reported that the personal nature of the interviews resulted in them feeling comfortable to share freely, unlike the formal process they had envisioned. The combination of Critical Reflection on Practice (CRoP), critical self-reflection (CSR), response journaling, and constant comparative method (CCM) resulted in my having personal data to share with the participants; in turn, this resulted in their own self-

reflective moments and disclosures during the interviews.

To that point, I do not assert that the data were there waiting to be 'discovered' (Charmaz, 2014); they were very much co-constructed through all of the research processes. Using the term 'emerge' to discuss the co-construction, I liken the experience to that of weaving a blanket. To weave a blanket, I need the structure of the loom and to that I add the warp yarn. The structure holds the yarn in perfect tension, this allows the weft yarn to be thrown through. The equipment, yarn, skill, time, and sometimes a pattern come into relationship and from that engagement emerges a blanket. So too did the co-constructed data emerge from the process.

Although there are criticisms of the method (as previously discussed), in this experience the informants provided a form of de facto triangulation, especially when held alongside constant comparison in the data analysis. Their voices offered a way for me to continually challenge my own internalised story (which also pairs with the CSR processes previously discussed). What I concluded was that while I speak about the findings generally, I situate myself within them. The generous sharing by the participants provided an essential frame for this research. Their data helped me stay grounded and furthered the contemplation myself in the social context, which is the goal of autoethnography. And ultimately, the theory I generate is informed by their data while remaining my own theory of sanctuary.

Review of the Findings

Autoethnographers employ an analytic autoethnographic methodology to clarify their perspective through the views of others, to orient their research in a more scholarly and less evocative frame, and to develop a theory grounded in the amalgamated data (Anderson, 2006a). This study did just that. The interview data from the participants informed my self-reflective processes which, in turn, broadened my understanding. This research primarily sought to understand the personal experience of sanctuary, and was contextualised by the experience of chronic health conditions. As I have quoted in earlier chapters, an O'Donohue quote guided the research and states there is

> a place in the soul that neither time nor space nor no created thing can touch… [W]hat it means is that your identity is not equivalent to your biography and that there is a place in you where you have never been wounded, where there is still a sureness in you, where there's a seamlessness in you, and where there is a confidence and tranquillity in you. And I think the intention of prayer and spirituality and love is now and again to visit that inner kind of sanctuary. (O'Donohue & Tippett, 2008)

The data quickly revealed that while chronic health conditions provided a useful frame for researching this type of sanctuary, the participants reported that they did not consider the two to be linked as I had prior to the start of the research. While the majority of participants self-identified as atheists or spiritual-but-not-religious (SBNR), they felt that the term sanctuary coupled with the non-theistic view of spirituality in the O'Donohue passage and congruent with the idea of the numinous (e.g. Otto, 1959) felt

most appropriate to articulate their experiences. Further, the data revealed that sanctuary comprises both elements and qualities that vary in prominence between individuals and with circumstance, but are all essential. Finally, the data was robust enough to allow me to generate a theory which is fundamental to analytic autoethnography. The theory from the data is that:

> the experience of sanctuary builds on itself. Often it is a largely personal or internal process though at times, it must be found in relationship. Sanctuary comprises elements (spirituality, nature, creativity, and purposeful occupation) and qualities (transgressiveness, nourishingness, and fluidity). These qualities and elements exist in relation to one another and are all essential for the true experience of sanctuary; however, the feeling of spirituality or 'connection to' is predominant among them.

Reflecting on the Findings

The participants made two key contributions to the sanctuary research. They first offered a much needed perspective that augmented the autoethnographic data, validating the methodology. Secondarily, they affirmed the need for more ‘insider’ voices reflecting the experience of chronic health conditions. Participants made explicit references to the ineffectiveness of third-party information, from brochures to health care professionals with no lived experience of chronic health conditions. The strength of feeling from the participants regarding the importance of insider research and peer support, especially for those who were newly diagnosed, caught me off guard.

Within the results themselves, the prominence of spirituality in the data surprised me. This was especially surprising as the majority of participants identified as atheists, many of whom reported advanced education in the sciences. I had asked a specific subsidiary question about the connection between sanctuary and spirituality, as prior to the research, I wondered if there were non-spiritual and spiritual experiences of sanctuary. This data revealed that for all of the participants spirituality and sanctuary are inextricably linked and within that were strong themes of the numinous.

The final broad reflection on the data comes from recognising that while the positive attributes of the elements and qualities are emphasised in this discussion, there were glimpses of where they can have dark sides to them as well. I would imagine that spirituality, taken too far, could evolve into fanaticism or disconnection. So too could nourishing cross from a positive comfort to self-indulgence which can be destructive. Those themes were not explicitly explored in the research but must be acknowledged. This would be an interesting area of future research.

Connections to the Existing Literature

Spirituality

The participants identified the importance of (largely) non-theistic spirituality. And even those who identified as belonging to faith-based organisations stated the importance of spirituality as something different from religion. For the participants, spirituality was largely identified as ‘connection to’, existing outside of any dogma or structure, and was deeply personal in nature. Participants reported that spiritual

experiences were important in all aspects of sanctuary. Spiritual experiences as part of sanctuary occurred in myriad experiences and circumstances ranging from walking to parenting. These experiences were largely what I have called ‘incidental spirituality’ in another (unpublished) paper. Incidental spirituality is the experience of undertaking an activity and, not until after one reflects, is it realised that there is a spiritual component to the activity or that it serves a spiritual purpose.

The prominence of spirituality in the data and importance of spirituality for the participants cannot be overstated. As the connections between social work and spirituality have been discussed at length in Chapter 2 they are not reiterated here. I will note that the importance of acknowledging spirituality as part of the continuum of health services from chronic conditions to mental health is also discussed at length, outside of the social work literature (e.g. Cook et al., 2009; Corbett et al., 2016; Corbett et al, 2021; Nolan, 2012, 2016).

Within spirituality or ‘connection to’ there existed a surprising and strong sense of vocation as opposed to duty (a discussion of which follows). All of the participants agreed to participate in the research as an act of service, hopeful that their contribution might make the experience of a chronic condition more manageable for even one other person. Or that one health care professional might engage with this research and in so doing, change their approach, even just a little. These sentiments as well as reflecting on my own motivations for this research and data, such as Bec’s experience of problematic creativity led me to consider the idea of vocation and how, or whether, it differs from

duty. I address this at length in the discussion of my personal reflections, later this chapter.

Further, within the data, spirituality clearly wove in and out of the other elements and qualities of sanctuary; both standing alone and inextricable from other elements. As stated, it became very difficult to tease the threads of spirituality from the threads of nature or creativity in particular. Just as the data revealed the interplay between spirituality and nature as a dominant theme, so too is it reflected in the literature (e.g. Grey & Coates, 2013).

Nature

Nature-based interventions that mirror the findings ranging from gardening to unstructured time in wilderness fill the literature. For example, Mori et al's 2021 occupation therapy-based study found therapeutic horticulture (TH) to be an effective intervention for dealing with cancer related pain. The Canadian Horticultural Therapy Association (2021) defines therapeutic horticulture as an informal practice employing horticultural activities to promote participants' well-being. Mori et al (2021) found that TH had long been "an occupation-based modality since the early days of the profession to improve physical, mental, and spiritual well-being" (p. 1). Their results demonstrated physical, mental, and spiritual well-being as a part of the participants' engagement with TH. What they do not discuss explicitly, though appears represented in their research, is the importance of purposeful occupation. The participants selected work, even laborious work, of interest to them. Although looking at different populations, a representative

sample of the literature (e.g. Diehl et al., 2019; Millet, 2009; Verra et al., 2012) had comparable findings.

Tsunetsugu (2007) focusses on the Japanese practice of Shinrin-yoku or "taking in the forest atmosphere or forest bathing" (p. 8), a practice grounded in long standing cultural practices and formalised by the Forest Agency of the Japanese government in 1982 (p. 12). Tsunetsugu notes myriad positive results from the experience from a self-reported sense of well-being to decreased blood pressure. In their meta-analysis of 64 studies, Hansen et al (2017) assert similar findings. They concluded that "significant empirical research findings point to a reduction in human heart rate and blood pressure and an increase in relaxation for participants" (p. 43).

Congruent with the sanctuary data they argue that their review "illustrates, honors [sic] and supports the increased awareness of the positive health-related effects (e.g., stress reduction and increased reports of well-being) associated with humans spending time in nature, viewing nature scenes via video, being exposed to foliage and flowers indoors and the development of urban green spaces in large metropolitan areas worldwide" (Hansen et al., 2017, p. 44). And most useful to the focus of this research is the finding that virtual engagement with nature, whether technologically mediated or through a magazine, offers benefits. This means those whose health conditions may force them to remain indoors, or who are simply not oriented to nature 'out there' can benefit from nature-oriented images.

Creativity and Purposeful Occupation

While nature was a dominant theme in the participant data, the presence of creativity as a practice with spiritual overtones was also very visible. The presence of creativity as a therapeutic or even spiritual act is also very present in the literature. Further, within both the data and the literature, creativity and purposeful occupation are often found entangled. Finally, within the creativity data there were both ‘making’ (or tangible) components and non-tangible components (such as problem-solving).

The creativity specific data were slightly confounding as they matched neither what I knew of the fine arts/art making processes nor did they fit with my reading about art therapy. I determined that while the literature of both had useful elements, they were also often oriented to goals in a way creativity in this data was not. Although the participants reported goals for at least some of their creative work, it was neither goals nor the intention to progress in a creative practice that were essential to the healing and spiritual aspects of creative practices in the data. I most unexpectedly found the answer to the question ‘what is this data revealing’ in the occupational therapy literature, where Reynolds, in particular, has been addressing a similar question (both with collaborators and solo). As such, I begin with Reynolds’ consideration of the therapeutic impact of creative leisure activities (such as textiles). I then bring in Collier’s (e.g. 2011a and b) work and conclude with others such as Garlock (2016) and Leone (2021) who are continuing these conversations in the literature, and, as Moon (2010) suggested long ago, challenging the primacy of art-based interventions in the world of art therapy.

Reynolds, Occupational Therapy, and Creativity

Reynolds has published on the relationship between creative leisure activity and health since the mid-1990s (e.g. 1997, 1999, 2000, 2002, etc). She began studying women using creative needlecraft to cope with chronic illness (Reynolds, 1997) and unresolved grief (Reynolds, 1999). She then focused on creative leisure activity and chronic health conditions including managing mood and/or reclaiming identity (2000, 2002, 2004). Collaborating with others she investigated chronic fatigue syndrome/myalgic encephalopathy (Reynolds & Vivat, 2010), cancer (Reynolds & Lim, 2007a, 2007b), and long-term health problems (e.g. Reynolds, 2003a, 2003b, 2003c, 2004a, 2004b, 2010, 2011a, 2011b). Not only does her work consistently highlight the importance of creative leisure activity, predominantly textiles, as part of rehabilitation or when experiencing chronic health conditions, it assisted my understanding of the element 'purposeful occupation'. While purposeful occupation was a distinct element of sanctuary, it has so many aspects in common with creativity and with the literature relating to creativity, I discuss them together here.

In her seminal (1997) paper 'Coping with Chronic Illness and Disability Through Creative Needlecraft' Reynolds notes that the participants reported "needlecraft activities as a vital means of coping with their illness or disability and maintaining a satisfactory self-image" (p. 355). Further, the activity "had then become central to their coping with hospitalisations, pain, limited mobility, unstructured time, and lack of paid occupation" (p. 355). In this paper, Reynolds argues the usefulness not only of crafts as part of a therapeutic plan but to consider all manner of "leisure counselling" to assist those with

chronic conditions. Her premise was consistent with the sanctuary data. The participants made statements similar to those in Reynold's work, as reported in the findings of this research. Statements like "[t]he needlework is my 'escape' and I can absorb myself in my work and let my imagination fly..." (Reynolds, 1997, p. 355) could just as easily be found in my data. I discuss my personal relationship with these findings later in this chapter.

Reynolds and Prior (2006) note the importance of art making as "a powerful means of regaining a positive self-image when health is poor" (p. 5) and in resisting the subsuming of their identity by their condition (Charmaz, 1993). Within this context Reynolds and Prior (2003, 2006) specifically address the difference between leisure activities and art therapy interventions. Just as with the sanctuary participants, while those in Reynolds and Prior (2006) engaged in leisure activities that offered them relief from the experience of their health condition, those activities were coincidental to the experience of their health circumstances. For example, when asked about a piece, Jessica (in Reynolds & Prior, 2006) "did not regard the imagery as expressive of illness at all" (p. 10). Some participants in Reynolds and Prior (2006) became so immersed in their art practices that they enrolled in formal art related educational programmes. For example, Joyce (in Reynolds & Prior, 2006) "gained a greater sense of mastery by absorbing herself in her artwork" (p. 15). Her engagement in "textiles all day obsessively helped her focus away from the effects of chemotherapy and to avoid thoughts about her prognosis" (p. 15) instead, offering her something future-oriented to focus on.

Further, Reynolds and Lim (2007b) found that with the advent of a challenging diagnosis participants either took up or intensified their leisure (craft and art) activities

with nearly all participants expressing a powerful need in the early stages of their illness to use these activities to manage their emotional turmoil. These activities also offered something pleasurable or even joyous in their lives, assisted them in enhancing or sustaining their personal identity, as well as offering a positive activity that could be shared with others around them. This very much echoed the sentiments expressed by the sanctuary study participants. In the sanctuary data, tangible creative activities were both enjoyed for the product as well as the process of making. They included formal and structured activities such as weaving to a pattern or a plan as well as informal activities, such as weeding or simply contemplating a garden; differentiating sanctuary activities from Flow (Csikszentmihalyi, 1990) which requires that the person is both working towards a goal and working at the edge of their ability. Finally the element of creativity also included such intangible aspects as contemplation of materials that might be used in a tangible project or words that might be useful in a written work.

Comfort From Creative Practices

I noted how all aspects of these processes offered a sense of comfort both expressed by the sanctuary participants as well as encoded in the language they used, or in non-verbal cues such as a faint smile appearing, change of tone, or even a relaxing of the posture. When I commented on what I noticed, participants such as Alexis responded with "yes. I do notice that. Even thinking about pottery or my garden just feels…" she paused and looked up. "I just feel more ease. I can breathe."

I further note the connection to the way creativity emerged from the data and how it very much, and unexpectedly, mirrored the response art used as part of my CSR process. This is another example of the usefulness of the methodological choice. Without analytic autoethnography, I would not have had the interview data that highlighted the similarities in my experiences with those of the participants and again, how this was also found in the literature. And as with the response art in the autoethnographic data, the participants also reported that the space made for a creative, non-directed (or as Reynolds says ‘leisure’) activity allowed a sense of well-being as well as insights to arise.

Just as the participants felt that their tangible creative engagements offered them a way to purposefully fill time as well as giving them something to focus on (both internally and socially) other than their condition, so too did the literature demonstrate this. For example, one of the participants in Reynolds (1997) states “[n]eedlework has most definitely given me a reason to get up each morning. When I don't have a project underway I find I start to dwell on my illness and ... the frustrations I feel at not being able to do all the things I used to” (p. 354). So too with Elaine, in Reynolds and Prior (2003) who finds that “doing the embroidery gives you a little bit of dignity because I feel I can give back because I don’t want to keep taking from life. I want to give as well (Elaine, with multiple sclerosis)” (p. 791).

Blank, Harries, and Reynolds (2014) found something similar. Their analysis showed two core themes: building and maintaining occupational identity and work and other ways of belonging. This echoes the sanctuary data in the ways that the engagement with purposeful occupation (creative or otherwise) offered many internal resources;

however, the external resources were equally important and contributed to a sense of well-being. For example, having work-like engagements were a point of social connection that offered participants a sense of purpose and meaning in their life. The sanctuary study participants, and Blank et al, echoed the sentiments of participants in other studies (such as Reynolds & Prior, 2011), that having activities offered something identity creating or preserving, helped participants have a sense of worth. It supported them to resist "being dominated by the [illness] label, and promoted relationships based on mutual interests rather than illness" (Reynolds & Prior, 2006, p. 11). Reynolds and Prior conclude their 2003 paper with the statement that "[l]ifestyle choices and meaningful occupations may be as important to quality of life in illness as specific illness- management strategies" (p. 794). The research of this dissertation, especially with regards to the element of purposeful occupation, absolutely concurs with their statement.

Collier and Others Build on the Existing Literature

While the data from Reynolds (with and without collaborators) best matched the creativity and purposeful occupation revelations from the sanctuary data, there are others writing from a similar vantage. For example, Collier's work begins with her dissertation, the first ever large-scale (n=891) research on the experience of textile handcrafters, specifically how they employed (or did not) their textile practice to cope with difficult mood states (Collier, 2011b). She continued her research noting that "textile-making provides an important source of cognitive coping or intellectual stimulation" (p. 110). She expands on that data in her text, *Using Textile Arts and Handcrafts in Therapy With Women*. Her work explored how these results might offer a new perspective to therapists

(2011a, 2011b) and later how textile work might contribute to mood repair (with von Károlyi, 2014) and decrease inflammation (with Wayment & Birkett, 2016).

Riley et al (2013) also note the importance of purposeful occupation and how textiles effectively fill that niche. They link textile work to a sense of identity, personal and cultural, both derived from and contributing to, as well as highlighting the importance of skills and capacities to be exercised through meaningful occupation in a way that contributes to health maintenance and personal well-being, linking this back to a sense of self as a spiritual being.

Art Therapy and Craft

Collier (2011a, 2011b) urges therapists to consider textiles and handicrafts as an entry point for therapy. Throughout her work, she urges bringing creative, especially textile-based interventions, into therapy generally. Likewise Moon (2010) offers a perspective on the history of art therapy's distance from craft materials. She suggests that "[m]ore dialogue on the place of craft in art therapy is needed. Despite shifting trends in the art world, the increasingly strong presence of traditional craft practices in contemporary society, and the long-standing association of crafts with those outside the art world elite whom art therapy professes to serve, art therapy has been slow to adopt craft practices and materials. This is particularly puzzling in a profession dominated by women, given the strong historical association of many craft practices with women's activity" (Moon, 2010, p. 20).

Kapitan, a professor of art therapy, calls crafts the "direct link to the human heart that people who work with traditional arts and handcrafts say is the essence of their drive to create" (Kapitan, 2011, p. 94). And yet, "the value of craft has been overlooked and under-appreciated in art therapy" (Kapitan, 2011, p. 95). The continued distance between art therapy and 'craft' based therapies is disappointing because those who may not feel that 'art' is accessible may well find that something in the realm of craft is, as was the case for me. As Kapitan (2011) points out, where the artist or art therapist may make the statement that there are no mistakes, the knitter making a lace shawl who has dropped a number of stitches or the weaver with a tangled warp has an entirely different understanding. I see this as an important part of the conversation relating to care of those with chronic health conditions. It is not about the lack of mistakes so much as what we do when mistakes (or challenges) appear.

Fortunately, there are those who are answering this call. In addition to Collier's text, there are those such as Garlock (2016), whose work considers the history of narrative textiles contextualised in modern, therapeutic applications, or Leone's 2021 *Craft in Art Therapy*, an academic resource directed to art therapists but useful to anyone working in therapeutic interventions. She discloses her own history with textiles and craftivism, recognising that when those interests drew her to art therapy literature, it was sorely lacking. Her doctoral research built on those interests which then led her to edit the aforementioned text. Leone specifically links craft to both mood and social power (linking that to community as well as social justice) as therapeutic elements of craft in

therapy. However, in spite of the growing body of research, textiles remain an unconventional material in the therapy world (Hinz, 2020; Leone, 2021).

This concludes the core findings reflecting the prominent components of this sanctuary research. As indicated above, while there is literature that corresponds with the findings, there are areas that would benefit from future study. Further, aspects of sanctuary that were glimpsed but not as well developed in this study would also benefit from further investigation and will be discussed later in this chapter. I now proceed with a discussion of the most prominent autoethnographic data that was not represented by the aggregate data. Following that are my initial recommendations for the application of the sanctuary data to social work practice. I then conclude with my recommendations and hopes for future, sanctuary-related, research.

Personal Reflections

Vocation and Duty

> [Vocation] is something I can't not do, for reasons I'm unable to explain to anyone else and don't fully understand myself but that are nonetheless compelling. (Palmer, 2009, p. 25)

> When the notion of vocational calling is embedded in institutional culture it means that good or effective professionals should be willing to sacrifice their mental and physical well-being to the cause of student learning (which translates into meaning for the overall institutional good). (Brookfield, 2016, p. 17)

> At the heart of each destiny is hidden a unique life calling. What is it you are called to do? In old-fashioned language: What is your vocation in life? (O'Donohue, 2008, p. 236).

One of the threads that was visible in my personal data and the literature but less present in the participant data was a notion best captured by the words: vocation/calling/duty. It first emerged in the CRoP process of this research, however, required reflection to fully understand the relevance in relationship to sanctuary. Understanding the nuances became even more pressing as themes of service continued to show up in the data.

Vocation was as nuanced and variable in the data as it was in the literature. On the one hand, it can be the deepest call from the soul, that thing that we were put on the earth to do (Hillman, 2008). Something that, as Palmer (2009) says is so compelling you just can't not do it. Or that thing that wants to come into the world through you (Hollis, 2018). On the other hand, we have Brookfield's (2016) caution: the notion of vocation can be weaponised by systems where the ultimate goal (of the system or key agents of the system) comes down to neoliberal capitalist ideals (such as maximising profit at the expense of people).

Through the CRoP process I discovered that what Brookfield identifies as unhealthy vocation is more akin to my internalised sense of 'duty'. I see vocation as something closer to the other definitions, something very akin to the spiritual notion of a

calling, that thing that we cannot refrain from doing, or that seems to be missing from our lives when we are not engaged with it (Palmer, 2009). For me, and I suspect for others, duty intersects neatly with vocation, which can make it difficult to tease out where one ends and the other begins. Brookfield (2016) affirms that women often end up disproportionately burdened by institutions as "[v]ocation becomes especially hegemonic when filtered through patriarchy, as is evident in predominantly female professions such as teaching, social work and nursing" (p. 17). He further links what I would call a false sense of satisfaction as a contributor to burnout. Brookfield (p. 17) says "[a] state of burn out becomes a sign of your commitment to your vocation. Anything less than total exhaustion indicates a falling short of the mark of complete professionalism". This resonated deeply for me. CRoP and my personal self-reflections uncovered the many components to vocation versus duty including: family history, broader culture, identity as a GenX woman who should 'have it all', and likely, aspects of my personality. For me there is also an element of duty rooted in internalised ableism. I think there is a relationship with the sanctuary quality of nourishingness to explore, which I elaborate on in the future research section.

Prior to the conclusion of this research, I thought my professional practice was moving towards disability advocacy. While I intend to use my privilege to advocate and educate, this research revealed that my real passion and vocation is about spirituality, especially the spiritually informed creative processes I find in sanctuary (a thorough discussion of which follows). I can see that focusing on the world of disability would be another trip down the road of duty where spirituality is what feels like vocation and

sanctuary. Perhaps predictably, O'Donohue has spoken to this as well. He (2008) notes that when we find what we are called to do, life takes on a focus and purpose. This brings us into rhythm with the deeper longing of your heart and harmony with your inner nature. O'Donohue (2008) cautions that having a sense of vocation does not simplify or smooth the life path. Indeed it can bring about sacrifice and risk, leading a person down unimagined paths.

This has been the case for me from applying to the DMin programme through to this research where I have routinely found my feet on paths I would never have dreamed for myself and yet the sense of rightness, or the Quaker concept of 'way opening' has persisted. This feeling, in conjunction with the self-reflective processes of this research have assisted me to not only feel but articulate the difference between vocation and duty. When I think about working solely in the world of disability, it feels heavy, like something I want but must be hauled up a big hill; this is duty. Working in spirituality, especially in relation to creativity, feels lighter; vocation. Perhaps most important to me was the recognition that when my internal language is 'should' in response to an activity or a job, rather than a feeling of curiosity or excitement, it is a warning flag. There may be times that 'should' is the right thing to do but because of this new awareness, there will be room for discernment allowing me to tease out the nuances of each decision.

The pursuit and promotion of sanctuary is one such example of vocation illuminated through my personal reflective processes. The other, which came to light through the dissertation process, was the importance of what I now think of as spiritually informed creative processes I call cræft and includes those creative practices we

undertake as part of purposeful occupation and/or therapeutic memorialisation, that offer us sanctuary (I elaborate on therapeutic memorialisation next).

Therapeutic Memorialisation

The term therapeutic memorialisation might beg the question: isn't all memorialisation therapeutic? While it may be, in the literature and in the data I see evidence of different types of memorialisation, some of which may be therapeutic and some most definitely is. There is also, I suspect, a substantial difference in the act of memorialising when one is memorialising oneself.

Memorialisation is an oft studied theme in folklore (e.g. Dorson, 1972; Everett 2002; Kukharenko, 2011) but "so-called 'makeshift memorials' have to date been relatively neglected by academic commentators, and consequently remain poorly theorised" (Frisby, 2015, p. 102). What I glimpsed in the sanctuary data and the literature confirmed was the presence of 'makeshift memorials' or memorialising activities that serve a commensurate therapeutic purpose, implicitly or explicitly. I first began to consider it during Willow's discussion of constructing the labyrinth and how she connected it to building her 'Inner Grove'. It was a physical representation of her internal process, but more than that, as she said, it was something that would survive her even if the cancer killed her.

Willow's labyrinth connected me back to my own experience of wanting to leave a legacy during the liminal time of waiting to rule out the brain tumour. During that period, I immersed myself in numerous textile projects, partly as an antidote to the

distressing physical symptoms and the soothing experience of creating. The materials I selected were pleasant in the hand, the colours were soothing to view, and all were natural, rather than synthetic materials as is my preference. Rather than my usual inclination to save my best materials for some unknown future I used them in these projects. Imay (in Riley, 2008) notes that engaging in creative, immersive activities such as weaving is "not just an externalisation of the self as an object but probably the expression of the internal self" (p. 70) I believe this is a critical aspect of my engagement at this time. The pieces I produced were a text that allowed me expression, not of the current experiences so much as the hope I held for the future, including the future I hoped to project for my family should not be there with them.

Even more fascinating in the context of this research is that, aside from the very first piece I created [image in Appendix], all of those pieces were consigned to a bonfire once an MRI had definitively ruled out the brain tumour. As I reflected on that through this research, I felt an unexpected sense of relief, rather than regret at their loss. While they were well made pieces, my data revealed that they functioned primarily as a spiritual practice and therapeutic outlet (through the making of them) and as well as potential memorials, capturing a particular time and experience that I no longer felt a need to retain.

Fisk, a lecturer in Theology and Religious Studies, shares my interest in the tangible and intangible aspects of textile creation (personal communication, Dec 6, 2019). Her research considers the intersection of textile arts and spirituality, specifically "how, for some practitioners, their knitting has an implicitly religious role in their life,

incorporating ritual, structure, belonging, identity, wellbeing and meaning" (Fisk, 2017, p. 134). Her work reveals how textile work both "process and product—may function as a ritualizing and rooting of relationships, traditions, and places" (Fisk, 2019, p. 555). She makes explicit the importance of textile creation as "part of a process of mourning and commemoration" (p. 555) but for "loved ones, especially mothers and grandmothers" (p. 558) rather than the self.

Her work in conjunction with the other literature assisted me in seeing the importance of meaning-making and textile working in the context of chronic health conditions which led to the concept of therapeutic memorialisation. Once I saw it in the literature and my own data, it became very clear to me. For example, Reynolds, Lim, and Prior (2008) note that "[c]ertain pieces of artwork strengthened participants' sense of continuity by functioning as memorials: 'here is an element of something to be left behind, something that is other than illness, something entirely separate and yet also so personal'" (p. 217).

There were other such examples in Reynolds et al (2008) grouped under the theme of 'continuity of the self'. The participants who "produced art that was in keeping with family traditions" used "creative skills acquired (usually) from mothers and grandmothers, thereby maintaining a personal and social continuity" (p. 217). These 'memorials' were something to leave of themselves as well as modelled after memorials connecting them to their roots. Fisk (2012, 2017, 2019) also notes the importance of connection to one's roots in her work. And although they do not connect these practices

to soothing the nervous system explicitly, the work dovetails perfectly with Perry's research (2006, 2014, 2020, 2021).

This brought to mind legacy related creativity which given my proclivities led me to the realm of narrative textiles or story cloth, textiles designed to convey a story or meaning by the creator. Better known examples of narrative textiles include The Prison Embroideries of Mary Queen of Scots, the Changi Prison story cloths, the arpilleras of the Chilean Mothers of the Disappeared, and the numerous memory quilts, stitch diaries, and tapestry diaries that have been create for preterm babies, chemotherapy patients, from the clothes of deceased family members and more recently, to record the effects of climate change and the COVID-19 pandemic. As I discovered this important facet of the research outside of the research period, I was unable to bring related questions to the participants. The aforementioned literature alongside the narrative textile examples accurately represents what is most important about therapeutic memorialisation. Primarily it provides the benefits of purposeful occupation alongside giving voice to the unspeakable while creating something that can be left behind that is more than a memory of one's suffering.

While I believe therapeutic memorialisation can memorialise others as well as ourselves, the its relevance in the sanctuary research is as an act of self-soothing that both occurs as a result of the activity (e.g. Fisk, 2012, 2017, 2019; Perry, 2006, 2021) and the soothing that occurs as part of the process of memorialisation (e.g. Fisk 2012, 2017, 2019). However, as this was not confirmed in the participant data, it is an area of future research for me.

Cræft

Contained in the word 'cræft' are (for me) the elements and qualities of sanctuary, as well as the ideas of vocation and therapeutic memorialisation. Where I feel sanctuary as a state of being, I see cræft as the practice that helps me both access and strengthen sanctuary. The term is drawn from Old English and 'revived' by Langlands (2018), a lecturer in material culture/experimental archaeology. In his text, Langlands distinguishes cræft from other, similar terms by linking it, unapologetically, to the types of materials (natural), connection to roots (yours, regional, or the practices'), connection to (and reverence for) the natural environment, and purposefulness.

Cræft is less about production and more about the interplay of wisdom and resourcefulness coupled with "knowledge, power, and skill" (p. 9). He urges an embrace of cræft as "not just a knowledge of making but a knowledge of being" (p. 21). The relevance to sanctuary comes clear as Langland delves further into Alfred the Great's writing. Alfred (in Langlands, 2018) equated the "labour and work associated with making and doing was comparable to the spiritual strivings of philosophy" (p. 21). Langlands builds on this stating that "[i]t seems we are finally coming back to this not in that making has a spiritual element to it, that making fits within a wider understanding of who we are and where we are going" (p. 22).

In *Things Worth Keeping: The Value of Attachment in a Disposable World* Harold (2020), a professor in the field of the rhetoric of consumer capitalism, picks up a similar

theme. Harold too, emphasises the relationship between cræft (and the Old Norse kraptr) to the importance of the relationship between maker and materials as well as the product. Harold also brings in the importance of inventiveness, connection to roots, and relationality in all aspects of the process from the inspiration to the ecological impact of making. She draws on Ruskin and others in the Arts and Crafts movement who, disillusioned with increasing consumerism, capitalism, pollution, and labour exploitation, sought to create a world emphasising beauty and nature over efficiency in production.

Harold, like Langlands and Fisk, draws on the work of Sennett (2008), a sociologist, whose vision includes the "carpenter, lab technician, and conductor [who] are all craftsmen [sic] because they are dedicated to good work for its own sake" (p. 49). Sennett notes that while the craftsperson may be engaged in practical labour, it is not the product so much as the condition of being engaged that distinguishes craft from other types of engagement. Sennett also draws the comparison with the Arts and Crafts movement. The movement's progenitor, Ruskin expressed concerns that would not be out of place in today's discourse, ranging from waste and consumption to concerns about worker's rights and safety (1912/1997). Morris, perhaps better associated with the Arts and Crafts movement, took up these concerns; however, while much of the Arts and Crafts movement aligns with this aspect of sanctuary, a fulsome discussion is beyond the scope of this dissertation.

Through the research process, I learned that cræft is my sanctuary practice. At this time, I find it in the domestic arts, primarily my textile work. My textile related interests have been equally balanced between creating and studying textile material culture/social

context, particularly from the Northern European regions that comprise much of my ancestry. I suspect the more unsettled the disease process makes me, the deeper my longing for the stability I find when connecting with my roots. This marries with Nash's (2008) musing on Irish diaspora culture. A feminist cultural geographer with research interests in geographies of identity, relatedness and belonging, she writes about the Irish diaspora from both personal and professional vantages. Nash (2008) posits that for many

> [h]aving an ancestor for whom the place was home means that their descendant is linked to that land via the genealogical tie. This can be imagined as an embodied inheritance: the descendant inherits the blood or genes that were shaped in the ancestor by generations of life and work on that particular land or landscape. Ancestors' bones are in the land and their genes are in the returning descendent, so the act of returning reunifies a bodily inheritance carried down the generations and the formative familial landscape. (p. 70-1)

This sense of embodied inheritance is integral to the spiritual aspects of sanctuary for me; I have a sense of returning to it every time I engage with cræft. I suspect there is an additional complexity in relating to my roots and history that comes with largely having Settler ancestry. Being a Settler in Canada means having connections to the land that cannot truly be considered roots. In turn this requires other ways of finding the feeling of stability that roots offer. For me, textile history has been a way to connect with those. My autoethnographic data revealed cræft as a deeply spiritual, personal practice that links the components of sanctuary.

Concluding Reflection

This concludes the clarification of the three aspects of the autoethnographic data (the awareness of duty versus vocation, therapeutic memorialisation, and cræft) that were not prominent in the aggregate data as well as their relationship with my sanctuary process. While initially they seemed to be only personally important, through this research I have come to see their relevance in my social work practice as well. The following discussion further considers this relationship, focusing primarily on craftivism (which for me is inclusive of vocation, therapeutic memorialisation, and cræft) as both a spiritual and therapeutic practice.

Sanctuary and Social Work Practice

Although I primarily sought to personally understand sanctuary through this research, I also hoped that my understanding would contribute to social work practice. I begin with a discussion of the importance of spirituality as it evolved in the sanctuary data and how my new awareness of that will inform my social work practice generally. I follow with a discussion of the similarities I see between the Neurosequential Model of Therapeutics (NMT) and the sanctuary structure, which will be discussed further in the recommendations for future research. I then clarify my personal critically-reflective practice, insofar as it has been formally developed. I conclude this section with a discussion of cræftivism, which incorporates the aforementioned cræft with the quality of transgressiveness and, I believe, can be applied to social work practice.

Spirituality

Perhaps most importantly, this data revealed the importance of spirituality in my life as well as my social work practice. While this has already increased my intentional engagement with my personal spiritual practices, especially through cræft, the sanctuary study revealed ways I can also incorporate my learning into my social work practice. In addition to the specific social work practice applications to be discussed, I will first state that this experience has illuminated the need to contribute to the discussions of spirituality in the literature and in social work education. Following the experience of both my studies and conducting this research, I see the importance of engaging with unconventional or unique expressions of spirituality. I further see the importance of active participation in organisations such as the International Network for the Study of Spirituality. My goal is to contribute to those resources in support of expanding the social work lens to be more inclusive of spirituality generally.

Neurosequential Model of Therapeutics (NMT)

With regards to the sanctuary research generally, the results bring to mind the structure of the NMT. While there is a need for more research (as I later discuss), just as with the NMT I see the potential for the sanctuary model to offer clinical decision making support and a way of approaching social work, in particular with those who have been diagnosed with a chronic health condition. I see the potential for this data to support me to consider circumstances differently and to approach the questions I ask differently. This is an area I am excited to explore further.

Individual Self-Reflective Practice (ISRP)

ISRP is a practice I am developing as a result of this study and will be subject to further research; as such these are preliminary thoughts only. While the primary application for me is a personally self-reflective practice that allows me an understanding of my experience of lupus, there have been applications of this in my social work practice as well. While I absolutely feel the most robust experience of professionally oriented self-reflection occurs within a community of practice, there are circumstances that necessitate an ISRP, such as immediacy, unsafe work environment, or being a solo practitioner. Further the vulnerability one can feel as a disabled person in an abled world can incline a person to need an internal process before sharing, even in a group that is largely safe. I suspect this would be true for anyone who does not identify as part of dominant culture.

Through this research process, my experience of CRoP was fed by my ISRP and vice versa. The self-reflective aspects of this research required both experiences. In this context I began to deconstruct my ISRP for the purpose of understanding and reporting on it. I noted it had grown rather organically, like an assemblage (Deleuze & Guattari, 1987), stitched together with experience, theory, and practice. As a result of the research process, I now explicitly include the CRoP framework for use with my ISRP journaling. Included within my ISRP is information gleaned from my NMT and Signs of Safety training. These were supported by my narrative therapy experiences, particularly externalising and naming the problem and considering my preferred 'story' (per NT). And finally, I can now articulate the importance of nature- and arts- based practices to assist me with uncovering what lurks beneath my conscious awareness.

At this time however, while my personal practice has become more explicit, there is a great deal that is largely intuitive which makes it difficult to accurately articulate. Making our processes explicit, even just to ourselves, allows us to better understand and employ them with intentionality. While I have become much more aware of my ISRP, there remain unanswered questions I hope to clarify in future. I intend to continue employing my ISRP as part of my social work practice, working to make the intuitive more explicit and intentional, as well as picking up this thread in my thoughts about future research.

While the limitations of this research mean the findings cannot be generalised there are certainly aspects of the results that can be integrated into my social work practice. Given the prominence of craft in the data and the literature, I have opted to focus on that aspect of the sanctuary research as the key element to apply to my social work practice, especially in the context of cræftivism and transgressiveness. Not only do these match the weight given to cræft in the data, this also marries with the literature referenced through this study. Following that discussion, I expand on the other related concepts that are present but require further study. From there I conclude the discussion with areas for future research.

Cræftivism/Craftivism

Amongst everything I learned through this research, most impactful for me has been the importance of cræft as a personal spiritual practice with the potential for social work application. I do not see instruction in how-to (knit or stitch, for example) as a

practice direction so much as supporting people to understand why engaging in cræft that speaks to them might be beneficial. This brings to mind Greer's (2014) craftivism, a term coined in response to her feeling "that artists needed a term for crafting that was motivated by social or political activism" or to denote the "connection between craft and activism" (p. 12).

Although the contributors to Greer's original work discuss the personal importance for them, in most cases it seems that craftivism tends to reflect an external process. Craftivism as envisioned by Greer missed elements that I think are critical for its application in my social work practice. For example, it does not include any overt discussion of the spiritual. As such I am employing cræftivism in recognition of Greer's foundational work but with the added elements of cræft, as discussed above. For me activism cannot help but include all of the aspects of sanctuary. Perhaps most importantly, especially in this context is the idea of transgressiveness which, while certainly applies to the external actions reported in *Craftivism*, does not truly reflect or embrace the internal sense of transgressiveness that can support personal development.

As stated, the sanctuary research illuminated the importance of cræft for me, especially in the form of textiles. However, alongside this it also illuminated the internal conflict I feel about my engagement with 'women's work' and its representation. This conflict was echoed by many of the participants. In much of the data there was a sense of constantly analysing one's interest in anything relating to the domestic sphere. After all there is a deep sense of women having been liberated from just such experiences and yet here we are, finding solace in them.

Challenges for Domestic Arts Loving Feminists

The sense of conflict in finding solace through engagement with domestic arts has become even more complex with the recent appearance of the #tradwife/#tradfem movement (Gawronski, 2019; Mattheis, 2018). As the name implies, this movement posits that women exist to function as homemakers and mothers in roles primarily reflective of the idealised 1950s era. Like the term Anglo-Saxon, the idea of the #tradwife may seem benign but has been shown to have clear ties to the Far/Alt-right (e.g. Gawronski, 2019; Mattheis, 2018; Oosthuizen, 2020; Rambaran-Olm, 2020). This movement claims that "[t]here are three important things for a woman and they are ingrained into our psyche. And, no matter how hard you try, they will never be removed. Beauty. Family. Home" (Lokteff in Mattheis, 2018). In this movement the role of woman is to be a beautiful ornament, content with a life subordinate to her husband.

What I have determined is that the reverence and appreciation for the domestic sphere expressed in the sanctuary study exists in opposition to the values of the #tradfem movement; they express empowerment, agency, and women reclaiming their sacred history. This does not domesticate or disempower women, rather it connects them to the vast lineage of women who clothed, fed, and nurtured their loved ones, even in the face of overwhelming odds, the women who managed to buy needed items with funds earned textile or other 'women's work' when there were no other funds to be had, the women for whom 'make do and mend' was always a way of life. Fisk (2019) too highlights the way that textile creation is often a way of "ritualizing… feminist attempts to reconnect with

the unsung women of the past" (p. 558) as well as a sacred act even in the most secular circumstances.

Ultimately, the engagement with the domestic sphere in the sanctuary context is a transgressive act, primarily transgressive in service to the self. This corresponds with the quality of transgressiveness as a core component of sanctuary. Well represented by in vivo codes and explicit statements, transgressiveness was also supported by the literature. It was especially prominent from those writing from a critical disability theory lens like Samuels (2020) writing about crip time and Ellingson (2017) who simply refuses to accept her disabled body as 'less than'.

Foucault and the Importance of Transgression

Foucault (1963/1977) who may be the most transgressive, postmodern theorist, argues the importance of transgression as an essential and illustrative experience. Ettorre (2010) argues transgression is a function of operating outside of social comfort, illustrating how even pregnancy can be seen as transgressive as it renders the body morphologically dubious and even monstrous. Further, a pregnant body cannot be trusted to act appropriately; there is no assurance that the pregnant body will remain orderly as it may leak or even expel a foetus with seemingly little warning (Ettorre, 2010). Consider that in light of disability, where the body might not ever 'behave'. The very act of existing or presuming to take up social space becomes a transgressive act; the disabled body, simply by existing, becomes transgressive.

Claiming (or re-claiming) that which nourishes you can also be a transgressive act, especially when it is in service of meeting the needs of your misbehaving body. And while there may remain a general association between textiles and docility or an undesirable domestication, as discussed, there is also an outspoken transgressive countermovement that speaks to women's strength within the world of craftivism (e.g. Fisk, 2019; Greer, 2014; Leone, 2021). This is echoed generally within the academic textile world where there is a renewed pride in reclaiming old practices (e.g. Davies, 2018; Fisk, 2012, 2017, 2019; Parker, 1984; Wellesley-Smith, 2015). This reclaiming is not as a romanticisation of the past or as a symbol of engagement with movements such as #tradfem, rather there is a deep embrace for the beauty, mastery, and skill brought into a modern and empowered context.

For the entirety of my life I have watched women's work relegated to second tier (or lower) status (England, 2011, 2020). This resulted in my own complicated relationship with loving much of what falls under the heading of 'women's work', apprehensive about my domesticity, and always feeling as though I should want something 'more'. Perhaps it is the work of the aforementioned academics discussing these topics that allows me the space to make my similar engagement with the domestic visible in this process.

England, (2011, 2020) states that the biggest barrier to equality remains the devaluing of women's work. Within a gender binary lens (as England's data was presented) while women make inroads into the male dominated fields, men will rarely opt to 'lower' themselves to the female sphere. This was significant to me long before I knew

the data. My interest in the domestic sphere, and even social work, felt like a betrayal to my sisters/foremothers. I felt an internal pressure to pursue a STEM-oriented career, or at least a desire to aim for upper management to break the glass ceiling. There was little room, in my self-characterisation, for 'pink collar' work and recreational engagement in domestic arts. Over time, I made an uneasy peace with my interests. Through the engagement with the literature and the data, I now better understand the value of these skills. Even more, I understand that I do not want to give up my 'pink-collar' interests, I want them to be valued.

While social stories perpetuating the low status of women's work abound, one of the most fascinating areas of historic textile scholarship offers a concrete challenge to those perceptions. Hayeur Smith (2020), an archaeologist, argues that women may have held a great deal of previously unacknowledged power and their textile work may provide the needed clues. She references her work in the area of vaðmál, a cloth woven to very exacting standards that formed at least a supplemental currency throughout the North Atlantic region during the Viking Age. Because of the importance of this cloth-as-currency that was solely women's purview, Hayeur Smith (2020) hypothesises that women may have been less powerless than previously perceived. Her text *The Valkyrie's Loom* offers a thorough discussion of this topic and is far from the only one reconsidering women's history.

Honouring Women's Work; Decoupling it From Oppression

The importance of textiles in the autoethnographic data reflects a change in my academic pursuits and relates to the importance of transgressiveness in the sanctuary research. Where I began my studies with an eye to understanding the lived experience of spiritualities, I found myself increasingly drawn to material culture, the current resurgence of domestic arts, and the meaning of that for women in particular. There was a transgressive element in this for me. My interests in domestic arts had always existed in the shadows of my academic and professional pursuits. Their prominence in the sanctuary research forced me to consider the reasons for this divide. Further, when I brought my awareness of this to the interviews, the participants noted similar struggles. Many expressed a conflictual relationship with 'pink collar' experiences; on the one hand, reporting a great deal of purposeful occupation when in 'pink collar' engagement, on the other hand, feeling as though they should want something more.

Following in the footsteps of Greer as well as those like Fisk and Leone who are explicitly integrating craftivism into their work as well as those like Collier and Reynolds who I suspect were before the term was in popular use, I envision my practice employing cræftivism, a way for people, especially women, to connect with and honour those domestic arts that have been dismissed and devalued. As discussed throughout this document, the data supports the use of textiles in clinical practice and there are practice frameworks (e.g. Collier, 2011; Leone, 2021) that can be employed, in conjunction with the sanctuary data. Given the important historical references that might affirm the importance of this type of work, or feeling validating to those who are questioning it, I

suspect that part of my practice will also include further study and writing on the topic of cræftivism. I discuss this in the recommendations for further study.

Areas for Further Study

Rather than concluding this research with all questions answered, I conclude with a great deal of personal understanding, a new sense of my practice direction, a clear view of the limitations of this research, and an abundance of questions. The potential represented in these limitations and future possibilities excite me. I discuss these possibilities beginning with the most prominent.

My first priority is to undertake a study focusing on cræft in the manner of this sanctuary study. While, in hindsight, I can see this concept throughout the research from proposal to conclusion, its importance only became clear to me in the final stages of the analysis. While the connections between cræft and sanctuary were clear for me, especially in light of the data, I suspect that this experience exists as strongly for others though I cannot make that statement based on the current data. I believe I see it in much of the aforementioned data but would need to undertake a formal study to confirm. Further, while I see it as intimately intertwined with my domestic arts experiences (especially textiles), I wonder too if a study would uncover congruences in other communities, such as smallholding, pottery, or woodworking.

I also see a study to understand and evaluate therapeutic memorialisation. I wonder at its presence in the literature, the lived experience, and whether it is, in fact, generally a therapeutic experience. A study of cræft and therapeutic memorialisation

could be incorporated into a larger study of cræftivism which could further clarify the components of cræftivism at the same time. Given how the idea of incidental spirituality might fit with both of these topics, a study of this nature might also be an appropriate place to consider those elements. Ideally, such a study would ultimately offer a practice context or structure to inform social work practice.

In the data there were topics that felt that they should be more prominent but were not. Two such were issues of liminality or threshold experiences (e.g. Turner, 1969/2017; van Gennep, 1960) and the importance of ritual. Ritual was explicitly mentioned during the interviews; however, there was insufficient data to foreground it in this dissertation. In addition to the general significance of ritual, as Bell (2009) says, we often think about ritual as a type of activity which creates an unnecessary dichotomy between thought and action. That leads me to wonder about the role of ritual in sanctuary generally, especially how thought, rather than enacted ritual, might have a place in sanctuary. Especially for those whose limitations may constrain them to only experiencing sanctuary through thought (such as later stage ALS).

The feedback that the interviews were nourishing led me to consider potential parallels with narrative therapy techniques and whether narrative therapy in particular, might form a type of sanctuary wherein the person is invited to externalise even the most internal of problems. And where they are invited to imagine and even narrate a preferred future. So too were the echoes of post-traumatic growth visible in the idea of nourishingness. There were what I would call glimmers of this in the data but again, nothing I could foreground and nothing that was obvious enough, early enough to bring

to the interviews. A further study might consider the relationship between post-traumatic growth and sanctuary. And finally, I wonder how the idea of nourishingness might fit with the idea of vocation as opposed to duty.

Beyond the faint echoes I would like to follow, I see a need to expand on this sanctuary research broadly. I envision many variations including a more diverse and larger population, condition specific studies, further investigations looking at the qualities of sanctuary, and a longitudinal investigation to assess any changes to the perception of sanctuary overtime. I feel that adding breadth is essential to addressing the homogeneity in this research. To this I might consider adding other concepts such as: how do, or could, sanctuary and narrative therapy work together? Alongside this, I envision cross-cultural comparisons of sanctuary, for example, what do the echoes of sanctuary look like in other cultural contexts? Can these echoes be seen in historical examples? I would also consider the evidence for sanctuary in the writings of the women mystics (such as Julian of Norwich). And perhaps along with that, considering the qualities and elements of sanctuary from their darker aspects and along with that, can sanctuary be harmful? And would it still be sanctuary if it were? These are questions I would have loved to explore in this research but were far too expansive to be done justice in this context.

And finally, I will undertake further investigation of my ISRP, focused on further clarification of the structure. Not only will this assist me in my practice, I hope that with increased clarity, it may also offer useful information to other social workers and/or therapists.

Conclusion

The title of this work, *A Field Guide to Sanctuary,* represents the intent with which I began it as well as the hope with which I now offer it. While a field guide serves a specific purpose in science, it also has a more open colloquial use that I think fits this work. The idea of a field guide, to paraphrase a friend, offers a snapshot of the lay of the land, but what you do with the information in there is up to you. And essentially, this is what I feel I have done. I have surveyed the terrain and offered up my reflections of it, including what those reflections mean to me. I have not, however, been prescriptive about what it would mean for anyone else or how another should interpret it. As the reader will by now know, this is congruent with my personal and social work practice values.

As discussed in Chapter 1, my social work lens and indeed this dissertation, is informed by the history of social work; this includes understanding where social work has been used as a tool of oppression. For me, it means actively working counter to that through anti-oppressive practice, part of which is active engagement with people ‘where they are at’. As a result of engaging with this practice philosophy, I recognised how my social work education and subsequent practice failed to acknowledge people as spiritual beings. As I explained, this contributed to my decision to undertake a Doctorate of Ministry (DMin).

At times I felt unmoored in the DMin, unclear about my purpose and goals. It was only at the end of my coursework that I saw the cohering threads that culminated in my desire to understand personal sanctuary. The most prominent of those formed the

foundation of this dissertation. As discussed above, this includes myriad aspects of social work practice, from the integration of spirituality to specific practice frameworks and interventions (e.g. anti-oppressive practice and narrative therapy). Beyond that however, my understanding of spirituality leans heavily on my engagement with Celtic spirituality and how I came to understand it through my folkloric education. I explored that in detail in Chapter 2, the literature review.

Beyond Celtic spirituality, I explored the idea of 'soul work', drawn from the world of psychotherapy. As I indicated in Chapter 2, this literature was essential in helping me clarify the direction of this research before I encountered the spiritually-oriented social work literature. Within this literature I found a structure and language to aid the aims of this dissertation but beyond that, it provided me with a practice framework incorporating spirituality.

With these foundational elements enumerated in chapters 1 and 2, I then provided an explicit clarification of my research methodology. My research structure, including how I might integrate seemingly disparate concepts, was informed by Ellingson's Crystallization Theory. Ellingson not only offers a map to generally instruct 'how to', she also articulates the numerous reasons 'why to'. Informed by Crystallization Theory, I continued with the methodology. As Chapter 3 outlined, I have brought analytic autoethnography into conversation with critically reflective practices, both critical reflection on practice (CRoP) and my own critically self-reflective practice (CSR). To support my critically reflective practices, I incorporated research-creation in the form of response art. I stitched these different research methodologies together with the threads of

my enthusiasm for the topic and my goal to deeply understand personal sanctuary, as stated by O'Donohue.

I believe, as Chapter 4 indicates, that the findings clarified the constitution of sanctuary. The data revealed that personal sanctuary, in this context, comprises elements (spirituality, nature, creativity, and purposeful occupation) as well as qualities (transgressiveness, fluidity, and nourishingness). While these elements and qualities were revealed as constituent parts in their own right, they also were incredibly entangled. The entanglement was so pronounced that initially, it seemed impossible to find clarity or distinctions with them. This is where the self-reflective processes, including response art, proved invaluable. It was through those processes that the areas of overlap as well as the areas of distinction, were clarified.

As discussed, these findings challenged me in numerous ways. For example, the surprising prominence of spirituality in the data and the way the participants honoured their own expressions of spirituality, regardless of their religious affiliations, were a surprise. Another surprise emerged as the autoethnographic data revealed the importance of textiles as both a therapeutic and spiritual practice for me. In this, I noted the start of a shift in the acceptance of my personal practices as well as my professional ones. The third significant surprise was the importance of transgressiveness in the data. It challenged me both in understanding it as a theme as well as how to apply this data in my practice. This quality of sanctuary does, however, require further research (as noted).

The discussion chapter (Chapter 5) presented new challenges. While the literature discussed in chapters 1 and 2 provided a foundation and direction for this research, as well as implicitly contributing to the gaze with which I viewed the data, the depth of revelation within the findings necessitated the introduction of new literature to facilitate my understanding. For example, in Chapter 5 I introduced the concept of forest bathing (Shinrin-yoku) which fit with some of the nature related findings. I also introduced the concept of cræft, a personal practice of sanctuary for me. Within cræft are all of the elements and qualities of sanctuary. Indeed, I articulate this as my practice in service to my experience of sanctuary. Given the integration of cræft and domestic arts for me, I then validated the importance of this work through a brief consideration of the historical record of women's textile work while also distancing it from the recent uptick in the #tradfem movement.

Because I had held an implicit goal of using this data to contribute to my social work practice, I then made those connections. I articulated the way this research reinforced my interest in including a spiritually-oriented lens (broadly defined) to my practice. In addition to that, I also saw preliminary potential to use the sanctuary data as an analogue to the Neurosequential Model of Therapeutics; where the ideas found in this research may form a way of conceptualising how to work with a person. Within the practice related findings, there exists the hope that eventually the results of this research will also provide a framework for people hoping to engage in their own critically self-reflective practices. However, as these were implicit goals and not fully realised in this research, they are among my suggestions for future research.

The exploration and initial creation of the Field Guide to Sanctuary has provided me an opportunity to explore the concept of personal sanctuary. This particular idea of personal sanctuary has been my companion since I first heard it in 2008. It is drawn from O'Donohue's statement that

> There is a place in the soul that neither time nor space nor no created thing can touch. What it means is that your identity is not equivalent to your biography and that there is a place in you where you have never been wounded, where there is still a sureness in you, where there's a seamlessness in you, and where there is a confidence and tranquillity in you. And I think the intention of prayer and spirituality and love is now and again to visit that inner kind of sanctuary. (O'Donohue and Tippett, *The Inner Landscape*, 2008)

While I leave this aspect of the Field Guide to Sanctuary with a richer understanding of what O'Donohue's statement means to me, in this moment and in this context, the potential for exploring this topic further offers me no shortage of eager anticipation. Indeed, rather than reaching the end of this research with a sense of having answered all of the questions related to this idea of sanctuary, I conclude this research filled with the excitement that comes with the awareness that there is so much more to discover and the enthusiasm to do so.

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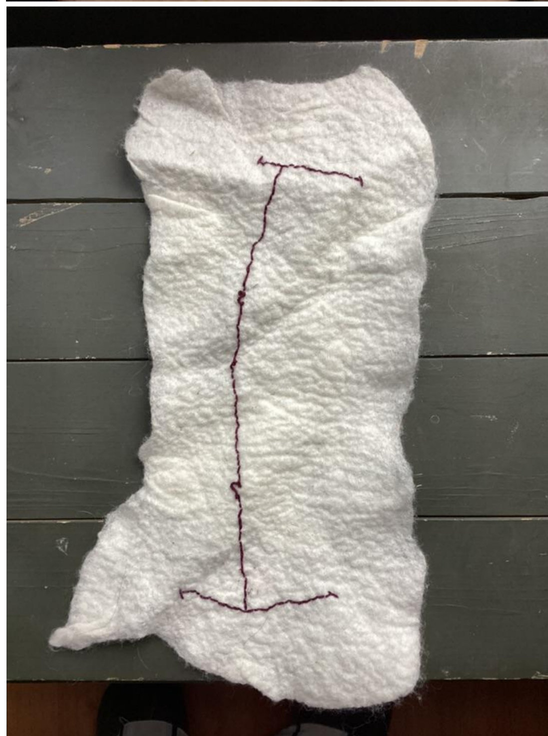
Appendix A
Participants

Alexis	Potter, gardener	Informed consent obtained
Allison	Writer, hiker	Informed consent obtained
Amanda	Crafter, cook	Informed consent obtained
Bec	Butcher, woodworker, gardener	Informed consent obtained
Cathy	Woodworker, gardener, hiker	Informed consent obtained
Lynn	Textile artist, cook	Informed consent obtained
Rebecca	Textile artist, hiker	Informed consent obtained
Robbie	Podcaster, writer, walker	Informed consent obtained
Willow	Labyrinth constructor, walkers	Informed consent obtained

Appendix B - Willow's Labyrinth

Appendix C

I have provided images from a representative sample of the creative, textile-based practices that form the response art/research-creation portion. In an effort to adhere to the intent, I opted to only use materials I already owned and treat the textile work as "doodles" which meant there was no planning of the piece and no finishing of them.



Appendix D

Participation Package and IRB Approval

St Stephen's College

University of Alberta Campus 8810 112 Street NW Edmonton Alberta CANADA T6G 2J6
phone 780 439 7311 **toll free** (Canada only) 1 800 661 4956 **fax** 780 433 8875
email st.stephens@ualberta.ca **website** www.ualberta.ca/st-stephens

Greetings! I am conducting research as part of my Doctorate of Ministry and wonder if you might be interested in participating.

The primary question guiding the research is:

What are the lived experiences of Generation X women living with chronic disease/illness and how do these experiences relate to the concept of sanctuary?

There are some terms that might be important to you. GenX means people born between the years of 1965 and 1980, inclusive. You might also wonder what I mean by sanctuary. This particular meaning is drawn from a quote by John O'Donohue and in this case, means an inner or personal sense of wholeness, peace, and certainty. The full quote is in the interview guide we will use. Chronic illness is broadly defined as a condition that lasts longer than a year. It also requires ongoing medical attention and/or limits your activities of daily living and must be diagnosed by a regulated health care professional.

The interview will take about 30 minutes and be conducted on Zoom.

If you are interested in participating, please get in touch either by email: deathera@ualberta.ca or by texting me at 250 402 9338.

A bit of housekeeping. The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

REB ID: Pro00103831

Thanks so much,

Colleen Deatherage MSW RSW

St Stephen's College
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phone 780 439 7311 **toll free** (Canada only) 1 800 661 4956 **fax** 780 433 8875
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INFORMATION LETTER and CONSENT FORM

Dear Participant,

You are being invited to participate in research considering the experience of chronic illness and how it might relate to a very specific idea of sanctuary.

Everything you need to know about the topic and what it means to participate is below but if you have any questions, please feel free to ask me at any point.

With thanks,

Colleen Deatherage

Study Title: Can 'Sanctuary' Be Found Within Chronic Illness?

REB Study ID: Pro00103831

Research Investigator: Colleen Deatherage MSW RSW

St. Stephen's College

University of Alberta

8810 112 Street

Edmonton, Alberta

Canada T6G 2J6

email: deathera@ualberta.ca

phone: (250) 402-9338

Supervisor: Dr. Laura Béres

St. Stephen's College

University of Alberta

8810 112 Street

Edmonton, Alberta

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email: lberes2@uwo.ca

phone: (519) 433-3491 ext 4575

Background

You are being asked to participate in this research project because you are a GenX woman who has a chronic illness and are willing to speak with me about your experience

of that and your spiritual beliefs or practices.

The results of this study will be used in support of my doctoral dissertation which means the final written work (the dissertation) will be an academic document which includes an analysis of the material including quotes from you and the other people who agreed to be interviewed. I will also present the work to my dissertation Committee and possibly others (for example, at a conference or in a class).

Before you make a decision about whether to participate, I will go over this form with you. You

are encouraged to ask questions if you feel anything needs to be made clearer. You will be given

a copy of this form for your records.

The primary question guiding the research is:

What are the lived experiences of Generation X women living with chronic disease/illness and how do these experiences relate to the concept of sanctuary?

The terms that might be important to you are GenX, which means people born between the years of 1965 and 1980, inclusive. You might also wonder what I mean by sanctuary. This particular meaning is drawn from a quote by John O'Donohue and in this case, means an inner or personal sense of wholeness, peace, and certainty. The full quote is in the interview guide we will use.

Purpose

This study is being conducted for research and educational purposes. My hope is that this research will, at a minimum, help people think differently about the experience of living with chronic illness.

Study Procedures

Each participant will be interviewed over Zoom. I will be in an office with a close door to ensure your privacy. You can participate from anywhere that feels safe and comfortable to you. The interview will be recorded so that I can go back to it to be sure I am accurate about what you have said.

I would ask that you allow our interview to take about 30 mins, though, if you would like to add more information, you are free to have more time than that.

I am asking that each participant agree to one interview and they can let me know if they might be willing to participate in a follow up interview. Reasons for a follow up interview would include if there was something I realized I wasn't clear about and needed to double check with a participant/participants or if I realized something was more important than I originally thought and wanted to discuss it further.

You are also encouraged to send me any images of art work, special places, or other things you think relate to the study. Please email me images, I do not wish to be responsible for any original art work! If you do send images, they may be included in the final document and future work. I will always attribute you to the image in whatever way

you would prefer. The images will not be returned to you and will be stored with the rest of the data.

My goal is that this study would be totally completed by August 2021.

The interviews will be recorded and I may take notes as well. That information will not be returned to you.

Your consent allows the storage of study information in a secure data repository to facilitate future research.

Benefits

There are no known benefits to you for participating in this study. In my professional experiences (as a therapist and a medical social worker), people have told me that they have felt 'better' after sharing their experiences or just being heard but I cannot assure you that will be the case for you.

I hope that the information from this study will help us better understand how women living with chronic illness are coping with it.

Risk

There are no known risks to you for helping with this project, though talking about the experience of chronic illness can be hard. If you are finding it challenging, you can stop the interview at any time. If that is the case, we can talk about what would be helpful

and we will only resume if you feel ok about that. Part of what we will talk about in the interview is self-care and for some people, a reminder about that will be enough. For others, if there are deeper feelings we can explore options that might work for you to have additional supports.

Cost of Participation

There are no costs associated with participating in this research.

Reimbursement or Remuneration

There is no reimbursement or remuneration associated with participating in this research.

Voluntary Participation

You are under no obligation to participate in this study. Participation in this interview is voluntary. You are free to withdraw at any time. We will meet for the interview over Zoom. I will record the interview(s) and Zoom will let you know that recording has started.

If there is a question you don't want to answer, you don't have to, you can simply say "pass".

People in the study can withdraw at any point, they can also withdraw parts of or their whole interview right up until I am writing the first draft (I will post about it on the blog so you know when that is happening). Withdrawing is no problem at all; no

questions will be asked and no explanations are needed. To withdraw you can contact me at deathera@ualberta.ca or text 250 402 9338. Alternatively, you may also contact my supervisor Dr. Laura Béres at lberes2@uwo.ca if you would rather or if you have any concerns.

If you do decide to withdraw, I will destroy your data so that there no longer is any record of it. This means deleting the recording as well as all of my notes (such as quotes) that are specific to the information you have provided.

Confidentiality & Anonymity

Keeping private information private is important to me. No personal information (like your name) will be attached to any published result of this study unless you say you would like to be identified. You can pick the name you'd like me to use instead or ask me to pick a name for you. The name you select will be written into the dissertation as well as possibly spoken about as part of presentations about the research, and/or other possible publications such as articles, blog posts, or books. Any identifying information (like your name on the consent form or your email address) will be stored only in my passworded email account or on a double passworded hard drive to make sure I protect your privacy. If you decide to send images to be included, I will use the name that you have instructed me to use to attribute that image to you.

This research will be used for my dissertation, to update the study blog, and may be used for future research as well (such as post-doctoral research, conference presentations, or journal articles). You will only be personally identified if you have said you would like to be.

All data will be kept confidential. Only I will have access to the data though I will share information with my supervisor as needed. The BC College of Social Work requires I keep all data for at least 7 years. It is possible that I may keep it for longer if I am still using it in my research projects. All of the data will be double passworded and stored in a secure office. If I do wish to use the data from this study in another study, it will have to be approved by a Research Ethics Board.

I will keep a blog that people can follow. I won't share anything that identifies the people in the study on the blog. I will be posting about my experience of the research, what themes I am seeing, and what questions are coming up for me. It will be sort of like a journal for me but one I hope you will comment on. You are welcome to contact me if there is something on the blog you would like to discuss or just to share your thoughts. This is also how the study participants can track what is happening with the study. You are not obligated to participate in the blog at all.

There is one really important thing to discuss about confidentiality. I will keep everything you say confidential, unless you tell me that someone vulnerable is likely to be at risk of harm, in which case, I will make the appropriate report.

Contact Information

If you need to contact me you can do so at deathera@ualberta.ca or text 250 402 9338. Alternatively, you may also contact my supervisor Dr. Laura Béres at lberes2@uwo.ca or (519) 433-3491 ext 4575 if you would rather or if you have any concerns.

If you have any questions, please do not hesitate to contact one of us.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____

____

Participant’s Name (printed) and Signature Date

____

____

Name (printed) and Signature of Person Obtaining Consent Date

If consent is verbal, name of person obtaining consent: Date and time of verbal consent

____

St Stephen's College
University of Alberta Campus 8810 112 Street NW Edmonton Alberta CANADA T6G 2J6
phone 780 439 7311 **toll free** (Canada only) 1 800 661 4956 **fax** 780 433 8875
email st.stephens@ualberta.ca **website** www.ualberta.ca/st-stephens

Can sanctuary be found within the experience of chronic illness?

Interview guide

Thank you for agreeing to participate in this interview. Please keep in mind that this is a semi-structured interview, so we're using these questions as a guide, but may spend more time talking about some aspects in more detail, some in less detail. This guide also does not include standard conversational prompts that may be used to delve deeper into each question, such as "Will you please tell me a little bit more about that?" and "What does that look like for you?".

I want to remind you that you can pass or skip any question you want to (whether the question is listed here or comes up as we're talking about a question in more depth). Participation in this interview is entirely voluntary. You are also invited, but not obligated, to ask me about the research and my interest in these questions.

Please read these questions in advance so we're both ready for the interview. Feel free to make notes on this guide if that's helpful.

This interview should take about 30 minutes, though you can feel free to expand on your answers if you'd like to respond in more depth.

The primary research question is

What are the lived experiences of Generation X women living with chronic disease/illness and how do these experiences relate to the concept of sanctuary?

So what I'm asking about is whether sanctuary can be found within chronic illness. This particular meaning of sanctuary is drawn from a quote by John O'Donohue and in this case, means an inner or personal sense of wholeness, peace, and certainty. The full quote is found below.

Feel free to ask any questions. If you're ready, we'll begin the interview.

Would you please state your name and say whether I have your permission to record this interview? We'll start with a general conversation where I will collect your

demographic information, whether you would be willing to do a follow up interview and/or review the data, and generally chat about how the day is going to warm up. This also allows me to make sure the recording is working.

Do you have any questions for me before we get started?

Chronic illness:

1. Would you share a snapshot about your chronic illness experience?

1. Life beforehand (if appropriate)?

2. Diagnosis:

3. History (e.g. age of onset):

4. Symptoms:

5. Life changes as a result:

6. Any unaddressed concerns about your chronic illness?

2) What supports do you have to help you cope with and/or manage your chronic illness?

Sanctuary:

This is the John O'Donohue quote that guides the research:

And one day I read in [Meister Eckhart], and he said: "There is a place in the soul that neither time nor space nor no created thing can touch." And I really thought that was amazing. And if you cash it out, what it means is that your identity is not equivalent to your biography and that there is a place in you where you have never been wounded, where there is still a sureness in you, where there's a seamlessness in you, and where there is a confidence and tranquillity in you. And I think the intention of prayer and spirituality and love is now and again to visit that inner kind of sanctuary.

For some clarity: for the purposes of this research, I'll just remind you that the term sanctuary draws on the above quote or could be more simply thought of like this: an inner

or personal sense of wholeness, peace, and certainty. Spirituality can be thought of as practices that tend to be more individual, loosely (if at all) structured, and connect people to something larger than their own ego (as Parker Palmer says). It differs from religion which generally is seen as a more organized set of beliefs and practices that tends to have a community aspect. I am happy to answer your questions about it, if you have any.

1. Do you feel clear on the definitions we will be using?
2. What do you think of when you hear the quote by O'Donohue?

3. Do you think this quote sums up something that you might call sanctuary? Why or why not?

4. Is there another word you would use to sum up what O'Donohue is expressing?

5. If I ask you to think of this quote and your chronic illness at the same time, what comes up for you?

6. When you think of the idea of sanctuary, what comes to mind?

Spirituality:

1. Can you please tell me about your spiritual identity?
2. Would you share a bit about your spiritual practices? (if any)
3. What does it mean to you to be spiritual?
4. Are you also religious?

1. ***If so:*** what religion do you follow?
2. Does it match with your spiritual practices?
3. ***If not:*** do you feel spirituality and religion can fit together?
4. Is there a religion you're interested in?

5. What role, if any, does your spirituality play in relation to your chronic illness?
6. Is there anything else you'd like to share about your spirituality?
7. Is there anything else you think this research should be considering?

Final question: what prompted you to participate in this research?

Thanks very much.

Ethics Application has been Approved

ID:	Pro00103831
Title:	Sanctuary Study
Study Investigator:	Colleen Deatherage
	This is to inform you that the above study has been approved.
Description:	Click on the link(s) above to navigate to the workspace.
	Please do not reply to this message. This is a system-generated email that cannot receive replies.

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