

A QUALITATIVE STUDY OF DELIBERATE SELF-HARM AND CONTROL AMONG
SEXUAL AND GENDER MINORITY PERSONS: NEGOTIATING THE HEALTHCARE
SYSTEM

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Abstract

Both non-suicidal and suicidal deliberate self-harm (DSH) are a significant cause of death among people of all ages, races, genders, and socioeconomic status. The risk for DSH is known to be particularly elevated among individuals from sexual and gender minority groups, yet potential benefit from contact with the healthcare system may be adversely impacted by a person's experiences and stigmatization within the healthcare system. Semi-structured, open-ended interviews were conducted with four participants to explore the experiences of gay, lesbian and agender persons and how these experiences may have affected their DSH behaviour and interactions with the healthcare system when seeking treatment. Interviews yielded rich and compelling narratives, which after analysis using Interpretive Phenomenological Analysis were consistently linked back to issues of control, more specifically, a lack of control, struggles to reclaim control and successes in establishing control. Results indicate that participants often felt out of control prior to and/or after engaging in DSH and while interacting with the healthcare system. Participants described feeling stigmatized, misunderstood, and judged by healthcare staff, but also described many successes in managing their and healthcare challenges. Suggestions for improved care include greater education and knowledge of healthcare providers about DSH and sexual and gender minority issues, improved active listening skills of providers and opportunities for peer counseling within this vulnerable group.

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Table of Contents

Introduction.....	1
Chapter 1: Literature Review.....	3
Chapter 2: Methods	
Design.....	24
Ethics.....	28
Participant Recruitment and Consent.....	29
Data Collection.....	30
Transcription and Analysis.....	31
Chapter 3: Findings	
Participant Profiles.....	33
Themes.....	39
Thematic Map.....	41
Chapter 4: Analysis	
Theme 1: Experiences of and Responses to Loss of Control.....	42
1.1. Abandonment and Betrayal.....	43
1.2. Stigma and Negative Labeling.....	49
1.3. Guilt and Shame.....	56
1.3.A. Self-loathing.....	62
1.3.B. Closeted Lives.....	66
1.4. Unsatisfactory Experiences with the Healthcare System.....	71
Theme 2: Active Struggles to Establish Control.....	76
2.1 Desire to Feel Understood and to Belong.....	77
2.1.A. Over-reliance on Significant Others.....	84
2.1.B. Seeking Belonging Within a Culture of DSH.....	87
2.2. DSH Behaviour to Reclaim Control.....	89
2.2.A. Seeking Hospitalization to Establish External Control.....	93
Theme 3: Successes in Establishing Control.....	95
3.1. “Coming Out” as a Sexual and/or Gender Minority Person.....	96

3.2. Positive Self-Labeling.....	99
3.3. Positive Experiences with the Healthcare System and Suggestions for Improved Care.....	103
Chapter 5: Summary, Discussion and Conclusion.....	108
Process and Self-Reflection.....	117
Limitations.....	123
Further Research and Recommendations.....	126
References.....	130
Appendix A: Sample Interview Questions.....	149
Appendix B: Consent Form.....	153
Appendix C: Debriefing Form.....	156
Appendix D: Recruitment Poster.....	157
Appendix E: Transcript Notation.....	158

Introduction

The Saskatoon Health Region (SHR) has identified, as one of its priorities, equity in the provision of services to people presenting with deliberate self-harm (DSH). SHR administrative data have established that some populations, such as those residing in areas of greater deprivation, are at high risk (Neudorf et al., 2009), but these data are not comprehensive enough to address DSH in other groups which are known to be at high risk. For example, sexual minorities have been found to be at high risk of DSH, yet information about this is not available on the SHR acute care databases. In addition to their high risk of DSH, sexual minority groups may face additional barriers to healthcare services which may negatively impact on health outcomes related to DSH. For example, discomfort with disclosure of minority sexual orientation, social stigmatization and previous adverse experiences with healthcare professionals may reduce successful participation in therapeutic programs and thereby perpetuate DSH behaviours and increase suicide rates.

Although there is a moderate amount of research into DSH in adolescents, there is not as much research with adults and older adults. My proposed research, therefore, aimed to explore the experiences (personal and those related to healthcare) and perceptions of self-identified cisgender (those whose self-identity conforms to their biological sex, i.e. not trans-gender [Random House Dictionary, 2017]) gay men and lesbian women of a variety of ages who had experienced or engaged in DSH. This approach would allow me to not only explore individual experiences, but also compare and contrast experiences of people who had grown up in different social-political contexts relating to their sexuality. For the purpose of this thesis, I will use the term DSH to refer to self-poisoning (i.e., overdosing on medications) and self-injury (most

commonly self-cutting, burning and hitting), regardless of the intent (Evans et al., 2000; NCCMH, 2004). As this study was initially conceived in response to SHR concerns about equity in the provision of services, I restricted my focus to deliberate self-harm acts which resulted in a visit to a family physician, hospital emergency room, or in-patient psychiatric ward. I hope to provide insights into the challenges experienced by gay and lesbian individuals of a variety of ages during interactions with health services. The ultimate goal of my research is to facilitate quality improvements in healthcare provision to better address their needs and to improve clinical outcomes relating to DSH. I also hope that this study will be useful in guiding future research in this under-explored field.

Chapter 1: Literature Review

Deliberate self-harm (DSH) is a term that includes a wide range of acts, ranging from repetitive cutting and poisoning to lethal activities like hanging, jumping off high places and shooting oneself. The intent behind the DSH act varies widely; therefore, more specific terminology includes terms such as non-suicidal DSH and suicidal DSH. The majority of DSH activities are likely *not* intended to result in death, but may instead have been intended to decrease or cope with stress or mental anguish or get access to support, among other possibilities (Klonsky, 2007). A significant motivator for engaging in DSH is that by self-inflicting physical pain, an individual does not have to endure negative emotional arousal such as in the form of shame, anxiety, anger, etc. (Simpson, 2015). However, a small but highly concerning number of DSH acts *are* intended to result in death and may result in completed suicide. Suicide is one of the most catastrophic mental health outcomes among young individuals especially, and the literature suggests that a previous history of non-suicidal DSH may be a risk factor for this (see later review of suicide in more detail). Therefore, it is important to include suicidal DSH in the consideration of DSH in general.

DSH can occur at any age, but is generally found to be most common in women ages 15-19 and men ages 20-24 (Perry et al, 2012). Although Van Camp, Desmet, and Verhaege (2011) estimate that 4 percent of the adult population in Western countries have engaged in non-suicidal DSH, definitive national statistics regarding DSH are largely unavailable and even regional data remain unreliable and inconsistent (Perry, Corcoran, Fitzgerald, Keeley, Reulbach & Arensman, 2012). Furthermore, many of those who engage in DSH do not present to a

healthcare facility, likely leading to an underrepresentation of all DSH estimates worldwide (Madge et al., 2008). While research shows that males are more likely to commit suicide (the most severe form of DSH), it is females who engage in more acts of DSH (Hawton et al., 2003). When males do engage in DSH, however, they tend to use potentially more lethal methods (Perry et al., 2012).

Factors contributing to DSH vary across different populations. For example, DSH in elderly people is often associated with burdens of physical illness, bereavement, and social isolation (Hawton & Harris, 2006), while among sexual and gender identity minorities it has been linked to feelings of guilt, discrimination, or other homonegative behaviour (Scourfield, Roen & McDermott, 2008). In adolescence, acts of DSH may be related to a deterioration of family caused by parental divorce or separation (Kokkevi, Rotsika, Arapaki & Richardson, 2011). Demographic correlates suggest that the developmental period of adolescence itself is a risk factor, with individuals aged 13 to 21 exhibiting the highest risk for DSH (Heath, Toste, Nedecheva, & Charlebois, 2008; Rodham & Hawton, 2009).

DSH is a marker of severe personal distress and poor functioning (Hawton et al., 1998). It has also been described as a reflection of poor self-esteem, self-loathing, self-punishment, guilt, an attempt to communicate suffering, and attention seeking (Batey et al., 2010; Skegg, 2005). Some individuals with personal experience of non-suicidal DSH have described it as a desperate survival tool – a way of preventing their own suicide (Hadfield, Brown, Pembroke & Hayward, 2009; Suyemoto, 1998). DSH is significantly linked to mental health issues, as seventy percent of individuals presenting to healthcare facilities with a DSH incident have been reported to have

at least one mental health diagnosis (Collier, 2011). Disorders most often associated with DSH include depression, anxiety disorders, bipolar disorder, schizophrenia, eating disorders, and borderline personality disorder (BPD; see Hadfield et al., 2009; Skegg, 2005). BPD especially has been linked to DSH with markers such as impaired impulsivity control and self-destructive behaviour (Evren, Cinar, Evren, & Celik, 2012). Sometimes there are several variables which may lead a person to engage in DSH. For instance, Hume and Platt (2007) found that in a qualitative study of fourteen individuals admitted to the hospital for DSH, thirteen had experienced either psychiatric illness (e.g., depression), alcohol dependency, and/or traumatic life events (e.g., sexual abuse), but that many also had other overlapping factors contributing to their behaviour.

There are a variety of theoretical frameworks with models for non-suicidal DSH behaviour, which Messer and Fremouw describe in their 2008 paper. The Depersonalization model they outlined, suggests that individuals who feel emotionally anaesthetized may harm themselves to *feel* something and validate that they are real and alive. The Biological model Messer and Fremouw mention, proposes that certain individuals may have a physiological vulnerability to DSH behaviour through abnormalities in neurotransmitters. Although the exact relationship between DSH and serotonergic and dopaminergic pathways remains largely unclear (Groschwitz & Plener, 2012), according to Sher and Stanley (2009), irregularities in brain systems that regulate dopamine, serotonin, and cortisol can lead to elevated stress levels which for some individuals may be decreased by engaging in DSH. Beta-endorphins have also been thought to possibly play a role in DSH, supplying individuals with a rush of positive feeling following DSH pain, although the precise relationship remains unknown (Klonsky, 2007; Stanley

et al., 2010). The beta-endorphin theories relating to DSH are consistent with knowledge about the role of opiates in other addictive behaviours, and provide a potential causal mechanism for some authors' reports of DSH as an addictive behaviour (Blasco-Fontecilla, 2016). Additional research reports consistent with this statement include those that suggest that for some individuals, the emotional state prior to DSH is comparable to that of drug users who are experiencing withdrawal (Fay, 1995).

Another theoretical framework for DSH behaviour which is pertinent to this study, is the Experiential Avoidance Model. This model asserts that individuals who experience negative emotional arousal (e.g., anger, frustration, shame, disappointment, and sadness) from psychosocial stressors find temporary relief in their DSH behaviour (Chapman, Gratz & Brown, 2006). In other words, individuals utilize DSH as a dysfunctional means to combat and cope with their stress (Nixon, Cloutier, & Aggarwal, 2002). The overwhelming desire to evade negative feelings may stem from a low tolerance for adverse emotions, high levels of impulsivity and/or poor coping mechanisms (Chapman et al., 2006). Poor self-regulation of emotions may also precipitate individuals to disassociate from a particular intolerable or intense situation (Simpson, 2015).

Trauma or strongly adverse experiences, especially those occurring in childhood such as parental neglect and physical or emotional abuse, have been related to DSH behaviour in later life (Simpson, 2015). Connors (1996) theorized that DSH serves a purpose related to trauma either by unconsciously re-enacting the trauma and thereby attempting to make sense of it, or by expressing emotions associated with the trauma such as shame, anger or fear. It is important to

note that not all trauma leads to DSH and DSH is not always associated with trauma, as some research suggests the association of DSH and past trauma is only present in 50 percent of individuals (Gratz, 2003).

The constructs of guilt and shame have been linked to DSH behaviour within the literature (Chapman, Gratz & Brown, 2006; Gilbert et al, 2010; Laye-Gindhu & Schonert-Reichl, 2004) and throughout this paper. Guilt and shame are concepts that are often discussed together and are sometimes even used interchangeably; however, while they appear closely related, they remain distinct from one another. Although both could be characterized as negative, self-conscious, moral emotions, they differ in how they are perceived by an individual. For example, shame relates to evaluations of the “self” whereas guilt reflects evaluations of behaviour (Tangney & Dearing, 2002). Research suggests that shame appears to be more detrimental as it has been more closely linked to depression (Tangney & Dearing, 2002) and to higher frequency of DSH (VanDerhel et al., 2013) than guilt. The linkage between shame and DSH has been further elucidated by Schoenleber, Berenbaum, and Motl (2014), who postulate that the physical pain experienced from DSH acts as a coping mechanism by decreasing one’s sensitivity to experiencing shame.

Issues relating to control, especially self-control and self-regulation, have also been linked to DSH. Albert Bandura proposed that human beings desire control (over themselves and others) because it is beneficial personally and socially. They often seek to obtain control over their own (maladaptive) thought processes (e.g., ruminating or cyclical thinking) to regulate their emotions (Bandura, 1997). Poor impulse control has long been associated with DSH as research

suggests that individuals who engage in DSH have a deficit in their ability to inhibit negative emotional reactions which can lead to impulsive behaviour (Allen & Hooley, 2014; Favazza & Conterio, 1989).

Locus of control, the extent to which individuals perceive they are in control of their lives (Rotter, 1975), is associated with the predictability of suicidal ideation and behaviour (Evans, Owens, & Marsh, 2005). Locus of control is measured on a spectrum ranging from largely internal (attributing successes to one's own agency) to largely external (attributing one's failures to others). Greater levels of family nurturance have been positively associated with internal locus of control, suggesting that locus of control is cultivated through positive or negative social experiences (de Man, Hall, & Stout, 1990). Some research suggests that individuals who exhibit an external locus of control are generally at a greater risk for suicidal behaviour (Evans, Owens, & Marsh, 2005). However, Wester and colleagues (2016) found that the presence of greater external locus of control does not necessarily predict future suicidal behaviour as much as current suicidal behaviour, suggesting that locus of control may be more a fluctuating state than a fixed characteristic.

A lack of control described in terms of uncertainty, chaos, untreated mental illness, and substance abuse has been suggested as a catalyst for DSH (Julia & Green, 2005). DSH may be employed as a strategy to evade emotional pain by replacing it with physical pain (i.e., method of DSH) which may seem more manageable to individuals who engage in DSH (Gulbas et al., 2015). These individuals may exhibit a deficit in their ability to control their moods, especially unpleasant emotional reactions (Allen & Hooley, 2014). This is supported by findings that

temporary loss of physiological control such as control over thoughts, motor control and general behaviour (disassociation) has been observed in individuals who engage in DSH (Karpel & Jerram, 2015). In these situations, individuals may not be able to recall the time period during which they engaged in DSH, which can be frightening and further compounds the perception of having little control.

Self-efficacy refers to a person's perception of her or his own ability to attain goals and complete tasks. Belief or doubt in one's own efficacy can hinder or enhance a person's performance in goal-setting and coping behaviour (Bandura, 1997). If an individual has low self-efficacy, s/he may seek alternative strategies or external sources to help her/him cope with personal issues. Higher levels of self-efficacy have been cited as a protective factor for risky behaviour that increases the ability to cope with stress, particularly in sexual and gender minority youth (Crisp & McCave, 2007). Lower levels of self-efficacy have been associated with reports of poor mental-health (Craig & Keane, 2014).

Given that poor self-efficacy may mean fewer skills for coping with stress, chronic over-reliance on the healthcare system may occur as a strategy to combat DSH, similar to users with other chronic illnesses (Gallagher, Donoghue, Chenoweth & Stein-Parbury, 2008). Both within and outside of a healthcare setting, individuals often utilize DSH in order to achieve some kind of external or internal reward. For example, Gallagher and Sheldon (2010) found that adult male patients at a high security hospital were motivated to engage in DSH for affect regulation generating physical sensations, suicide prevention, and self-punishment, but also to control their environment and staff, influence others and to obtain revenge.

DSH appears to have its own culture, with individuals sharing similar beliefs and practices related to it. School settings, in particular, have been noted as environments where DSH may be recognized and even encouraged by other peers (Simpson, 2015). According to Brausch and Gutierrez (2010), DSH rates range from fourteen to twenty-five percent in high school settings. Teenagers especially are also highly susceptible to the social contagion aspect (ideas and information spreading from person to person) of DSH (Jarvi, Jackson, Swenson, & Crawford, 2013). The Internet, too, is a significant contributor to DSH behaviour, with many websites hosting message boards where individuals share experiences or tips about how to engage in DSH and/or hide DSH scars (Hodgson, 2004).

It was previously noted that DSH is driven by a wide range of intents, including the wish to die, but that even those engaging in non-suicidal DSH acts (especially self-cutting) are at greater risk factor for eventual suicide than those who do not have a history of non-suicidal DSH (Andover et al., 2012; Hamza, Stewart, Willoughby, 2012). Suicide is the seventeenth leading cause of death worldwide and was responsible for 800,000 deaths in 2015 (WHO, 2015). Because death by suicide is highly stigmatized, some deaths are not accurately recorded, resulting in likely under- representation of the data (Jenkins, 2002). Official mortality data cited in the 2012 report by Statistics Canada (Navaneelan, 2012) indicate that 3,890 Canadians lost their lives to suicide in 2009. Navaneelan notes that suicide rates per 100,000 population vary by demographic group. For instance, suicide rates in males are three times higher than in females, and single individuals have a rate of suicide over three times higher than those who are married. Navaneelan also reports that individuals aged 40-59 have the highest rates of suicide overall, although the small number of males 85 years and over actually had higher rates between 2005 to

2009, according to the primary data tables cited (Statistics Canada, 2012). Finally, suicide is the leading cause of death among young people aged 15-34 (Naveelan, 2012).

Completed suicide and factors motivating an individual to engage in suicidal behaviour have long been the subject of research and debate. The French sociologist, Émile Durkheim, for instance, famously discussed the nature and potential causes of the phenomenon in his 1897 book, *Suicide: A Study in Sociology*. In this document, he expressed his belief that societal constructs and social circumstances may be more important to suicidal behaviour than individual characteristics.

Durkheim suggests that all suicides can be separated into one of four categories, each with distinct influential factors. Egoistic suicide, for example, is said to result from feeling detached and isolated from society. Its counterpart, altruistic suicide, occurs when being too involved with society causes one to feel secondary to the group at large and therefore insignificant. Anomic suicide arises from disillusionment following adverse experience. It reflects a state of moral confusion and upheaval. Finally, fatalistic suicide is attributed to oppressive societal conditions in which individual desires and goals are stifled (Durkheim, 1978). While these suicide types are quite basic and Durkheim's model has been criticized throughout the years, many of his assertions are still relevant today, likely underlying differences in rates of suicide within societal sub-groups.

Although the presence of active mental health disorders such as depression (“the third variable”) have been noted as most strongly associated with suicide (Harris & Baraclough, 1997; Jacobson, Muehlenkamp, Miller & Turner, 2008), a past history of DSH has also been found to

be a risk factor for eventual suicide (Cooper et al., 2005). For example, research suggests that approximately forty to fifty percent of individuals who commit suicide have a previous history of DSH (Ayton, Rasool, & Cottrell, 2003; Cavanagh, Carson, Sharpe, & Lawrie, 2003; Willoughby, Heffer & Hamza, 2015). Completed suicide following DSH is thought to be particularly likely when the earlier method of DSH had high potential lethality (Kuo et al, 2012). This is illustrated in Runeson et al.'s (2015) work with linked Swedish national registers which shows that people admitted for DSH are more likely to commit suicide eventually if the initial method was hanging or other self-injury (more lethal) rather than poisoning (which is generally more treatable).

The strength of suicidal intent is often found to be related (Haw et al., 2003) to the lethality of the DSH action, although this presumes that the person has an accurate perception of the lethality of the method. However, in spite of this difficulty, the concept of intent is clearly very important. Literature addressing DSH therefore generally distinguishes non-suicidal from suicidal DSH (Wilkinson, 2011). Suicidal DSH may appropriately also be referred to as a suicide attempt – a term which should not be used (although it unfortunately often is) to describe non-suicidal DSH, as this includes widely disparate acts occurring for different reasons and contexts. Examples of non-suicidal DSH include superficial cutting, asphyxiation, bruising, burning and self-neglect (Skegg, 2005; Wilkinson, 2011).

A population at high risk for both suicidal and non-suicidal DSH is sexual and gender minority groups, sometimes referred to as the LGBTQQIP2SAA (lesbian, gay, bisexual, transgender, queer, questioning, intersex, pansexual, two-spirit, asexual, allies) community, commonly shortened to LGBTQ (Gruskin et al., 2007; Qmunity, 2013). Studies have found that

sexual minority status is linked to other adverse outcomes such as elevated levels of smoking, substance abuse, depression, suicidal ideations and suicide attempts when compared to heterosexual peers (Russell & Joyner, 2001). Jorm et al. (2002) reported that gay and lesbian individuals have greater levels of mental distress and mental disorders (i.e., higher levels of suicidality, anxiety, and depression) than heterosexual individuals, due to childhood adversity and inadequate familial support. A meta-analysis and systematic review of 25 studies on mental disorders, DSH, and suicide in the lesbian, gay, and bisexual population found that the risk for depression and generalized anxiety disorder is 1.5 times greater in sexual minority individuals (King et al., 2008).

Reliable population rates of DSH and completed suicide within sexual minority (gay, lesbian, bisexual) and gender identity minority (transgender) groups are not well established. The World Health Organization's annual reports on suicide, for example, do not specifically identify rates for specific sexual orientations. This is likely due to several factors, such as sexual and/or gender identity not being recorded during an autopsy of a completed suicide, individuals not being open about/disclosing their sexual or gender minority identity, and the complex concepts of sexual and gender minority status, which are both culturally and individually dependent (Gates & Newport, 2012; Haas et al., 2011). Some regional researchers have found, however, that the lifetime prevalence of suicide attempts is four times greater in gay men than heterosexual men and two times higher in lesbian women than heterosexual women (King et al., 2008).

In 2003, Skegg, Nada-Raja, Dickson, Paul, and Williams studied men and women who reported varying levels of same-sex attraction and found that the greater the level of same-sex

attraction, the greater the likelihood of DSH behavior was. It should be noted, however, that while minority sexual orientation is associated with greater risk of DSH, this association is likely not a direct causal link, and is likely mediated through intermediate factors, such as the challenges and adversities that accompany a sexual or gender identity minority status (e.g., pressures of heteronormativity, peer victimization, internalized homonegativity, marginalization, and the stresses of “coming out”; Cover, 2011; Whitlock et al., 2011).

Unfortunately, while political attitudes towards sexual and gender identity minorities have been improving in recent years, individuals belonging to these groups are still victims of overt discrimination, harassment, and violence (Ash & Mackereth, 2013; Huebner, Rebchook, & Kegeles, 2004). There is even discrimination within and among members of sexual and gender minority communities where bisexuality appears to be “at the bottom of the totem pole.” Research suggests that “biphobia” is quite common among sexual and gender minorities, with bisexual individuals being the most ostracized and least visible (Welzer-Lang, 2008).

An important model that attempts to account for greater mental health disparities in gay and lesbian individuals is Meyer’s Minority Stress Theory. This model borrows from sociological theories, emphasizing the role of social interactions and societal environment stressors that can lead to adverse health outcomes (Meyer, 2003). Meyer posits that individuals who self-identify as gay or lesbian experience unique stressors throughout their lifetime, such as ongoing stigma, discrimination and internalized homonegativity due to their sexual minority status (Meyer, 1995). In this model, stress mediates the relationship between social status and adverse mental health outcomes. Stressors can be categorized as either distal events (e.g.,

victimization) or proximal personal perceptions (e.g., expectation of rejection) which accrue over time (Meyer, 2003). Hatzenbuehler (2009), expanding on Minority Stress Theory, asserted that Meyer failed to account for the psychological processes of stress and stress management. He therefore proposed that emotional and cognitive factors, such as coping mechanisms, feelings of hopelessness or negative self-image further mediate the relationship of discrimination and adverse mental health outcomes.

Meyer's model may be directly relevant to framing the problem of DSH within the gay and lesbian community. Blosnich and Bossarte (2012), for instance, found that sexual minorities such as gay, lesbian, and bisexual college students reported greater levels of both social stressors (e.g., discrimination, family problems, and intimate partner violence) and suicidal behaviours (e.g., DSH and suicidal ideation), than their heterosexual counterparts. Hatzenbuehler's (2011) research lends credence to the minority stress model, noting that less stressful environments (i.e., gay and lesbian supportive communities) are associated with fewer suicide attempts.

Sexual and gender minorities typically face discrimination throughout their childhood, adolescent and adult life, and with increasing age are also affected by age-based discrimination (ageism). Ageism results in further devaluating, excluding or ignoring elderly individuals regardless of current abilities and functioning (Hunter, 2005). Older individuals of sexual and gender minorities, therefore, may experience twofold prejudice and stigma and have been aptly referred to as a "twice hidden" population (Blando, 2001). Lack of consideration of this doubly disadvantaged group in clinical or academic research and planning likely reinforces its marginalization and decreases potentially positive interventions.

Many societies have an unfortunate tendency to suppress and deny the sexuality of aging individuals. For example, Claes and Moore (2000) argue that the sexual identities of aging gay and lesbian people are often ignored, usually through heterosexist assumptions (e.g., asking if they are married instead of asking if they have a partner). Furthermore, older gay and lesbian individuals tend to be less visible within sexual and gender minority communities. This may be due to their lack of participation within the community, beliefs that they have little in common with the younger population, or their fear of being rejected or dismissed by younger individuals (Berger, 1982). Claes and Moore (2000) suggest that because gay and lesbian individuals are identified primarily by their sexuality, and aging individuals are viewed as sexless, they may be exposed to greater levels of homonegativity.

The clichéd archetype of the lonely, aging gay or lesbian has remained a stereotype for decades (Ellis, 2001). As more research is conducted in sexual and gender minority populations, it becomes clear that this is not an accurate representation of most aging individuals in these groups. For example, one study found that many gay and lesbian individuals adapted to aging more effectively than heterosexual people (Berger & Kelly, 1996). The authors suggest that this is because gay and lesbian individuals are subjected to high levels of discrimination and stigma throughout their lifetime and have therefore learned to deal with it more effectively. This is not to suggest that the aging gay and lesbian population is a homogeneous group, but rather illustrates that, similar to their heterosexual counterparts, the diversity of lesbian and gay individuals' challenges, coping strategies, and life choices lead to endless permutations of experience and perception.

Most research on barriers between patients and healthcare providers has been explored through opinions and experiences of healthcare providers. These studies provide an important (albeit one-sided) perspective into factors contributing to client dissatisfaction with healthcare services. It has been reported that some clients presenting with DSH feel stigmatized, blamed, or humiliated by hospital staff, exacerbating feelings of shame and promoting distrust in healthcare services. For example, Hadfield and colleagues (2009), found that doctors perceived some acts of DSH to be manipulative (e.g., attention-seeking) and disclosed feelings of anger that could potentially jeopardize their ability to act professionally. In a meta-analysis of 74 studies assessing perspectives of healthcare professionals towards individuals who present with DSH, attitudes were largely negative, especially towards those who repeatedly present with DSH. These negative attitudes, however, were not as prevalent among psychiatric professionals, suggesting that a greater understanding of DSH and co-morbid issues (i.e., mental health diagnoses, history of adverse experiences) may improve attitudes and therefore patient experiences and outcomes (Saunders, Hawton, Fortune & Farrell, 2012).

Adverse experiences of individuals with DSH when seeking professional help might further contribute to potential feelings of self-hatred, which may affect future episodes of DSH (Hadfield et al., 2009). Contact points for patients within healthcare delivery systems (like outpatient clinics, inpatient units or emergency departments) likely vary in how well they are equipped to deal with DSH and other mental health issues. For instance, Canadian patients who visited emergency departments with mental health concerns found that their care appeared to be the last priority for nurses and doctors. They were discouraged by lengthy wait times and sometimes even gave up and went home. This was believed to occur because the nurses did not

feel qualified to address their patients' needs. Furthermore, patients often felt ashamed and guilty for seeking care, which likely affected patient and provider rapport, which in turn has been found to be important for successful rehabilitation (Claes & Moore, 2000; Clarke, Dusome, & Hughes, 2007). Sinclair and Green (2005) found that young individuals being treated for DSH felt out of control during hospital visits, experiencing little autonomy relating to their care. These individuals also found difficulties in connecting with staff and felt that they would have benefitted more from simply talking about their problems than from the physical medical care they were offered. A meta-analysis of attitudes towards healthcare services revealed that individuals who self-harm felt largely dissatisfied with the care they received and suggested the need for better communication between staff and patients, greater provider knowledge of DSH, increased sympathy for those who engage in DSH, and improved access to resources and aftercare (Taylor, Hawton, Fortune & Kapur, 2009). The usefulness of this recommendation was supported by research showing that explicit training geared at increasing knowledge about DSH improves attitudes among healthcare professionals (Saunders, Hawton, Fortune & Farrell, 2012).

The aforementioned issues with the healthcare system may be particularly acute for people from vulnerable populations, such as those from sexual and gender minorities who often feel discriminated against in healthcare settings where client heterosexuality is assumed (Neville & Henrickson, 2006). As evidence suggests that individuals with DSH who do not complete their necessary treatment (e.g., rehabilitation, therapy, etc.) have a recidivism rate of DSH three times higher than those who do not (Crawford & Wessely, 1998), it is important to identify factors which maximize continued participation in the treatment of individuals who engage in DSH.

Often disclosing and discussing one's sexual orientation to a healthcare professional may be necessary to address specific issues or questions which can affect an individual's overall health (Bjorkman & Malterud, 2009). An open dialogue about sexual orientation is likely affected by the comfort experienced by healthcare professionals with the topic. This is important, as Rondahl (2009), for example, found that gay and lesbian individuals experienced significant anxiety in "coming out" to nurses, and although they perceived most nurses to be kind and understanding, were wary of being treated by nurses who were perceived to be religious or belonging to an older generation for fear of being judged. Furthermore, lesbian women reported that the most important qualities in healthcare providers are their medical knowledge pertaining to lesbian health concerns, an open and respectful attitude to their sexual orientation and an awareness that not all patients are heterosexual (Bjorkman & Malterud, 2009).

Research also suggests that past negative experiences with healthcare services can cultivate distrust with the system which may affect future visits. For example, Gabrielson's (2011) qualitative study of older-aged lesbians regarding past interactions with healthcare services revealed several incidents of discrimination. These adverse experiences included negative reactions from staff upon learning of their patients' (or their patient partners') sexual orientation and refusal to acknowledge partners as family and therefore withholding information or denying visitation. These experiences, in turn, may affect expectations of further interactions with healthcare and can lead to feelings of fear, dread, and avoidance (Gabrielson, 2011).

While the literature surrounding sexual and gender minority groups, including their risk for DSH, has expanded in recent years, the most prominent focus has been on adolescents and

young adults rather than older-aged adults, which likely decreases the ability of health planners to optimally target strategies for intervention for this group with different social and physical needs.

The dearth in research among older generations is likely due to the current trend to early “coming out” (Hunter, 2005), whereas older people from gender minorities may be still largely hidden within the larger community. Reasons for this likely relate to different lived experiences by currently older people, having grown up in a much less accepting social and political climate than younger individuals. For example, prior to the “gay liberation” movement following Stonewall riots in 1969, during which sexual and gender identity minorities took forceful action against their ongoing oppression, the political climate was permeated by intensely unwavering homonegativity. Therefore, heterosexism went largely unchallenged and the pathology of homosexuality was accepted as fact (Grossman, D’Augelli, & Hershberger, 2000). People from sexual and gender minority groups had little sense of community, role models, supports, or resources from which to seek solace or understanding (Bohan, 1996; Ellis, 2001). It is, therefore, no surprise that they are more hesitant than younger individuals to disclose their sexual orientation (Huebner, et al., 2004).

Consistent with the above, is a review of the literature on social and healthcare needs of lesbian, gay, bisexual and transgendered individuals, which suggests that considering the historical tendency to suppress these sexual minority identities, older individuals belonging to these groups tend to avoid disclosing and discussing their sexual orientation with their healthcare providers, ultimately contributing to further healthcare inequalities (Addis, Davies, Greene,

Stewart & Shepherd, 2009). Further connecting this finding with DSH is a recent study of older-aged lesbians which found that the social alienation and discrimination of their generation was a significant source of DSH behaviour (McCann, Sharek, Higgins, Sheerin & Glacken, 2013).

Many older gay and lesbian individuals who require mental health services still face barriers to adequate care, including a scarcity of both age-sensitive and LGBTQ-sensitive providers (Grant, 2010). The assumption that all individuals are in, or desire to be in, a sexual relationship with someone of the opposite sex, otherwise referred to as heteronormativity, is very prominent in healthcare settings (McAndrew & Warne, 2010; McIntyre & McDonald, 2012). While it is not necessary for sexual and gender identity minorities to be treated by someone who also belongs to the same community, there may be a need to train all healthcare providers on how to provide their clients with appropriate and sensitive services and have basic knowledge of sexual and gender minority issues (Rutherford, McIntyre, Daley, & Ross, 2012). Qualitative researchers working with mental health professionals noted that healthcare providers themselves have identified a dearth of training in sexual and gender identity minority issues both during their schooling and throughout their professional career, and recommended that this kind of training should be mandatory in future practice (Rutherford et al., 2012).

Research has shown that therapeutic interventions that are adapted to gay and lesbian needs may be more effective in treating mental health disorders in sexual minorities. For example, “gay-tailored” cognitive behavioural therapy (CBT) showed a greater decrease of depressive symptoms in gay and bisexual men compared to the use of conventional CBT treatment (Jaffe, Shoptaw, Stein, Reback, & Rotheram-Fuller, 2007). This suggests that

healthcare services should continue to develop sensitive and appropriate care for special groups to maximize client participation and alleviate hesitation in seeking treatment.

Despite the growing amount of literature in recent years, virtually no research has qualitatively examined how aging gay and lesbian individuals with DSH interact with healthcare services. While existing quantitative research about DSH and sexual and gender minorities supplies statistical and epidemiological data important to the field, it tends to only address concrete questions such as *how* DSH is carried out or *what* the outcomes are. By using qualitative methods to explore this topic, we can complement the numerical data with exploratory inquiry of *why* individuals engage in DSH through their rich experiences and interpretations. But what is qualitative research? As Silverman (2001) notes, this term “covers a wide range of different, even conflicting activities,” and it should not suffice to define it merely as a negative epithet, i.e., as non-quantitative (p. 25). As Payo (2018) suggests, qualitative research understands human behavior as “subjectively meaningful for the people engaged in that behavior and it attempts to provide a fuller understanding of that behavior,” in two ways, by describing “the complex qualities that make up social phenomena, and how these qualities relate to one another and have meaning within a broader, more holistic cultural context,” and by “interpret[ing] and understand[ing] behavior within its context rather than trying to explain it” (p. 253). Anthropologist Geertz (cited in Payo 2018, p. 253) similarly describes description and interpretation in qualitative research, clarifying description’s particular role as “thick description” in offering not only “a vivid account of the social interactions taking place between people,” but also seeking to “put those interactions against the wider cultural framework that serves as the background for further interaction, while showing how things ‘make sense’ from

the perspectives of the participants involved” (p.253). It is Geertz’ “thick description” that I have found most fruitful in my efforts to provide my readers with a sense of my participants’ generous reflections on my questions.

The purpose of the proposed research is to focus on DSH in exploring, through “thick description,” how older gay and lesbian adults experience their contact with healthcare services, so that we can identify possible barriers to involvement in therapeutic programs which might result in sub-optimal outcomes. Hence, the following research questions:

1. What are some experiences and perceptions, positive and negative, of sexual and gender minority persons regarding their childhood and coming out?
2. What are the connections between personal and coming out experiences of sexual and gender minorities in relation to DSH?
3. What experiences, positive and negative, do sexual and gender minority persons with DSH face in accessing the healthcare system?
4. What suggestions do sexual and gender minority persons who engage in DSH have for improving the healthcare system?

Chapter 2: Methods

Design

I worked closely with OUTSaskatoon (formerly the Avenue Community Centre), a not-for-profit agency that offers supports, resources, information, organized events, and health services for individuals of all sexual and gender orientations, and the University of Saskatchewan Pride Centre. OUTSaskatoon acted as an advisory team which provided feedback, critiques and insight throughout the research project. They also functioned as an access point to potential participants in the study. The collaboration between me and these organizations was ongoing, beginning in the initial planning phase of the project and continuing throughout data collection and writing up the results. . Three key members of staff at OUTSaskatoon, the executive director, program manager, and administrative coordinator, offered their expertise in sexual and gender minority appropriate and up-to-date terminology and provided current reading material and statistics. At the Pride Centre, the coordinator reviewed initial documents and provided feedback. For my own information, I also attended a “Queer 101” seminar held at the University which taught resident assistants how to be sensitive to and aware of sexual and gender minority issues which they may encounter during their roles at the U of S. This was helpful as I designed the questions for my own interviews.

Foremost, I used semi-structured, mixed-formal interviews to guide and stimulate the discussion. Participants were encouraged to speak freely, but I asked a number of standard questions if they not covered spontaneously. I did not always ask questions in the same order, nor did I necessarily cover all questions. I chose a semi-structured interview format because it not

only facilitates a rapport between researcher and participant, but is a flexible method that can generate rich data. For example, questions were permitted to be slightly modified in light of how the participants responded to the questions, providing the opportunity to probe avenues of discussion that may not come up in an otherwise rigidly structured format (Smith & Osborn, 2015)¹.

An exploratory approach using Interpretive Phenomenological Analysis (IPA) was employed to examine the interviews of participants. As is common with most qualitative research methods, IPA is “committed to the examination of how people make sense of their major life experiences”; however, in contrast to other qualitative methods, Smith and Osborn emphasize IPA’s this phenomenological approach is “concerned with exploring experience on its own terms” (Smith, Flowers, & Larkin, 2009, p. 1). Building on philosopher Dilthey, the authors focus on experience as a “comprehensive unit,” where an experience has a larger significance in a person’s life (“lived experience”), is connected to important events in the past, and may be signified as a marker of recovery; parts of the experience may be separated in time albeit linked with common meaning (p. 2). In this process, researchers play a dual role (“double hermeneutic”): they try to make sense of their participants trying to make sense of what has been happening to them; however, while more systematic, researchers’ sense-making is of a secondary order since they depend on their participants’ experiences (p. 3). For the purposes of my research, IPA’s focus on meaning in participants’ narratives seemed more useful for analysis than, say, Riessman’s focus on the ways how participants structure their narratives (2008). In these ways, IPA is said to allow for more creativity and freedom than other methods of analysis

¹ For a complete list of interview questions please refer to the interview guide in appendix A

(Willig, 2001). Moreover, IPA is believed to be ideal for hard-to-reach samples of participants (Biggerstaff & Thompson, 2008), and particularly for small samples like mine. Smith et al. (2009) recommend $n = 3$ as a “default size” for an undergraduate or Master’s level IPA study, allowing for detailed analysis of the sample”. This allows sufficient in-depth engagement with each case as well as detailed examination of similarities and differences across cases (p. 52). Furthermore, IPA – as most qualitative methods - is not concerned with the generalizability of data; rather, it highlights the nuances of independent cases, recognizing that each individual interview may highlight completely new and insightful information. The goal of IPA is not to represent a population, but rather to represent a perspective (Smith, Flowers & Larkin, 2009). IPA also suggests that overarching themes, patterns, imagery, and metaphors that can be uncovered in an individual’s interview can be revealing and meaningful for both researcher and participant (Smith & Osborn, 2015).

As I hoped to do justice to the participants’ meanings in my study reported here, I took seriously Smith and Osborn’s note that these meanings are not transparently available; rather, “they must be obtained through a sustained engagement with the text and a process of interpretation” (Smith & Osborn, 2015, p.66). This systematic rigour in the engagement with the texts is an important part of rigor to achieve achieving good quality analysis (known as “validity” in quantitative contexts) - as laid out in the following. I chose to code my transcripts manually rather than via computer program as it has been suggested that the former process can cultivate an intimacy between researcher and data which may lead to conclusions otherwise missed (Pringle, Drummond, McLafferty & Hendry, 2011). Next, I began my analysis by examining each interview in great detail and then contrasting and comparing all four interviews

in order to understand the shared as well as distinct experiences of each participant. Thus, I started out with a process otherwise known as “Close Reading” (Lehman & Roberts, 2013), attentively reading, and re-reading a number of times, each transcript. I followed the 5-step IPA process closely, systematically looking in each transcript first for low- and higher-level themes, connecting the themes, then continuing the analysis with the other transcripts, and finally writing up my analysis (Smith, Flowers, & Larkin, 2009, p. 82ff). I constantly reflected, with much assistance from one of my supervisors’ (UT)my supervisor’s narrative lab (of which I was a member at the time), on the generation of emergent and fully-fledged themes, as well as their clustering, while making sure that “the actual words of the participant” (in the transcript) bear my connections and conclusions out (Smith & Osborn, 2015, p. 45). By including direct quotes from my participants to anchor my claims, I have been presenting my findings to be deemed either credible or non-credible by the reader (Pringle, Drummond, McLafferty & Hendry, 2011), allowing for external auditing of my interpretations. In all these ways I have been aiming to follow Smith’s guidelines for quality, base on four broad principles developed by Lucy Yardley (cited in Smith, Flowers, & Larkin, 2009, pp. 179 – 185). These principles include showing a) *sensitivity to context* (i.e., participants’ socio-cultural milieu), b) *commitment and rigour* (i.e., sensitivity to the needs of participants during interviews; thorough and systematic analysis), c) *transparency and coherence* (i.e., explanations of and reflections on the research process; logic of conclusions), and d) *impact and importance* (i.e. research providing readers with interesting, important, or useful information). The members of my lab, as well as my supervisors, provided independent audits along the way by following my research process, offering their own interpretations and conclusions, thereby guiding me in developing a transparent account of my

analysis as is appropriate for qualitative analysis (p. 183). At this point it may be important to point out that analysis in qualitative research constitutes a creative process that does not follow a rule book; thus, “criteria for validity need to be flexibly applied; something that works for one study will be less suitable for another” (p. 184).

A few more notes regarding my sample: while DSH is clearly a problem among various sexual and gender identity minorities, including bisexual and transgendered individuals, specific groups face very different challenges which I felt could not all be addressed in a small, qualitative study such as this one. Therefore, the research was initially limited to investigate gender differences between self-identified cisgender gay and lesbian individuals. Furthermore, as much of the existing literature focuses on adolescent and young adults, I wanted to recruit a wider age group, ideally including adult and older adult participants to allow for individual exploration as well as contrasts between experiences of the different age groups.

Ethics

University of Saskatchewan ethics approval (BEH 13-400) was obtained for the interviews as well as for the digital recording (there were a few amendments during the process) and a variety of recruitment strategies were employed to find participants. These included advertising through OUTSaskatoon, the Mental Health and Addictions Services of the Saskatoon Health Region, and the Saskatoon Crisis Intervention Services. I also sent out an email request to all the child psychiatrists in Saskatoon asking them if they had any patients who might potentially be interested in participating.

As per the partnership with OUTSaskatoon and Pride Centre, both organizations agreed to display in their establishments the posters I created. OUTSaskatoon also sent out several calls for participants in their weekly e-mail and bi-monthly newsletter which reach approximately 400 and 100 people, respectively. The posters and briefs in the e-mails and newsletters asked for gay and lesbian volunteers who had dealt with healthcare services following experiences with DSH or thoughts of DSH. My contact information was provided on the recruitment poster and individuals who were interested and met the inclusion criteria were invited to contact me for further information. Alternatively, prospective participants could also leave their information (e.g., phone number) with the OUTSaskatoon staff who agreed to pass it along to me.

Participant recruitment and consent

Recruitment proved to be a challenge, taking place over nine months between March 3rd and November 10th, 2014. Upon making contact with interested individuals, I asked a few screening questions to determine if they had experience with DSH or related issues (e.g., substance abuse issues, depression), explaining that DSH was the particular focus of the study. If individuals had not had experience with suicidal or non-suicidal DSH, I thanked them for their interest, informing them that their information would be kept in case the focus of the research shifted.

Participants who met the research requirements were then asked some basic demographic information (age, sex, orientation) as well as their phone number, following which a date was arranged for a lengthier telephone call. During this call, I went into further detail about the study including the purpose, context of the research within existing literature, and what to expect for

the interview (i.e., length of time, nature of the questions, etc.). Participants and I agreed on a convenient date and time to meet. I had arranged for private rooms at both OUTSaskatoon and the Qualitative Research Lab at the University of Saskatchewan, so participants were able to choose whichever location they found to be more convenient or comfortable.

The interviews took place at the convenience of the participants, at which time the purpose and procedures of the study were further explained. Potential participants were provided with a consent form to read over and sign and were invited to ask questions they might have about the study. All participants were also verbally informed that they were free to refuse answering questions and could stop the interview at any time.

Data collection

One interview was conducted at the University of Saskatchewan and three interviews were conducted at OUTSaskatoon. All interviews occurred face to face in private rooms to ensure confidentiality. All dialogue was recorded using a digital voice recorder. I also took field notes throughout the interview to record personal reflections throughout the process and document non-verbal cues such as body language, which proved informative during the transcription and analysis phase. All interviews were expected to be no longer than sixty to ninety minutes, although one was almost two hours in length.

Participants were invited to reflect on a variety of topics, including general life history, experiences of being gay or lesbian (e.g., coming out, reception from family members, etc.), mental health history (including their experience with DSH), and their interactions with the

healthcare system. Although the planned focus of the research was on how these individuals experienced healthcare services during crises (particularly those resulting in a DSH activity), seminal moments in their past, such as coming out, were included to provide a contextual framework as well as greater depth of understanding of the individual's perceptions of their interactions with healthcare services. For example, if an individual experienced a negative reaction from family and friends when coming out as gay or lesbian, s/he may have also perceived or expected negative reactions from nurses, doctors, or other patients.

Transcription and analysis

After the data were collected, they were transcribed into a word document for analysis. Transcription took place using the recorded interviews and a desktop computer. Interviews were typed out verbatim to the recordings including pauses, laughs, verbal missteps, intonation, and emphasis. A modified version of Jefferson's (1984) notations was used to indicate nuances in speech and body language².

In the analysis, I attempted to understand the central meaning of a participant's experiences with being gay or lesbian, DSH, and the healthcare system by engaging in multiple close readings of all four interviews. Detailed and colour-coded annotations were made in the margins of the transcribed documents to note important and interesting parts of the text. Comments were identified as descriptive, linguistic, or conceptual in nature. I identified underlying concepts, themes, and patterns, some of which were not necessarily readily available on the surface, but began to emerge through iterative interpretations of the transcript. Through

² For my modified version of Jefferson's transcript notations, please refer to Appendix E.

these interpretations, I was able to identify connections, parallels, and differences within and between interviews to generate a cohesive summary of the findings.

Chapter 3: Findings

Participant profiles

Four participants, with ages ranging from seventeen to fifty-one, were recruited. Two were female, one was male, and one identified as agender (neither male nor female). Two identified as being lesbian and two identified as being gay. Two out of four had full-time or part-time jobs and two were unemployed. Two of the four were upgrading their grade twelve education. None had completed any post-secondary education. Three out of four had a romantic partner with relationships ranging between four months and twelve years. Three out of four lived alone. All four had experience with DSH, while three had attempted suicide at least once, sometimes with the stated intent of wanting to die. All four had at least one mental health diagnosis.

Participant one (designated as Andrew from now on) was a male who was fifty-one years old at the time of the interview. Now employed as a technical support agent, he had grown up in a prairie city in a deeply religious home with his mother, father and sisters. Andrew said he did not have a great relationship with his parents during childhood and adolescence; he now believes that his mother was (and still is) living with untreated bipolar disorder and, therefore, had erratic moods. He described his father as distant and largely absent during his formative years. Andrew stated that when he was a young boy, both he and his sisters were molested by their grandfather. His first experience with self-harm and suicide was at age sixteen. Andrew himself was diagnosed with bipolar disorder at approximately age 40, at which time he also divorced his wife of twelve years. Soon after that, he came out as a gay man – news that was received quite well by family and friends. At the time of the interview, he had a long-term partner of approximately

twelve years (they were not living together) whom he brought along to the interview. His partner had no known history of DSH. Andrew also had a seventeen-year-old son whom he has been co-parenting with his ex-wife for many years.

Andrew had contacted me via e-mail about one of my research posters that he had seen at OUTSaskatoon. The initial meeting at OUTSaskatoon lasted for approximately two hours. Andrew's narrative was very rich and highly detailed. Since he came out as a gay man, divorced his wife, and was diagnosed with bipolar disorder all around the age of forty, a lot of the narrative was focused on that period of his life, although he also spoke about his childhood, teenage years and more recent years up to and including the present.

Andrew was charismatic, outgoing, and did not need much prompting to answer questions or go into more detail. Rapport was easily established, which led to the interview becoming more of an informal conversation with a relaxed tone. Andrew tended to talk about serious or even traumatizing events (like sexual abuse) in a casual, almost flippant and non-emotional manner, sometimes even laughing while he spoke of them.

Participant two (designated as Lucy) was a twenty-three-year-old female when the interview took place. She had been dating her female partner, who also had a history of DSH, for at least six months, but lived alone in her own apartment. Lucy had also grown up in a prairie city. She was born with a significant childhood onset mobility impairment which limited the use of her legs and required her to be in a wheelchair. Lucy described good relationships with her mother, step-father, and brother, with whom she had grown up. Her biological father was largely absent and emotionally abusive throughout her life and had died six months prior to the

interview. Lucy came out as a lesbian around the age of twenty-one. She was unemployed but volunteered for numerous associations around the city. She had been diagnosed with several mental health illnesses including “irrational panicked anxiety and mood” disorder. She described suffering physical and emotion abuse and rape from an ex-boyfriend and others during high school. She stated that her first experience with self-harm or suicidality was at age four.

The interview with Lucy was held at OUTSaskatoon after she had contacted me through e-mail. Like Andrew, she had learned about the study from one of my posters at OUTSaskatoon. The meeting lasted for approximately one and a half hours. Although there were a few stories from her childhood which appeared to be important memories for her, including mistreatment from her father and details about her years in high school where she was often bullied, the majority of Lucy's narrative concentrated on the past two years since she came out as lesbian.

Lucy's partner accompanied her and stayed in the room for moral support for the duration of the interview. Although Lucy's partner did not actively participate in the interview, Lucy called on her from time to time to corroborate dates or facts, share a joke, or request physical comfort such as a hug. There were a few times when Lucy was hesitant to answer a question or go into detail because she did not feel comfortable with her partner listening. At these times her partner would offer to leave the room, but Lucy eventually chose to continue. Lucy exhibited strong reliance on her partner for mental and emotional stability.

Lucy's narrative style very emotional, with a wide range of affect. Of all the participants, Lucy's experiences were some of the most disturbing, including the abandonment, degradation, and emotional abuse by her father.

Lucy was very pleasant to talk to. Rapport was established easily, with Lucy talking about her artistic pursuits and sharing anecdotes. Lucy mentioned a few times that I made her feel comfortable, citing that I was not an intimidating professional, but more or less her contemporary. Much like the interview with Andrew, the conversation did not need much initiation from me, as she naturally talked about a variety of the topics of interest to the research.

Participant three (designated as Melissa) was eighteen years old at the time of the interview and was upgrading her grade twelve with a part-time job. Her parents were separated and had joint custody, but her mother was having a baby and did not have room for her in the house. Melissa described her father and step-mother as overbearing, so she lived with her grandparents, who were described as very supportive. She had realized and accepted that she was a lesbian around the age of fifteen. She was the only participant who did not have a partner at the time of interview. Melissa saw a psychologist regularly and described being given diagnoses of depression, general and social anxiety disorder and, most recently, ADHD. She also described a previous history of an eating disorder (binging/over-eating). Melissa said she had engaged in DSH for two to three years although she never sought treatment for it at an emergency room or clinic.

Melissa had contacted me via e-mail having heard about the study from a friend. The initial meeting lasted for approximately an hour at the University of Saskatchewan in a private lab in the Arts and Science building. Most of Melissa's narrative was focused on the present or recent past (around two years), since she came out as a lesbian. She made almost no mention of her childhood and rarely spoke about her parents or their involvement in her life.

Melissa appeared to be a very intelligent, analytic, shy but anxious person. She seemed to be the most introspective of all the participants and also the most concerned with other's perceptions of her. Melissa's narrative provided the least amount of usable data in that she had never sought medical attention for her DSH, had never attempted suicide, never been in a relationship, and had suffered no significant adverse experiences, unlike all the other participants. Much prompting was necessary to cover the topics of interest.

Participant four (designated as Alex) identified as agender, meaning that they self-identified as neither male nor female (American Psychological Association, 2015). Alex preferred the pronouns "they" and "them" rather than she or her.³ Alex also identified as polyromantic (attracted to some, but not all genders [Carrigan, 2011]) and demisexual (needing a strong emotional connection before engaging in sexual activity with a person, [Mosbergen, 2016]), yet also identified as gay. They (i.e., Alex) were seventeen years of age, living alone following life in several foster homes, and attending grade twelve at the time of interviewing. This participant did not have a relationship with the majority of the family of origin, least of all the father who was described as a recovering drug addict. Alex had a romantic partner of four months who also identified as agender, had a history of DSH and reported to have received medication for depression since the age of six. They (Alex) had seen a therapist regularly and had been diagnosed with several mental health conditions including OCD, trichotillomania,

³ Throughout the thesis, I will frequently refrain from using any pronouns when referring to Alex and simply use Alex's given name. Although it may read as repetitious, it has been done to minimize confusion when using "them" or "they" while also respecting Alex's preference to not employ gender pronouns.

ADHD and Borderline Personality Disorder. Alex described at least fifteen episodes of DSH (many of which were described as suicide attempts).

Alex had contacted me through e-mail and the initial interview occurred at OUTSaskatoon where Alex had originally seen the poster for the study. The interview lasted just under one hour, making it the shortest of all four interviews. The majority of Alex's narrative concerned the present or recent past, with very little focus on their early life. They (Alex) spoke a lot about their positive activism within the sexual and gender minority community and within their high school, crusading for equality for all genders and orientations. Alex used a very flat, even tone throughout the interview with little emotional expression, regardless of subject matter, provided the least detail of all participants during the interview, and rapport was not easy to develop.

Some of the interviews were natural and fluid, with the participants being very open to disclosure. These interviews yielded the richest transcripts and addressed most (sometimes more) of the initially developed research questions. In general, my interviews with Andrew and Lucy were the most effortless and rewarding. They flowed more like a conversations between two friends than a formal interview between researcher and participant. The interviews with Melissa and Alex were more structured, formal, less layered and stayed more superficial. Alex, in particular, was the least comfortable in discussing some of the topics, providing shorter answers, and appearing to be the most guarded.

All of my participants were unique, with varying backgrounds and experiences. Each contributed, in their own way, to the rich data I obtained through the interviews. In the following section, I will broadly outline the themes that emerged through analysis of the transcripts.

Themes

During a long and intensive process of close reading and re-reading, searching for patterns and differences and after many discussions in the narrative lab of which I was a member, I explored many themes, but struggled to find a concise and cohesive set. Eventually, after more than two months of searching, I had a moment in which three major themes seemed to crystallize from the richness of the interview data. These themes, which are discussed further in three separate sections, were chosen as they over-arch (to various extents) through all four interviews. The themes, I found, all appeared to revolve around control, ranging from desire, loss, and struggle for self-control (physically and mentally), control over events or circumstances (e.g., mental health issues, relationships, workplace environments), and control over other individuals. The three major themes were identified, therefore, as “Experiences of and responses to lack of control”, “Active struggles to establish control”, and “Successes in establishing control”.

In section one, “Experiences of and responses to lack of control”, I discuss pieces of the four different narratives which illustrate events or attitudes in which the participants perceived they had little or no control over a particular situation or mental state. The sub-themes I identified and describe were incidents of adverse experiences and experiences of stigma and feelings of guilt and shame (resulting from primarily their sexual orientation, DSH behaviour, or mental health issues). These often lead to leading secret or closeted lives and contributed to feelings of self-loathing. Finally, I explore some of the unsatisfactory interactions my participants had with the healthcare system (primarily when seeking treatment for DSH).

In section two, “Active struggles to establish control”, I outline seminal moments in the participants’ narratives to illustrate how these individuals strive to achieve control over themselves, other individuals, and general circumstance. Participants often struggled to claim control in their search or desire to belong and/or feel understood, often leading to spousal/significant other dependency and engaging in the culture surrounding DSH. Most striking, however, was the struggle for control in the act of DSH itself which also related to self-efficacy and hospital dependency.

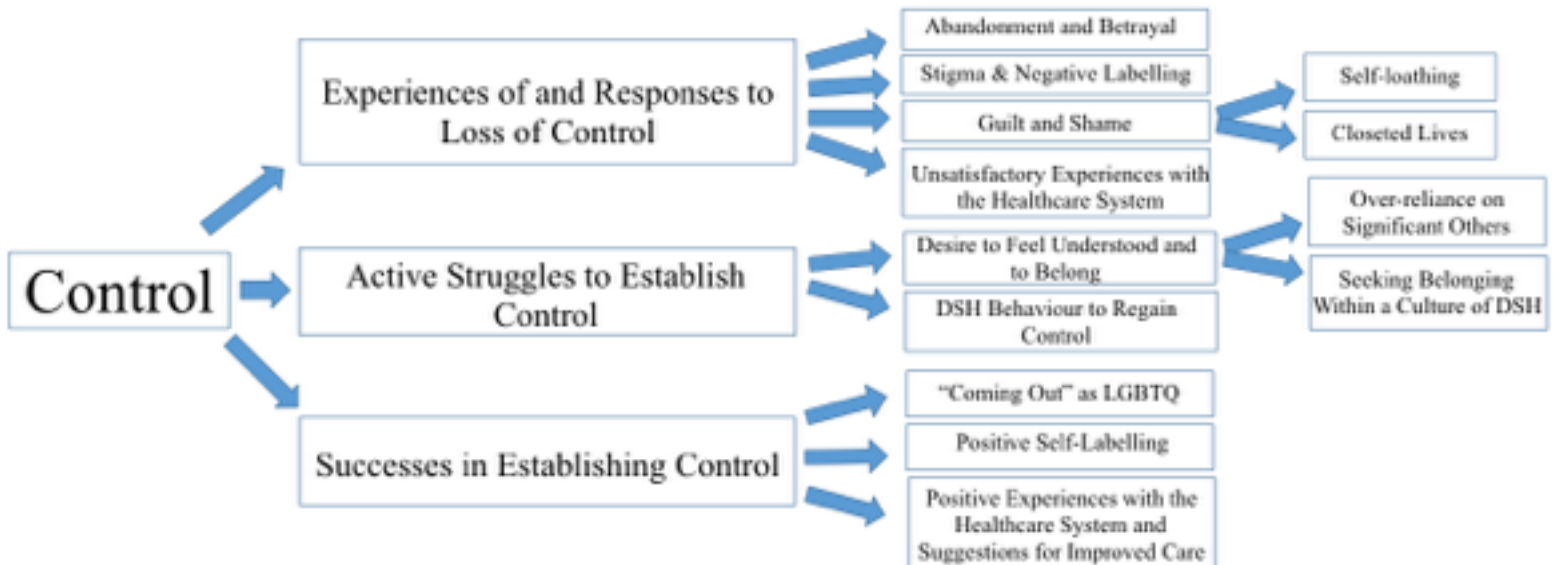
In the third and final section, “Successes in establishing control”, I discuss events or attitudes in which the participants were able to reclaim some degree of control over themselves or circumstances. This was often evident in their experiences of coming out to family, friends, and the general public, which were largely positive in nature. Control was also established through the participants’ choice of labels (whether pertaining to sexual minority status or mental health) as opposed to being assigned by others. Participants also shared a number of positive experiences with the healthcare system (for DSH care and other) and, finally, participants voiced their ideas and suggestions on how the Saskatoon healthcare system can better serve people seeking treatment for DSH and for sexual and gender minority populations at large.

Locus of control permeates all of the three themes and their sub-themes. In some situations, participants attribute control over something or someone to themselves, acknowledging their role in their successes or failures. At other times, participants externalized control, deeming it to be outside of themselves and beyond their personal control.

I should note that I identified most sub-themes to some extent across all interviews, but in instances where I deemed a sub-theme to be particularly important to the narratives of only two or three participants I included that sub-theme anyway. Some themes and sub-themes presented very similarly across participants, while others manifested themselves differently from one individual to another. Many experiences were pertinent to two or more themes. For example, being sexually abused fitted both into “Guilt and shame” and “Abandonment and betrayal.” Instead of using quotations for both themes, I quoted briefly in one theme and then expanded on with more detailed excerpts from the interviews in the other theme.

For clarity regarding the themes and their sub-themes, I have attached a thematic map as a visual aid:

Thematic Map of Control



Chapter 4: Analysis

Theme 1 - Experiences of and responses to loss of control

Loss or lack of control was a strong theme throughout participant interviews and often seemed to be a trigger for DSH behaviour. Participants appeared to use DSH as a strategy of reclaiming control; sometimes relating to external situations, but even more frequently relating to participants' own emotions or thought patterns. For example, all participants at some point described cutting or otherwise harming themselves to quiet or slow down racing thoughts, to cope with negative or anxious emotions, or to feel less numb (refer to Experiential Avoidance and Depersonalization models in the literature review). External situations resulting in a person's perception of loss of control leading to DSH included mental health problems and interventions (such as involuntary hospitalization or treatment) or being the victim of an assault or other crime.

Throughout this chapter, I will explore distinct sections of the most prominent and recurring themes of the experiences, perceptions and feelings related to a loss or lack of control such as “Stigma and negative labeling” (1.2.), “Guilt and shame” (1.3.) which includes its own sub-themes “Self-loathing” (1.3.A.) and “Closeted lives” (1.3.B), closing the section with “Unsatisfactory experiences with the healthcare system”.

I will begin section one by exploring how participants experienced loss or lack of control through abandonment and/or betrayal. The experiences from participants in this section include sexual, verbal, or emotional abuse, intense bullying from peers or others and the perceptions and emotions that resulted.

1.1. Abandonment and betrayal

Three of the four participants described experiencing life events which could be construed as acts of abandonment and/or betrayal, and which affected them adversely both at the time of the event and in later life. These were generally events over which they had - or perceived to have - little control. Some participants elaborated considerably about these experiences whereas others referred to them concisely, without much additional detail. Out of concern for the emotional health of the participants after the interview, individual reluctance to pursue details of adverse experiences were respected with no attempts made to obtain further revelation of potentially traumatizing details.

Andrew described suffering abandonment and betrayal beginning in his childhood due to his very unstable relationship with his mother. When he was invited to provide details about himself, he immediately began explaining how difficult his childhood was. He stated that his mother was very likely an undiagnosed and un-medicated victim of bipolar disorder, that she was not pleasant to be around in general, and volatile and scary when she was suffering from a bout of mania or depression:

“Um, one year, I remember distinctly, it was about 1971, and I remember for instance, um, being in the way while she was vacuuming- and she was yelling, and screaming and bumping into things and I was in her way so she literally picked me, picked me up and threw me out the back door- I was in my pajamas- in the winter, she threw me out into the snow for 15 minutes at least I was out there” (pp. 2, l. 6-7, 9-11).

Andrew's perspective on how his mother treated him as a child is an illustration of the typical vulnerability of children, who have little control over their treatment by others, especially by authority figures or caregivers. This particular incident may have made a significant impression on Andrew illustrated by his vivid description and emotional impact continuing into his adulthood.

Lucy also shared experiences of abandonment and/or betrayal. Like Andrew, Lucy's adverse experiences began in her childhood with verbal abuse from her biological father. He routinely called her "*an abomination in the eyes of God*" (p. 16, l. 34) and blamed her for his divorce from her mother. Before he removed himself from Lucy's life permanently, she described his major rejection and abandonment, when he attempted to leave her at a group home when she was twelve:

"...he already hates me enough, you know. <He, he thinks that my, uh, disability is some kind of hindrance to him and uh>, he wanted to institutionalize me when I was twelve. Yeah he actually, uh, this is something I never told you ((*looks at partner*)), honey, but when I was- when was that? I was really young, actually. He had actually taken me from my mom, it was one of our- 'cause we had visitation with him when I was young, that was how the divorce panned out. He had actually taken me for the day and he tried to stick me in a group home that day. Yeah. Yeah. My mom had to come pick me up, yeah. <I was stuck in this strange place with all these old people and I didn't understand why I was there> and he just kinda- didn't even sign anything, he just kind of picked the first place he saw, and just kinda dropped me off. (.)Yeah." (pp. 16-17, l. 44-46, 1-7).

Unlike Andrew and Lucy, Alex was far less communicative, providing sparser information about various abandonments and betrayals throughout childhood. However, Alex did describe being moved from foster home to foster home, being disowned from the family, and having an absent, drug-addicted father. These experiences may have been perceived as instances of abandonment, although the personal impact on Alex was hard to judge because of the brevity of the descriptions.

Several participants were victim to betrayal in the form of sexual abuse from family members or friends. Andrew's narrative, for instance, included molestation of him and his sister by his grandfather, which was likely worsened by his mother's refusal to believe him. The revelation of abuse was delivered in Andrew's typical flippant manner, chuckling and stating, "*we do not want to go there*" (p. 29, l. 35). However, compared to Andrew's focus on the difficulties with his mother, who was his strongest childhood parental figure, his focus on the sexual abuse was minimal and may have been less emotionally significant. When asked if he felt that this incident had any bearings on his DSH behaviour, Andrew maintained it did not and that it was "*just another bonus ((chuckles))*" (p. 29, l. 45). Since Andrew had freely initiated discussion about the other aspects of his past, but referred only minimally to the sexual abuse incident, I chose to respect his boundaries by not pressuring him to provide more details.

Lucy, too, suffered severe betrayal and abuse at the hands of her ex-boyfriend, whom she described as having stalked, raped, pimped out, and forced her to do drugs against her will. The treatment from her boyfriend led to a further crisis, as rumours began to circulate about her alleged promiscuity, affecting public perceptions of her which she was unable to counteract.

Lucy, already a victim of “otherness” from her physical disability, became the target of a peer group at school which was physically, verbally and emotionally abusive. To further compound Lucy’s negative experience, she felt she could not disclose what happened to anyone at school because of the institution's religious affiliation. The following quote details her sense of betrayal, the adverse actions of her peer group and her inability to inform her superiors:

Lucy: “Um(.) first time was I was- actually I was younger than 16, I was 14(.) and um(.) *just gonna warn ya, it’s gonna get a little hairy*, uh, it was the first time I had been raped and uh, I had been stalked by this guy and uh, (hhh) sold to his friends, actually. Yeah, like, he would(.) pay them money(.) to do(.) whatever they wanted. Or they would pay him money, you know. Yeah and you know, I was force fed drugs and stuff like that so, um-...You know, 14 years old, you’re a sucker for the “1 word”, you know. Guy tells ya he loves you, you’re gonna believe him, right? (.hhh) And uh, yeah (hhh), so that had been happening and I had been bullied profusely because word about it had circulated throughout the school and now it wasn’t that [Lucy’s name] had gotten raped, it was that [Lucy’s name] was a whore and she was, you know, selling herself out to guys and this is how she was making money, right? (.hhh) And uh, I had been targeted by one senior girl who would beat the crap out of me on a regular basis. Like, behind the school she would have like, her little friends help her and they’d hold me down and, you know, kick the crap out of me and(.) I had one instance where they threw eggs at me and one of them wrote “slut” on my forehead in lipstick and yeah. It was pretty intense so that was happening and <(.I didn’t feel like I could talk about it because the school I was in was fairly, you know(.I don’t know...Christian.>” (p. 12, l. 25-29, 31-41).

To further compound her terrible experience, when she arrived at home, Lucy was punished for being late and absent at school “...so instead of, you know, people worried about where I was, I got grounded and I took punishment at school as if I hadn’t taken enough punishment. . .” (p. 13, l. 8-9). These events culminated in Lucy’s first incident with DSH and the first of several suicide attempts which lead to hospitalization.

Suicide attempts were also prominent in Andrew’s and Lucy’s accounts. For example, both spoke of their own suicide attempts as traumatic episodes where they felt out of control of their bodies and minds. Andrew, in particular, described vivid and disturbing memories of his three failed suicide attempts. He also spoke at length about intense bullying in his elementary and high school years. It was, as he described, “*vindictive*” (p. 4, l. 41), not the “*generalized boy-type bullying*” (p. 4, l. 39). I speculated that, perhaps, this ongoing treatment from peers during his formative years may have impaired his ability to maintain intimate relationships or achieve emotional closeness with other people. In one particular account, Andrew described an overdose event which he found very frightening. The overdose resulted in loss of control over his rational thoughts, and included hallucinations. This was a source of much distress while he was at the hospital waiting to be admitted.

Exposure to the suicidal thoughts or actions of others was also framed by participants as moments of betrayal or abandonment. Alex, for example, discussed the suicide of a close friend as being a deeply upsetting loss with ongoing, distressing impact. Similarly, Melissa described strong negative emotional responses to suicide attempts in close friends. In these cases,

participants were not present during the attempt, which meant they could not help their friend or control the situation and could only deal with the aftermath.

Ostracism, as a form of abandonment by peers, appeared to be a longstanding pattern throughout Andrew's life. He repeatedly attempted to search for belonging to a community, but was turned away from both the church and an organization to which he belonged for a number of years when they found out that he identified as a gay man. Andrew described significant betrayal and abandonment related to religious disapproval of his homosexuality. He stated, that as a young boy, he had been deeply religious, attending mass regularly and taking on the title and duties of an altar boy. As a young man, however, he confessed his homosexual orientation to the priest, which resulted in him being denied forgiveness and being stripped of his altar boy title and duties. Andrew became categorized as a sinner and a bad Catholic, an identification which he was unable to escape. In response to being shunned, he began skipping church and shying away from religious institutions altogether. I speculated that, for a deeply religious young man like Andrew, whose entire value system and role in the community had been influenced by his faith, it is likely that this repudiation of his identity may have been highly significant and, quite possibly, contributed to his future relationships with both individuals and organizations.

Although Melissa did not mention this explicitly, she may have experienced betrayal and abandonment following her parents' divorce when she was young. Furthermore, at the time of the interview, Melissa was living with her grandparents as there was no room in her mother's house after the addition of a new baby, which may have been perceived as an extrusion or

abandonment. While Melissa may not have been ready to discuss aspects of the parental divorce within the interview setting, I thought that this situation likely had a profound impact on her.

Often, events or life circumstances can result in feelings of powerlessness and lack of control. For the participants in this study, these feelings were often related to experiences of abandonment and/or betrayal, typically from a trusted individual. Sometimes these events were catalysts for self-harm and/or self-loathing which affected future events and relationships. However, other adverse experiences such as stigma or negative labeling may also contribute to feelings of powerlessness and loss of control, which I will explore in the next section of this chapter.

1.2. Stigma and negative labeling

Stigmatization and negative labeling⁴ was a major theme across all four interviews, pertaining to the mental health diagnoses, sexual orientations and identities of participants, as well as DSH behaviours. Both public and self-stigma are common in people with mental illness and include three components consisting of stereotypes, prejudice, and discrimination (Mental Health Commission of Canada, <http://www.mentalhealthcommission.ca/English/focus-areas/stigma-and-discrimination>). Stigmatization results in a loss or lack of control because the stigmatized individual cannot control or mediate how others perceive them. Stigmas can be highly detrimental to a person's self-concept, especially in the case of self-stigma, in which stigmatization is directed inwards and leads to self-discrimination (Corrigan & Watson, 2002).

⁴ Differentiates negative labeling from general labeling, as in chapter 3.2 where labels are explored as a positive.

On the other hand, public stigma can reduce individuals to a single identifier or a narrow set of ideas and/or pejorative labels which are then used to justify devaluation of an individual as a whole. For example, most of the participants in my study have, at one time or another, been reduced to only their sexual orientation (e.g., “*the gay one*” [p. 10, l. 37], “*fag*” [p. 6, l. 3] , etc.) or a mental health diagnosis. Self-stigma and public stigma can further reduce opportunities, quality of life, and participation in the overall community (Corrigan & Watson, 2002).

In the arena of mental health, self-labeling can lead to an individual seeing him or herself as defined by the diagnosis rather than being a complex individual with many skills and challenges who happens to be living with the diagnosis. Labeling may also be used to distance oneself from socially undesirable behaviour or negative thoughts, attributing these to the disease or illness. While there may be some secondary gain to this loss of accountability, it may also result in dependence on others, medication, or the healthcare system (Edgerton, 1986), with the eventual outcome of institutionalized behaviours similar to those well described in physical institutions. Some of my participants resented physicians, psychiatrists and psychologists for diagnosing them with multiple disorders and sometimes believed the diagnoses to be inaccurate. Feelings expressed during discussion of assigned diagnoses appeared to have been related to the belief that the diagnostic label (or the terminology used for description of their symptoms) had been forced on them. This was particularly acute in a hospital setting if participants felt that their individuality had been reduced to their DSH behaviour or mental health diagnosis.

Throughout these interviews, all four participants described themselves as having had stigma and negative labels attached to them. This was particularly evident in participants’

narratives surrounding others' assessment of their sexual orientation and how they were subsequently treated as a result, mostly during childhood and as patients within the healthcare system. Often, participants responded angrily to this treatment, whether they overtly addressed this with the perpetrator or not. At other times, the participants experienced internalized stigma, which may have contributed to a poor self-concept. First, I will discuss the participants' experiences of stigma as it pertains to their sexual and gender minority identities and then I will explore stigma and mental health.

As a young man, Andrew was labeled as gay in school long before he acknowledged this about himself. He was routinely and aggressively harassed and even often physically assaulted because people perceived him to be different than others. For the first half of his life, Andrew did not acknowledge that he was gay, yet he retrospectively noted that his bullies had always known and he had been persecuted as a result. As a teen and younger adult, Andrew engaged in sexual activity with males, yet never identified as a gay man, believing that all males behaved this way. While he initially did not use a label regarding his own sexuality, others did, stigmatizing him. Andrew appeared to find the topic of his childhood bullying difficult to talk about, and probably because of these adverse early experiences delayed coming out until about the age of 40.

Lucy, too, clearly described negative aspects of stigmatization regarding sexual minority status within the healthcare system. For example, she described receiving care for a non-DSH health issue and hearing nurses commenting inappropriately (as the issue was unrelated), and with a negative tone, on her sexual orientation: “...*this nurse came in and I could hear them like whispering in the hallway and she was like flipping through my chart, right? And she's like, 'Oh*

no, is, is this the gay one?'" (p. 10, l. 36-38). Although it was not clear what the outcome of this healthcare encounter was, Lucy's vivid memory of the event suggested ongoing psychological effects. Stigmatization and negative labeling were experienced by Lucy as resulting in inferior care, and even avoidance of further clinical contact from professionals. She described how one nurse, whom she perceived to be harbouring homonegative attitudes, began refusing to care for her. Lucy described the nurse as "*obviously homophobic*" (p. 10, l. 44) and "*totally rude*" (p. 11, l. 6). As a result, she was unable to receive the level of care she needed, and had no control over making a change in this.

Andrew also mentioned an event in which he perceived his care was compromised due to his sexual orientation. He described meeting with a doctor to become a new patient and, after the doctor saw his rainbow bracelet (suggesting some extent of involvement with the gay community), the doctor immediately declined taking him on as a patient:

"But he said after the whole interview, he said I wouldn't be a good fit because I wouldn't quit smoking. And I went, that was a two-second conversation at the very beginning. 'Why are you still smoking?' I said, 'Cause I'm trying to quit and I just haven't done it yet'. So he's all of a sudden, 'We're not gonna work out because you won't quit smoking' (mocking voice), but meanwhile he's asking me all these other questions and then he's like, you know, it just seemed like a snap decision to me-... "And that's the first time that I noticed that I was being- I think I was being thrown out?" (p. 39, l. 8-13; p. 39, l. 15).

Andrew's interpretation was that the doctor was rationalizing the rejection as an issue about smoking rather than the doctor's prejudice. Andrew's use of a mocking tone to imitate the way the doctor spoke suggested that this particular interaction affected him adversely and that it still presently bothered him. I found it understandable that Andrew's perceptions of this event would give rise to a certain level of bitterness and possibly excessive hesitancy related to future interactions with the healthcare system.

Throughout the narrative analysis (also supported by the literature), it became apparent that there was also some stigma among sexual and gender minority communities themselves. Whereas it might be an easy assumption that these populations present uniformly with solidarity because of their shared cultural struggles, this is clearly not the case in all instances. For example, Melissa appeared to harbour some stigmatizing beliefs about bisexuals, which is consistent with the LGBTQ community where bisexuals are the least accepted sexual minority (Cox, Bimbi, & Parsons, 2013, Welzer-Lang, 2008). Before Melissa realized she was a lesbian, she thought she was bisexual and was "*really worried*", stating that her friends believed it to be "*stupid*" and "*gross*" (p. 6, l. 29). Melissa's father also felt similarly about bisexuality, stating that it was "okay" that she was a lesbian, he was just glad that she wasn't a bisexual. This may have affected the way in which Melissa chose to identify herself. It appears that, even if Melissa may have identified as bisexual, the influences of others resulted in her own internalization of the stigma of bisexuality, which she was unable to escape.

Mental health labels and stigma were also strong themes across the four interviews. Lucy, for example, noted that significant stigma comes with being treated for psychiatric illnesses and being in the psychiatric unit in general. She believed that often both hospital staff and the public

at large automatically considered that something was “*wrong*” (p. 19, l. 1) with her once they were aware that she had or was currently receiving care in a psychiatric unit. She also believed that it was difficult to escape the resulting judgments. Many participants felt that similar negative judgments pertained to DSH behaviour itself, possibly due to a general lack of knowledge about mental health and DSH and their causes.

While a detailed analysis of the effects of mental health labeling during childhood and early development is beyond the scope of this research, it is likely that this adversely affected the self-perceptions of participants. With the exception of Andrew, participants were given mental health diagnoses at a young age. Melissa for example, had several mental health labels throughout her life, beginning in grade eight which she understandably found stressful:

“ . . .they figured out that it was more than just anxiety about a year ago and they- so they added on the depression, they added on the ADD, the eating disorder, like everything kind of mashed into one, all around the same time period, so it was very overwhelming for me” (p. 3, l. 19-21).

Melissa’s choice of wording suggests that she perceived her diagnoses being added casually by health professionals as labels to categorize her behaviour without careful consideration. Alex began seeing a psychologist when he was diagnosed with depression at an even earlier, more sensitive developmental period (age six), and therefore likely had to cope with an even greater adverse impact of mental health labeling.

While some of the participants sometimes appeared to describe their diagnoses as positive individual characteristics, it is likely that the effect of being labeled as “disordered,” “wrong,” or

“mentally ill” at such a young age would have had a major impact to their self-concept, and might have coloured all of their subsequent life experiences.

As previously mentioned, albeit briefly, Andrew did not focus as much as the other participants on the adverse effects of the mental health labeling on his development, likely because his bipolar disorder was not diagnosed until mid-adulthood. He expressed acceptance of this diagnosis, and even suggested, on a few occasions, that he may have misbehaved as a child because of the (then) undiagnosed bipolar disorder. Although this may have been true, his association between mental disorder and the behaviours may also have represented his own internal stigmatization of mental disorder. This in turn might then have resulted in Andrew not taking responsibility for his own actions, and increased his feelings of lack of control. For example, Andrew attributed fighting, semi-violent behaviour, and getting in trouble at school for his disorder and he therefore believed that these behaviours were beyond his control (external locus).

Lastly, some participants mentioned stigma in conjunction with DSH. Melissa described fearing the judgmental (even scathing) reaction of others if they discovered her DSH. For instance, she described a couple at work asking her about the cuts on her arms, which she explained as being accidental work injuries: “...*some people were like, 'Oh, well you better be careful when you're wrapping stuff like that 'cause you don't wanna look like a slasher', one of them said*” (p. 10, l. 27-28). Melissa then began to worry if she really *was* a “*slasher*” (self-stigmatization); if that is what people thought of her when they saw the scars on her arms. In

particular, it appeared as though Melissa was internalizing her label as a slasher as a global personal characteristic rather than a behaviour that she resorted to on occasion.

I have described how DSH scars, mental health labels, and struggles with accepting one's sexuality may result in stigma and negative public perception, which in turn can lead to feelings of lack of control. In the next part of this section, I will explore how these same constructs can lead to feelings of guilt and shame and even further loss of control.

1.3. Guilt and shame

Feelings of shame and guilt related to their sexual orientation, mental health problems, and/or DSH behaviour were described by all four participants. While shame and guilt are not identical concepts, they are closely linked. Shame may be viewed as a failure to live up to expectations set by oneself and is often in relation to an idea of how a person is seen by others, whereas guilt can be described as an emotional state associated with regret and/or possibly the need for some kind of punishment (Kaplan & Sadock, 2009). I believe that the shame and guilt experienced by my participants might have resulted in lack of self-worth, dehumanization, powerlessness and fear of future social interactions, and may have resulted in adverse impacts on their physical and mental health (Mereish & Poteat, 2015).

It appeared that feelings of guilt and shame controlled, to some extent, personal decisions, emotions, and even dictated the nature of some relationships. This was evident through the use of DSH. Other individuals in the lives of the participants also appeared to utilize guilt and shame in

an attempt to shape or change behaviour, for example, peers discouraging participants from disclosing their sexuality.

Across the interviews, it was clear that most participants felt particularly ashamed and/or guilty after they engaged in DSH. Two participants specifically volunteered that aspects of interacting with the healthcare system after an episode of DSH worsened their guilt and shame, contributing to later avoidance of seeking medical help. Furthermore, stigma (as discussed in the previous sections) and discrimination regarding DSH and treatment of mental health disorders (whether in or out-patient) also tended to precipitate guilt and/or shame. Other events, such as coming out as a sexual or gender minority, also tended to arouse feelings of shame, particularly when family members, close friends, peers, or authoritative figures responded negatively.

Guilt and shame were frequently described by my participants as sequelae to their DSH activities. Participants described performing DSH (almost exclusively) alone, and, although there was a temporary relief of tension and anxiety during the DSH, they described an onset of (self-driven) shame or (usually externally-driven) guilt for harming themselves shortly after the event. This was typically described as a cyclical pattern of behaviour, starting with a significant adverse event. This would precipitate feelings of guilt and/or shame, and lead to DSH behaviour to manage short-term distress which, in turn, would result in longer term increases in guilt and shame, keeping the cycle going. For example, most of Andrew's guilt stemmed from his DSH behaviour. He always tried to keep his scars and fresh wounds from cutting hidden from his friends and family for fear of disappointing them.

“I'll tell you also, friends and family have *not* been a help for that. . .nope. *Don't* talk about it. I don't want them to know about it. I stay away from things. I didn't do this, I didn't do that. If it was visible, if I happen to scratch my face, I wouldn't go out. And I just didn't wanna, you know. . .I just don't wanna let 'em down” (p. 42, l: 34; pp. 36-38, l. 40).

This description clearly illustrates Andrews's feelings of guilt and shame following his self-harm attempt, which was followed by decreasing social interaction in order to avoid further public condemnation. Unfortunately, at least in my view, this might have also avoided potentially helpful interactions with others, including healthcare providers.

Both Lucy and Melissa echoed similar feelings about feeling guilt and shame following DSH. For Lucy, the feelings were primarily elicited when she thought about how her partner would feel once she found out about the DSH. Melissa felt “*stupid*” (p. 6, l. 29) and ashamed that her DSH might appear as attention-seeking behaviour to others. She also expressed distress at the thought of people judging her if they were to see her cuts.

Guilt and shame related to sexual minority status or gender identity were also observed throughout the interviews. Unfortunately, many of these feelings occurred following contacts with the healthcare system. Like the other participants, Melissa described feeling ashamed of her sexuality during interactions with others. For example, Melissa initially thought she was bisexual when she was discovering her sexual identity. She had told friends and even her mother, who accepted this news quite well. She was, however, afraid to tell her father as she thought that he did not support or understand bisexuality. Once she realized that she was not bisexual but a lesbian she felt relieved - as she described to me.

Alex only alluded to shame briefly when Alex's father's family was described as being devout Jehovah's Witnesses who would not support the coming-out process and would consider the sexual and gender minority statuses to be shameful. Alex, therefore, only disclosed to his father, but even so, was disowned and forced to move out of the house. Alex's rejection by those who would typically have been expected to supply unconditional love and acceptance would likely have resulted in damage to self-esteem and self-worth.

By contrast, Andrew did not appear to display as much shame and guilt as some of the other participants, possibly because he tended to attribute events and their outcomes to external sources (displacement). He began by expressing how he wished he were a part of the younger generation who had an easier time being freely gay:

“Just...would have been great. Instead, I had to take a girl and also I would have liked to have been able to be who I was supposed to be I guess at the beginning because I would have hurt less women”...“Because we were going nowhere. I didn't know that.”...“You know, we're friends, very friendly and all of a sudden something happens and I don't call 'em back again because ((*makes uncomfortable sound*)), you know?”...“So I'm- I, I feel bad^ for that, and two of those three are friends with me now on Facebook. Then other one won't talk to me yet. Still working on her ((*chuckles*)).” (p. 37, l. 8-10, 12, 14-15, 17-18).

While Andrew did not employ the term “guilty”, he did express some awareness how denying his “true” sexual nature had potentially negative effects on women. However, at times, he minimized his own responsibility and guilt by justifying an ongoing need for deception.

In Andrew’s narratives, external constructs of guilt and shame (which he initially tried to resist were more evident than internal ones. For example, Andrew described being discouraged by others from disclosing his sexual orientation to certain individuals or groups. In one instance, a fellow member of an organization to which he belonged for many years told him not to share his sexuality with the rest of the group. Unfortunately, when he did, he was shunned and had to leave the organization. Although Andrew had initially resisted taking on individual guilt and shame, saying that telling his peers about his sexual orientation was the right thing to do in terms of being true to himself and honest to others whom he kept in high esteem, this changed after his actions had negative repercussions. He then described feeling shame which resulted in later reluctance to be open about himself in his communications with others.

Similarly, Lucy also mentioned experiencing shame in relation to her sexual orientation. She describes an incident in which a cab driver began asking her inappropriate and intimate questions about her sex life (i.e., “*who’s the woman and who’s the man in the bedroom*” [p. 10, l. 43-44]). She also describes being persistently harassed during her high school years for being a lesbian. One of the more shaming incidences for Lucy, however, was not in response to her sexual orientation, but concerning her DSH. It occurred within the healthcare system from a nurse when she was hospitalized for a DSH episode:

Lucy: Yeah. Oh yeah. She would. She picked on me constantly. She’s like, “So”, you know, “what kind of theatrics are you up to today?”. Yeah. “Oh, here’s, here’s your pills

today, don't try to kill yourselves with these". Yeah. (#3) Yeah, yeah, yeah. Yeah, and she would like, check underneath my pillows for like cutting devices. She wouldn't give me a plastic fork(.) for my uh, my dinner. No. I was allowed, I was allowed spoons. Yeah, no, they, they basically treat, treated me like I'd gone completely nuts and no one had even bothered investigating my reasons for doing it. (p. 14, l. 4-10).

This excerpt suggests feelings of dehumanization and subsequent increasing vulnerability. Lucy believed that healthcare staff took all control away and treated her as though she was not worthwhile, shaming her for her struggles such as mental health issues and resulting dysfunctional coping mechanisms over which she felt she had no control.

Like Lucy, Andrew described several incidents when healthcare providers made him feel inferior and alluded to feeling ashamed in his interactions with them. Andrew described approaching the triage station at a hospital emergency department with fresh cuts from DSH. He described that the nurse embarrassed him publicly by loudly questioning if he had made the cuts himself. Not only did this cause Andrew to leave the hospital because of what he described as shame and fear, but it made him hesitant to revisit the hospital for professional care in later DSH episodes. Andrew also described another shaming event where he was waiting for a medical professional to see him after being admitted for DSH. A medical student entered his room and asked him why he had cut himself, suggesting that only teenage girls engage in DSH, which is also stigmatizing women and teenagers:

“But someone came down from the psych floor and said, 'Oh, look at those arms of yours, right? And I went, 'Yeah'. He said, 'That's what teenage girls do. Why are you doing that?

You're like, what? 40?', and I went, 'Yeah'. I said, 'I got some issues'. . .And I remember the whole conversation because it took a long time and he never once said that, 'You're doin' alright'" (p. 24, l. 20-22, 38-39).

Andrew experienced this exchange as extremely belittling and thought that it caused him to become more guarded when communicating with his caregivers in later interactions. As previously mentioned, Andrew also believed he was denied care from a doctor who saw his rainbow bracelet and surmised that he was gay. In these incidences, he allowed others to control his future behaviour (i.e., appropriate health seeking action) by making him feel guilty and ashamed.

Guilt and shame (especially chronic), whether implicated by oneself or others, is strongly linked to poor self-esteem and even self-loathing (Skegg, 2005). In the next sub-theme of this section, I will explore how self-loathing can be a detriment to obtaining and exercising control over one's life and how it might play a significant role in DSH behaviour.

1.3.A. Self-loathing

Self-loathing has been chosen as a sub theme for "Guilt and shame" because, throughout the interviews, a negative self-concept can be, at times, attributed to these negative emotions. Feelings of self-loathing sometimes appeared to control the behaviour of participants (i.e., giving into peer pressure, avoiding social interaction, and engaging in DSH). Throughout their interviews, most participants exhibited significant evidence of self-loathing or, at best, a negative self-concept. At times this was made explicit, such as with the expression of dissatisfaction with their bodies, but it was subtly visible in the way participants spoke about their behaviour or

relationships. The poor self-concepts (which appeared related to the DSH in many instances) were often linked to treatment by significant people in their lives (i.e., ex-lover, parent, other authority figure). This is consistent with the literature, which suggests that DSH behaviours are closely linked to poor self-concept and self-esteem, particularly in adolescents and teens (Andrews, Martin, Hasking, & Page, 2014).

While Andrew did not explicitly say that he was unhappy with himself, his sexuality, his physical appearance, or any aspect of his personality, his DSH behaviour might reflect some degree of self-loathing, as this has been linked with DSH in the literature (Batey et al., 2010). While self-loathing might have contributed to his DSH, Andrew was not as vocal about it as some of the other participants (i.e., Lucy and Melissa). His generally decreased focus on self-loathing compared to the others could have been because of his older age (bringing with it greater self-acceptance and a more positive and stable self-concept) or, unlike Lucy and Melissa, because he was the only participant who identified as male and was therefore less likely than the women to vocalize low self-concept, especially concerning body image, as research suggests (Forbes, Adams-Curtis, Rade & Jaberg, 2001).

Lucy's narrative had the most evidence of negative self-concept of all the interviews and she even explicitly voiced her belief that her deep self-loathing was a main contributor to her DSH behaviour. She explained that she was bullied, never fitting in with peers because of her physical handicap, and therefore began to strongly resent her physical appearance: "*I was always the weird fat kid with four wheels under her butt, ya know?*" (p. 17, l. 32). Often, outward appearance can be controlled to some extent (i.e., make-up, clothing, dieting, surgery, etc.), but

Lucy had no control over the fact that she was in a wheelchair, which appeared to affect her self-esteem.

Melissa also displayed a lot of self-loathing throughout her interview, almost exclusively in relation to her physical appearance. She was very clearly deeply self-conscious about her weight, general outward appearance, and how she was perceived by others. She struggled with over-eating and expressed her wish that she could stop this and change her the way she looked:

“I wish- like at one point in time, I wish I could be able to starve myself and kind of, I don’t know, it just got out of control for a while where everything was about my weight, and so everything still is a little bit centered around that, my self-image, everything like that, but it’s definitely, definitely better now than it used to be” (p. 3, l. 29-33).

It appeared throughout the interview that, for Melissa, sentiments of self-loathing contributed to her DSH behaviour. She cited sadness for the reason that she engaged in DSH, with the most permeating thought being that she wished she was someone else, or as she put it, “*not me*” (p. 12, l. 30).

Negative treatment from others also appeared to adversely affect my participants’ self-image. For example, Lucy suffered emotional abuse as a child from her biological father, which compounded her own negative attitude about herself. She believed that this treatment from her father was also, in part, attributed partly to her disability. She believed that he had always hated her and considered her disability “*some kind of hindrance to him*” (p. 16, l. 30), blaming her for his divorce from her mother. It is unclear whether Lucy internalized these sentiments, but they appeared to still bother her at the time of the interview as she spoke about her father with sadness

and resentment, suggesting continued adverse impact on her current relationships and functioning.

Feelings of inadequacy were also exemplified by Lucy when she mentioned, fairly bashfully, that she felt less than human or like a “*dirty caged animal*” (p. 17, l. 41) because her impaired abilities did not allow for her to properly care for, clean, or successfully navigate her apartment. While she knew that her physical disability was beyond her control, Lucy also described her self-loathing as being due to poor life choices she had made, and she expressed fantasies of rewriting the past and doing things differently. This focus on the past suggested that her self-loathing was still adversely impacting her current behaviour, and was unlikely to improve as it was something she would not be able to change.

Lucy also stated that self-hatred was prominent in precipitating her DSH, but also noted that her lack of success in completing the suicide worsened her feelings of inadequacy. Lucy’s feelings of self-loathing appear to be so strong that she believed that even her presence must be adverse to others. For example, she stated that certain “*people would be better off if I wasn’t around*” (p. 5, l. 26-27). This belief was described as one of the precipitating factors behind some of her suicide attempts.

While Alex, much like Andrew, did not explicitly describe feelings of self-hatred, it was difficult to fully explore origins of the DSH because Alex was the least communicative about personally important information. However, it is likely that growing up not feeling comfortable with the traditional binary gender roles may have resulted in feelings of self-directed frustration

and anger. The self-destructive DSH behaviours, including suicide attempts, would be consistent with experiencing self-hatred toward the self and subsequent punishment.

In summary, feelings of guilt and shame were closely linked to self-loathing throughout at least half of the interviews. Another construct which appeared to resurface often with the participants, and was also relevant to guilt and shame, was their active role in maintaining secret practices or denying truths to themselves or others in regards to their DSH behaviour and/or sexuality. In the next sub-theme of guilt and shame, I will discuss closeted lives and how they contributed to participants' attempts to control their lives and influence their self-image.

1.3.B. Closeted lives

“Closeted lives” was also chosen as a sub-theme for “Guilt and shame” (1.3.) because participants often kept (possibly) undesirable information (i.e., DSH, sexual minority status, mental health issues) from close friends and family as well as the public to avoid feelings of guilt and/or shame. This may have been an outcome of past adverse experiences after disclosing certain sensitive information. Thus, some participants kept much of their lives very private, even actively living a double life to prevent others from knowing the truth. The term “being in the closet” fits this description, and also suggests the sense of being locked in, hidden, trapped and unable to escape. Individuals described worrying about how others would react to the news or if they would be treated differently (i.e., discrimination). In the case of most participants, this led to an avoidance of disclosing important things about themselves, or even a self-denial of those issues. In some participants, efforts to prevent disclosure of their sexual minority status to themselves or others was so strong that they dated (or married) the opposite sex.

Most of the participants initially kept information about their orientation private to protect themselves from the judgments of others. Strategies used to do this ranged from denial of their own orientation to establishing legal relationships (including marriage) with the opposite sex. This sometimes involved a significant amount of deception, especially when the participant had ongoing same sex relationships as well as an official, mainstream relationship. One participant, in particular, described two very different, but parallel lives, trying to negotiate his hidden same sex relationship as well as his public persona as an apparent heterosexual partner. DSH activities were even more hidden because of fear of judgment of others, resulting in very private, solitary actions and frequently active strategies to disguise, hide or deny its physical effects.

This theme, specifically denying or disguising same sex orientation to both others and oneself, was most prominent in Andrew's interview, presumably because he came out much later in life than the other participants, and freedom of sexual expression and orientation may have been much less accepted in his youth. Andrew's closeting began with the ongoing bullying he experienced about his perceived sexual orientation in elementary school and adolescence, during which he publicly denied being gay at school, although frequently engaging in sexual activities with other boys. Around the same time, following his fall-out from the church (as previously discussed) due to his sexual proclivities, he also felt for several years that he had to pretend to his mother that he was going to church while he was really going out for coffee by himself. As a teen and young man, Andrew never consciously acknowledged that he was gay despite his extensive experience with sexual activity with multiple men. He claimed that he believed that every male engaged in same-sex activities which demonstrated some degree of self-deception: "*I didn't- I*

wasn't gay. So, even at that point, right? And I'm going out with her and you know, friends on the side...and I'm going, "Crap, everybody does this!" (p. 9, l. 19-21).

Hiding his orientation by cultivating two separate lives (one gay, one apparently straight) carried on into Andrew's adulthood while he was dating his future wife, which appeared to lock him into unrewarding relationships in both lives. Leading up to his engagement with his wife, he was frequently sexually active with men (one man in particular), leading to long-term relationships without his future wife's knowledge. Andrew kept a long-term lover and explicitly described maintaining these two lives which he tried hard to keep separate: *"...so you go through that and then you kinda got two separate lives and you don't want the two to meet, right?"* (p. 9, l. 24-25). When he was confronted about this, whether by his girlfriend, lover, or his own conscience, he rationalized that all men behaved in this manner and he would quit after the official marriage ceremony. He described a scenario wherein his then-fiancée questioned him about an ex-lover claiming to her that Andrew had been cheating with him. When she pressed him for details, he told her that his behaviour was normal and that all men engage in sexual activities with each other, but he denied that the two men ever had full intercourse.

Eventually, Andrew's two lives did cross paths, which forced him to be disclose his sexual orientation to himself, his wife and the rest of his family. And while it may have been a relief to no longer hide his orientation, there were also adverse consequences. For example, when Andrew told his wife about his sexual orientation, he believed that they would maintain their marriage. He soon found out that wife and their son would not follow him to Saskatoon where he had to move for work. As he saw it, his life collapsed:

“So when you guys comin'?", she says, 'We never were comin". And that's when everything started crashing down. My whole- whatever I built up, everything was seriously coming down on me. Like, 'I'm getting divorced', is what came to mind. Um, 'I'm not gonna see my kid anymore', uh, whatever. All this other stuff is crapping down on me and she said that a separation would be good” (p. 12, l. 10-15).

Eventually, Andrew's misgivings about his double life began to manifest themselves in other aspects of his life. He described moments in which he demonstrated some preoccupation and fears about being outed about his sexuality, even before he came out to himself. Being outed as a sexual minority person (involuntarily) represents a major loss of control, as it occurs despite personal consent and possible lack of readiness. For example, Andrew described a hospitalization following a suicide event during which he began to hallucinate that the doctors and nurses were calling him a liar. Andrew himself attributed this experience to his secrecy with his sexuality:

“ . . .there was a nurse standing in the corner of my room with a clipboard going, 'You're a liar! You're a liar!' ((*chuckles*)). I'm going, 'Why? I'm not lying, I'm not lying!', 'Yes you are, you are lying!' and I think she was talking about my- me and my sexuality. . . 'cause I was coming out of the closet but I didn't know it.” (p. 14, l. 9-11, 13).

While Lucy came to terms with her sexuality earlier in life than Andrew, she nevertheless experienced a period of vacillation about her orientation. This was apparent when she described the period when she openly came out as a lesbian woman and her concern that people would not believe her because she had been “*playing like this, 'in the closet, out of the closet game'*” (p. 7, l. 36) for many years.

Unlike Lucy, who did not indicate any secrecy about her DSH behaviour, Melissa hid the secret of her DSH from her family and friends for years. At school, she would keep her wounds covered and deflect concerns of friends, yet later she experienced much guilt about this. Melissa recalled an event where she lied to her mother after she noticed cuts on Melissa's arms, insisting, *“No, it’s just from like wrapping mouldings at work, I promise. Like, don’t worry about it”* (p. 10, l. 45-46). Melissa explained these types of lies as a bid to decrease her mother's concerns and therefore control her mother's perceptions and emotions surrounding her daughter. Lying or withholding truths was often interpreted by participants as an attempt to protect loved ones from disappointment or stress.

Melissa also felt pressure to live a closeted, hidden life in regards to her sexuality, especially at her former workplace. She talked at length about her discomfort in disclosing that she was a lesbian to her co-workers and boss. Melissa described her boss as being extremely homonegative, often making bigoted and shaming comments to and about those she believed belonged to a sexual minority. She was therefore very fearful that her boss would find out that she identified as a lesbian and worried that this would affect how she would be treated at work. For this reason, Melissa felt that she had to quit working there despite otherwise enjoying her job.

In addition to keeping his intimate sex life private and separate from his everyday life, Andrew also described hiding certain information or aspects of his personality and certain thoughts from his psychiatrist and doctors for fear of being put into treatment or having changes to his medication, which he thought might lead to unnecessary and negative consequences. I

speculated that Andrew's avoidance of disclosing less socially acceptable information to those around him and the resulting fear of these interactions caused him to become a secretive person who became highly selective about what or to whom he disclosed emotionally important aspects of himself.

Andrew, like the other participants who alluded to withholding selective information from their healthcare providers (i.e., usually mental: psychiatrists, psychologists, etc.), had learned this behaviour from previous adverse and/or unpleasant experiences with healthcare, whether it be through staff, circumstance, or procedures. In the next section, I will explore some of these negative experiences and the ways in which they may have translated into a loss of control for the participants.

1.4. Unsatisfactory experiences with the healthcare system

Unsatisfactory experiences within the healthcare system may be perceived as a lack or loss of control because many or most aspects of medical care (e.g., quality, access time, comprehensiveness of services, etc.) are generally determined by a healthcare system rather than an individual. For example, hospitals and outpatient services do not have unlimited resources and, therefore, these may not be available to the extent an individual patient wishes or requires. This is especially true in mental healthcare where access to individual therapists, rather than group treatments, may be particularly limited. If a patient does not feel comfortable or fails to develop rapport with a first therapist, it is less likely that he or she will be prioritized to a second therapist, as priority would likely be given to individuals who have not yet seen a therapist at all. While the priorities and specific resources of the healthcare system are beyond the scope of this

paper, it is well recognized that the Canadian healthcare system is very complex; in spite of good intent, much cost and many public reviews over time, it still does not appear to meet the wishes and needs of all patients. Consistent with this general recognition, were the experiences of my participants, most of whom expressed frustration with some of the care they had received.

The theme of this portion of the section focuses on the participants' descriptions of unsatisfactory interactions with the healthcare system (often, the emergency department), although three out of four participants also noted that they (fortunately) were under the care of a good psychiatrist, psychologist, counsellor, or therapist⁵. Many participants felt that medical personnel and caregivers were judgmental about their DSH behaviour as well as their sexual orientation. Participants described experiencing trivialization or criticism by healthcare providers of their DSH, the latter attributing DSH to attention-seeking behaviour. Interestingly, participants' own descriptions of these interactions suggested a high level of unmet personal need, which, then appeared to contribute to DSH actions in an attempt to obtain a higher level of care, such as hospitalization. Unfortunately, this response might then have appeared to treatment providers as attention-seeking behaviour, and therefore obscured the impact and need for interventions of real, underlying needs.

Overall, participants described less disrespect of their sexuality or mental health issues by healthcare providers than about their DSH. They did, however, voice wishes that caregivers were able to take more time with them to listen to their concerns, understand the difference between

⁵Positive experiences with the healthcare system and subsequent suggestions for improved healthcare will be addressed and discussed in section 3.3.

non-suicidal DSH and DSH, and to take their DSH behaviour more seriously when seeking care for it.

Alex shared a number of negative and positive experiences with the healthcare system based on extensive contact with both private and public care including psychiatrists and general practitioners. Similar to Andrew, Alex expressed feeling judged when going in to the emergency department with DSH, believing that hospital staff was making negative comments: *“It can be judgmental. You just get those dirty looks like, ‘Oh, it’s another one of you guys’”* (p. 11, l. 38-39). Alex felt that DSH in general was often written off as an irritant by nursing or clerical staff members, rather than understood as a behaviour in response to the serious underlying needs of an individual. This, similar to Andrew's situation, made Alex believe that concerns would have to be framed in a more emergent fashion in order to obtain a higher level of care:

“I’ve had times where I’ve actually wanted to hospitalize myself and then gone home and then actually had to be hospitalized because I ended up hurting myself so It’s very, ((whispers)) what’s the word, it’s not to stop- they won’t do it unless it’s already happened...Um, you do need to make a dramatic statement or else you don’t get- I’ve had times where doctors thought it was an act.” (p. 12, l. 5-8; p. 12, l. 13-14).

Lucy felt very similarly about judgmental and trivializing responses from hospital staff to her DSH. She stated that when she went to the hospital with non-suicidal DSH issues, she was treated as though she was seeking attention instead of a presenting with a serious underlying issue which needed addressing: *“I mean, I was listened to but when I told them why I had done it*

and that it wasn't a suicide attempt I would get the, the roll of the eyes and "Oh, you're wasting our time" (p. 14, l. 45-46).

Conversely, Lucy, Alex, and Andrew also described moments when DSH was misunderstood due to a lack of knowledge. Healthcare staff sometimes mistook self-inflicted injuries for suicide attempts without exploring alternate causes. Alex in particular expressed the belief that staff tended to use the DSH behaviour label to unfairly categorize the individuals in a pejorative and one-dimensional way, rather than spending the time to see them as individuals with specific needs and issues. This sentiment was echoed by Lucy who believed that most healthcare professionals were interested only in treating the outside wounds rather than asking questions about the source of the behaviour.

Even when successful in obtaining treatment from the healthcare system, some participants felt that the treatment itself was not helpful, or that the side effects overwhelmed any benefits. For example, Andrew did not find his psychiatrist to be of great help to him. He explained that when he was first diagnosed with bipolar disorder, his psychiatrist put him on far too many medications, so much so that he could no longer function normally:

So by the time my psychiatrist determined I was bi-polar he put me on a shit-load of meds and we're talkin', whatever he could throw at me it was there ((*laughs*)). It was like, I'd never taken meds my whole life and I've got all these things things...so I'm poppin' like these like [medication unknown] and anti-depressants, anti-psychotics and it wasn't a good ride, and it's partially his fault. He over-medicated me" (p. 13, l. 29-33).

Alex, like Andrew, did not find the time on the psychiatry ward to be helpful, citing the lack of appropriate or sufficient care from staff. Alex also felt that the hospitalization was not long enough, with premature discharge occurring before full recovery. Alex described making a strong case against discharge after which Alex was still released from care despite protest and ended up back in the hospital within a month.

Gender and sexual identity also appeared to be an issue within the healthcare system for some of the participants. While Andrew felt it did not affect his care at all, Lucy believed that she was discriminated against and treated poorly because of her sexual minority status. She described getting “*weird looks from people*” (p. 18, l. 16) because she was wearing Pride paraphernalia (i.e., bracelets), from which people would know that she identified as LGBTQ.

Alex also felt that gender identity was not respected within the healthcare system. For example, Alex claimed hospital staff did not try to use Alex’s preferred pronouns when being addressed. This was thought to be either carelessness or a deliberate disregard of the preferred gender identity:

“As far as the queer identity stuff, they don’t respect it at all. Um, I still- I’ve had to remind doctors multiple times that I prefer to go by [Alex’s name], um, it’s always ‘she’, ‘her’. Always ‘she’, ‘her’, or if they try, it’s ‘he’, ‘him’, when I always tell them it’s ‘they’, ‘them’.” (p. 12, l. 20-22).

There were many similarities in how the participants in this study described their experiences with a lack of or loss of control. These experiences were generally adverse events such as bullying or sexual abuse or problematic relationships with themselves or others (e.g.,

abandonment, self-loathing). Often, participants described trying to minimize the distress related to these feelings of powerlessness by engaging in DSH. Unfortunately, the gradually increased reliance on DSH as a self-management strategy often eventually resulted in a greater loss of control.

Lack of success in regaining control, passive acceptance of adverse situations and use of problematic and self-defeating coping strategies in managing these, were not the only outcomes of adverse experiences encountered by my participants. Throughout the participant narratives, there were many moments in which individuals took active initiative to establish new control or regain control that was lost. In the next chapter, I explore some of the ways in which these four participants actively strove to establish and maintain control over themselves, their emotions, their life circumstances, and their relationships.

Theme 2 - Active struggles to establish control

Analysis of responses from participant interviews had previously been categorized into three major themes, the first one entitled Experiences and Responses to Loss of Control. This was described in the previous section and included sub-themes 1.1 abandonment and betrayal, 1.2 stigma and negative labeling, 1.3 guilt and shame and 1.4 unsatisfactory experiences with the healthcare system. The second major theme identified was entitled Active Struggles to Establish Control, which built upon attempts to modify the difficulties described in the first theme and is the focus of this section. This second major theme identified two sub-themes: 2.1 the desire to feel understood and to belong (further divided into two sub-sub themes, 2.1A and 2.1B) and 2.2 DSH behaviour to regain control. Participants expressed the need to belong - whether it be in

regards to peer groups, family units, the workplace, or social organizations. Their narratives also suggested a desire to be accepted from these groups or individuals for their sexual orientation, their mental health diagnoses and their DSH behaviour. Two sub-sub themes emerged under the desire to feel understood and to belong, which were over-reliance on the spouse or significant other (related to excessive needs to belong rather than functioning autonomously) and the internet culture that appears to surround DSH behaviour, especially among adolescents. The second major sub-theme identified within the struggle to reclaim control was DSH behaviour itself, which sometimes appeared to be used as a tool to achieve this. As discussed in the literature review, DSH may be a way to exercise personal control over both the body and mind in an attempt to quiet or minimize negative emotional arousal (Chapman, Specht & Cellucci, 2005). Participants at times also appeared to use DSH to gain control over others (i.e., hospital staff) or their situations (i.e., treatment trajectory), especially within healthcare settings.

2.1. Desire to feel understood and to belong

Not belonging and feeling misunderstood are two distinct concepts, yet I chose to relate them closely within the context of this thesis. Throughout the interviews, feelings of not belonging often emerged in relation to organizations, peer groups, family, or the general public. This was often perceived by the participants to lead to marginalization, discrimination, or simply being misunderstood. They often struggled to change this, employing various strategies to fit in and be accepted, thereby achieving a greater amount of control over their social environment and how others perceived them (e.g., impression management).

Participants mostly described feeling as though they didn't fit in because of their sexual orientation and/or physical appearance. For some, this exclusion took the form of bullying (typically in school settings) or being ostracized from particular groups based on sexual/gender minority status. Participants also described feeling misunderstood by family, friends, and healthcare professionals about the motivations for their DSH behaviour, or people passing judgment about their mental health diagnoses without real understanding.

Concerns of not belonging and seeking acceptance came up a lot for Andrew. These feelings were associated with both organizations and peer groups with which he was affiliated throughout his adolescence and adulthood. While he did not explicitly state that he felt that he didn't belong, the subject of exclusion appeared to be prominent throughout his life. As a young boy, for instance, he described having no male friends because the males in his community had all "*branded*" (p. 2, l. 42) him as being gay. As a result, he was severely bullied by his male peers and instead, he attached himself to female friends whom he thought were more likely to accept him without judgment.

Exclusion or not belonging was also a major issue for Lucy. At the crux of some of her feelings of not belonging, were her insecurities surrounding her physical appearance. As soon as the interview began, she disclosed that she had never had many friends and was treated like an outcast in school, hypothesizing that her peers viewed her as an "*outcast*" (p. 19, l. 8). She described feeling "*alone*" (p. 19, l. 10) during her years in high school and that the few friends she did have were very "*backstabby*" (p. 19, l. 9), while other students physically harmed her.

Not belonging or not quite fitting in was also an important theme in Melissa's narrative. She described feeling as though she didn't belong either within her peer group or her family and, as a result, sought to find a place of acceptance with others. For example, as she had always been self-conscious about her physical appearance, she tended to develop intense and intimate friendships over the Internet where she found a likeminded community of peers (who, unfortunately, introduced her to the world of DSH, described in more detail in 2.1.B).

Fitting in came up a lot for Andrew as well. This began with feelings of not being masculine enough to belong in the boys' peer group, an issue that seemed to parallel Andrew's relationship with his father in his formative years. Andrew believed that his father considered him as un-manly and, as a result, Andrew appeared to believe that he was a constant disappointment; Andrew was not a good enough son because he did not fulfil the necessary criteria to be one of the boys: *"He used to be quite distant, through my whole life. . .but I'm not- I was not a 'boy'. I was in- I was not- I didn't enjoy getting my hands dirty"* (p. 17, l. 40-41, 43-44). Andrew also lost the feelings of belonging to his faith community when he disclosed to his priest that he was having sexual thoughts and was engaging in sexual acts with other boys. The absence of forgiveness (penance) and exclusion from the altar boys group made Andrew feel that he no longer belonged to his religious community and was less of a Catholic than the other members of his church⁶. The resulting feeling of exclusion and resentment over this may have led to further self-imposed exclusion from the Catholic Church later as he came to believe that it didn't care about gay and lesbian people, stating, *"They accept the fact that you're gay, they just don't accept*

⁶A parallel situation also occurred to Andrew later in life when an organization he belonged to for a number of years excluded and marginalized him after he had disclosed his sexuality.

that you do anything with that. . .so they expect you to be in a love- in a loveless life” (p. 7, l. 42-43). Andrew was, of course, unable to control the values or beliefs of the church, which appeared to frustrate him and eventually turned him away from his faith and caused him to shy away from church activities such as mass.

As an adult, Andrew’s adverse experiences with the church generally continued, although he did find one priest who appeared more supportive. Andrew describes this priest as putting his and his partner’s hands together on the steps outside of the church, blessing them. While this was a gesture of some acceptance of his orientation and loving same-sex relationship, it was still not fully equivalent to the real blessing within the actual place of worship. Andrew’s laugh during the recounting of this anecdote suggests some discomfort with the ongoing actions that indicated that he was, therefore, still being treated as a second-class citizen within the church.

Lucy was not excluded from religious practice like Andrew, but she did express similar sentiments of feeling misunderstood throughout her narrative. This is especially evident when she discussed how she came out as a lesbian to her family. While she explained that her mother was very understanding and even unfazed by her announcement, others in her family were not as open or familiar with what it meant to be a lesbian. Her grandfather, for example, attributed stereotypes and clichés to Lucy (e.g., wearing flannel shirts, driving trucks, etc.).

Andrew described his distress and hurt by the fact that, as a gay man, he was excluded from donating blood to the blood banks, stating:

“ . . .but you know what bothers me is that I can't donate blood. (Andrew's partner) can't donate blood. Um. . .we're not only monogamous, we're two old guys ((*chuckles*)), it's a

pretty boring life...and now I can't donate blood? I can't donate my organs? Well that makes me feel *really* special” (p. 43, l. 33-35; p. 44, l. 5-6).

Not being able to control what he was able to do with his own body, and not being allowed to help people who were in need of something he could offer really appeared to frustrate and hurt Andrew. The donation of his blood, which could be life-giving to others, was devalued because he was a gay man, and not because of anything he could have controlled.

A source of misunderstanding for many participants dealing with DSH was that people around them found it difficult to distinguish between DSH with the intent to cause death and cutting or otherwise harming oneself for the sake of tension release. Lucy was exposed to this perspective from many people in her life, such as her mother: “. . .*she can't really differentiate between the times when I'm trying to kill myself and the times where I just need a release because there is a difference, for me there is a difference*” (p. 6, l. 35-37). Lucy stated that others, especially within the healthcare system, also mirrored similar misunderstandings regarding the motivations and intent behind DSH behaviour.

Alex expressed similar sentiments about DSH being misunderstood, especially during the last emergency visit for DSH. Alex described the nurses as judgmental, misunderstanding the emotional causes and precipitants for the DSH. For example, Alex explained that the DSH behaviour was not necessarily a suicide attempt, but a coping strategy: “. . .*they're like, 'Did you do this to yourself?' and I could hear after they left my little room or whatever, they'd be talking about me. . .pretty. . .badly. And you get a lot of judgment.*” (p. 11, l. 14-16). In this moment, Alex was attempting to seek help for DSH, which had been undertaken in an attempt to take

control over a difficult situation. Instead, the DSH was met with judgement and shame, which may have contributed to Alex's ongoing resistance to seek professional care during subsequent incidents of DSH. This event was another example (similar to Andrew's when he felt he was humiliated at triage) of when participants had difficulty controlling reactions or judgments from others, even while seeking refuge in a safe place such as a hospital.

Other participants also described misunderstanding of mental health issues. Melissa discussed how her depression and anxiety was not understood by her family, particularly her father. She stated that her father attributed her problems to being an unmotivated teenager rather than acknowledging the very real and distressing mental health disorders underlying her behaviours. She was upset that he could not understand her inability to function as he thought she should because of these disorders over which she had no control.

Alex recounted many experiences of being misunderstood and feeling a lack of belonging. These related to DSH behaviour as well as those of sexual identity. A self-proclaimed "Tomboy" (p. 4, l. 44), Alex (born a female) even felt a lack of belonging within the physical body. Alex wished to begin taking testosterone injections to make the internal feelings and external body less discordant. Alex shared initial experiences with exploring sexual identity as a younger teen and found likeminded people as a result. It was apparent, when Alex was speaking about learning about sexual diversity, that it was exciting and comforting to find an inclusive niche with others in a similar situation: "*Cause I had no idea what- I felt like something might have been wrong with me and then I was like, this is a part of the community too! Look! You fit in somewhere!*" (p. 5, l. 23-24). Alex had also found solace and like-mindedness in a romantic

partner in the four months prior to the interview. This partner, too, identified as agender and struggled with mental illness and DSH, suggesting a mutual understanding and a sense of solidarity.

While Alex described a sense of belonging within Saskatoon's sexual and gender minority community and with the new partner, Alex felt that the rest of the community, including those within healthcare, did not exhibit similar understanding and inclusiveness. Alex believed that the current psychological health team did not listen to the real issues and instead focused their therapy on things that were less important: "*Um, they think- I've had a psychiatrist tell me that my identity is a phase. They don't listen to me.*" (p. 1, l. 34-35). Due to frustration with, and resentment of, the care-provider, Alex stopped going to the psychiatrist for over a month, only returning for a refill of medication.

Alex found that foster homes were not only unsupportive or poorly understanding of gender identity preferences, but were disrespectful, refusing to call Alex by the preferred choice of pronoun (*they* and *them* instead of *she* and *her*). Alex felt that this treatment was mirrored within the healthcare system, which refused requests to use the new gender-neutral name and preferred pronoun. Alex did not believe these incidents were unintentional, even when I pointed out that, out of habit, I accidentally used the female pronoun a few times throughout the interview. Alex, however, felt this was a different situation and that the healthcare professionals and foster parents were intentionally disrespectful of Alex's preferences regarding forms of address, which Alex could not control, despite many objections. This issue was clearly sensitive, as Alex wanted to stop talking about it at this point.

2.1.A. Over-reliance on significant others

Three out of four participants (excluding Melissa) were in relationships with significant others during the time of the interview. None lived with their significant others, but most indicated that the relationship was relatively serious regardless of the length of time they had been dating (this ranged from four months to twelve years). Both Andrew and Lucy had their boyfriend/girlfriend with them at the interview for moral support, while Alex did not.

Over-reliance on romantic partners was chosen as a sub-theme for the desire to be understood and belonging because it came across quite strongly and it appeared that the participants were quite invested in their romantic relationships, making mention of them often. Although close romantic relationships are often positive and protective against negative emotions, it seemed that some of the participants, especially Lucy and Alex, were so heavily reliant on their romantic relationships to bring them personal happiness that there might be unfortunate consequences if the relationship were to falter. Allowing the relationship to control their emotional life might also result in less self-directed changes in their own lives, and result in reduced overall self-control and increased risky behaviours. For example, the romantic relationship was sometimes implicitly or explicitly described as the sole reason participants were no longer self-harming, which suggested that if these relationships did not last or meet expectations, the DSH behaviour might reoccur.

Andrew was the participant who displayed the least over-reliance on a romantic partner. However, when he spoke about the separation from his wife, the emotional importance of the relationship became more apparent. For example, after he first came out as gay to his wife, they

remained married and lived together for an unknown amount of time. Then, when she announced she would not be moving to Saskatoon with him, he attempted to overdose on over-the-counter medication:

“Anyway, I didn’t know about that, >but so anyways, uh< I am here and I come to Saskatoon, we pick up the phone, I say, “Oh I got the job!”, she says, “Oh, good”, I said, “So when you guy’s comin’?”, “she says, “We never said we were comin’”. And that’s when everything started crashing down. My whole- whatever I built up, everything was seriously coming down on me. Like, “I’m getting divorced” is what came to my mind. Um(.), “I’m not gonna see my kid anymore”, uh, whatever. All this other stuff is all crapping down on me, and she said that a separation would be good. Trial separation, or whatever...And uh, it- when she did that I was kinda comatose here for probably most of a weekend?...And then I took a whole bunch of sleeping pills. That was the first time I had done that since I was a teenager”. (p. 11, l. 7-13, 15, 17).

Andrew’s emotional investment in the romantic relationship may have been more understandable than that of the other participants since he was married and also had a child with his ex-wife.

On the other hand, Lucy appeared to be very invested and reliant on her romantic partner throughout her narrative, mentioning a few times that her partner was her “*reason to care*” (p. 7, l. 9) about attending therapy and the rehabilitation of her DSH behaviour. When I asked Lucy how she felt after the incidents of DSH, she suggested that she wanted to stop self-harming because she did not want to let down or upset her partner:

“Guilty and scared 'cause you know that, you know, when *she* gets a look at it, she's gonna look at me the way she does and I know that it hurts her, you know, I know that she, she gets heartbroken every single time she sees me do it, you know, and I, I *hate* that and I wish I could control it better” (p. 6, l. 31-34).

Based on Lucy's narrative, it seemed as though she was delegating control over her DSH behaviour and mental wellbeing to her partner. As suggested earlier, this raises concerns that the end of the relationship might result in a renewal of DSH ideations and actions.

Finally, Alex described valuing a romantic relationship similarly to Lucy, framing it as the most important aspect of the quality of Alex's life, despite only having been in the relationship for four months. The importance of the relationship was clearly identified in relation to modifying and controlling suicidal or homicidal ideation. For example, when I asked what would stop Alex from DSH, the reply was: “[*Partner's name*]. *That's the only thing. My partner...if they're around I don't even think about it, but the minute I'm alone I'm very destructive towards myself*” (p. 9, l. 33-34). Alex also believed that the only reason Alex was “*still here*” (p. 3, l. 17) is because of their partner. Although I did not follow up on the exact meaning of the term, the suggestion seemed to be that Alex would have committed suicide if it were not for their relationship.

In summary, all four participants identified situations over which they were trying to gain control. Unfortunately, some of the strategies used, such as over-reliance on romantic relationships in controlling their happiness, could play roles in future adverse outcomes, such as DSH, if the relationships were to fail.

2.1.B. Seeking belonging within a culture of DSH

Self-harm has, in recent years, become a cultural phenomenon, especially among adolescence and teens. This may, in part, be due to the attention it has received in the media with teen celebrities (e.g., Demi Lovato) being open about their struggles with it. It can also be further fueled by its depiction in teen movies (e.g. *Thirteen*, 2003) and books (e.g., *Thirteen Reasons Why*, 2007) where the protagonists who engage in this behaviour are popular and attractive. This may impress upon young people who consume this media that DSH is glamorous or trendy. This concept of DSH is a dangerous one and has serious repercussions. The internet, in particular, appears to be a significant contributor to the recent popularity of DSH among the younger generations. While it can be a supportive platform for individuals to seek support, it can also be a source of encouragement for DSH behaviour (Lewis, Heath, Michal & Duggan, 2012). The three younger of the four participants (Andrew being the older one) touched on the role of culture and peer groups in the origins of their DSH. The culture of DSH throughout the interviews was largely discussed in relation to the internet, specifically social media websites (i.e., Twitter, Tumblr, Facebook, etc.). Participants described finding individuals their age who either promoted or endorsed DSH behaviour on these internet platforms.

Melissa provided the most evidence for the role of culture and peer pressure in seeing DSH as a positive activity worthy of emulation. The following quotation from Melissa illustrates this, also indicating the role of social media, and her wish to be part of a peer group. In her last statement, Melissa suggested that she had some awareness at times of the negative aspects of

these DSH role models, although it was not clear how deep her insight was, especially as her DSH had only very recently stopped.

“Especially since at the time I was surrounded by people who glorified that kinda thing, who like, 'Oh, depression and self-harm and eating disorders are so tragically beautiful', or something like that...I was upset about- like this was the period when I thought oh, like romanticizing kind of self-harm and depression things and I thought, 'Oh, well why can't I be like that too? Like all those pretty girls who hurt themselves and get the attention of boys for it' or whatever-” (p. 3, l. 33-35; p. 9, l. 41-44).

When asked if these were peers at school, she said that they were all from different social media websites. Fortunately, Melissa eventually indicated that these were “*toxic*” friendships and she therefore became inactive in these groups, ending further communication with her online friends.

Alex also clearly described the role of the internet in shaping DSH behaviour, stating:

“...I was one of those kids that spent a lot of time on the Internet on chats and people were talking about it and I saw these titles about different ways to self-harm and I'd Google it and I did eventually just tried it myself and it. . .hooked.” (p. 9, l.6-8).

Not all descriptions of DSH culture were internet-based, however. For example, both Lucy and Alex noted that their partners also had experience with DSH, suggesting that the ongoing behaviour might also be shared offline to some extent as a mutually supported coping strategy.

Andrew was the only individual who did not mention anything that would suggest DSH was culturally significant to him. This may be due to the large generation gap between him and the other participants. He did not appear to know anyone else who engaged in these behaviours and was not, throughout the time of his DSH, using the internet, nor was DSH represented in popular media. It may also have been that as an older male he was less vulnerable to pressures from peers or contemporary trends. It is possible therefore that his DSH was more self-directed than influenced by external cultural stimuli such as peers or various media.

2.2. DSH behaviour to reclaim control

As discussed in the literature review, although the understanding of DSH is incomplete, it is known to be a (maladaptive) coping mechanism for individuals who suffer from anxiety or depression. DSH can also be a response to negative stimuli or conditions (e.g., poor treatment from others, negative self-image, traumatic event, etc.) which helps individuals to regain a sense of control over themselves, both in mind and body (Chapman, Gratz & Brown, 2006).

Descriptions provided from participants included using DSH as a tactic to ending racing or repetitive thoughts, or choosing to feel physical pain as a confirmation of being alive rather than feeling a numbness or emptiness. Participants often suggested that episodes of non-suicidal DSH might be necessary to prevent an actual suicide attempt.

All four participants described strikingly similar experiences in regards to control relating to their DSH behaviour. For instance, Andrew experienced his bipolar disorder and treatment for it as a loss of control. While the medications may have helped stabilize his mood swings, he also felt that they blunted him, often referring to DSH as an attempt to feel. In the following quote, he

also described DSH as a way to regain control over his emotions, even if that meant causing physical pain:

“ . . .to make something feel. 'Cause you can't feel anything. When I'm- when you're on so many medications you literally can't *feel* anything. . . I couldn't say 'I *feel* good' because I don't feel. It's like, hard to explain, it's more like, not in a fog really, but you're not really experiencing all this stuff that's going on half the time. . . But I was creating, uh, it was very, um, gratifying. . . and I was cutting to stay alive is what it was. It's because it was the only thing I could *feel*” (p. 22, l. 15-16, 18-20; p. 18, l. 40-41, 43-44).

Not only did Andrew believe that his medications numbed him to external stimuli, but he also felt that they adversely impacted his behaviour and independent thoughts (i.e., controlled him), claiming that he could not keep a job, maintain healthy relationships, or manage his finances because of their use. For these reasons, Andrew chose to go off his medications several times. However, he did not describe this as effective in re-establishing lost control. For example, he described the medication withdrawal as resulting in the resurgence of his bipolar disorder, typically culminating in suicidal ideation and behaviour. Similarly, Andrew described some of his DSH events as also contributing to a worsening of his situation, including his sense of control. For example, after an overdose, he felt very frightened when he lost control over his rational thoughts and began hallucinating, not knowing what was going on while he was in the hospital waiting to be admitted.

In contrast, engaging in cutting DSH behaviours (e.g., cutting) resulted in the pain becoming his main focus and his emotional pain becoming more manageable:

“I could feel pain for a short amount of time and then it was just like, everything goes away. All the, all the, the you know, bad thoughts and everything like that. All that just disappears...I could be sitting here like this ((lies back on the couch, staring)) and I can feel the- even still I can feel the pain. You know, the stinging. But that feels really good in comparison to the other stuff which is in your head- all these words. Not voices so to speak, but they're voices, but they're me” (p. 18, l. 44-46; p. 25, l. 24-27).

While Andrew appeared to use DSH as a form of reclaiming control, Lucy described the entire experience of DSH itself as something over which she had no control. She maintained that when something upsets her, she instinctively “*black(s) out*” (p. 4, l. 36) of the situation rendering her incoherent during these episodes. Like Andrew, Lucy also viewed DSH as a strategy of regaining temporary control over some aspect her life and also felt she would rather endure physical pain than mental turmoil. When I asked her how she usually felt before she engaged in DSH, she replied:

“Usually it’s like- kinda feel like my world is just sort of crashing around me, you know. Just feel like everything’s kinda falling apart. Feel like I don’t have control over whatever it is that’s frustrating me or making me upset...I feel kinda like it’s like a release, you know? It’s, it’s like I can’t get *rid* of the *emotional* pain so I’m trying to distract from that by giving myself *physical* pain, because if I’m not focusing on it then, you know, I feel relieved, you know, I feel like it’s kinda better, you know? Um, but yeah, usually I’m in a fairly like panicked, catatonic state- it’s just, it’s almost like just white noise up there. . .” (p. 6, l. 15-17; p. 6, l. 20-24).

Melissa, like the others, mentioned her inability to control mind-racing and negative thoughts which often caused stress and anxiety. She described using DSH as a strategy to control mental unrest. When Melissa first tried DSH after she had heard about it from peers, it was a voluntary coping strategy to control her distress, but eventually DSH took on the less controllable role of an urge she needed to satisfy:

“I think it just gave me something to think about. It like gave me a sense of like, oh *now* I have something to- ‘cause a lot of the time my thinking just turns into. . . rambles of just blank sadness- ((*whispers*)) I guess that sounds really cheesy but um. . . I guess with *this* it gave me something to focus on, it gave me something specifically that I could just think about until I fell asleep...And I tried it and I think after a while it stopped being a sad thing and it started being an addiction kinda thing, which is the deal for many people who self-harm from what I understand. Um, like *from* what I understand. And yeah, it just became this. . . *craving* for like. . . the sensation I guess” (p. 12, l. 12-15; p. 9, l. 12-15).

While DSH may have controlled her distress temporarily, the effects quickly gave way to fears that her habit may have led her to an eventual loss of control; had she cut too deep? Would people ask questions? However unpleasant the outcome, at least she had at created a situation that was (to some extent) still under her control.

Melissa also struggled with overeating and described secondary body image issues previous to and during the time of the interview. She explained that she was unable to control either her over-eating habits or change her sexual orientation, both of which were closely related

to her feelings of self-loathing. As exerting control over this aspect of her life had been unsuccessful, she appeared to turn to the more controllable DSH instead.

Alex attributed a similar role of DSH to regaining semblance of control over life. Alex also explained that cutting was not necessarily meant to be an attempt to end life, but was often the opposite. For Alex, there is a clear distinction between self-harming to attempt suicide and self-harming for “*more of a coping mechanism*” (p. 8, l. 20-21). Alex also, like other participants saw DSH as a way to “*feel something*” (p. 12, l. 17), both physically and emotionally:

“Nothing. It’s just blank. My mind isn’t really thinking. I don’t remember things, I’m just walking around like a zombie...I am not for the pain. I like- I have an obsession with blood and to see something coming from me when I have no emotion is the main reason why I do it. It feels like relief. I feel something. I am not numb” (p. 8, l. 1-2; p. 7, l. 40-42).

Alex also stated that when the DSH was precipitated by anger or depression, there was loss of control of independent actions and, similar to what Lucy stated about her experience, sometimes Alex didn’t even feel present (depersonalization) during the DSH.

2.2.A. Seeking hospitalization to establish external control

While all participants appeared to use their DSH behaviours to reclaim or maintain internal control (i.e., over negative thoughts and emotions), some also utilized DSH as a way to gain control over others, specifically when interacting with the healthcare system. Participants often spoke of not receiving prompt or thorough care when seeking treatment for their DSH and

therefore felt they needed to make their presentation more acute by emphasizing more serious suicidality.

Andrew described various episodes during which he was feeling suicidal and was wanting to talk to someone about his issues, or thought he needed to be admitted, but described having to wait many hours in the emergency department (possibly even ignored) by staff, even when he disclosed at triage that he was feeling extremely suicidal and needed psychiatric attention. This treatment (perceived or real) resulted in a pattern wherein Andrew believed he needed to present with increasingly more serious injuries to get in to see a doctor or talk to somebody about his condition. From his experience, he surmised that he would be treated in a timelier manner if what he presented with appeared to be more of a suicide attempt than superficial DSH injuries:

“... 'Cause unless I had taken medication, I did not get in within a reasonable period of time” (p. 40, l. 20-21); “‘Cause I know if I take pills I will get in. Right?” (p. 41, l. 36). Instead, he sometimes was given a tranquilizer and sent home only for him to return at a later date with the same issues which reinforced the hospital staff’s ideas that the DSH may be attention seeking behaviour. It appears in instances such as this that Andrew was attempting to control the healthcare system by threatening DSH.

Similar behaviours and strategies in navigating the healthcare system emerged in Alex’s narrative. Alex felt that in order to be seen at the hospital quickly, one had to make “*a dramatic statement*” (p. 12, l. 13), otherwise one may be overlooked. Specifically, Alex believed that presenting with an even more significant problem than non-suicidal DSH injuries was the key to

being treated sooner and that it helped to establish that Alex was not simply self-harming for attention.

Resorting to DSH as a means of communicating emotional issues appeared to relate back to a general lack of self-efficacy amongst participants. When these individuals did not have the confidence to successfully convey their emotional distress or manage their own behaviour, they felt the need to seek external aid to supplement their poor coping skills. While this may also have been an attempt to establish control (over another person), it may as well be seen as a bid to have that other person take control over them (i.e., make treatment decisions, prescribe medication, etc.) because they felt inadequate. Relinquishing this aspect of control may have then shifted their personal accountability to another person perceived to be more capable.

All four participants displayed internal and external struggles for control throughout their narratives, ranging from seeking to be understood and feeling a sense of belonging with peers, community groups, or significant others, to practicing their DSH behaviours in an attempt to gain control over themselves or others. In the final section, I will explore how the participants succeeded in establishing control over various aspects of life.

Theme 3 - Successes in establishing control

I have explored some of the experiences of participants losing or never having control over different aspects of their lives, as well as some of their active struggles in reclaiming control. This research, however, is not only about adversity but it also describes successes that participants identified in reclaiming or establishing control over themselves (i.e., emotions,

thoughts), their image (i.e., how they are perceived by themselves or others), or their circumstances (i.e., relationships, treatment from others, etc.). Ways that participants established some degree of control over the aforementioned constructs include 3.1 coming out as a member of the sexual and gender minority community (i.e., gay, lesbian, or agender), 3.2 reclaiming positive (self-assigned) labels regarding sexuality or mental health, 3.3 discussing positive interactions they have had with the healthcare system and making suggestions for the improvement in the quality of healthcare regarding DSH, LGBTQ-sensitive issues, and beyond.

3.1. “Coming out” as sexual and/or gender minority person

Coming out as a gay, lesbian, or agender individual is a highly personalized experience which can result in myriad outcomes, ranging on a spectrum from highly negative to highly positive (Corrigan & Matthews, 2003). Regardless of the reception of this, disclosing important aspects of oneself that were previously kept hidden may be a powerful, emotionally wrought and seminal moment in one’s life. Ideally, the decision to come out should be initiated by the individual rather than forced, coerced or outed by someone else. When individuals are able to make this decision on their own terms, it may establish a degree of control over their identity and relationships between themselves and others (Griffin, 2008). While coming out can be viewed as somewhat of a calculated risk (i.e., effects on careers, relationships, lifestyle, public perception, etc.), it may be worth it when considering the ability to no longer have to hide an important facet of ones' identity.

In Andrew’s experience, he had a range of reactions from family, friends, and peers. A number of reactions were less than positive, particularly those from his peers in the organization

to which he belonged and his church. Both incidents resulted in rejection and judgment, and while he was aware of the risks associated with revealing his sexuality (i.e., being advised against it), he chose to go through with it none-the-less. Andrew also received mixed reactions from his family, including his mother blaming herself for his sexuality, his wife leaving him and his father embracing him for the first time: “*we’ve had a good relationship ever since. He used to be quite distant, through my whole life*” (p. 16, l. 38-39). After sharing this aspect of himself, Andrew appeared to have a more open relationship with not only his father, but also with his ex-wife (with whom he has remained good friends).

For Andrew, personally coming to terms with the fact that he was gay also appeared to be a reclaiming of control. He describes a moment in time where he comes to the realization that he’s gay and it appears to be a relief to him: “*This time I believe it was the fact I was coming out of the closet and that couple days of euphoria about, ‘Oh I figured out everything in my whole life’*” (p. 28, l. 5-6). He also found his long-term partner quite soon after coming out, acknowledging that he was “*pretty promiscuous*” (p. 29, l. 40) prior to this, despite being married. While, ultimately, this led to a period of transition and trying times (e.g., divorce, cast out of social organizations, etc.), coming out (to himself and others) allowed Andrew to establish some control in re-defining or re-organizing a part of his life which he previously had to hide from himself and others.

For Lucy, “*coming out as gay was a good experience on a whole*” (p. 17, l. 34). She was fortunate enough to have an understanding mother who supported her from the moment Lucy came out, even suggesting that she had known for a long time. Lucy described oscillating

between dating both men and women, describing it as “*playing hetero*” (p. 7, l. 12) which she had grown tired of following a final break-up with her then ex-boyfriend:

Uh, positive but frightening ((*chuckles*)). Well, I had actually gotten out of my last hetero relationship just prior to that. It was a really bad relationship, I was living with him for three years and he was really abusive, and uh, it was actually like right after that we had broken up and I went, screw this, I’m gay ((*laughs*)). Like, I can’t do this anymore, this is dumb. Like, why am I doing this, I’m 22 years old ((*chuckles*)). (p. 7, l. 28-32).

Lucy, although making light of the situation, was able to end her abusive relationship and reclaim control over not only her physical and emotional well-being once she stopped denying her sexuality. She appeared to realize that she had wasted a significant amount of time trying to be someone she was not, despite her own hesitation to do so.

Unfortunately, Melissa did not speak at length about coming out, but she did mention having an overall positive experience when she told her mother and father. Initially, Melissa thought she was bisexual, about which both of her parents expressed uncertainty (a common attitude, as previously discussed), but they were very accepting of her when she eventually came out as a lesbian. She mentioned several times that her sexuality became a large part of her identity, which she incorporated into her relationships with herself and others, and was able to explore in her ongoing therapy.

Similarly, Alex described coming out as a relief despite being “*forced out of the closet*” (p. 5, l. 36) by an ex on Facebook. It was a realization of belonging somewhere, among others, and

that nothing was “*wrong*” (p. 5, l. 23) with the particular feelings regarding sexual identity. Alex was also disowned by the family as a result of coming out as gay, which may signify a certain loss of control over the personal relationship with parents, but it also allowed Alex to forge new relationships with a more comfortable identity. For instance, Alex chose a new name to go by and began requesting that people use gender-neutral pronouns when addressing Alex. These changes allowed Alex to control (to some extent), or at least modify, treatment from other people in a way that felt more consistent with Alex’s identity.

For Andrew, Alex, Melissa and Lucy, each experience of coming out was unique and accompanied by a spectrum of reactions from both themselves and others (anxiety, hesitation, rejection, and relief). In most cases, it appeared to be an empowering moment to concretely declare an aspect of their identity which they had kept hidden. For some, it may have even assisted in the beginnings of more positive identities and improved self-concepts.

3.2. Positive self-labeling

As discussed in section 1.2. (Stigma and negative labeling), being labeled by others can signify some degree of loss of control over one’s own identity or image. In 1.2., most of the labeling by others related to participants’ mental health status (i.e., diagnoses). In this chapter, however, I explore the moments where participants reclaim and repurpose old terms, even once derogatory ones, regarding their sexuality (e.g., “*queer*” [p. 6, l. 25]) or (to a lesser extent) owning and embracing their mental health diagnoses. While, sometimes, these diagnoses may have initially been met with hostility or disbelief, it appeared that if the participants were able to develop acceptance of these they were able to reframe their impact in a more positive way.

In 1.2., it was suggested that when others (e.g., doctors, family members, society, etc.) referred to the mental health diagnoses of participants, they tended to be unfavourable. Labels regarding sexual or gender minority status (on their own terms), however, were largely embraced. Sexual and/or gender minority status was often described as or alluded to as being an empowering facet of their identity rather than a detrimental one. This seemed especially true for participants following coming out.

Andrew, for example, expressed feelings of relief and even joy when he finally came to grips that he was a gay man: “...*but I was extraordinarily happy that day. The day that I discovered, ‘Oh! That’s why- my whole life has been like this because I’m gay.’ I mean, I didn’t know that. Now I know that so everything’s fine now*” (p. 14, l. 15-17). In realizing that he was a gay man, he suggested that this allowed him to understand his desires, behaviours, and thoughts, which he did not experience as a shameful experience, but a liberating one.

Based upon the interview with Andrew, he did not appear to assess his mental health diagnosis as being either negative or positive, but generally accepted it pragmatically. He appeared very aware of its presence in his life, yet the role it played was left ambiguous. When I asked if he believed his self-harm could be attributed to his struggle with his bipolar disorder to some degree, he disagreed.

Lucy, during a break in recording, also shed some light on her self-identified label as a lesbian. I had noticed that when we moved from the subject of DSH to sexual orientation, her demeanour changed from serious to relaxed, almost excitable. She nodded, confirming that identifying as a lesbian made her happy and that she was proud to call herself a lesbian. Given

her previously fluctuating history of acceptance of her orientation (and fluctuation between dating genders), her final acceptance of being a lesbian was likely a relief and an opportunity to exert some power over her future romantic relationships.

Melissa, unlike the other participants, appeared to embrace most mental health labels that were given to her. She expressed embracing them and growing with them, identifying them as a part of her:

“It’s who I am, it’s helped to build my identity with forming my experiences, stuff like that. So it’s definitely a big part of my life and I don’t see it as a negative thing all together- it can be negative, but also like I said, how it’s shape- basically it’s helped shape my i-identity” (p. 4-5, l. 53-54, 1-2).

Not only did Melissa not appear to question her mental health labels, she had even appeared to have internalized them. Melissa felt similarly about her sexual orientation labels which she had assigned to herself. She framed being a lesbian as a positive aspect of her identity; a label to be proud of: “*I think, I think I like the label*” (p. 6, l. 33).

Finally, Alex expressed consistent acceptance rather than ambivalence about the self-identified gender labels. This stood in stark contrast to how Alex felt when asked about the mental health labels imposed by health professionals. As discussed in 1.2., Alex viewed mental health diagnoses negatively, and claimed to not like labels of any kind. However, when I asked what the (self-assigned) sexual orientation labels meant to Alex (i.e., agender, polyromantic, and demisexual), Alex proudly offered a personal interpretation: “*agender um, agender can also be described as genderless, so that’s probably the best way to describe it because I don’t conform*

with any gender and so that's wha- how I label myself." (p. 1, l. 12-14). Although Alex claimed to dislike all labels, I wondered if, like my other other participants, Alex only disliked those labels assigned by other people because they had led to feelings of discomfort and powerlessness.

Overall, participants expressed more negative feelings about their mental health labels, especially when it concerned DSH, compared to labels related to their sexuality, which were often personal, self-identified and not assigned by others. It largely appeared that once participants came to terms with their own sexuality, they were able to own labels which they deemed to be self-positive and even reclaim those which used to have a negative connotation. Labels concerned with mental health and terms related to DSH appeared to be less positive when assigned by others (i.e., medical professional or peer) but also may have been a source of relief for explaining symptoms of an otherwise unknown cause (e.g., depression).

Participants previously discussed ways in which the healthcare system let them down or did not fulfill expectations when being treated for DSH or other issues. While their qualms were discussed with respect to feeling out of control in chapter one, in the next section I will explore the suggestions that were made by participants regarding how their personal healthcare experiences could have been improved. Included are many ideas (whether feasible or not) about how services could be altered or added to better aid future clients of the system.

3.3. Positive experiences with the healthcare system and suggestions for improved care

Positive experiences with the healthcare system and suggestions for improved care were identified as a theme of successes in establishing control because it showcased the moments where participants felt heard, accepted and respected by healthcare staff and personnel. These events stand in contrast to the moments of feeling disrespected and dismissed (as previously explored) and possibly feeling powerless as a result. Participants were informed that the finished thesis would be passed along to the Saskatoon Health Region and, therefore, their suggestions may be seen and acknowledged by policy makers and healthcare staff. Furthermore, as this thesis is exploratory in nature, it would seem incomplete to only mention negative experiences with the healthcare system and negate those times when participants left healthcare interactions satisfied.

Lucy had many concerns about the healthcare system, based on her extensive history with it from an early age, but also noted that she had a great therapist who had helped her deal with a lot of her complex emotional issues. In hospital settings, however, Lucy described feeling intimidated by doctors, especially psychiatrists, expressing concern about their powerful position and hinting at dehumanization and stigmatization of patients, especially those who self-harm:

“I think this [idea] that doctors are [superior] needs to crumble a little bit because I think there is a thing that, you know, patients are a little bit less human than doctors. You know- they- a little bit less, you know, *knowledgeable* and that’s not necessarily the case, I don’t know. I just, wish that people who were self-harming were treated more like people and less like head cases I guess” (p. 20, l. 40-44).

Based on these observations, Lucy made a number of suggestions which she thought might better help her and others dealing with DSH, starting with what she referred to as “*peer counselling*” (p. 19, l. 11), a scenario in which she could talk with someone around her own age that was not in an authoritative position of power, but rather more of a friend:

“ . . . I much preferred it when I had someone that was close to my age that was- still, you know, had the training and was like being paid to be there, but it was like having a friend, you know? It was just like, they weren't grilling me, they weren't writing stuff down, they weren't, you know, putting me in that spotlight, that hot seat where it's like well I have to *tell* you everything. I could tell them whatever I wanted, you know, and it was cool, it was not a pressure situation 'cause I mean, it's gonna be harder to talk to someone when you're being pressured and when you're being you know, *stared* at and grilled, you know?” (p. 19, l. 28-35).

In Lucy's idea of peer counselling, there would be a great deal less intimidation in communicating with (particularly mental) healthcare staff, and less pressure to “*give up the goods*” (p. 19, l. 22) by telling professionals what they would like to hear.

Lucy also echoed the thoughts of other participants in regard to addressing the dearth of knowledge with respect to DSH, which she felt she was exposed to first hand in healthcare settings. She speculated about the general emotionally-driven factors behind DSH and, she believes, for her and many others:

“ . . .it needs to be really investigated. Not even in like a *medical* perspective, but from an *emotional* perspective because that is nine times out of ten the reason that something’s happening, is that they’re going through something *emotionally* or *psychologically* that is not, you know, it’s not something that they can deal with on their own” [P. 18, L. 36-40].

This observation prompted Lucy to add that the healthcare system could benefit greatly from caregivers taking the time to listen not only to their patients but also to their families (thereby following our health region’s promotion of patient- and family-centered care) and personalizing their responses in order to address each individual patient and her, his (or “their”!) unique circumstances. Lucy stated that there is likely no “cure-all” treatment for DSH, and it should not be treated as such. DSH, unlike physical, corporeal injuries/illnesses, does not have a clear-cut treatment procedure, nor does the behaviour have a common trajectory or prognosis: “‘Cause, you know, what works for Joe Blow over here is not *necessarily* gonna work for me, you know? I don’t know I think what needs to happen is that people need to be *asked* what they need. . .rather than it just being assumed” (p. 20, l. 30-32).

Alex, after prompting, also shared that positive experiences with the healthcare system were not a rare occurrence amidst a series of adverse ones. Alex mentioned that doctors, for the large majority, were kind, conveying the attitude that the patient would be fine and everything would be sorted out. Alex did, however, echo Lucy’s sentiments that care for DSH would benefit by doctors taking the time and care to listen to each individual’s needs and not employ a fix-all

treatment. Alex, like Lucy, acknowledged that this shortcoming was likely due to the lack of DSH-specific education:

“Actually *listen* to what the people are saying. Sometimes they might be right and they might know more- they obviously know more than you because it *is* themselves that- who have done it. They’re gonna know more about themselves than you ever will if uh- simple education that you’ve gotten ‘cause *it is* personal” (p. 14, l. 40-44).

Unlike Alex and the other participants, Melissa did not have as much experience with the healthcare system. The feedback she did have, however, was largely positive. While her DSH never caused her to visit a clinic or emergency room, she had been seeing a psychologist for a number of years and felt that this had been helpful. Melissa’s greatest praise for the care she received from her psychologist was that this professional was very accepting and supportive of her sexual orientation. She mentioned that they spent a lot of time talking about this aspect of Melissa’s identity, and that it was always met positively and was integrated into her care program. Before her current psychologist, however, she had one which she did not connect with, explaining that she felt that this woman didn’t really listen to her, mostly discussing “*redundant things, talking about things that weren’t actually affecting me...*” (p. 14, l. 4-5), which reflected some of the other participants’ ideas that they are not entirely listened to when seeking care.

Andrew, unfortunately, did not have many stories to share about positive experiences within the healthcare system. While his concerns were mentioned in chapter two, he did have some feedback for how care can be improved for DSH. Like many of the other participants, he noted that hospital staff could be more educated in DSH, namely differentiating between DSH

and suicide attempts. Listening to patients' concerns and requests for continued care or admittance to the Dubé Centre were also ideas that Andrew shared. In addition, Andrew noted that he often had to wait for many hours to be seen by doctors. When he was asked if he felt that his long wait times at clinics could be at all attributed to discrimination regarding his sexual orientation, he believed it wasn't, noting that it was likely due to a lack of hospital resources (i.e., rooms, staff, equipment, etc.) and high demand by other patients wanting to be seen.

Overall, the four participants had several suggestions for how to improve healthcare, many of which were suggested by more than one participant. For instance, the most overwhelming response was that healthcare practitioners (largely those in hospital settings) could use some education regarding DSH and its underlying factors. One such issue that was addressed throughout the narratives was that healthcare providers often mistook DSH as a suicide attempt or conversely, did not take the DSH seriously enough. Participants also wished that their caregivers adopted a more emotion-oriented perspective as opposed to the traditional approach of curing the symptom. Like many other mental health issues, DSH may not be best addressed by a medical formula or medicine; rather it should be understood in patient-centered ways, based on patients' personal experiences. While this approach may not be entirely feasible in a fast-paced environment with limited resources, perhaps a peer-counselling initiative might be useful where patients with DSH can speak to an individual who is closer in age, with more time to give, and who might appear less intimidating than a professional healthcare provider.

Chapter 5: Summary, Discussion and Conclusion

Throughout the previous chapters, I have explored the narratives of four participants who identify as members of the sexual and gender minority community and have previously engaged in DSH. I examined their perceived experiences with the healthcare systems when being treated for DSH and other problems, in settings ranging from private psychiatrist offices to emergency rooms. I illustrated how control (internal and external) appears to be a pervasive theme throughout the narratives, not only pertaining to their struggles with DSH and their sexuality, but also in more general terms (i.e., relationships, health, self-concept, careers, etc.). The analysis began in section one of chapter four, with experiences and responses to a lack or loss of control. In sections two and three, I discussed how participants appeared to struggle with, and then consequently re-establish, control in some aspects of their lives. In this summary, I will briefly re-visit the previous themes and sub-themes of the previous three chapters, using examples.

In section one I explored struggles for control through experiences of abandonment and betrayal by family, friends, peer groups, and organizations. Most participants experienced some degree of rejection or feelings/events of abandonment (usually at the hands of someone close to them or someone held in high regard). These events were often spoken of within a framework of external locus of control. This means that participants regarded these events to be beyond their scope of control; these actions were perceived as having been done *to* them, by someone else. These particular experiences (e.g., sexual or emotional abuse, peer bullying, rejection from parental or authority figures), illustrate how their peers and/or would-be protectors not only were seen to have failed participants emotionally, but may have entrenched within, some of my

participants, perceptions of patterns of deceit. Based on their narratives, this may have had lasting effects, causing participants to feel consistently “on edge”, unable to fully trust anyone, and may have cultivated a dysfunctional view of trust and honesty within intimate relationships. Furthermore, these skewed patterns of social interaction and relationships may have contributed to their perceptions of healthcare visits when presenting with DSH. For example, two participants experienced sexual abuse by a trusted individual. Both participants also described being verbally or physically abused and neglected by a parent throughout childhood while another described a significant abandonment as being disowned from the family upon coming out as gay. These examples illustrate how important figures in their lives betrayed and abandoned them, all of which were decisions and acts beyond the scope of their control. Some of these events were described as directly or indirectly contributing to DSH behaviour.

Stigma and negative labeling was the second theme discussed in chapter one in relation to DSH behaviour, sexual identity and mental health. Upon learning of a diagnosis or sexual identity, people may form an opinion of an individual according to their pre-conceived notions and it becomes the main identifier about that individual. When an individual is reduced to a single label or idea, it may be dehumanizing and may represent someone a one-dimensional character instead of a complex, rich individual. Participants felt stigmatized by others (and often themselves through internalization) upon exposing their DSH scars to others or being categorized as a “*cutter*”. Along with being stigmatized by healthcare staff, all participants were given various mental health labels (i.e., depressed, anxious, bipolar, etc.) at impressionable ages. These labels, as discussed, may have been internalized and even used as a “crutch” upon which to blame poor behaviour. Finally, some participants felt their sexual minority status was

stigmatized. Andrew, for example, experienced this from childhood bullying, being ostracized from an adult peer group and refusal of care from a physician. Being stigmatized and labeled by others appears to be out of the scope of control of the affected individual. Often stigmas and labels are accompanied by preconceived notions and judgements which can be harmful for all parties, including resulting guilt or shame for the victim.

Feelings of guilt and shame (closely related to self-loathing and closeted lives) often controlled or influenced behaviour, relationships, or decision-making for my participants. These feelings were related to DSH behaviour, healthcare experiences and sexual minority status. Most striking was the idea that DSH itself was both a reaction to, and a catalyst for, guilt and shame. The idea that DSH would temporarily decrease these negative emotions and/or be felt directly after DSH was described by all four participants. Half of participants also claimed to have been made to feel guilty and ashamed from healthcare professionals during visits for their DSH. Lastly, all participants experienced guilt and shame in regards to their sexuality ranging from disapproval of family to aggressive bullying from peers.

Self-loathing was the first sub-theme of guilt and shame because it appeared to be concurrent throughout the interviews. Self-loathing (or at best, a poor self-concept) to some extent was present for all participants. It appeared to control behaviour at times such as giving in to peer-pressure, tolerating abusive relationships, or contributing to the desire to engage in DSH. For three of four participants (especially the two women), self-loathing was in direct relation to a dissatisfaction with personal body-image. This led to feelings of inadequacy and even, in some instances, the need to self-punish with DSH.

The topic of closeted lives was the second sub-theme chosen for guilt and shame because these feelings appeared to be a large contributor to why participants had not disclosed (or had even been deceptive about) aspects of their lives to those close to them. In other words, feeling ashamed or guilty of their DSH behaviour or sexuality controlled, to some extent, what they felt comfortable sharing with others. Andrew, in particular, was most affected by his double life, disguising his sexual orientation and even denying it to himself for decades. Although the rest of the participants came to grips with their sexuality earlier in life, they still struggled with and sometimes denied their sexuality from others and themselves. This may have been detrimental to relationships, entrenching patterns of deception and exacerbating feelings of stress and loneliness. Three out of four participants also described hiding their DSH from family, friends and peers. They often made up excuses or alternate stories to explain their scars or injuries and as such, isolated themselves from those who could help or to whom they could possibly confide in, reinforcing a belief that their personal truths were shameful.

In the final part of section one, I explored negative interactions with the healthcare system. These experiences were believed to be a lack or loss of control because the care and resources are largely out of the control of those being treated. Three out of four participants felt that they were being judged by healthcare professionals when being treated or screened for DSH. Participants expressed that a general lack of knowledge about DSH contributed to a misunderstanding of it, citing that it was either taken too seriously (treated as a suicide attempt) or too lightly (treated as an act of attention-seeking). Three out of four participants also perceived that their sexuality was being judged or scrutinized by healthcare professionals, citing experiences ranging from disregard of sexual identity to refusal of care. Lastly, three out of four

participants also felt their care was compromised due to a lack of resources such as time, education and available space.

In section two, I explored themes which were considered to be active struggles to establish or re-establish control beginning with the desire to feel understood and to belong which appeared to lead to an over-reliance on significant others and seeking belonging through the culture of DSH. It appeared throughout the narratives that a desire to fit in with others directly affected behaviour and decisions of participants (e.g., tolerating abuse) in order to gain control over their status or image with respect to other people. This was usually attributed to sexual and/or gender identity or perceived, or real, physical appearance. All participants mentioned (some more extensively than others) that fitting in with peer groups during childhood and/or adolescence was, at some point a struggle and a significant concern. Andrew, for example, struggled with fitting in long-term, from early childhood and its peer bullying to late adulthood and its ostracism from his church. My two female participants, while also having experienced some degree of bullying regarding sexual minority status, also expressed self-consciousness surrounding body-image. Lastly, all participants described being misunderstood with regard to either DSH behaviour or their mental health diagnoses by either family, friends and/or healthcare professionals.

As an apparent consequence of the desire to feel understood and to belong, three out of four participants displayed some degree of over-reliance on their significant other at some point throughout their relationships. Throughout their interviews, the three participants made comments about their significant others which intimated that their romantic relationships held a

lot of external power over an otherwise precarious mental state (i.e., attributing that they were not cutting themselves to their partners, or potential suicidality if the relationship were to fail, etc.). These perspectives about romantic partnerships appeared to suggest an effort to establish control over DSH, although, the obvious corollary that the failure of these relationships would result in potential relapses also suggested that any control gained may also be illusory or fleeting.

Seeking belonging within a culture of DSH was a sub-theme for a need to belong and be understood, and was consistent with the overwhelming evidence for DSH culture within the literature. As was discussed, DSH has garnered increasing attention in the media, especially within the internet where young adults can find resources and like-minded individuals who either struggle with or encourage DSH behaviour. This sub-theme, although not at all prevalent with my oldest participant, was present with the youngest two, and was even being cited as a reason for first trying DSH. Seeking this community of peers was interpreted as being an attempt to find and control a feeling of belonging and understanding to compensate for a lack of this from other sources.

I also examined how DSH behaviour itself was a struggle to reclaim internal control over emotions or thoughts which lead to seeking hospitalization to establish some external control. All participants described resorting to DSH as a reaction to negative stimuli (i.e., traumatic events, stress, etc.). DSH would temporarily distract from or numb mental pain by replacing it with a physical alternative. Conversely, DSH also served as a conduit to feel something when otherwise feeling numb or emotionless. This is consistent with the depersonalization model of DSH by Messer and Fremouw (2008). Lastly, one participant also described feeling completely out of

control and would black out during episodes of DSH. While these are obviously maladaptive strategies to cope with adverse emotions or experience, my participants' experiences were largely consistent with the more general literature on DSH behaviour.

Another common sub-theme for using DSH behaviour as a strategy for controlling emotions was seeking hospitalization to establish external control of their environment, healthcare treatment or of other people. Half of my participants described a worrying observation that because they felt they were not being taken seriously or not given adequate care for their DSH, they therefore needed to present with more serious symptoms. That led participants, especially Andrew, to attempt suicide simply to be taken seriously for his non-suicidal DSH. Alex also felt that dramatic statements were the best way to receive expedited care. This strategy is clearly an attempt to gain control over the courses of their care and treatments from professionals in the medical field because they felt that merely presenting with DSH was not able to get them the care they felt they needed, coupled with a lack of confidence in their own coping mechanisms (i.e., poor self-efficacy).

In the final section of chapter four, I explored some of the participants' successes in establishing control. One such success was evident in the decision and/or act of "coming out" as a member of the gender and sexual minority community. Making the choice to share an important and sometimes sensitive aspect of one's identity can be viewed as a powerful statement of control. Fortunately, all participants described feelings of relief and receiving largely positive reactions from either family, friends and/or the community. The act of disclosure

also appeared to help claim some degree of control over or help for self-concepts for my participants.

“Coming out” was an aspect of the next theme of positive-self labeling. Labels considered positive and accepted largely pertained to those of sexual and gender identity. All participants accepted, felt happy with, or were often proud of, the labels they adopted (e.g., gay, lesbian, agender). Another common feeling surrounding owning sexual and gender identity labels was one of relief; being able to accept it themselves and openly share this label with others and/or cultivating a sense of belonging and community with others who share these self-given labels. To a lesser extent, mental health labels were also accepted (with a wide range of accompanying attitudes), with one participant embracing them and citing them as part of her identity while others felt these labels were thrust upon them by healthcare professionals.

In the final part of the last section, I gave participants some even more control than just sharing their stories. Participants were aware that their feedback was likely going to be passed on to the health region and thusly, I gave them the opportunity to share positive experiences with the healthcare system and ideas of how to improve upon some of the grievances they previously cited (e.g., treating DSH as a suicide attempt). Generally, all participants agreed that healthcare institutions and their staff have several areas in which they could improve their services. Participants were more forthcoming with suggestions for improvement such as individualized or specifically tailored care when treating DSH issues. This was generally proposed more one-on-one with healthcare professionals in conjunction with active listening. All participants also stressed the necessity for a greater understanding of sexual and gender minority-specific issues

and DSH behaviour. These included discretion and respect for patients and their personal details, greater knowledge and understanding of gender and sexual minority vocabulary and issues, a grasp of the main differences between suicidal and non-suicidal DSH, and feeling heard rather than just listened to. Others suggested shorter wait times, quicker access to mental health evaluation, peer counseling, and that medical staff should take DSH seriously and that the latter is not only attention-seeking behaviour. All participants could share at least one positive memory of their hospital experiences. All participants had, at one point in time, had a psychologist or psychiatrist whom they trusted and felt were helpful and understanding.

The analysis of the four interviews showed that many participants shared similar experiences and opinions regarding identifying as a sexual or gender minority person, dealing with DSH behaviour and navigating mental health diagnoses. Through analysis of the interviews, it was clear that participants all felt that some aspects of their life were beyond their control whether it was their negative thoughts and emotions, how others viewed them, their environment, medications, or relationships with others.

Having summarized the findings of the research, I wish to now discuss my experiences with the research, beginning with the process of recruitment and interviewing and then turning to some of the challenges I faced throughout. I would also like to share my personal self-reflection as a researcher including my biases, concerns, strengths and vulnerabilities.

Process and self-reflection

While the initial focus of the study was to be on older adults, there was very little recruitment response. This might have been because sexual and gender minority adults over the age of 25 who have had experience with self-harm and interacted with the healthcare system are a very small population. While we believe that this population exists, it may be difficult to identify and engage with in a research setting. For many individuals, self-harm may be a very difficult subject to discuss. It may also be that individuals experienced self-harm in the past, and they have moved on and would rather not revisit these painful experiences.

Older members of the gender and sexual minority community may also not be very eager to share their experiences surrounding their sexual and gender identities. Some may have grown up in a very heteronormative and intolerant environment where identifying as anything but “straight” was met with hostility, ostracism, and humiliation. This may have led to a fear of disclosing their sexual identities or it may be entirely too uncomfortable to discuss (Claes & Moore, 2000). Furthermore, while the younger generations of gay and lesbians may be quite involved in the sexual and gender minority community, older adults, having grown up and come out in varying sociopolitical climates, may not have had the same opportunities to be a part of such a community and therefore may not wish to be a part of it now. Some of these adults may be more integrated into our heteronormative society and therefore have less of a need for a specific community.

It was somewhat ironic that the first participant was an older adult, volunteering within mere hours of the study being advertised at the ACC, fueling my hopes that this population might

have a strong desire to share its stories. However, the apparent lull in interest following the enrolment of the first participant suggests that older participants may perhaps not feel the need to revisit these aspects of their past. Although there are most likely numerous older adults who fit these criteria, there are likely far fewer than members of younger generations. For example, Andrew mentioned after his interview, that he was unique among his LGBTQ friends his age, in regards to his mental health and DSH struggles.

Throughout the interview process, I made field notes when something struck me as interesting or worth revisiting later. Notations were wide ranging and included acknowledgement of certain terms or phrases which seemed unusual, reflections of participants' overall effect on me during their narration, the timeline of their narrations, what they chose to mention, emphasize in more detail, gloss over or leave out, as well as my general rapport with them.

I also recorded my own insecurities as a beginner researcher and interviewer, of which there were many. One concern which has been present throughout the whole research process was regarding my status as a straight woman doing research with sexual and gender minority adults. As an outsider to the community, I thought participants or even people hearing about my research would be offended or find me an unqualified or inappropriate researcher. I did not want to be thought of as a person who was exploiting the "otherness" of the sexual and gender minority community (and more specifically the sub-group of those who engage in DSH) for a perverse sense of curiosity. To my relief, this did not appear to be a point of contention for any of my participants, as my sexual orientation, if at all mentioned, did not seem important to them. I chose to not disclose if I identified as a sexual or gender minority or not unless my participants

asked, not because I had anything to hide, but because I did not believe it to be relevant to the research.

I currently identify as a heterosexual woman. I have speculated that if I was a noted member of the community, my research process from start to finish would have been vastly different. This may have been a benefit or a detriment depending on various factors. For instance, it may have been easier to recruit individuals who feel more comfortable or safe talking to someone with whom they have a common bond (i.e., sexual or gender identity). Conversely, it may have been more difficult because they may have been worried to talk to someone they know of (albeit peripherally) within the community for fear of judgement or condemnation.

Despite my insecurities, I believe it takes both insiders and outsiders as researchers to provide equally important perspectives on many research issues. I believe that biases vary both within and between individuals and groups, which can affect all aspects of the research process. Having only insiders or outsiders conducting research on certain subjects may skew results and, therefore, lead to a biased perspective in the field.

I also, to a lesser extent, harboured some self-doubt regarding my lack of personal experience with DSH. While I had done a lot of research into its mechanisms, theories, and history, I am persuaded that someone who had engaged in DSH themselves would have undoubtedly had more insight into what it means to self-harm and/or struggle with suicidality. I was, however, employed as a youth care worker for two years at the Saskatoon Downtown Youth

Centre/EGADZ⁷ and interacted with many teenage girls (a number of whom also identified as lesbian or bisexual) who struggled with DSH and various mental health issues (i.e., depression, anxiety, bipolar disorder, ADHD) and I formed significant long-term bonds with a few. On a few occasions, I helped girls in the aftermath of their DSH episode to disinfect and bandage their wounds, arranged rides to hospitals, and provided emotional support. I also took a course on how to best help someone who is suicidal (Applied Suicide Intervention Skills Training) which I put into practice throughout my time at EGADZ. I should acknowledge, therefore, that EGADZ helped me to supplement my own research on DSH, mental illness, and the sexual and gender minority community.

Throughout my meetings with Drs. Thorpe and Teucher, I often brought up my concerns about my participants reading the finished thesis. I did not want my participants to see anything unfavourable or hurtful written about them. Thus, protecting my participants and feeling guilty for my opinions became recurring themes within my own process of researching and writing. I felt that I had much difficulty finding participants for many reasons, including the challenge of the sensitive subject matter. My participants have been gracious, candid, and vulnerable by meeting with me and disclosing very personal, private details of their life (some of which they had never told anyone else) that I felt indebted to them and responsible for their feelings.

⁷ The Saskatoon Downtown Youth Centre, more commonly known as EGADZ is a not-for-profit organization which has many programs directed at aiding at-risk youth and their families. These programs include outreach services, teen parenting classes, drop in centres and half a dozen group homes. During my time at EGADZ, I worked in group homes, almost exclusively with young women.

While protecting their anonymity was of utmost importance so that nobody could identify or judge them, I could not help but worry about my own judgements coming through in my writing. Naturally, I had gut reactions or snap judgments when first hearing their stories and throughout the iterative process of reading, re-reading and analyzing, these opinions changed, evolved, or strengthened. And while opinions are never right or wrong, interpretations, especially those backed up with data (i.e., excerpts of interviews) are more weighted and carry more significance, designed to illustrate a case or support a theory. Therefore, I found myself censoring or re-wording thoughts that might be considered unfavourable, in order to spare the feelings of my participants, and, in part, to protect myself from a possible confrontation. For instance, during a few interviews I heard stories that at the time seemed sensationalized or convenient and, upon analyzing them further in relation to the rest of the story, may have not been factual. But, then, how much did my desire to leave a good impression with my participants affect my research and writing?

I also pondered how my participants' performative presentation of their experiences (possibly edited for social acceptability) may have further affected my findings. It has been said that all narrations (i.e., autobiography, memoir, etc.) are, to some extent, a performance (Riessman, 2008). The audience is always at the front and back of a narrator's mind and a different audience (i.e. researcher) might have elicited a very different presentation. For example, it is possible that my participants subconsciously or purposefully told me things that they thought I wanted to hear, to put themselves in a better light, or emphasize points that they thought a researcher might like to hear.

In addition, the process of making meaning of qualitative interviews is not simple but multifold. As the participants struggle to make meaning of their experiences and pass their meanings on to me, I as the interviewer and writer of this thesis then try to make meaning of what was said (and readers of this thesis then come to their own conclusions). This process, known as a double hermeneutic, has been well identified in qualitative work (Smith & Osborn, 2015), and was an interesting experience throughout the research process. While I realize that it is an important practice in interpretive work, I felt challenged by the concept. If we assume that memory is fallible and that every individual experiences life through her or his own imperfect lens, then every iteration of interpretation becomes more derivative and less rooted to the initial experience of the participant. Then again, “initial experiences” may not be so “initial” after all but coloured by the quicksand of impressions at the moment, as well as a persons’ past, present, and hope for the future, their always changing personal and cultural backgrounds - and the little self-knowledge that people may have about themselves. My interpretations of the interviews were therefore only some of potentially many interpretations and perceptions which could be made by researchers from variety of different backgrounds.

Lastly, I would like to comment on my experience with interviewing my participants. For me, the interview process was undoubtedly the most enjoyable aspect of the research. As a rather social person, I enjoyed interacting with the participants on a personal, “human” level, connecting by means of sharing stories about the human condition, getting to know their stories, and possibly even – though unintentionally - providing an outlet for them to share some painful or sensitive memories that they otherwise would not talk about.

While my research process and the data it yielded were undoubtedly rich both in experience and academic merit, my personal challenges (discussed above) as a beginner researcher were far from being the only limitations of the project. The limitations of the study design, population, topic, etc., that I came across also brought to light some areas in which to improve upon and new directions for further research in the field.

Limitations

As with any research project, there are many limitations (avoidable or not) which can, to some extent, compromise or complicate the results and meaning of the study. The qualitative methodology of the study of course shared the methodological characteristics of all qualitative studies that, typically, focus on the richness and variety of data, where researchers are invariably involved in the meaning-making process and where one would not expect researchers to set themselves artificially apart of the persons whose stories they are trying to understand. Researcher bias (also known as “observer-expectancy effect”) could be part of such work, which is why qualitative researchers – and I myself in this very thesis – declare their (my) awareness of any biases that could be influencing my interpretations. In addition, there is no anonymity between my participants and myself as researchers – although I am of course held to guarantee confidentiality. Furthermore, the large amounts of data may make it difficult to organize and perhaps visualize, requiring researcher skill (Anderson, 2011). Then again, researcher skill is of course also required in quantitative studies; in addition, many of my qualitative findings about participants’ life stories and specific life experiences would not have been elicited by a quantitative approach, such as with an administration of a standardized interview questionnaire.

Therefore, I believe that my qualitative approach is justified and entirely appropriate for the research reported in this thesis.

There are some limitations that are important to note such as participant bias. It is clear that some people will be more willing to volunteer to be interviewed for a research project than others. These individuals, for example, might have more spare time, may be more willing to share personal information, may be more inclined to help others, may be more extraverted, or may simply have a greater need to talk about the subject matter. Participant bias may also have been affected by our choices of primary recruitment locations, which included OUTSaskatoon and Pride Centre where the study was publicized. Many potential subjects fitting our inclusion criteria may not have been associated with those organizations. For example, older subjects may have been less involved in the organizations where I publicized the study, resulting in a predominance of younger participants. This unfortunately resulted in our inability to fully broaden the limited, existing literature on older gender minority adults with DSH experiences, who likely had very different life experiences than those of the younger cohorts. Therefore, for the reasons mentioned, the four participants included in the research may not be very representative of the overall sexual and gender minority population who have experience with DSH, particularly older subjects, on whom I had intended to focus. Then again, since my hopes were to learn about the variety of people's DSH experiences, and I have already been afforded an abundance of personal experiences by the participants in this study, it appears as obvious that much more research is possible, beyond the limited room that a Master's thesis can provide, making further doctoral work a necessity!

My participants, for the most part, were a tremendous source of rich data. I did find, however, that one participant seemed to share less information that I could use for analysis, and I wondered if this was perhaps because s/he had somewhat less life experience. Although this is by no means a fault of the participant, it was possibly due to me not being fully confident in my interview skills at the time, and while it would undoubtedly be important to connect with younger individuals, I believe it further emphasizes the need to interview older individuals, as they may have more life experiences to share.

Another specific limitation of my study was the inability to recruit a more balanced number of gay males and lesbian females to examine gender differences between and within groups. Given the few number of responses, while not a problem with my chosen method (IPA), I elected to add a fourth participant who identified as agender. As this is also a gender minority group with potential vulnerabilities, this addition seemed reasonable in light of the overall focus and might have increased the richness of the findings, although it may not have met the ideal homogeneous sample for an IPA study (Pringle, Drummond, McLafferty, & Hendry, 2011). While this is a general guideline and not a requirement for an IPA study, my participants, although vastly different from one another in many respects, appeared to have many overlapping commonalities (e.g., shared experiences of guilt and shame, feeling judged within the healthcare system, using DSH as a control strategy, etc.). My research, therefore, may be an incremental advance towards a departure from the preference for a homogenous sample as suggested for IPA studies.

Lastly, there are limitations related to me personally as a new researcher. For instance, during transcription and analysis, I noticed that I unwittingly asked some leading questions (e.g., “*So were those doctors and nurses kind to you?*” [p. 13, l. 30]) or did not follow up on certain issues participants raised. Sometimes I did not feel comfortable pursuing a topic because I did not want to appear overly intrusive and other times I had not noticed, at the time, that it would have been beneficial to ask further questions. Now at the end of this research process, I would have loved to have the opportunity to do the interviews over again. I feel that I learned so much between the beginning of the first interview to the end of the final interview that I could have done better with more skill and practice, possibly generating an even richer and more complex interpretation of the participants’ experiences. Then again, I am also aware that any interview represents only a very small slice of a participant’s life – a slice that might be smaller or larger the following day, or with another researcher. As researchers, we try to do our best but can do only so much – and yet we can learn much already about a condition like DSH in sexual and gender minority adults about which so little is known.

Recommendations for future research

In the future, I would like to see an increase in focus on DSH in transgender individuals. The transgender population faces many of the same struggles as gays and lesbians, as well as an entirely new set of challenges. For example, some of the participants noted that their healthcare practitioners were not aware of their sexual or gender identity and, therefore, their care was not usually affected either positively or negatively by their minority status. Some transgender individuals, however, may find that their sexual or gender identity is more obvious, either

visually, audibly or otherwise and therefore they may find it becomes a more tangible factor in their interactions with healthcare practitioners. Conversely, other transgender individuals who have successfully transitioned fully may be impossible to identify and may not want to identify themselves. Furthermore, research on the gender minority population is sparser than that of the gay and lesbian population.

While my research spanned a broad age range, this breadth also has strengths, revealing why and how people engage in DSH with different people, telling different stories, with different problems, showing an astounding diversity of the issues at hand and whom they might affect, in a variety of ways. However, it would also have been interesting to have been able to recruit four participants of the same age. Analyses of these interviews would, perhaps, provide a richer picture of what it might mean to be members of a sexual and gender minority group during a shared social climate, cultural period, and specific age. Moreover – as originally intended in this thesis - it may also be beneficial to conduct a similar study with older (50+) gay and lesbian individuals, although major recruitment challenges may again need to be addressed. Social media may not be the best strategy for recruitment as many people from older generations are perhaps not regular users. Recruiting from community centres may also not be useful as older generations may not be as involved in clubs or groups. These specific research avenues, therefore, may be more fruitful in a larger city where there are larger potential participant pools and more resources for recruitment.

As this research only examined perceptions and experiences of healthcare users, attitudinal research regarding DSH from the perspective of healthcare providers may lend itself to a clearer

picture of dynamics surrounding DSH in healthcare settings. This might include focus groups with healthcare providers about how they feel when treating DSH patients (e.g., frustrations, challenges, concerns, and ideas for improvement). Furthermore, many participants voiced disappointment and frustration with a lack of knowledge regarding LGBTQ issues and specific care, research directed at a focused initiative in educating first-line professionals may be useful. This could include a survey which assesses not only existing knowledge, but personal perspectives and attitudes.

Lastly, it would be interesting to explore DSH, ethnicity, and sexual orientation together. For example, Saskatchewan has a large indigenous population, some of which could identify as Two-Spirited (embracing both or neither gender). Immigrants coming into Canada who identify as sexual or gender minorities may also be a promising sample for future research as sexual minority status might be heavily shamed or even forbidden in their former home countries. Finally, since the original discussion was written there has been lots of media attention on the “Black Lives Matter” movement, where African American individuals find that they are still stigmatized or less visible within the LGBTQ community. It would therefore be valuable to research this population in general, and more specifically in regards to DSH.

While acknowledging the challenges of my research, I also believe that my project provides valuable information for the fields of DSH, healthcare, and sexual and gender minority research. Although my participants had four vastly differing backgrounds, it was interesting to find that control and the struggle, desire, and pursuit of it was significant to all of them. Furthermore, it was heartening that participants, describing experiences and actions that would

be seen in most circumstances as highly stigmatizing, were so open to sharing these with an unfamiliar interviewer and allowing these to be transcribed and analyzed for the purpose of a Master's thesis. Also remarkable was the resilience of the participants, some of whom literally survived most challenging life circumstances and who had many successes in overcoming them. Perhaps sharing these stories in various forums within the healthcare system might increase awareness about DSH in this vulnerable gender minority population and increase the capacity of healthcare providers to respond to their needs.

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Appendix A: Sample interview questions

Introduction, current life situation:

- I'd like to start with reminding you what this study is about, and wondered if you had any questions? Are you still OK with talking with me?
- Before we start, can you tell me a bit about yourself?
- Do you live with family members, a partner, or friends? Do you live in a house or an apartment?
- Can you tell me a little bit about what you do for a living (or are you a student)?
- Is your job/study a positive or negative experience for you? Tell me more about that...
- If working: Does your job grant you sick leave of any kind?
- What sort of supports do you have in your life? Do you have a partner?
- Does anyone depend on you? Do you have a lot of obligations or expectations to live up to?
- What has been happening recently in your life? Have you had any losses, such as a loss of a job, house, family member, or friend?
 - If “yes”: Sounds like you have a lot on your plate. How do you deal with stress or worry?

Personal and family mental health history:

- Are there some things that you worry about often? Do you consider yourself an anxious person?
- Are you often sad... more than most people? Do you occasionally or often think of dying or think you might want to be dead?

- Have you ever had any unusual experiences, like seeing things other people don't see or hearing things other people don't hear?
- Have you ever been diagnosed with a mental illness or substance abuse (or think you had this)? Did anyone give you a diagnosis?
- Has anyone close to you ever has ever talked to you about wanting to commit suicide, or has anyone in your family (or someone else close to you) ever committed suicide?

Experiences of being gay or lesbian:

- I would like to talk a little bit about what it means to you to be gay/lesbian. Can you tell me a little about when you first realized you might be gay/lesbian? How old were you? How did you feel about this realization?
- When did you decide to come out as gay or lesbian to your friends and family? Was there anything holding you back from telling them?
- Tell me a bit about how you were received when you came out to family, friends, authority figures, others, etc?

DSH experience:

- I understand that at some time in your past you have harmed yourself intentionally, perhaps at a time of crisis or major stress, and that you had an interaction with healthcare services at that time. Can you tell me a bit more about that? What was going on for you before it happened? Can you tell me more about what you did to harm yourself?
- What did it feel like after you had harmed yourself? Were you relieved or perhaps disappointed that you didn't die (at the time and also looking back now)? What other feelings did you experience afterwards?

- Looking back now, do you think you wanted to die? Do you think you will harm yourself again? Why or why not? What would stop you from harming yourself?
- Have you ever hurt yourself before? Has it happened often? Is it still happening?
 - If “yes: Is self-harming a small part of your life or a rather somewhat bigger part? How much of a role does it play in your life?
- Was life different before you started to self-harm? If so, in what ways has it changed? In what ways has it stayed the same?

Healthcare interactions:

- Do you have a family doctor?
- Is your family physician aware of your being gay or lesbian? If not, can you tell me why you haven't told him/her
- We talked before about you hurting yourself. At some point you were in contact with healthcare services about that. Was your first contact a counsellor, your family doctor, a clinic or the emergency department? How did that go?
- Did you go to the hospital?
- Did anyone help you get to your family doctor or the hospital? Tell me a bit more about that experience
- Were you admitted to hospital for this episode or another one in which you had hurt yourself? Was it your first time at the hospital? How long did you stay?
- Now, what was it like in the hospital? Let's start with admission. Usually they ask you for your story. Did you feel comfortable talking about your story with your nurses and doctors?

- What was your contact like with the treatment team like the doctors, nurses and other therapists? Did you feel that you received good care, or could things have been better?
- How was your overall experience at the hospital? What were some things that worked for you and what were some things that didn't work for you?
- Do you feel that your experiences while getting help (good or bad) were at all affected by your being gay or lesbian?
- Would you go back to the hospital if you ever started thinking about hurting yourself again? Why or why not?
- Is there anything else you can tell me about your experiences with the healthcare system as a gay/lesbian person?

Participant Consent Form

Appendix B: Consent Form

Project Title: Qualitative exploration of deliberate self-harm and experiences with the healthcare system among gay and lesbian adults in the Saskatoon Health Region

Researcher(s): Nina McKinstry, Graduate Student, Department of Community Health and Epidemiology, University of Saskatchewan, (306) 717-7414, nina.mckinstry@usask.ca

Supervisor: Lilian Thorpe, Department of Community Health and Epidemiology, (306) 966-7977, lilian.thorpe@usask.ca

Purpose and Objective of the Research:

- The purpose of the proposed research is to explore how gay and lesbian adults who engage in or have engaged in deliberate self-harm (DSH) perceive their interaction with healthcare services in the Saskatoon Health Region. Perspectives and attitudes of three self-identified gay men and three self-identified lesbian women over the age of 25 who have experienced deliberate self-harm and have interacted with the healthcare system as a result by conducting semi-structured interviews.
- **The objective of the research is to obtain data to complete a Master's thesis** and to provide insights into the challenges experienced by gay and lesbian individuals during interactions with health services, with the ultimate goal of facilitating quality improvements in healthcare provision to better address specific needs and to improve clinical outcomes relating to DSH. It is also anticipated that this study will be useful in guiding future research in this under-explored field.

Procedures:

- You will participate in a face-to-face individual interview in which you will be asked some questions about your life, any history of deliberate self-harm, and your interaction(s) with the healthcare system. The interview will be recorded with a digital voice recorder and later transcribed by the researcher into a computer for analysis. **Please be aware that you can ask to have the voice recorder turned off at any time.** The interview will take place at either the Avenue Community Centre or at the University of Saskatchewan in Saskatoon. Each interview will be a few hours in duration. The researcher anticipates interviewing 6 participants in total.
- Following transcription of the interviews, you will have an opportunity to review the transcript. A verbatim copy of the interview will be provided to you in written format and you will be able to add, alter, or delete any of the document as you see fit to ensure that

what you said in the interview is accurately documented and that the interpretations of your words reflect your intentions at the time of the interview.

- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

Potential Risks:

- **There may be a risk of emotional discomfort in discussing sensitive issues such as DSH and experiences with healthcare treatment. After the interview, you will be provided with a form that includes several contact numbers of counseling and health services that may be useful to you.**

Potential Benefits:

- This study may not benefit you directly, but may benefit other people in similar situations as you have experienced.

Confidentiality:

- All interviews will be conducted in a private, secure room, and all information collected during the research process will remain confidential, **except in the unlikely situation that the researcher finds you to be at immediate risk, in which case the researcher would have to take appropriate steps to ensure your safety.** All identifying information collected will be removed for analysis and study numbers will be used for all participants to ensure that your contribution cannot be linked back to you.
- **Storage of Data:**
 - All physical data on voice recorders and paper will be securely locked in a filing cabinet that only the primary investigator will have access to. Transcribed and coded data will be securely encrypted and kept on a password-protected computer that only the primary investigator may access.
 - When the data no longer required, the data will be destroyed.

Right to Withdraw:

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your position of employment, class standing, access to services or how you will be treated.
- Should you wish to withdraw, you can do so at any time during data collection without any consequences and your data will be destroyed and omitted from the final study.

- **Your right to withdraw data from the study will apply until completion of analysis. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.**

Follow up:

- Following your participation, you will be asked if you wish to know about the results of the study when the data has been analyzed. If so, the researcher will collect your contact details, and eventually provide a letter including findings and implications. Requests can also be made later by contacting the researcher using the email address at the top of page 1.

Questions or Concerns:

- Contact the researcher using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Consent:

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

Name of Participant

Signature

Date

Researcher's Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Thank you for your participation!

University of Saskatchewan research study

Behavioural ethics approval # _____

Thank you very much helping us with this research project. We understand that sometimes talking about difficult topics leaves people with a need to talk more afterwards. The following resources might be of help to you, and are free.

Mobile Crisis Service:

- Saskatoon Crisis Intervention Service (SCIS) provides comprehensive crisis response services to individuals and families 24 hours each day, 365 days of the year.
- You can call the 24-hour crisis phone line at (306) 933-6200.

Avenue Community Centre:

- The Avenue Community Centre for Gender & Sexual Diversity is a non-profit agency in Saskatoon working to address health and social issues in the lesbian, gay, bisexual, transgender, two-spirit and queer (LGBT2Q) community.
- You can call the regular office number for further information at (306) 665-1224 or the toll-free crisis line at 1-800-358-1833.

Mental Health & Addiction Services:

- A variety of services are offered by Mental Health & Addiction Services. More information can be obtained by phoning the access line at (306) 655-7777.

Suicide Support Saskatoon:

- Suicide Support Saskatoon offers varied services to meet the needs of survivors. For further information contact (306) 249-5666.

The USSU Pride Centre:

- The USSU Pride Centre seeks to work with people of all sexual orientations and gender identities in an open and progressive environment that advocates, celebrates and affirms sexual and gender diversity.
- You can contact the centre by phone at (306) 966-6615, or email at pride.centre@ussu.ca

**Department of Community
Health & Epidemiology
University of Saskatchewan**

**HEALTHCARE EXPERIENCES OF
SELF-IDENTIFIED GAY AND LESBIAN
ADULTS AFTER SELF-HARM**

I am looking for volunteers, aged 25+ to take part in a study about interactions with the healthcare system in Saskatoon after experiencing thoughts or actions of self-harm.

As a participant in this study, you would be asked to take part in a face-to-face private interview about your life, experience with self-harm, and specific healthcare visits.

Your participation would involve 1 session
of approximately 90 minutes.

For more information about this study, or to volunteer for this study,
please email:

Nina McKinstry
Community Health & Epidemiology
at
Email: ninamckinstry@live.com

**This study has been reviewed by, and received approval
through, the Research Ethics Office, University of Saskatchewan.**

Appendix E: Transcript Notation

I chose and modified a version of Gail Jefferson's (1984) transcript notation method for transcribing my interviews. I only employed and included the notations of speech which I believed would best highlight the nuances of my participant's oral and non-verbal narratives which may otherwise have been lost through only text.

^	An upwards arrow marks rising shift in intonation.
(.)	A period indicates a stopping fall in tone or the end of a sentence.
:	A colon points out the extension of the sound or syllable it follows. More than one colon prolongs the stretch.
((action))	Double parentheses are used to enclose a description of various phenomenon ((laugh)) or other details of the conversational scene ((telephone rings)).
-	A dash indicates a halting, abruptly cutoff of a sentence.
?	A question mark indicates a rising inflection, not necessarily a question.
!	An exclamation point indicates an animated tone, not necessarily and exclamation.
<u>text</u>	Underlining indicates emphasis.
<text>	Guillemets indicate a word or sentence is delivered in a rushed speech.
text	Asterisks indicate a word or sentence is delivered in a whisper, or significantly lowered voice.
(hhh)	Three h's in parentheses indicates an exhale.
(#3)	A parentheses with a pound sign and number indicates the number of seconds of silence within or between sentences.