Accessing Intimacy: The Experience of Younger Long-Term Care Residents

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Abstract

The sex and intimacy needs of persons with disabilities are increasingly highlighted in research, particularly during the last two decades. There is also research to examine the experience of staff within long term care related to the sex and intimacy needs or behaviours of long-term care residents. However, there is limited research examining the experience of sex and intimacy from the viewpoint of residents, particularly younger residents of long-term care. This qualitative research study uses a phenomenological approach to explore the experiences of persons with disabilities, under the age of 70, living in a long-term care facility, accessing a sexual and intimate life. Four participants were recruited using a purposive, criterion sample. Through the data analysis, a central theme of *It’s About Belonging* emerged along with four subordinate themes, which include; *Being Different From Others, New Relationships and Connections, Being Left,* and *Staff Facilitated.* The discussion includes suggestions for increased education related to sexuality and intimacy for long-term care staff, the need for increased social work support, and long-term care alternatives. Improvements to the current long-term care system, such as smaller community homes, increased investment in community care are some ways in which the isolations experienced after moving to long term care could be alleviated.
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Dedication

To Chris, thank you for coming along with me on this adventure, as always you were my rock, giving me a solid place to lean when I needed the rest and the push to get going again. My boys, Clark and Bram thank you for your patience. Mom is done school; however, I hope I can continue to show you that learning is never complete.

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Chapter 1 Introduction

Touching, kissing, hugging, intimacy, and sexuality are all aspects of human connections, yet for some, these connections are difficult to attain. Taleporos and McCabe (2001) found that despite being interested in and thinking about sex and intimacy, persons with physical disabilities had a difficult time starting and maintaining sexual relationships due to physical and societal barriers. Human beings are social beings; we respond to touch. It calms us, makes us feel safe and that we belong. Hospitals have long understood the connection between touch and thriving and thus have instituted programs, such as the baby cuddle programs, which have shown that human touch helps improve the health outcomes of premature babies (Benoit, Boerner, Campbell-Yeo, & Chambers, 2016). According to a summary provided by Stadler, Snyder, Horn, Shrout and Bolger (2012), physical intimacy has been shown to decrease heart rate and blood pressure, and increase immune function and oxytocin and serotonin levels. Their own research on the effects of physical intimacy on somatic symptoms such as a headache, insomnia, and upset stomach, indicated that physical intimacy decreases these symptoms (Stadler et al., 2012). According to Seidman (2015), sexologists, such as Kinsey, and Masters and Johnson, argue that sex is a natural instinct, much like sleeping and eating. Yet for persons with disabilities (PWD), intimate touch and connection are often unrequited.

The sexual and intimacy needs of PWD have historically been misunderstood. Their sexuality, demonised, made pathological or ignored altogether. Research indicates that those with disabilities are typically seen as asexual, or hypersexual, and not as a sexual option for able-bodied persons (Davies, D., 2000). In accessing intimacy, PWD
have come up against many barriers, both physical and societal. However, there seems to have been an explosion of research, media, and advocacy all bringing issues of sexuality and intimacy for PWD to the forefront of public discussion (Alexander, 2018; Brabaw, 2018; Burgmann, 2016; Dremousis, 2016; Takeuchi, 2018). All the aforementioned articles highlight that yes, many PWD have sex and want intimate experiences. Sexuality and intimacy for PWD has also been written about differently in academic writings, which has helped to encourage other ways of viewing sexuality and intimacy (Rembis, 2010; Shakespeare, 1999; Shildrick, 2007). During the last several decades, the disability rights movement has encouraged different ways of acknowledging sexuality outside of the heteronormative views of sex and sexuality (McRuer, 2006; Shakespeare, 2000). The evolving perception regarding sexuality is particularly important for those living in long-term care facilities, which have typically ignored the sexual health of residents (Davies, D., 2000). There has been much research in the last twenty years, which recognises the importance of continued access to sex and intimacy while living in long-term care facilities; however, this research has focused mostly on older residents over the age of 65 (Mayers & McBride, 1998). There is a small but growing population of younger disabled residents who have been ignored in much of the research.

A review of the long-term care population published by the former Saskatoon Health Region (2015), indicates that 12.41% of residents in long-term care were between the ages of 18-70. According to its SnapShot report in 2017/2018, the Canadian Institute for Health Information (2018), records Saskatchewan long term care residents under the age of 64 making up 9.8% of the provincial long term care population. The demographics of the long-term residents are changing and so too must the delivery model of long-term
care. Delivery models must consider the whole person and include a diverse way to meet the needs of residents at different stages of life.

Increasingly, there is an understanding that long term care and rehabilitation staff require increased education focused on the sexual health needs of young disabled residents so that they may be supported to enjoy ongoing sex and intimacy experiences (Canadian Healthcare Association, 2009; Mayers & McBride, 1998). This research provides insight into the experiences of younger residents accessing a sexual and intimate life while living in long term care, which will help staff develop programming, and policy to better meet the needs of this long-term care population.

1.1 Purpose of Research

The purpose of this phenomenological research project is to understand better the experiences of PWD, who are under the age of 70 and living in a long-term care facility, accessing a sexual and intimate life. In addition, the research project helps to understand what policies, systems, and supports are currently in place to both support and obstruct their efforts in long term care facilities in Saskatoon, Saskatchewan. Understanding the experiences of persons with disabilities who are accessing a sexual and intimate life in long term care will also help to guide social workers in their roles to better support and empower PWD living in long term care.

1.2 Role of the Researcher

Both Moustakas (1994) and Van Manen (2014) indicate that the researcher should write out their experience of the phenomena to make clear what the position of the researcher is. As an ally of people with disabilities, I became interested in the experience of sex and intimacy in long term care while I was working as a social worker in long term
care. I often felt that resident sexuality and intimacy needs were not addressed, or at the very least done so disrespectfully. Staff were given no clear guidelines and reacted at times with disgust, and if they did want to help, they did not know how. Conversation with residents nearly never addressed their need for intimacy, and when it did, it was centred on how lonely they were. One conversation struck me as being the central theme. One day a resident came to my office door to talk. Our conversation moved to his feelings of loneliness and depression, as they often did. However, this time, he could articulate that other than the ability to move his arms or legs, what he missed most and desired most was human intimacy. He was touched daily by care staff, yet the touch was therapeutic based, such as physical therapy exercises or task-oriented such as bathing or dressing. He longed for touch outside of caregiving; he needed to be hugged, to be caressed and kissed. It was more than sex; it was to feel an intimate connection with someone else the way he once had. From this conversation, I began to think more about how although long term care staff try hard to meet the psychosocial and spiritual needs of residents, institutional care as it is now, has limits to what support is offered for intimate, social, and sexual opportunities. It is not only the current long-term care model which places limits on PWD, but also society and its view of disability, sexuality, who can be sexy, and who has the privilege of engaging in acts of intimacy. It is also more than the act of sex; it is how we connect with each other and interact in intimate human ways.

1.3 Definitions

1.3.1 Disability.

For the purpose of this research, the term disability refers to an evolving concept, resulting from the interaction between persons with impairments and attitudinal and
environmental barriers that hinders their full and effective participation in society on an equal basis with others as suggested by the United Nations Convention on the Rights of Persons with Disabilities (UNCRDP). Article 1 of the UNCRDP further clarifies that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006). Another widely used definition of disability is from the World Health Organisation (WHO), based on the International Classification of Functioning, Disability and Health (ICF). The ICF was created to standardise the language and descriptions of health and a framework on which to define disability (World Health Organization, 2002). The ICF defines disability as a continuum, which changes based on environmental, societal, access to services, and level of health (World Bank & World Health Organization, 2011). Canada has used this same definition to define disability within the Canadian census.

The definition of disability has generated public debate over the years. Currently, Merriam Webster (www.merriam-webster.com) defines disability as “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions”. This definition is typically how disability has been defined and fits with the medical model of disability. However, disability is more nuanced than this. Disability also includes a societal component because of the way society chooses to perceive those who are differently abled.
1.3.2 Sexual life and Intimacy.

A sexual life is defined as ‘access to sexuality’, defined by the World Health Organisation (WHO) working definition of sexuality, which states:

A central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors (WHO, 2006).

Intimacy is more challenging to define. Merriam Webster online defines intimacy as “the state of being intimate: familiar” or “something of a personal or private matter”, while the Cambridge dictionary online defines intimacy as “a situation in which you have a close friendship or sexual relationship with somebody”. Mashek and Aron (2004) suggest that intimacy cannot necessarily be defined; rather, it is something that is experienced. They posit that there are common themes which “include such features as a sense of connectedness shared understanding mutual responsiveness mutual dependence self-disclosure or intersubjectivity” (p.417).

1.3.3 A sexual and intimate life.

These terms refer to the ways participants have sexual and intimate connections with others; these connections may be defined differently depending on the person and their understanding of what sex and intimacy are.
1.4 Research Question

The research question for this project is: What are the experiences of PWD, under the age of 70, living in a long-term care facility, accessing a sexual and intimate life?

There are several reasons why this research question is significant. Firstly, although there is literature exploring sexuality within long term care facilities (Bauer, Nay, & McAuliffe, 2009; Bauer, Fetherstonhaugh, Tarzia, Nay, & Beattie, 2014; Bentrott & Margrett, 2011; Bradley, 2016; Breland, 2014; Elias & Ryan, 2011; Everett, 2007; Everett, 2008; Vacha-Haase & Hinrichs, 2010), there is minimal literature which explores the experience from the long term care resident’s perspective (Aizenberg, Weizman, & Barak, 2002; Frankowski & Clark, 2009; Mahieu & Gastmans, 2015). Further, there is a research gap regarding the experience from the voices of younger residents between the age of 18 and 64 who are living in long term care. Secondly, as the next generation ages, there will be demands made on the long-term care system to change how care is provided. These changes may include policy change related to sexuality in long term care and how it is addressed or supported by staff.

Within the Canadian context, the Vancouver Coastal Health Authority (Breen, Carlson, Clements, Everett, & Young, 2009) has created a policy guideline document to help support staff in situations where residents express sexual and intimate needs. It outlines the rights of the resident, clarifies the responsibility of the facility, defines the roles and responsibilities of staff, describes staff education programs, and offers suggestions to increase privacy. Policy documents such as this are important, because the baby boomers (ages 51-69), and generations after have a more open view of sexuality due to growing up in the 1960s during the sexual liberation era, which is likely to influence
the current long term care home policies in terms of addressing this need (Frankowski & Clark, 2009). This research documents the experiences of current long-term care residents and helps to guide future policy and education needs of care and support staff, such as social workers. This research is explored through a critical, constructivist, social justice, and feminist lens, which helps to understand the power relationships between caregiving, institutions, disability, and those PWD accessing a sexual and intimate life while in long term care.
Chapter 2. Literature Review

2.1 Introduction

To understand the current context of PWD, living in long-term care, and their access to sexuality and intimacy, we must first understand how historically, PWD have been cared for and viewed within society. The literature review explores the history of institutionalisation and deinstitutionalisation of PWD and sex and intimacy within the context of long-term care.

2.2 History of Institutionalisation

Early accounts of care for PWD in institutions begin in England in the 19th century after the passing of the poor laws (Davies, M. J., 2003). Before this time, care was provided by churches and monasteries, which were tasked with caring for the poor and chronically ill. Over time, the population in need increased, and churches were no longer able to continue with the same level of support (Davies, M. J., 2003). The enactment of the poor laws in England instituted the poor rate, which was taxation on a property to help fund relief for the poor. Funds were distributed among the aged, sick and deserving poor. Support for the poor started with the out-door relief (individuals could stay in the communities while receiving help) and later shifting to in-door relief (poor houses and houses of industry). Those who were viewed as more deserving, such as the elderly, children, and infirmed, were sent to workhouses where they worked for their upkeep. The undeserving poor, such as vagrants and criminals, were sent to houses of correction or poor houses. However, after the industrial revolution, the poor rate was increased, and the division of funds was eliminated. Everyone, no matter of age or ability, was sent to the poor house (Davies, M. J., 2003).
This was also true within Canada. Institutional care for the elderly and disabled began in the 1800s in the form of poor houses or houses of refuge. These homes provided housing for the poor, criminal, and the vagrants of society. Invariably, within these populations were the elderly and the disabled. These homes were predominately operated by churches and religious groups, with a focus on custodial care. However, in the mid-1800s, ownership began to drift into municipality control and eventually evolved to fall under medical care (Kishchuk & Kishchuk, 2010). By the 1900’s the care of children, the disabled, and elderly were separated, and the eventual establishment of long term care for the elderly and asylums for PWD was created (Davies, M. J., 2003).

2.3 Care of Persons with Disability

As the 1900s progressed, the care of PWD shifted from poor houses to larger institutions and asylums. This shift was partly encouraged by the Eugenics movement. As Withers (2012) describes, “Eugenics is the belief that human evolution can be crafted by the encouraged breeding of people who are considered the most desirable -the ‘fit’- and the discouraged breeding of those who are considered the least desirable – the ‘unfit’” (p.13). With increasing concern over the fitness of society and a belief that PWD were undermining the health of society, eugenics offered a solution (Withers, 2012). Persons with a disability were frequently associated with crime, poverty, physical degeneration and sexual immorality; and therefore, to protect society, the solution to this threat was to segregate PWD from the general population and place them in institutions (Simmons, 1982). There were also other punitive measures for persons with disability, including sterilisation.
In the early 1900s, the custodial movement gained momentum in Canada. Custodial care protected the feeble-minded from the rest of society who could be vicious towards them; and custodial care also protected the rest of society from the feeble-minded (Simmons, 1982). Within institutions, PWD suffered abuses, which included seclusion from family, as well as physical, psychological and sexual abuse (Humphries & Gordon, 1992). In Canada, these abuses also included forced sterilisation, which, as Malacrida (2015) suggests was the culmination of the eugenics discourse. Sterilisation was viewed to be an alternative to a life of institutionalisation. Without the threat of procreation, those who were deemed unfit and a threat to the health of society could safely be released back into society (Malacrida, 2015).

Other abuses within institutions have been documented as well. In his account during his time as Director of the Division of Mental Retardation\(^1\) with the Department of Mental Health in the United States, Blatt (1970) describes the state of institutions for the ‘mentally retarded’ at the time. He describes buildings in disrepair, dormitories so full “that it was impossible, in some dormitories, to cross parts of the room without actually walking over beds.” (p.13-14). He describes seeing children with their legs, hands or waists bound and restrained.

Although the institutionalisation of persons with physical disabilities also occurred (Humphries & Gordon, 1992), documentation of their experiences is limited. Instead, they were moved into long term care homes as disabled, elderly residents. Over time as long term care developed, invariably younger residents moved in.

\(^1\) The term Mental Retardation is no longer used however at the time the book was published this term was used frequently, and still is used in some parts of the United States.
2.4 Nursing home care

Institutional care, specifically for older adults with disabilities, evolved into nursing homes. However, nursing or long term care homes did not begin until the post-war era when older adults began to be recognised as a distinct social group (Emodi, 1977). Many of the early long-term care homes began under religious organisations who felt obligated to care for those older adults without family to care for them. After World War II as medical care evolved, so too did the nursing homes we know today. Care moved to more specialised medical care provided by nurses and physicians. Governments took over funding of homes and created legislation and regulations (Brandeis & Oates, 2007). Nursing homes have also become the predominant institution for younger people with physical disabilities, whose care needs, such as specialised wound care, occupational therapy or nursing care, are not able to be met at home (Marshall, 2008).

2.5 Deinstitutionalisation

During the mid-20th century, there were small groups of professionals and families who questioned the existence of large institutions. This was supported by medical advances and the demise of eugenics. There was an increasing understanding that feeble-mindedness was not hereditary, and therefore, those inflicted did not pose a risk to the gene pool and could be supported to live outside of institutions. It also became clearer that large institutions were increasingly overcrowded and expensive to run, and governments were looking to downsize. However, it was not until the 1970s, and 1980’s that deinstitutionalisation began in Canada (Simmons, 1982). Several factors instigated the push for deinstitutionalization. In Canada and the United States, there were highly publicised reports and tours of institutions, which drew attention to the state of the
institutions (Malacrida, 2015; Simmons & National Institute on Mental Retardation, 1982). These reports shocked the public, who then pressured the government to address the inhuman care provided in institutions.

As deinstitutionalisation gained momentum, so too did disability rights and new ways of understanding disability and approaches to care. The trend towards community care evolved and emphasised care within group homes, supported by family and social networks (Niles, 2013). However, as Niles (2013) suggests, the move to the community was not always well planned, and it left families overburdened, and those without family living in poverty, on the streets, or (re)institutionalised in a hospital or correctional facilities. Niles (2013) argues that the move to community care was based mostly on budget constraints and the desire from the government to cut costs.

Although persons with physical disabilities were also in institutions, the reality of deinstitutionalisation was not always theirs. With the growth of nursing homes, those with physical disabilities were often moved into these care facilities (Legal Aid Atlanta, 2019), and the opportunities for community living were, and remain limited. In 1990, the US federal government passed the Americans Disabilities Act (ADA), which recognised that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem” (Legal Aid Atlanta, 1990).

The ADA has been used many times to support cases of discrimination against PWD, most significantly in 1995 in Helen L. v Didario. This case involved a young mother with a physical disability who was living in a long term care facility. She used
section 2 of the ADA, which states “a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” to argue for her right to receive funding to receive attendant care in the community, at home (Michigan Law University of Michigan, 2019). This would prove to be a significant ruling for the landmark case of Olmstead v. L.C. in Georgia.

According to the Olmstead website, in 1995, the Olmstead case began in Georgia and involved two women who were in institutional care. Although the medical staff agreed that they did not need to be in institutional care, these women did not have access to the community funding and care which was required to be successfully be discharged from institutional care. Legal aid lawyers took their case and used the verdict from Helen L. v. Didario case to support their argument using section 2 subsection 35.130 of the ADA to fight for community care options. The court case went all the way to the Supreme Court and in 1999 was ruled that the state of Georgia and all states needed to provide access to community care for PWDs. The Olmstead verdict has been influential in numerous cases since and is now known as Olmstead Rights.

Within Canada, there are no clear laws of such nature. Instead, there is a tapestry of reports and policies (McColl, Schaub, Sampson, & Hong, 2010), beginning most significantly with the Canadian Charter of Rights and Freedoms. Specifically, section 15 of the charter states “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability”(Government of Canada, 1982).
Secondly, The Canadian Human Rights Act outlines universal human rights all Canadians should enjoy. Within the purpose, it states:

All individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability (Government of Canada, 1985).

Despite this, there remains no federal disability act in Canada, though the federal government has discussed it for many years. In 2016, the newly elected Liberal government reaffirmed the government’s commitment to the creation of such an act and set up community consultations to influence the creation of a disability act. Such an act has yet to come to fruition.

The discussion of the rights of PWD is in several UN documents; however, most importantly, the Universal Declaration of Human Rights (United Nations, 1948) outlines rights that everyone is entitled to. Specifically related to housing, Article 3 ensures the right to liberty, article 12 ensures the right to be free from interference with privacy, article 21 ensures equal access to public service, article 25 ensures standards of living for health and wellbeing, including housing. Finally, article 27 ensures rights to a cultural life. The rights of PWD gained greater importance when the UN declared the International Year of Disabled Persons in 1981. The objective of the year was to bring attention to disability and promote acceptance of PWD.
Following this year, there was increasing recognition that the rights and integration of PWD needed more focus, so in 1983, the UN went further and declared a decade of Disabled Persons. During this time, the UN released the World Programme of Action Concerning Disabled Persons. This document outlined many actions that member states could take to ensure full participation of PWD in society. Finally, in 2006, the United Nations released the Convention on the Rights of Persons with Disabilities, which offers a comprehensive rights document for all aspects of life. Specific to housing and long-term care, Article 19 outlines the rights of PWD to live in the community. It specifies that PWD have the right to “choose their place of residence and where and with whom they live on equal bases with others and are not obliged to live in a particular living arrangement;” it goes on to state “Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;” (United Nations, 2006). Importantly, in 2006, Canada became a signatory to the UN CRPD and therefore must uphold the agreements set within.

2.6 Sex and Disability

The sexuality of PWD over the last several centuries has been imagined to be asexual and childlike, and in need of protection, or as sexual deviants with an insatiable appetite. As Humphries and Gordon (1992) indicate, in the early part of the 1900’s segregation of boys and girls in educational and recreational activities was common. However, it was even stricter with PWD. PWD had been thought of as being highly promiscuous and fertile, and this was an issue for eugenicists who strongly believed that
feeble-mindedness and disabilities were passed down through heredity and were the main cause for unemployment, criminality, and alcoholism. Their solution was to prevent disabled persons from reproducing and in doing so would maintain racial purity. Over time eugenics grew out of favour and the sexuality of PWD became dominated by medical professionals, seeking to control their bodies.

Sexuality and disability remain pathologised within medicine. In rehabilitation, the discussion regarding sexuality is typically ignored, or discussed within the context of the physical mechanics of sex and helping to ensure an erection is obtained, or that sensation is felt (Eisenberg, Andreski, & Mona, 2015). There is little attention given to the psychosocial components of sexuality and intimacy.

However, there are those in disability research who are attempting to make visible the sexual experiences of PWD. Research has begun to explore disability and sexuality from the everyday lives of disabled people (Rembis, 2010). Much of this research and writing is challenging the heteronormative and able body presumptions of the medical model, challenging the beliefs of who and what is sexy (Esmail, Darry, Walter, & Knupp, 2010; O'Toole, 2000; Rembis, 2010). McRuer and Mallow (2012) pose the question “what if disability was sexy? What if disabled people were understood to be both subjects and objects of a multiplicity of erotic desires and practices?”(p. 1) Newer understandings of sex and intimacy are emerging, which position sexuality outside of the act of penetrative sex, and there is a greater emphasis on intimacy and feelings of connectedness and belonging, of different ways of being a sexual being (Shakespeare, 2000).
2.7 Sexuality in Long Term Care

According to the Canadian Healthcare Association (2009), in 2006, approximately 299,390 Canadians were living in long term care facilities, and approximately 24,000-25,000 of those were between 15-64 years old. This report also outlines that many seniors are admitted into long term care facilities following dementia, stroke, or falls, whereas younger disabled residents move when familial care breaks down, or there is no other alternative option due to care needs. Historically facility-based long term care is managed like an institution, where care has focused on tasks and documentation (Canadian Healthcare Association, 2009). One of the consequences of the predominance of the medical model and custodial care within long-term care facilities is the neglect of the psychosocial and spiritual needs of residents (Canadian Healthcare Association, 2009). However, increasingly there is an acknowledgement of the need for the whole person, or resident centred care (Bentrott & Margrett, 2011; Li & Porock, 2014; Syme et al., 2017), which emphasises care directed by the resident.

Sexuality in long term care is increasingly researched, particularly over the last 20 years. Most of this research has focused on the sexual behaviours of older adults with a diagnosis of dementia (Mahieu, Anckaert, & Gastmans, 2014; Roelofs, Luijkx, & Embregts, 2015; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). Within this research, sexual behaviour is examined within the context of staff strategies for managing sexual behaviour (Aizenberg et al., 2002; Villar, Celdrán, Fabà, & Serrat, 2014), family reaction to their loved one’s sexual behaviour (Bauer et al., 2014), or with the controversies related to consent surrounding sexual activity (Mahieu & Gastmans, 2012; Syme & Steele, 2016). There are a few studies which have explored the sexual and intimacy
experiences of residents of assisted living homes and long-term care homes. Much of the literature has indicated that residents face several barriers to sexual and intimacy activities.

A literature review completed by Mahieu and Gastmans (2015) suggests that residents of long term care continually are challenged by a lack of privacy and privacy of information, limited availability of sexual partners, and negative staff attitudes towards older adults and sexual activity. Marshall and Baffour (2011) also indicate that privacy and access to private space is a challenge in long term care. Residents may not have their own room and may be forced to share a room with several other residents. It has been reported that care staff enter rooms without prior permission (Marshall & Baffour, 2011). Access to meeting new people, who may be a viable sexual partner is limited. It has been reported that many residents in long term care facilities feel segregated and isolated from the general community (Magasi & Hammel, 2009; Parish & Lutwick, 2005). They do not regularly participate in community activities, or socialisation, such as going to the bar for a drink, or the movies.

Despite the move to more person or resident centred care, many researchers have noted that the preoccupation of care remains on the tasks of caregiving (Braedley & Martel, 2015; Donnelly & Macentee, 2016). Research completed by Wiersma and Dupuis (2010) highlights the experience of residents’ bodies becoming institutional bodies. Through the acts of caregiving and policies in place within the long-term care facility, they argue, that bodies become objects of care and owned by the institution. If residents are merely objects of care, how then can they be considered sexual? When residents are considered sexual, it is most often defined within a behaviour resulting from dementia,
which is seen as negative and in need of being managed or controlled (Bauer et al., 2009).

2.8 Summary

This section has contextualised the experience of PWD, institutionalisation, and sexuality within society over the previous 150 years. It has covered the history of institutionalisation and deinstitutionalisation of PWD. The history of segregation and human rights violations are important to understand the perceptions of the sexuality of PWD and the need for intimacy. The complex understanding and evolution of disability were also examined to give context to the experience of PWD and how they are shaped by and are shaping society. Although society is shifting its understanding of disability and sexuality, the medical model continues to be how long term care is delivered under the medical model. Institutions are set up to benefit staff, lacking privacy and autonomy for residents. Although there are shifts to provide person or resident centred care, which would embrace the sexual and intimacy needs and desires of residents, these changes are slow to materialise.
Chapter 3. Philosophical Assumptions

3.1 Overview

Understanding the theoretical or philosophical assumptions is an important part of the research process. According to Creswell (2013), these assumptions help to form the research question and the approach for exploring. This chapter begins with a summary of the leading models or theories through which disability is understood, as well as a brief discussion of new theories. Theories of sexuality are also explored before a self-reflection on my own philosophical assumptions. Denzin and Lincoln (2011) state that all researchers have thoughts about what is the nature of reality, what is the relationship between the inquirer and the known and how we gain knowledge of the world (p. 12). Philosophical assumptions have three components, ontology, epistemology, and methodology (Creswell, 2013; Denzin & Lincoln, 2011). Ontology relates to the way we understand the world (Creswell, 2013), and the nature of our reality (Denzin & Lincoln, 2011). Epistemology is how we know (Creswell, 2013; Denzin & Lincoln, 2011), and the methodology is “the best means for gaining knowledge about the world” (Denzin & Lincoln, 2011, p.91).

3.2 Theoretical Framework

There are three dominant models in which disability has typically are understood. The three models include the medical, social and critical realism models. There have been and continue to be many models in which to understand the construct of disability. As Withers (2015) notes “There are so many models for inventing and understanding disability because disability is not a fixed category. Rather, it is a fluid definition that depends on not only the context in which it is defined but also who defines it” (p.3).
Disability has, for the most part, is viewed as either something within the body, such as in the medical model or because of an unwelcoming society, as described in the social model. However, other models are growing in response to a criticism of the social model. These models are more critical of societal beliefs of disability and impairment. Critical models position disability not as an impairment, but as a different way of being, which society has not yet accepted. Finally, critical realism acknowledges the criticism of the medical and social models, however, also acknowledges the reality of impairment which can be physical pain and exhaustion; and argues that society is not responsible for this reality.

3.2.1 Medical model.

Until the 1980’s the medical model had been the predominant view of disability. This model places disability at the biological or individual level, viewing disability as something abnormal with the body and in need of intervention. As Withers (2012) notes, disability, under the medical model, is pathologised and controlled by medical experts. It continues to oppress PWD and ignore the social structures which oppress. From a medical perspective, bodies are compared against each other to create a normal. Using the bell curve as a diagnostic tool, those who do not fall within the average are then considered abnormal and subject to professional medical expertise (Withers, 2012). However, even within this, there is room for interpretation. Withers (2012) gives the example of dwarfism, which by medical standards is an affliction suffered by those who measure less than 4 feet 10 inches. For those who belong to a cultural group who are typically shorter in stature, they are exempt from this definition of disability.
A criticism of the medical model evolved, as disability activism grew during the 1970s. There was a shift in thinking and a new approach to understanding disability developed. No longer was disability seen as a failed body; instead, disability is viewed as the consequence of an unaccepting society.

3.2.2 Social model.

The social model of disability grew from a criticism of an economic world shaped by industrialisation and urbanisation which, as Barnes (2012) describes justified “the systematic removal of disabled people from economic and social life” (p. 13). As Oliver (2013) notes, the social model of disability is rooted in the belief that people are not disabled by their impairment, but rather by the barriers placed by society. It is this understanding of disability, which pushed forward disability rights. Hughes and Paterson (1997) state “in focusing on how disability is socially produced, the social model has succeeded in shifting debates about disability from biomedically dominated agendas to discourses about politics and citizenship” (p.325). It created discussion and change regarding access to buildings, transportation, workplaces, education and leisure and changed laws to recognise the rights of PWD (Oliver, 2013). The social model provided a way to understand how society creates disability and provided a way forward to a more inclusive policy (Barnes, 2012). Critique of this model evolved as PWD continued to experience discrimination. Some conclude that physical access to space is not enough.

3.2.3 Critical model.

Overtime criticisms of the social model became dominant in the literature (Goodley, 2013; Hughes & Paterson, 1997; Shuttleworth, 2007). Critics of the social disability movement agree that physical access to society was and continues to be an
issue, however as Goodley (2013) suggests, focusing on material access can only account for part of the experience for PWD. Understanding the how isn’t enough for change, critical disability thought aims to understand the why (Shildrick, 2012). For advocates of the critical model, making physical access and social conformity key to social acceptance does not challenge the norm of the able body. Withers (2012) notes, disability is a social construct, as much as the able body is, and it is this construct, which perpetuates the able body as the norm. For Shildrick (2012) critical disability studies questions why a disabled body cannot be a possibility among many options as a way of being. For others, the critical model does not challenge the normative ways of being enough.

3.2.4 Crip theory.

While building on critical disability perspectives, McRuer (2006) further questions the assumptions of a compulsory able-bodiedness within Western society. With the introduction of Crip theory, McRuer (2006) adds to the criticism of the heterosexual, able body as the norm. Crip theory posits that disability and ability are social performances. Crip theory disrupts the cultural performances and encourages people to embrace their impairments and “come out Crip” (McRuer, 2006). Others, such as Alison Kafer (2013), propose that Crip theory is inclusive of anybody who rejects the social norms. These include friends, family and other allies of PWD, as well as others who feel they just do not fit the mould. However, there is also a criticism of the above theories, which considers the reality of impairment as disabling.

3.2.5 Critical realism.

To not romanticise disability, Shakespeare (2014), provides a criticism of both the social model and what he calls cultural disability theory, noting that physical access and
psychosocial access does not change the reality that impairment itself can be disabling. The physical pain and exhaustion of impairment can make going about life difficult, as well as the predominance of social norms based on able-bodiedness. For Shakespeare (2014) then, “critical realism offers a non-reductionist perspective, in which neither culture nor economics nor biology dominates” (p.74).

Understanding from critical realism acknowledges that there is not one theory or model with which to understand disability and the interaction with society because as Shakespeare points out, it allows for complexity. Through a critical realist approach, disability is a relational concept which considers the interplay and relationship of many factors including both individual factors such as personality, and the nature of impairment and structural factors such as societal attitudes, accessibility, and economics (Shakespeare, 2014). Within the newer models of disability, sexuality and disability are also being explored, challenging what it means to be sexual.

3.3 Views of Sexuality

Human sexuality has been a topic of concern for many thousands of years with many theories to understand why we are sexual. The most basic understanding is biological. According to biology, we are sexual beings to procreate, and this is driven by hormones (Bancroft, 2002). We are attracted to strong, non-disabled individuals who will help to ensure the procreation of strong, able-bodied offspring who will carry our genetic makeup for generations to come (DeLamater & Hyde, 1998). Biology can only account for part of human sexuality, and many believe that sexuality is socially constructed.

Sexuality, according to constructivist theories, is shaped by social scripts, interactions and norms within society (Baber & Murray, 2001; DeLamater & Hyde,
Human sexuality, according to Foucault (1978), was created and controlled by the ruling class beginning in the 1800s. Under the guise of repression, the bourgeoisie has controlled the narrative of sexuality, first to maintain and control their dominance and ensure a healthy elite, and then to control the production of goods and services provided by the lower class. Accordingly, only those who are strong and capable were encouraged to reproduce; the discourse of sex is controlled for the outcomes of those in power. This belief plays well into Marxist thought, which according to Seidman (2015), suggests that sexuality is reserved for marriage and the purpose of sex was only a means to produce the next group of workers. If one was disabled and therefore not able to reproduce, then they were of no use to the working society.

Intimacy is also recognised as an essential part of mental and physical health. Research completed by Floyd et al. (2005) showed that not only does receiving affection and intimacy reduce stress and depression, so too does giving affection. Additionally, there has been shown to be a relationship between quality of life and reported satisfaction with personal relationships, sexuality, and intimacy (Robinson & Molzahn, 2007). As the authors point out, the results indicate that the sexual and intimacy needs of individuals should be supported to increase the quality of life (Robinson & Molzahn, 2007). This is something that everyone has the right to.

3.3.1 Sexual rights

Sexual rights is an emerging topic in literature, international communities and non-government organisations for the last half century (Ali, Kowalski, & Silva, 2015; Dixon-Mueller, Germain, Fredrick, & Bourne, 2009; Dupras, 2015; Kontos, Grigorovich, Kontos, & Miller, 2016; Miller, Gruskin, Cottingham, & Kismödi, 2015; Starrs &
Anderson, 2016). The evolution of what has constituted sexual rights has been central to much of the discussion. Many agree that the beginnings of sexual rights came with the momentum gained by the feminist and women rights movement (Giami, 2015; Starrs & Anderson, 2016), which focused on women’s rights to control their fertility. Within this movement, the International Planned Parenthood Federation has advocated for access to control of fertility, family planning, and sex education for all (Giami, 2015). Over time, a broader understanding of what sexual rights encompass has grown, and they are now recognised as human rights and citizenship rights and are framed within social justice discourses (Kontos et al., 2016).

The more recent shift in focus away from only fertility rights to the inclusion of the right to sexual pleasure is led by The World Association for Sexual Health (WAS). In its Millennial Document, chapter 8 solely focused on establishing sexual pleasure as a valid part of sexual health. As noted in the Millennial Document concluding remarks,

> Within the totality of human development, the experience of sexual pleasure and fulfilment must be recognised for what it truly is; a basic human need on par with other basic requirements necessary for a healthy and productive life. This reality must be reflected in sexual health promotion policy and programs aimed at contributing to healthy community development. (WAS, 2008, pp.141-142)

This sentiment is evident in both the United Nations and the World Health Organisation statements regarding sexual health. In their working definition, the WHO offers this definition of sexual health to the ongoing discussion,

> Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or
infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (WHO, 2006)

The WHO working definition recognises the possibility of having sexual experiences, such as intimacy, and sexual relationships, as part of sexual health. Despite this, concrete developments of sexual rights documents have stalled due to the influence of conservative political influences (Dixon-Mueller et al., 2009; Higgins, 2010; Schaaf, 2011). This influence is seen within the UNCRDP (2006). The convention placed rights for PWD as central within human rights. The convention also discussed the rights to sexual health for PWD, however, as Schaaf (2011) argues, the influence of more conservative countries and religious groups weakened the language used to discuss the right to full access to sexuality. It remained a water downed version of what was originally proposed.

One conversation about sexuality has taken place which frames sexuality through the establishment of sexual citizenship, an idea that citizenship rights would be extended to include not only race and gender but disability as well (Kontos et al., 2016). Citizenship is one way in which human rights are materialised (Basok, Ilcan, & Noonan, 2006) and as Sieber (2012) posits sexual citizenship would include access to information about sexuality, would ensure the right to freedom of association, and would place the sexual needs of people as part of health care.
3.4 Ontological Assumptions

Ontology is concerned with the nature of reality (Creswell, 2013). A constructivist ontological view suggests that reality and experience are multiple and dependent on the interpretation of the individual. Lincoln, Lynham and Guba (2011) summarise “that we construct knowledge through our lived experiences and through our interactions with other members of society” (p. 102). While I agree with the above statement, I also believe that reality is created within a power relationship understood within a critical framework (Lincoln, Lynham, & Guba, 2011). A critical framework contends that power relations mediate our thoughts and that there are certain groups in our society which hold more power, or are more privileged than others (Kincheloe, McLaren, & Steinberg, 2011). For this reason, the basis of my ontological assumptions is a critical constructivist view, where we construct our realities within historical, cultural, and social contexts. As Steinberg (2014) posits “we create ourselves with the cultural tools at hand”. Our reality is created within the context of our social location, which includes gender, age, ethnicity, geographical location, class, sexual orientation, impairment or level of disability, and time. The realities of a PWD living in Saskatoon, Saskatchewan is different from a PWD living in another city, town, province, or country. The context of these realities is also dependent on the time; someone living with a disability in the 1970s would have a different experience from today as society has changed.

I am interested in understanding the experience of residents under 70 accessing a sexual and intimate life while in long term care while recognising that the historical and social history of PWD, institutionalisation, and power dynamics contribute to the
construction of these experiences. I believe that, as Kincheloe, McLaren and Steinberg (2011) indicate, knowledge has come from those in power, and I believe that PWD are marginalised. Knowledge and understanding of their experiences are disseminated from the medical community or others. As is evident in the gap in research, their voices have not been heard when it comes to experiences of intimacy and sexuality within long term care. Through understanding and approaching research with a critical consciousness, Holstein and Gubrium (2011) suggest that “the everyday realities of our lives, whether they are being normal, abnormal, law-abiding, criminal, male, female, young, or old – are realities we do. Having done them, they can be undone” (p. 353). Steinberg (2014) goes further, stating that “knowledge is constructed in the mind of human being, minds that are constructed by the society around them” (p. 204). I believe that through understanding the context within which these realities of been constructed, we can work to deconstruct and rebuild more equal ones.

A feminist lens fits well to this research because as Garland-Thomson (2002) indicates, feminist theory “investigates how culture saturates the particularities of the body with meaning and probes the consequences of those meanings” (p.3). While making arguments for a feminist disability theory which questions the “dominant assumptions that disability is something that is wrong with someone”, Garland-Thomson (2002), goes on to indicate that by using a feminist lens to understand disability it “mobilizes feminism’s highly developed and complex critique of gender, class, race, ethnicity, and sexuality as exclusionary and oppressive systems rather than as the natural and appropriate order of things” (p.6). Tied to a feminist lens is critical studies, such as the emerging critical sexuality studies. Critical sexuality examines not only the relationship
of power, the social construction of gender, race, class, and sexuality but also “focuses on those who are overlooked in sexuality research because of the abject status” (Fahs & McClelland, 2016). Research that is guided by critical sexuality studies acknowledges who and what is silenced in research and which experiences are presented as universal (Fahs & McClelland, 2016).

I also believe that a social justice framework is compatible with a critical approach. According to Creswell (2013), a social justice framework leads to an understanding of “the conditions that serve to disadvantage and exclude individuals or cultures, such as hierarchy, hegemony, racism, sexism, unequal power relations, identity, or inequities in our society” (p.34). As Ife (2012) indicates, research can provide a way for the voices of the oppressed to be heard.

### 3.5 Epistemological Assumptions

Epistemology is concerned with how knowledge is acquired, which, according to Creswell (2013), within qualitative research, is obtained by “getting as close as possible to the participants being studied. Therefore, subjective evidence is assembled based on individual views” (p.20). A constructivist approach understands realities as multiple and meanings of reality are constructed by individuals and their interaction with others. My epistemological assumptions are based on constructivism, which suggests that the findings within research are co-created and understood by both the researcher and the participant. Furthermore, it is from this learning and understanding that change can occur, and empowerment is sought (Lincoln, Lynham, & Guba, 2011), meaning that reality is co-created.
3.6 Summary

This chapter outlined the philosophical assumptions, including a summary of the three dominant models of understanding disability, medical, social, and critical, as well as emerging models and theories. Theories of sexuality and the emergence of sexual rights were discussed, as well as my own epistemological and ontological assumptions.
Chapter 4. Methods

4.1 Overview

This chapter provides a summary of the methodology used within this research, the recruitment strategy, data collection method, and data analysis. Methodology is concerned with the process of how we approach research. My approach is one of qualitative research which is an inductive approach, meaning that inquiry is discovered from the ground up rather than starting with a theory (Creswell, 2013). Denzin and Lincoln (2011) suggest qualitative research is the site for “critical conversations about democracy, race, gender, class, nation-states, globalisation, freedom, and community” (p. 3). Qualitative research seeks to understand the meaning of social phenomena people experience (Denzin & Lincoln, 2011). I employ a phenomenological approach to understand the experiences of PWD, under the age of 70, living in a long-term care facility, accessing a sexual and intimate life is used within this research.

4.2 Phenomenology

Phenomenology is described throughout the literature as both a philosophy as well as a methodology (Byrne, 2001). As a philosophy, phenomenology provides an explanation for understanding knowledge separate from a quantifiable way (Byrne, 2001). Rather, phenomenology considers knowledge as coming from everyday life experience (Byrne, 2001; Flood, 2010). Phenomenology, as a research method, seeks to explore the lived experience of a phenomenon through questioning and wonderment (Van Manen, 2014). Its roots began with the philosopher Husserl who believed that human consciousness shaped experiences (Koch, 1995; Lopez & Willis, 2004) and that “subjective information should be important to scientists seeking to understand human
motivation because human actions are influenced by what people perceive to be real” (Lopez & Willis, p.727). Furthermore, the experience of everyday life is unknown as much of the experience is based on common sense or that which is taken for granted (Koch, 1995; Lopez & Willis, 2004). It is only through examining the lived experience that the essence of the experience can be known (Lopez & Willis, 2004).

According to Lopez and Willis (2004), Husserl believed that it is possible and essential that the researcher put aside his or her knowledge of the experience being studied and enter research with transcendental subjectivity. Through this process, the researcher is continually assessing their biases and preconceived ideas about an experience through bracketing (Lopez & Willis, 2004; Wojnar & Swanson, 2007). There is an assumption that there are features of lived experiences that are common to everyone who experiences them (Wojnar & Swanson, 2007) and for this reason; reality is objective and free from contextual understanding (Lopez & Willis, 2004). Furthermore, Husserl believed that history, society; culture and politics had no impact on someone’s freedom to choose (Lopez & Willis, 2004).

As a critique of these beliefs, a second stream on phenomenology emerged through Heidegger, known as interpretive or hermeneutic phenomenology (Koch, 1995; Lopez & Willis, 2004). Heidegger was a student of Husserl; however, was critical of his belief about human consciousness and experience. Heidegger moved beyond describing experiences, to looking for the meanings within the experiences (Lopez & Willis, 2004). In contrast to Husserl’s belief of humans as free agents, Heidegger’s understanding was that “individuals’ realities are invariably influenced by the world in which they live” (Lopez & Willis p. 729). Humans can make free choices. However, freedom is limited by
their world (Flood, 2010). Heidegger also disagreed with bracketing; rather he believed that a researcher could not put aside their understanding and knowledge of a research topic, in fact, it is this understanding that gives the research topic importance (Lopez & Willis, 2004). Both the researcher and participants experience, and interpretation of the phenomenon work together to “cogenerate an understanding of the phenomenon being studied (Wojnar & Swanson p. 175).

It is from the hermeneutic branch of phenomenology that I approach the research of the experience of PWD, under the age of 70, living in a long-term care facility for adults, accessing a sexual and intimate life. As discussed by Lopez and Willis (2004), critical hermeneutics considers the social influences of experiences and recognises that “the lived experiences, and personal voices of persons who are not members of privileged groups are often discounted” (p.730). Feminist phenomenology also leads from an understanding of experiences are multifaceted. As Fisher (2010) so clearly states

Phenomenology can provide the style for an analysis which retrieves and retains the immediate, vibrant, tangible, and compelling lived experience, and enables our understanding of the phenomena and meaning of this lived experience and situation; while feminist thought and analysis can expand and deepen phenomenological investigation by recalling and insisting on the importance of the lived context, and the multiple aspects, particularities, and dynamics of the social and cultural world, of social and political being in that world and the necessity of a phenomenological analysis and framing of these phenomena.(p.94)
For this reason, I believe phenomenology is well suited to look at this topic as I do not believe that we can understand the experience without also considering the historical, societal beliefs of disability and sexuality.

4.3 Recruitment.

The sample for this research is both purposive and criterion. Within a phenomenological approach, it is imperative that research participants have direct experience with the phenomena being examined (Creswell, 2013, p.155). Purposive sampling is common in qualitative research, which according to Creswell (2013), is “because they can purposefully inform an understanding of the research problem and central phenomenon in the study” (p.156), for this reason, a purposive sample was used.

The sample was also based on specific criteria to ensure the participants have experienced the phenomena. To ensure this, the participants were required to be currently living in long term care or had previously lived in long-term care. Long term care defined for this study is government subsidised facilities in which individuals live, where nursing and personal care is provided and offered 24 hours per day by trained staff who work or are affiliated with the Saskatchewan Health Authority (SHA). Participants were required to be between the ages of 18 and 64; however, due to limited interest, the age range was opened to those between 18 and 70 years old. Participants all had experience with a disability (or disabilities) as previously defined.

A sample size of four was obtained, which according to Creswell (2013) falls within the recommended number of participants, between 3 and 10 for phenomenological studies. Phenomenological research aims to have data which is rich in quality, not quantity (Smith, Flowers & Larkin 2009). Quality in this study is provided by the use of
multiple quotations, which reflect the participants’ perspectives of their experiences of accessing intimacy within long-term care facilities. The sample consists of three Caucasian and one Indigenous participant. Two participants are married, and two are divorced. The age range of participants is 44-67 years and have been living in long term care between 2 and 7 years. Three participants are male, and one is female. One participant had been living in assisted living prior to moving to long term care, one had been living independently, and two had been living in their own apartments with support from home care. None of the participants chose to use a pseudonym, so I have provided them with one.

Participant recruitment began only after approval was obtained from the University of Regina Ethics Review Board (see Appendix A). Prior to obtaining research approval, I obtained conditional operational approval from the SHA. Once final approval from the REB was received final operational approval from the SHA was also received (see Appendix B).

At this time, I had already been in contact with the Department of Senior’s Health and Continuing Care as their approval was needed for the SHA operational approval. I forwarded the recruitment posters (see Appendix C) and a letter of introduction (see Appendix D) to the manager of the department who assisted with the distribution of my research information package to the directors of care within the Saskatoon area long term care homes. Additionally, I reached out to personal contacts I had within several of the long-term care homes, to request assistance with recruitment. From these communications, I was invited to speak at a resident association meeting to present my proposed research. I also shared my poster on social media, including my personal
Facebook page and the Facebook page of the Saskatchewan Association of Social Workers, Saskatoon branch.

The initial recruitment took place between May 2018 and July 2018; however, there was no interest expressed. I then changed the recruitment poster, with the approval of the REB (see Appendix C), to focus less on sexuality and more on intimacy as I thought that focusing on sexuality was deterring individuals from volunteering to participate. After this change was made, I forwarded the new poster to the manager of Senior’s Health and Continuing Care again and requested that she again reach out to homes on my behalf. After this, I was in contact with one participant and with the ethics board of another long-term care home. Between July 2018 and September 2018, I provided this second ethics committee with my approved REB application, consent forms and interview guidelines. This resulted in two more participants; however, one was unable to continue due to a health decline, and his information is not included in the research. In September 2018, I reached out again to my contacts working in long term care and was able to recruit two more participants.

4.4 Data collection.

Creswell (2013), suggests that within phenomenology, in-depth interviews are used to obtain a description of the phenomena, this is supported by Smith et al. (2011), who state “one-to-one interviews are easily managed, allowing a rapport to be developed and giving participants the space to think, speak and be heard” (p.57). An interview guide was used to help guide the conversation. Smith et al. (2011), suggests that between 6 and 10 open-ended questions are used. Due to the sensitive nature of the phenomena being explored, I decided to break the interviews into two, the first one being more rapport
building and focused on three open-ended questions about how they came to be living in long term care, what their social connections are, and if the nature of their relationships has changed since moving (see Appendix E). The second interview asked participants what their understanding of intimacy is, and what experience they have had with intimacy since moving to long term care. Prompts were used in each interview to understand the experiences better.

One participant contacted me by phone after seeing the recruitment poster in the long-term care home, and we arranged to meet at the home in a private area. The remaining three participants were forwarded to me by staff working in the home who had spoken with residents about my research. Two participants and I spoke by phone to arrange a time for the interview, and two were arranged in person after I attended the home to meet them as they did not have a personal phone. One participant required several visits to arrange a suitable time as he was ill when I arrived to interview and was not able to contact me to cancel.

Before beginning each interview, I reviewed the consent form with the participant (see Appendix F), and they were told explicitly that they could drop out at any time without any punitive measures. The risks and benefits were also explained to participants and were provided with a list of mental health support agencies should our conversations bring up difficult emotions. All participants indicated they understood this and wished to participate in the research. All interviews were recorded on my personal cell phone, which is password protected. Interviews took place for the most part in the rooms of the participants as they all had private rooms. One participant chose to meet in a more public area. However, we were able to close the door.
Interviews were between 20 and 40 minutes each and were transcribed verbatim onto a word document on to my personal computer then transferred to a USB stick. Additionally, the word documents are password protected.

4.5 Data Analysis Procedure.

I began data analysis using a hermeneutic approach. Data analysis within hermeneutic phenomenology is known to be flexible, with no rigid techniques. Underpinning it though is the hermeneutic circle, in which, as Smith et al. (2009) state “to understand any given part, you look to the whole: to understand the whole, you look to the parts” (p. 28). Van Manen’s (1990) approach to analysis is more philosophical, allowing for a more fluid back and forth through the hermeneutic circle, while Moustakas (1994), offers more guidelines to assist researchers with analysis. I followed the clearer steps provided by Smith et al. (2009). As a novice researcher, I need clearer direction to assist with my navigation through the data analysis. I began first, though, as suggested by Moustakas (1994) and Van Manen (1990) by writing my own experience of the phenomena. I chose to reflect on my own experience and as Van Manen (1990) suggests “make implicit our presupposition” (p.47), rather than bracketing off my experience. Smith et al. (2009) suggest that the interpretation of the experience is co-created by researcher and participant, both through the way questions are asked, and questions are answered.

Following the Interpretative Phenomenological Analysis (IPA) steps suggested by Smith et al. (2009), I then read the transcripts while listening to the audio recording to ensure that the participant was the focus of analysis (p.82). Transcripts were then re-read several times, and initial notes were recorded. Statements and phrases that appeared to be
of interest or importance were highlighted. As Smith et al. (2009) suggest, the “aim is to produce a comprehensive and detailed set of notes and comments on the data” (p. 83). IPA methods suggest analysing the transcripts and making descriptive, linguistic and conceptual comments. Descriptive comments are notes which take what was said at face value and could be words or phrases; linguistic comments highlight the language used, tone, fluency and use of metaphor, for example. Conceptual comments lead the researcher more towards interpretations and questions about meaning will arise.

The exploratory comments are then read for emergent themes. Smith et al. (2009) suggest that the researcher will break apart the narrative in search of the themes. However this is part of the hermeneutic circle, the narrative is broken; however, in the end, it is put together again as a new whole, one which is a deeper understanding of the phenomena being examined. Once emergent themes are highlighted, the researcher looks for connections within these themes. Some themes may fold into others, some may cluster together, and some may fall off. These steps are complete for each case, after which the researcher then looks for patterns across cases.

4.6 Ethical Considerations

According to the ethics framework outlined in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2) (2014), there are three important principles to consider when examining the ethics of research. First is that of respect for persons through acknowledgement of their autonomy. The guidelines indicate that autonomy is ensured by seeking “free, informed and ongoing consent” (p.7). To meet this guideline, participants autonomy is respected through ensuring that they understood what the research topic is and that they understood their right to revoke consent up until
their interview is transcribed and written into the final document. I ensured this by providing participants with a written synopsis of the research which I also read aloud. They were provided with a consent form which outlined their rights as participants. Participants were provided with their transcribed interviews for review to ensure they are comfortable with what was said.

The second guideline is the concern for welfare, which includes physical, mental, spiritual, economic and social circumstances. Given the sensitivity of the research topic, I ensured that participants were aware that they were consenting to speak about their sexuality in the context of living in long term care. Data was collected over several interviews, with the first interview focused mainly on building trust and familiarity with each other. I also ensured that if the interviews raised feelings that they are unable to manage independently, that they are given mental health contact information for further support. For one participant, the interview proved to be very emotional, and though we had reached the final questions, we cut the interview short as he was not comfortable any longer. Before leaving, I asked if he wanted me to get somebody from the staff to support him and ensured that he had access to outside support if needed. He was able to continue with the subsequent interview and continued his consent to participate in the research.

The last guidelines highlight the importance of justice and the obligation to treat people fairly and equitably. It also recognises the power imbalance, which can arise between researcher and participant. To address any possible power imbalance, participants who have been my clients in the past were disqualified from this research. I ensured that participants had access to their transcribed interview as I hand delivered each and will hand deliver the final report should they request it.
4.7 Strengths and Limitations

The strength of qualitative research is based on rigour, which, according to Creswell (2013), is achieved through validation strategies. One such strategy is triangulation, whereby a researcher makes use of other research, or theories to support their findings. My research has strong triangulation as many of the themes that emerged from the interviews are congruent with other research findings. Creswell also suggests that validation is achieved through the researcher making known their own biases. I achieved this by situating myself and my own experience and bias at the beginning. Finally, Creswell suggests that providing detailed descriptions of the experiences supports validation. In my findings section, I provide detailed accounts of the participant’s experiences using multiple excerpts from their transcribed interviews.

Except for one participant, none of the participants felt that they had the opportunity for physical intimacy in long term care.

4.8 Summary

This chapter outlined the research methods undertaken following a phenomenological approach to qualitative research. A purposive, criterion sample was obtained with the assistance of Health Authority gatekeepers. The research is focused on the experience of residents of long-term care under the age of 70, accessing intimacy. Semi-structured interviews were used for data collection and analysis.
Chapter 5. Findings

5.1 Overview

In this chapter, I provide analysis of the interviews conducted with the four participants to understand what the experience is of younger residents accessing a sexual or intimate life. To help give context to the participant's experience, a brief description of what moving to long term care was like for the participants begins the chapter followed by a shared definition of intimacy. As discussed earlier, intimacy is difficult to define. Thus participants were asked how they define intimacy to help situate their own experience. I then analysed the participant's definition to find a common definition of intimacy. Within phenomenological research, an essential or central theme often develops as one theme that appears to reflect the nature of the live experience. Intimacy in long term care is discussed within the context of the central theme. It's about belonging. From the central theme, sub-ordinate themes emerged; Being Different From Others, New Relationships and Connections, Being Left, and Staff Facilitated.

5.2 Moving to Long Term Care

Overall, moving into long term care provided mixed reactions for participants. Some felt shock and anger, while others seem to have accepted the move quite quickly. Frank states:

Well, it was a shock to start. But pretty quickly I realised the benefits because at home I’d get up in the morning and wash up and get dressed then do essentially nothing all day. Stare at the tv.

While Nick states he accepted it quite quickly, he felt that there was no other option because he did not want to be a burden to his family.
They wanted me to go stay with them, but I told them I didn’t want to be a burden. I told them I’d come to long term care, I said it would be hard for you, you have your own lives to live, and I already lived mine. I didn’t want them to be there looking after me all the time; then they couldn’t do anything because I got to be constantly looked after and my medication I gotta get every four hours, doing my dressings on my wounds, and moving me at night, turning me. They really wanted me to go stay with them, and I told them I’ll go to long term care, I’d be better off there with somebody to look after me with the things I can’t do.

Everyone agreed that they needed to be in long term care because their care was not manageable at home. As Anne states:

I moved into long term care because I have MS, and it became too difficult to live on my own. I was living by myself, and trying to do the, you know normal activities, but it’s hard because you know I was not expecting the MS to get bad you know, but it started affecting my ability to walk, so moving here was like, I knew it wouldn’t be safe at home anymore.

This was also echoed by Leon who states “Truthfully, I’d rather be at home, but I can’t. I fell once in the month, and then I fell three times like I had to come to long term care because I couldn’t do it by myself anymore.”

The sense of being provided with no other option but long-term care was overwhelming. Participants noted feeling that moving to institutional care was the only way they could be safe and be provided with the care they were needing.
5.3 What is Intimacy?

To provide a common definition of intimacy, all participants were asked to describe what their understanding of intimacy was. Most of the participants included physical, sexual contact in their definition of intimacy; however for the participant's intimacy seemed to be more about taking time, feeling important or belonging, and having connections with others.

5.3.1 Physical touch.

All participants spoke about intimacy including an aspect of physical touch, at times it was more sexual, while other times it was more innocent, such as holding hands. Nick indicated “It’s getting close with someone, and getting intimate with them, like, you know touch and kissing and all that, that’s what it means to me.” While Anne, in describing the first intimate moments with her husband stated, “Before you know we were just starting our relationship, you know we would kiss, we liked to kiss, we can’t kiss anymore, but we liked to kiss.” Although most participants mentioned physical touch as a part of intimacy, it was not highlighted as the only way to be intimate.

5.3.2 Taking time and feeling important.

For most of the participants, intimacy was more about taking time to be with somebody and feeling like they were important enough to spend time with. Frank describes an intimate relationship with a friend

There’s somebody out there besides family that likes to get together with me that likes to have a chat and get up to date, with what each of us is doing, although he’s got a whole bunch of other things going on his life. [It is] nice he can take
time out to visit me in particular, even though it may be a couple times a month.

It’s something I still really value.

For Frank, it really is about taking time, it made him feel good knowing that there was somebody who wanted to visit and stay connected. While Anne describes intimacy within her relationship with her husband,

Intimacy, for me is when I get to spend time with my husband. We watch television together every night, so I know that I will have somebody visiting to watch tv. He knows when I’m not having a good day and holding his hand, knowing there is somebody, you wake up [with] somebody in the morning and you have somebody to talk to and spend time with that you like.

Anne was a single mom until moving to long term care and having someone present, even if it is just in the same room is enough to feel comfort and connection. Taking time and being present with each other is sharing intimacy.

Finally, Leon describes intimacy as not only being physical; there is also a different level of connection with that person,

Being with a girl, I don’t know, share your feelings and your thoughts and everything. That’s the way I was brought up. When I was growing up, when my mom was still alive, …she said it to me, give your heart and soul. You can tell that person a lot about yourself, think[ing] and feel like, express myself

For him, intimacy is feeling safe to be yourself, feeling a special connection to somebody else and feeling accepted.
5.4 Intimacy in Long Term Care

Participants all agreed that intimacy in long term care is relatively limited, and only one participant had experienced sexual intimacy since moving into long term care. From the analysis of the interviews, a central theme of *It’s about belonging* developed, and four sub-ordinate themes emerged, *Being Different from Others, New Relationships and Connections, Being Left, and Staff Facilitated.*

5.4.1 It’s about Belonging.

The central theme of *it’s about belonging* developed when analysing the experience of younger residents under the age of 70 accessing sex and intimacy in long term care. Although most participants agreed that sexual intimacy was not a reality for them, all participants spoke about the desire to connect and seek out companionship with a sense of belonging. Whether it be at the meal table as it was for Frank, or outside in the smoking circle for Nick, both seemed to be seeking a sense of belonging.

For Anne, the sense of belonging came after her marriage, while Leon seemed to be still searching for where he belonged within long term care, focused on belonging within his family.

5.4.2 Being Different from others.

The feeling of being different was present in all participants, and the sense of being different manifested in a variety of ways. For some, it was experienced as being different from others, while for some, it was experienced as being different from their previous selves.

For Anne, being different is experienced as being different from other residents because she is in a relationship, and able to have physical intimacy. She had always felt
different and had limited social connections before moving into long term care. However, after moving into long term care, she met and married her husband. Although she feels she and her marriage are accepted in long term care by staff and other residents, there is still a sense of being different because she and her husband are young and married, something which is uncommon, she states “we recognise, for us to get married in long term care, and for us to be as young as we are…nobody else has gotten married here.” There is a sense of being different because they have an intimate relationship, which, according to Anne, is not a common arrangement in long term care.

Additionally, there is the feeling that because they got married, their relationship is more legitimate than those who are just dating. This makes them different; she states, “there are other couples who weren’t given the pleasure we’ve gotten, we’ve gotten our room. We’re married, so we’re accepted.”

Being different for Anne is experienced as being different from others in long term care, particularly other couples who are not married as she is. Being different is felt as something special and privileged because she is young and married to another resident in long term care. There is a sense that their marriage has legitimatized their physical intimacy.

For another participant, being different had been felt for a long time and is associated with how they experience their disease. For Frank, feeling different from others began well before moving into long term care. He too spoke of having a small social circle before moving, and this may have been partly due to his disease. He spoke about his inability to participate in regular activities as a barrier to developing more friends, “I always had a small group of friends and given the limitations on what I can do,
no sense in me trying to go lawn bowling or whatever, go to concerts and stuff like that or you know.” The sense of being different and limitations to social connections continue after he moved into long term care “I don’t go out of my way to make new friends, whether it be here or outside”. Even in long term care, he has a sense of being different from others. His sense of being different from others has affected his social connections.

For Nick, the sense of being different from others occurred shortly after becoming a quadriplegic. Before his illness, he was an active social person, who enjoyed physical intimacy; however that changed after his illness, he states

I guess it’s because I really can’t do anything, I only have the use of one arm, I can’t move, and it makes me feel helpless. So, I don’t bother with anything there. I don’t think about it anymore, I guess when I first became a quad. Like I don’t mind having friends, I’ve got a lot of friends here, but that’s all I really need, is to have good friends. I just decided I didn’t need that anymore.

For Nick, being different from his old self and not being able to move independently seems to have changed his views on what he needs and wants. Being different is experienced not only as being different from others, but different from his old self. He has decided that his new self does not need or is not interested in physical intimacy. Frank also noted that his desire for physical intimacy has diminished; it is no longer something interests him.

Leon also describes how being different has affected his social and physical intimacy. Leon describes having many friends while growing up and was able to engage socially in a variety of activities. He states:
There’s a lot of stuff I used to be able to [do], but I can’t now. Like I used to be a pool shark, but now I can’t. That’s pretty much all, well like I can’t go camping and stuff. When I was growing up, I was like, I’m going to the lake. But not no more.

Being different from his old self has impacted what Leon believes he can be involved in socially, and his social connections.

Being different from their old selves or being different from others has had an impact on what the participants believe they can or cannot do. This has affected the quantity and at times, the quality of social and physical intimacy.

5.4.3 New relationships and connections.

Participants all spoke about their experiences forming new relationships and connections in long term care, and how important those connections were. The new relationships offered a community of sorts where participants felt connected to others who experience the same environment as themselves.

Frank often spoke of forming new relationships since moving into long term care and feeling isolated at home. He noted that he has “more access to a few people around the lunch room or in the concerts or whatever than when there was when I was at home staring at the walls.” For him meeting new people in long term care meant that there was a group to belong to and “just keeping tabs with my acquaintances or friends at the table, rather than each of us staying in our rooms staring at the tv. [It’s] a chance to get together and continue or bolster the friendships”. Feeling connected to others is essential for Frank, and he appreciated the opportunity to engage in conversations with others. Having friendships made him feel good and less down. Moving into long term, care also helped
Frank to feel less isolated. He felt isolated at home, unable to engage in the community despite having a ramp in and out of his home.

The feeling of connection and belonging came for Anne when she met and married her husband while living in long term care, something she did not expect. She describes what it was like finding a new relationship

I thought that had passed in my life because I had been looking. I figured nobody wants me because I have an illness, so it’s kind of exciting to think that somebody thinks I’m beautiful and loves me unconditionally. I never never thought that would happen. I thought that ship sailed.

For Anne, she did not think that moving into long term care would offer this kind of opportunity, and yet she found somebody to spend time with and have a connection. This connection helped to enhance her sense of self,

I didn’t feel very pretty or attractive because I spent 17 years raising my daughter, so I thought I was ugly I had no prospects until he came along, and then I realised that I am pretty and there is something.

Having an intimate connection with somebody helped to give her sense of worth and value, that she is loveable and pretty. She found acceptance of who she is both from somebody else and from within herself.

A sense of belonging was also experienced by Nick when he spoke about the connections; he has made in long term care with other residents through the sharing of their experiences. For him, these new friendships offer a connection and support

I have lots of female friends and male friends here, and how we all sit outside in the smoking area, we talk about different things, and we talk about how some of
us are treated in the home here, It’s just we talk about a bunch of different things, it’s just like ah, when you want to get something off your chest, it’s something like a therapy group, we all have things that we talk about.

Shared common experiences allow for friendships to form. For Nick finding support in sharing the struggles and good things experienced while living in long term care was important. Having others to commiserate and offer a normalisation of the experiences of long-term care helped to create a small community of support.

However, not all participants had positive experiences forming new relationships. The new relationships are not necessarily chosen because they got along well; instead, it was the proximity. As Leon states “once you see them long enough, you just, I just switch, automatically becomes a friendship”, indicating that relationships form more from convenience and familiarity than from choice. Frank echoes this sentiment when he states:

There’s always people usually the goods and the bads, um the doofuses and the guys are more up here (gestures to head) and easier to talk to and get along with, there’s other people in here you can’t converse with them, so you just take what you can.

Although participants note making it work and creating relationships with residents whom they would not usually associate, they show resilience in making their environment work for them. There is also a risk that this could further isolate residents who are not as resilient and ready to make situations work for them.

For the participants, moving into long term care meant that they had the opportunity to meet new people and form new relationships, which provided them with a
sense of community and belonging, however as two of the participants indicated, it can be limited by who is living with you. Some participants noted that the people they are living with now are not necessarily the ones they would choose to live with; however, they are making it work.

5.4.4 Being left.

All participants spoke about the loneliness and isolation they feel since moving to long term care. There was a feeling that they were left or forgotten by friends and family whom they had previously been close. They found that they were no longer visited by those with whom they had felt a strong connection in the community before moving to long term care.

Leon spoke about continuing to have visits from family and how this was important to him, they helped him by purchasing items for him and visiting as often as they could. However, he spoke of feeling left by old friends with whom he grew up and the pain and confusion this has caused,

My family is awesome, but I have lost a couple of friends, because I’m in here, you know, they don’t come here. They see this, I don’t know for sure, but they see disabled people as something, as something else. It makes me feel sad that they think I’ve got a disease and they’ll catch it or whatever.

There is a feeling of being abandoned by those who had previously been a friend. Nick experienced a similar feeling with his family stating “Oh, I hardly ever see anybody now. My son only comes once in a while, and same with my daughter, only once in a while, and my sister never comes.” Anne also spoke about the difficulty of keeping friends since moving into long term care; she states “then I got sick and couldn’t stand. Sad, I just,
you’re not a person anymore. People I thought were my friends are no longer”. There was a sense that they had become something else since moving into long term care, and participants noted feeling left behind, feeling less important to those with whom they had close connections since moving to long term care.

Sometimes the isolation is self-inflicted. Many of the participants spoke about not wanting to engage in social activities since moving into long term care. Nick spoke about his self-isolation after becoming a quadriplegic and moving to long term care,

I had lots of friends, a lot of young people used to come around my house, they would sit there, watch tv or movies. Yeah like I don’t see them anymore. The friends I got here, the ones here, a few lady friends and male friends here, sometimes I just mostly stay by myself, I don’t try and interact with anybody any more. I don’t know it’s changed since I became a quad. I don’t really socialize as much as I used to, I just go off on my own, even when I’m smoking outside there, I sit out there by myself. I just don’t feel like interacting with anybody really.

Prior to moving into long term care, Nick’s home was a centre of social activity, and now he would rather be alone. Although he was unable to express why he was isolating himself, two other participants spoke about feeling as though long-term care was the end of the line. Leon spoke openly about it stating “I just feel like a shut people out, it’s being in a place like this I think, I know I’m going to die here, but, yeah. It’s to me, it’s a last resort.” Leon also describes the loss of a friend

They have a pub night every second Thursday here. But I like I started to [go] because there was a girl, and she, ever since she passed, I haven’t gone to pub
night. [She was a] very good friend. She always knew how to make me laugh and do whatever, but not now.

The grief following the loss of his friend impacted Leon’s willingness to engage in social activities within the home, even though he enjoyed them previously.

Anne shared a similar sentiment when she spoke about forming new friendships and the risk, she takes in doing so,

In long term care, it’s hard to form relationships because people die. I was, there was a person next door, some old lady and I talked to her, she had Alzheimer’s, and I knew it was coming to be her time. Most people are older than me; there aren’t many young people. It’s scary to form attachment because you know you are going to lose them.

All participants spoke of the experience of loss in long term care. Loss and grief appear to be the end result of all new relationships, which has turned intimacy into something that at times seems too risky to experience either because of the feeling that they are going to die, or because those around them are going to die.

5.4.5 Staff facilitated.

All participants spoke of experiencing intimacy as something that is facilitated by staff. From group activities to setting up opportunities to be physically intimate, staff in long term care have an integral role in creating space for intimacy.

Participants spoke about the opportunities created by staff through organized activities which for Frank included meal time which he describes as “a chance to get together three times a day, just getting together with people, we’re assigned to spots at given tables, and fortunately, people at my table are reasonably good to talk to.” These
opportunities to socialise are facilitated by staff in that residents do not choose whom they would like to have meals with; they are assigned table mates, which for Frank, he notes he thankfully enjoys those he is assigned to sit with. However, Frank notes that outside of these times, he did not feel that there were not many opportunities to socialise, he states,

On the whiteboard out there, they got activities listed and usually if your name is not on the list you are not invited. So, one day, even though I’m not big into cribbage, I decided to drop in, now my name is on the list. So, a bunch of things that I’m not interested in…they do have movies and concerts and what not, yesterday there was a concert, it was nice to get together, listen.

The reliance on staff to facilitate opportunities for social and intimate experiences is felt by this participant; however, there is also a feeling of not being interested in what is being offered but doing it anyway to pass the time.

Leon also spoke about activities which are facilitated by staff; however, he did not feel that they were a good fit for him, when talking about the concerts in the home he states, “I don’t care for a lot of them. It’s a thing my grandparents listen to; that’s who they bring.” Although there are opportunities to meet others, the facilitated activities don’t always fit with their interest, particularly for younger residents. For Leon, the musical concerts that are played in long term care are not the music of his era.

Facilitation does not only mean facilitation of opportunities, but also the physical facilitation of communication due to the potential physical or technological barriers faced by residents. Nick spoke about the difficult time he has had adjusting to feeling the loss of independence in keeping up his connections, and the reliance on staff to help facilitate
those connections

If I use a phone or a computer somebody has to help me with the computer, they have to hold the phone to my ear, and like I’m on Facebook and they have to, the computer guy that works here has to open up Facebook for me and he has to scroll down on that so I can see what messages I got. I really don’t like it because I was always independent; I was the one who looked after people. I used to look after my grandmother, both my grandmother and my grandfather.

For Nick, having somebody help him to stay connected is a loss; being dependent on somebody else to read personal messages is hard.

Anne spoke about the experience of being physically intimate with her husband and that being facilitated by staff in a variety of ways. She often spoke of staff providing private space for her and her husband to be intimate

When we first met, we liked to kiss, and people used to say it was inappropriate because we would kiss wherever, and he liked to touch parts of my body that people didn’t think was appropriate. So, they gave us this room; it gives us some privacy…because not everybody wants to see that. I don’t think I ever felt like I was being reprimanded or scolded. These were helpful things, have that room to ourselves. They were very generous to us.

However, privacy did not necessarily mean that it was easy to be intimate,

It was quite difficult when we first got married. We had a bed, and it’s hard for them to understand that just because you live-in long-term care doesn’t mean we don’t have sexual feeling for somebody…we just spend the night because we find it difficult to initiate any sexual interaction.
Though she and her husband have the private space to be together, they are not able to initiate sexual activity because of their physical limitations.

Anne also spoke often of staff, allowing her and her husband to be married and have a private space, as though it were up to staff to control this behaviour. She indicated that staff “know that we are together, and we like to do things together, and they don’t mind.” When describing when she got married, she states “when we got married, they let us spend the first night together.” She describes the experience of being intimate as being supported by staff and accepted, but also feeling as though the staff are allowing it to happen, which presumes that they could stop it as well.

5.5 Summary

This chapter provided the findings of the research exploring the research question, what is the experience of younger long-term care residents, under the age of 70 of accessing sex and intimacy. Through an interpretive phenomenological approach, it is found that although physical intimacy and sexual experience is limited for the four participants, they experienced intimacy within the essential theme of It’s About Belonging. All the participants spoke in some way about finding someone or a group of people with whom they felt a connection to and were able to share in the comfort of being in each other’s presence.

For the participants, sex and intimacy were experienced in different ways; however, there emerged four sub-ordinate themes in which experiences are understood. They include Being Different from Others, New Relationships and Connections, Being Left, and Staff Facilitated. Within the first theme, Being Different from Others, most of the participants noted feeling different from others, at times this started before moving to
long term care, and that this sense of being different impacted on the types of intimate activities and relationships they held. Under the theme *New Relationships and Connections*, all participants spoke mostly positively about the new relationships and connections they had made since moving to long term care. Whether meeting their future spouse, or a new group of friends to lean on for support, these connections provided a strong sense of intimacy. Within the theme *Being Left*, participants spoke about the isolation experienced since moving to long term care, where family and friends with whom they had been close no longer visit. This isolation also manifested in a hesitancy to connect with co-residents because those relationships would be ended typically by the death of one of them. The final theme, *Staff Facilitated*, included both the experience of sexual and physical intimacy being facilitated by staff, as well as social intimacies facilitated by staff.
Chapter 6. Discussion

6.1 Introduction

In this chapter, I will discuss the findings in relation to the literature and theoretical frameworks. Each of the four themes from the findings, being different, new relationships, being left, and staff facilitated, will be explored. As noted earlier, there is limited research on the experiences of younger long-term care residents. Thus I will mostly be using literature based on research with older adults.

This research study has shown that for the participants, belonging, opportunities for socialisation, and developing relationships are an important part of the experience of intimacy in long term care. Having access to private space to engage in physical intimacy or social intimacy is also important. This research study also highlights that staff have a significant role in supporting the intimacy needs of residents.

6.2 Being Different

The theme of Being Different was expressed by participants as either feeling different from others, or different from their old selves, prior to their disability. The feeling of being different from others placed limitations on the type of social interactions they could partake. Because of this, participants typically reported have a very small circle of friends, made up of a couple of people and their family.

Feminist thought urges us to examine what is considered the norm, a norm which has been built based on the male body. Any deviation from this is viewed abhorrently as something which is to be fixed or hidden (Garland-Thomson, 2002). PWD encounter what Garland-Thomson (2011) calls a misfit in society due to the misfit between their
bodies and the heteronormative body from which society is built. This idea of a misfit spans across environmental access to social access.

Limited access to a social life has been highlighted as a factor in the quality of life for PWD. Several studies have shown that having high-quality social connections have a positive impact on quality of life and that compared to able-bodied persons, PWD report higher levels of loneliness and decreased participation in social activities (Daley, Phipps, & Branscombe, 2018; Russell, 2009). Research by Jespersen et al. (2018) revealed that PWD felt that there was social discrimination against them and did not always feel accepted or that they belonged in society. Additionally, there are physical barriers which hindered full participation in social activities. The authors note that “a determining prerequisite for social participation is physical access to the locations at which events take place” (p.8). Although there are now building codes which require a certain standard of access to buildings, many older buildings are grandfathered in meaning that they remain inaccessible (Saskatchewan Government, 2018). As such, bars and nightclubs or restaurants in older buildings may not have accessible entrances. These and other social gathering points are where people meet to find potential partners; however, they often remain inaccessible for PWD.

Shakespeare (2014) suggests that persons with disabilities are at increased risk of isolation because “they are less likely to be well integrated into networks and friendship circles” (p.191) because of continued physical and social barriers. Though many PWD live in the community, they continue to be isolated in their homes, Shakespeare (2014) suggests that PWD may face isolation due to their physical health and stamina, lack of financial resources, or lack of social skills.
6.3 New Relationships

Whereas at home, many of the participants found themselves isolated and alone, moving into long term care allowed for other relationships to develop. They grew a sense of comradery that had been missing at home. There is some thought that relationships can develop due to a shared situation or space. Research completed by Salas, Casassus, Rowlands, Pimm and Flanagan (2018) suggests that for individuals who had experienced a traumatic brain injury, they found it easier to connect with others who had experienced a traumatic brain injury as well. There was a great sense of understanding and coming from the same place because of the shared experience of a traumatic brain injury.

Friendship plays an important part in continued social and physical wellbeing, however friendships which provide this type of benefit, is not always provided from other residents in long term care. Research completed by Casey, Low, Jeon, and Brodaty (2016), suggests that residents in long term care facilities did not view themselves closely connected with their co-residents. They concluded that the social opportunities present in long-term care does not support independence to develop friendships of their choice. The authors suggest that staff be mindful of this and regularly consult with residents about their social experience and their expectations.

6.4 Being Left

Residents all spoke about the increased isolation they felt after moving into long term care. They no longer engaged in socialisation and intimate experiences with friends and family as they once did. Virpi and O'Dwyer (2009), suggest that this is a common experience. Their study on the coping strategies of residents in a long-term care facility in Ireland suggests that despite being surrounded by people, residents report having limited
involvement or opportunities to foster friendships with other residents. Residents also reported decreased time spent with their family members as well due to either travel requirements or limited private space within the facility. One participant of the current research spoke of the importance of privacy to be able to engage in intimate experiences. Research indicates that the lack of privacy is as a major obstacle in creating sexual opportunities. As Everett (2007) states it is “discriminatory not to let residents use the private areas of their homes as an appropriate place for adult sexual activity and we are compelled to find ways to ethically and legally manage residents’ sexual lives” (p.22).

The Law Reform Commission of Saskatchewan (2013) recently published a report on the civil right in long term care facilities, which suggests that civil rights violations of residents may include disrespect for autonomy and privacy of residents. The Commission provides several recommendations, including the creation of a Resident Bill of Rights, which would be prominently displayed within the building. Additionally, residents and their family need to be provided education regarding what their rights are, and what avenues they can pursue if they believe their rights are not being upheld. Finally, staff education is mentioned, as it is noted that violation of rights is likely not intentional, rather the result of not knowing or understanding.

Research also suggests that opportunities to engage in socialisation are limited while in long term care. Virpi and O’Dwyer (2009) also found residents unfulfilled by the social activities offered, noting that much of the time is spent watching TV. This speaks to how society has controlled the bodies and activities of PWD. Through segregation to institutional care, young disabled residents are “in the prime of their lives,” and “experience social withdrawal and disengagement prematurely” (Davies, D., 2000,
This segregation to long term care facilities limits opportunities to meet and engage with potential sexual partners (Davies, D., 2000), or people with whom they would like to be friends. Feminist thinking challenges us to think about who is labelled as other and how they are left out of the accepted ways of interacting. Garland-Thomson (2011) posits that “disability is a cultural system which stigmatizes certain kinds of bodily variations” (p.5). However, this is a culturally fabricated narrative of the body. I believe that the results of these stigmas include beliefs about friendships, sexual partners, and which bodies are worthy or unworthy of companionship. Garland-Thomson (2011) also speaks about the de-stabbling effect of disability on the able-bodied and the reminder of the fragility of the able body. There may be an uncomfortableness with being friends, or partners with PWD, because of the reminder that the able body will likely at some point become a disabled body.

Social inclusion and opportunities for social accesses fall under the general principals of full and effective participation and inclusion in society, equal opportunity and accessibility outlined by the United Nations (2006) Convention on the Rights of Persons with Disabilities. While many of the research participants indicated a lack of social support and feelings of loneliness and isolation since their admission, research by Marshall and Baffour (2011) indicate that care plans do not meet the social, employment or volunteer needs of younger residents. Care plans remain, for the most part, focused on the medical care of residents, something which is created and perpetuated by the medical model of care. Though I know from my own experience working in long term care, care plans have included some facet of psychosocial care such as outlining hobbies and interests, care plans remain highly focused on care tasks and not on enabling social
interaction. According to feminist thinking, relationships are for those who fit the societal norm, while those who challenge the concept of normal, such as PWD, are disregarded and separated from society. Change within long term care settings is happening; however, it is slow, and PWD who live in long-term care remain isolated.

6.5 Staff facilitated

The staff who work in long term care have an important role to play in supporting the intimacy of residents in long term care. All participants of this research indicated that staff helped to facilitate intimacy, whether it be through organised groups, or helping to find space for intimacy. The assistance of staff was instrumental in ensuring residents remain connected through social media, organised card games, movie nights, and simple conversation during care activities.

Though only one participant was involved in physical intimacy, there are many more residents in long term care who do have physically intimate relationships. All participants referred to others in the building who are dating, however, were not comfortable participating in the research. It has been well established in literature that staff understanding of intimacy and sexuality makes a difference in the experience of the resident (Barmon, Burgess, Bender, & Moorhead, 2017; Heath, 2012; Villar et al., 2014; Villar, Serrat, Celdrán, & Fabà, 2016). However, the formal education of staff does not always include education on human sexuality. Increasingly there is an understanding of the need for education of long term care and rehabilitation staff to understand better and support the sexual health needs of young disabled residents to enjoy ongoing sex and intimacy experiences (Canadian Healthcare Association, 2009; Mayers & McBride, 1998). There exists a gap in knowledge and education for those working with persons
with disabilities regarding their sexuality. There has been some literature which has explored staff training in long term care facilities. However, this has been aimed at the elderly population (Hinrichs & Vacha-Haase, 2010; Mayers & McBride, 1998; Walker & Harrington, 2002). This literature has shown that education modules created for staff have had some success in increasing caregiver knowledge and understanding of sexuality in long term care (Mayers & McBride, 1998; Walker & Harrington, 2002), however other research indicates that although knowledge and understanding is increased, attitude is more of an influence on staff reaction to sexuality (Hinrichs & Vacha-Haase, 2010). Education is only a piece, cultural and personal attitude towards sex and intimacy has a significant impact on staff perception of resident sexuality.

There has been an increasing amount of literature within rehabilitation studies that have focused on the lack of education health professionals have regarding sexuality and disability, and as a result people with disabilities working with staff have limited opportunities to discuss their question and concerns regarding sexuality (Eisenberg et al., 2015; Esmail et al., 2010; Fronek, Booth, Kendall, Miller, & Geraghty, 2005). Valvano et al. (2014) conducted research with students in various health disciplines, including dentistry, psychology, and nursing and found that there was a significant lack of sexual health education within their programs of study. Valvano et al. (2014) suggest that early, quality sexual health training in education needs to occur to “prevent and alter stigmatising beliefs around sexual health and disability” (p.423). The Canadian Healthcare Association (2009) suggests that long term care facilities become centres for research and education, as this would help to change the institutional culture to one of whole person-centred.
For the one participant, staff assisted in putting her and her husband in bed together; however, they then left the room, leaving the two to figure it out, so to speak. There are examples of how staff can further facilitate intimacy while not being directly involved. In Denmark, social workers are trained to be facilitators and sexual advisors (Kulick, 2015). In this case, social workers meet with residents of long-term care homes or group homes and discuss with them their sexuality and intimacy needs. A sexual care plan of sorts is created and shared with staff only who are comfortable with supporting these activities. Staff are then trained and supported to help residents set up of physical intimacy; they are not involved in the acts outside of setting up, such as setting up toys or positioning residents.

For this same participant, she noted several times that she had been given the privilege of being with her husband and that she was allowed to be married or allowed to be intimate. Though this is a positive encounter, the language she uses speaks to the power imbalance that exists in long-term care. These comments suggest that the decision and power are not within the resident’s means but remain with the dominant able-bodied. Feminist theory would have us challenge these power imbalances and be aware of opportunities for change.

6.6 Intimacy is more than sex

When I reflect on the findings, it highlights for me the many privileges I have as a white, able bodied, heterosexual, cisgender woman. I have strong family connections, close friends, a successful career, and no impairments which negatively affect my interactions with the physical world. I have many opportunities to experience intimacy
and I have a sense of belonging and place in society. For me, sexual intimacy is a by-product of the many ways that I belong and fit in society.

Most of the participants spoke about deciding not to engage in physical intimacy since moving to long term care; however, they indicated that they still experience intimacy. Similar results were found by Fritz, Dillaway, and Lysack (2015), in their research examining sex and intimacy after spinal cord injury. They found that for women after spinal cord injury, penetrative sexual intimacy may not be as important as other intimacy such as feeling a closeness with a partner, cuddling, and kissing. Shakespeare (2000) also comments that there may be an overstatement on the need or desire for sex when it is closeness and friendship that everyone, including PWD, want. This seems to hold true for participants in this study, who all defined intimacy as belonging and being connected.

6.7 Future Directions

There are other options outside of facility care which have been implemented in Saskatoon, Saskatchewan, as well as nationally. Programs which provide PWD direct funding to hire their own personal care workers have been established, as well as alternatives to the large institutional care model.

Individualized Funding (IF) has been an alternative program in Saskatchewan for several years. The basis of IF is that individuals or guardians are provided funds to hire privately for caregivers to provide care in the home. Participants still have access to nursing care, community therapies provided through provincial home care services (Government of Saskatchewan, 2019). Reported benefits of this funding model are that PWD and families have increased control over their lives and are more “in charge of their
homes and community lives” (Dozar et al., 2012). However, it is a model of funding that is not clearly understood and is not administered comprehensively enough to meet the ongoing needs of PWD (Dozar et al., 2012). Often there are too many restrictions in place, and it does not meet the full potential of the program. The underlying beliefs of IF are that “funding, services, and supports should not define the individual’s needs, but should respond to, and be built around them. IF further recognizes that these needs must be identified by the individual, not by the professionals around them.” (Dozar et al., 2012). PWD and their family can access funding to meet not only disability-related support needs but also support for access to a community life.

Saskatchewan has implemented IF however, it is limited and had not been discussed openly as an option despite many who could have benefited. There were many restrictions on the program, which led to an investigation by the provincial ombudsman who ruled that the then Saskatoon Health Region needed to provide information to those interested (Saskatchewan Ombudsman, 2019). Despite IF being a valid possibility, most care in the community for PWD is provided through home care services or private care.

There are many alternatives outside of institutional long-term care. Cohousing and investment in home care have created successful community alternatives (Borbasi, Bottroff, Williams, Jones, & Douglas, 2008; Stuart & Weinrich, 2001). Cohousing places similar individuals in an accessible home together with a care team. Benefits of this model are a closer relationship between resident and staff and more of a home life feel. Residents also report increased participation in community and available choices (Borbasi et al., 2008).
In Nova Scotia, the provincial government built 11 new long-term care communities made up of several cottages. Each community housed 12-15 residents and a small care staff. Although research into the success demonstrated that residents and staff reported increased resident autonomy and privacy, staff reported a concern about isolation (Roberts, 2015). Easy access to communal areas was reported to be a problem, but so was staff presumption that residents wanted to socialise together. This highlights the importance of residents being able to choose whom to live with and of selecting residents who like minded.

In Denmark, institutional long-term care homes have essentially been closed. Instead, they invested in community care, including providing 24-hour home care, rehabilitation and community day care centres, and increased adaptive dwellings (Stuart & Weinrich, 2001). This too, has created more autonomy and choice, and a great sense of community. In the USA and Canada, Eden Care philosophy has gained popularity as a form of change model within institutionalised care. This philosophy aims to maximise the quality of life of both residents and staff through creating a meaningful experience (Brune, 2011). The underlying belief in Eden Care is that traditional long-term care creates loneliness, helplessness and boredom. The environment is restructured to include plants, animals, children and smaller living units (Brune, 2011). Residents participate to their maximum potential in daily life.

These alternatives all recognise choice and autonomy and of community access as important contributors to quality of life. They also work towards social justice and are closer to a human rights framework than the traditional model of long-term care.
6.8 Significance for Social work

Literature suggests that social workers are uniquely positioned to help persons with disabilities address their sexual health needs. Marshall and Baffour (2011) suggest that social workers working in long term care play important roles in advocacy, educating and seeking change in both long term care facilities as well as in families and residents. Social workers work from a place of empowerment, and social justice, concepts that are key to help people with disabilities begin to discuss their needs for sexual health (Ballan, 2008; Marshall & Baffour, 2011). Using community development strategies, social workers can ensure that programming and policy changes are made with PWD rather than on behalf of. Social workers are uniquely positioned to assist with policy development for access to sexuality in long term care. Starting conversations about ways to promote sexuality and intimacy in long-term care is one way of doing this; this could include adding sexual health sections to care planning documents to encourage the normalisation of sexual health conversations.

Social workers can act as advocates and educators to dispel myths of asexuality within PWD, promote human rights, and normalise sexuality at every age and level of impairment. Many authors have written that it is through education that people will understand the universal rights everyone is welcome to. This is part of working towards a just society, a role that Kam (2014) indicates that social workers must return to focus on.

As guided by the Canadian Association of Social Workers and the International Federation of Social Workers documents, social workers are obliged to pursue social justice and to uphold and advocate for human rights (Canadian Association of Social Workers, 2005; International Federation of Social Social Workers, 2014). Furthermore,
(Marshall & Baffour, 2011) argue that within long term care, social workers have a unique opportunity to not only advocate for change within family systems and institutional settings but also to empower residents to be part of the conversations needed to change policy. They also argue that social workers must be part of addressing existing policy and creating new solutions, including the development of effective assessment instruments.

One such policy change is a re-modelling of the long-term care system. A review is needed to determine if long-term care is effectively meeting the needs of residents, particularly in terms of social inclusion. Within the current system, there will always be a need for some form of institutional care. However, I believe this care could be provided in a smaller home-like environment with residents who are closer in age. This would ensure age-appropriate social opportunities are present and could increase social engagement.

To be prepared to be part of these conversations, though, social workers themselves must be educated in issues related to PWD. As Ballan (2008) argues, little attention is given to disability and issues of sexuality and disability in social work education. To be better advocates and policymakers, social workers must be given the tools to help empower PWD to be self-advocates. Ballan provides numerous examples of ways in which this can occur, ranging from lecture points, which would include an examination of the various views of disability and sexuality to classroom exercises which could include values exercises.
Chapter 7. Summary

This study was completed to better understand the experience of younger residents, under the age of 70, residing in long term care accessing a sexual or intimate life. This section will discuss the literature review, methodology, limitations, findings, and offer future considerations and concluding remarks.

A literature review was completed to understand and situate PWD and institutional care within history. This was to better understand the complex history of segregation of PWD from public life. Historically PWD have been viewed as different, and something which should be feared and avoided. This type of segregation has continued to a certain degree into the social lives of PWD. PWD are not typically viewed as a viable option for sexual relationships by able-bodied people. Although disability advocates are increasingly advocating and talking about access to sexuality and intimacy, it is still misunderstood.

In relation to access within long term care, research has focused primarily on older adults with dementia, and staff managing their sexual misbehaviours. For younger residents, their need for socialisation may be overlooked in care planning. They may have barriers to sexual and intimate experiences, including lack of privacy, staff attitude, the need for staff facilitation, and lack of access to possible partners.

However, as this research has identified, the inclusion of PWD in everyday social activities may be more important than focusing on sexuality. Supporting other intimate connections which increase feelings of belonging and value may be more of what is needed. One way this may be achieved is through strengthening the community care
PWD have access to. With less institutionalisation may come increased community involvement and connection.

There is also a need for increased support within long term care homes to support a variety of socialisation opportunities. Having a greater social work presence to help advocate for those changes and educate both staff and residents on the importance of intimacy and the options of sexual intimacy is also important.
References


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Appendix A

Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR
Dr. Randy Johner

DEPARTMENT
Faculty of Social Work

REB#
2018-046

TITLE: Accessing Intimacy: The Experience of Younger Long Term Care Residents

APPROVED ON:
April 12, 2018

RENEWAL DATE:
April 12, 2019

APPROVAL OF:

Full Board Meeting ☐
Delegated Review ☒

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.uregina.ca/research/faculty-staff/ethics-compliance/human/forms1/ethics-forms.html.

Ravneet Sinclair, BA, CISW, BISW, MSW, PhD
REB Chair

Please send all correspondence to:
Research Office
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775    Fax: (306) 585-4893
research.ethics@uregina.ca
Principal Investigator: Dr. Randy Johner
Department: Faculty of Social Work
REB#: 2018-046

Title: Accessing Intimacy: The Experience of Younger Long Term Care Residents

Amendment Approval of:
- Recruitment Poster

Next Renewal Date: April 12, 2019
Amendment Approval Date: June 13, 2018

Full Board Meeting [ ] Delegated Review [x]

Amendment Certification:
The University of Regina Research Ethics Board has reviewed the changes to the above-named research project as outlined in your memo dated June 8, 2018, and they are approved.

Ongoing Review Requirements:
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for the renewal and closure forms:

https://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/ethicsforms.html

Ara Steininger
Research Ethics Board

Please send all correspondence to:
Research Office
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775
Fax: (306) 585-4863
research.ethics@uregina.ca
April 19, 2018

Dr. Randy Johner
Faculty of Social Work
University of Regina.

Dear Dr. Johner,

Saskatchewan Health Authority is pleased to provide you with operational approval of the following research project:

Research Ethics Board (REB) #: 2018-046
Project Name: Accessing Intimacy: The Experience of Younger Long Term Care Residents
Protocol: N/A

This approval applies only for the Saskatchewan Health Authority unit/program(s) that have approved this project and are copied on this letter. Kindly inform us when the data collection phase of the research project is completed. We would also appreciate receiving a copy of any publications related to this research. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatchewan Health Authority.

We wish you every success with your project. If you have any questions, please feel welcome to contact Shawna Weeks at 655-1442 or email shawna.weeks@saskatoonhealthregion.ca

Yours truly,

M. Suzanne Sheppard, Ph.D.
Director, Interprofessional Practice, Education & Research
Saskatchewan Health Authority

CC: Vanessa Ripley, Manager – Strategic Initiatives, Seniors’ Health & Continuing Care
Saskatoon, SHA
PARTICIPANTS NEEDED FOR RESEARCH IN LONG TERM CARE

We are looking for volunteers to take part in a study called Accessing Intimacy: The Experiences of Younger Long Term Care Residents.

As a participant in this study, you would be asked to: participate in individual, face to face interviews. This will be volunteered time, there will be no compensation for your time.

Your participation could involve 2 interviews, 30-45 minutes each.

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

Maggie Sawatsky
Master of Social Work student
306-270-5301 or
Email: sawamegh@uregina.ca

Or my research supervisor

Dr. Randy Johner
Faculty of Social Work
Call collect 1-306-585-4549 or
Email: randy.johner@uregina.ca

This study has been reviewed and received approval through the Research Ethics Board, University of Regina on April 12, 2013.

Any questions regarding your rights as a participant may be addressed to the committee at 306-585-4775 or research.ethics@uregina.ca Out of town participants may call collective.

Image by Unknown Author is licensed under CC BY-NC-SA
Do you currently live in Long Term Care?

Did you use to live in long term care, but have moved out?

Do you have experience making new friends, keeping old friends, or romantic relationships while in Long Term Care?

We are looking for volunteers to take part in a study called Accessing Intimacy: The Experiences of Younger Long Term Care Residents

As a participant in this study, you would be asked to: participate in individual, face to face interviews. This will be volunteered time, there will be no compensation for your time.

Your participation could involve 2 interviews, 30-45 minutes each.

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

Maggie Sawatsky
Master of Social Work student
306-270-5301 or
Email: sawamegh@uregina.ca

Or my research supervisor

Dr. Randy Johner
Faculty of Social Work
Call collect 1-306-585-4549 or
Email: randy.johner@uregina.ca

This study has been reviewed and received approval through the Research Ethics Board, University of Regina on April 30, 2018
Any questions regarding your rights as a participant may be addressed to the committee at 306-386-4775 or research.ethics@uregina.ca. Out of town participants may call collect.

Image by Unknown Author is licensed under CC BY-NC-SA.
Appendix D

University of Regina

To whom it may concern,

I am a graduate student with the University of Regina, completing a research thesis for my Master of Social Work. I am seeking your assistance and permission to place recruitment posters within your home, as well as to help facilitate a meeting with the resident council.

My research topic is examining the experiences of younger residents, ages 18-64, attempting to access intimacy. I became interested in this topic while I was working in a long term care home as a social worker. My hope is that through better understanding the experiences of residents, both positive and challenging, sexuality and intimacy can be better supported in long term care. The results of the research could inform future staff education, and policy guidelines.

My research has received ethics approval through the University of Regina Research Ethics Board, as well; it has received Operational approval through the Saskatchewan Health Authority. Participants will be asked volunteer their time, there will be no compensation or benefit, other than opportunity to share their story and potentially influence future policy guidelines and staff education.

I am happy to discuss with you further my research and any questions or concerns you may have.

Thank you in advance for your assistance.

Sincerely,

Maggie Sawatsky
Ph 306-270-5301
Email: sawmeph@uregina.ca

Research Supervisor

Dr. Randy Johner
Faculty of Social Work
Ph 1-306-585-4549 or
Email: randy.johner@uregina.ca
Appendix E

Initial Interview Guide

Thank you for agreeing to take part in this interview. Your experiences and perspectives will be very helpful with exploring intimacy in long term care. Your participation will also help me with the completion requirements of my Master of Social Work degree.

You will be asked to read a consent form, and sign if you agree to participate.

The interview will be audio – recorded with your consent and the recording will be destroyed after the study as been completed.

Before we begin the interview, I would like to review the consent form with you.

Questions

1) What is your age?
2) What gender do you identify as?
3) How long have you lived-in long-term care?
4) Describe how it is you came to be living in long term care?
   Prompts: What was the move like?
   How did you feel moving into long term care?

5) Describe your social connections
   Prompts: how are they different since moving to long term care

Summary

Thank you for participating in this interview. Your responses will provide me with a better understanding of your experiences in long term care. If you are comfortable, the next interview I would like to ask you about your experiences with intimacy, and your relationships since moving to long term care.

If you feel our discussion today has raised any difficult issues for you, or if you feel that you would like to pursue any additional support about the topics discussed today, feel free to talk to the staff at the agencies provided on this piece of paper.
Interview 2 Guide

Thank you for agreeing to take part in this interview. Your experiences and perspectives will be very helpful with exploring intimacy in long term care. Your participation will also help me with the completion requirements of my Master of Social Work degree.

You will be asked to read a consent form, and sign if you agree to participate.

The interview will be audio – recorded with your consent and the recording will be destroyed after the study has been completed.

Before we begin the interview, I would like to review the consent form with you.

Guiding Questions

1) Last time we met we spoke about your experiences with social connections. I’d like to now better understand your experiences with intimacy. Can you describe for me your understanding of what intimacy is?

    Promts: How did you come to this understanding?

2) Can you describe an experience you’ve had with intimacy while living in long term care?

    Promts: What was that like for you?
    How was it different from before moving to long term care?

Summary

Thank you for participating in this interview. Your responses will provide a better understanding of the experiences of younger residents in long term care, accessing intimacy.

If you feel our discussion today has raised any difficult issues for you, or if you feel that you would like to pursue any additional support about the topics discussed today, feel free to talk to the staff at the agencies provided on this piece of paper.
Appendix F

Participant Consent Form

Project Title: Accessing Intimacy: The experience of younger long-term care residents

Researcher(s): Maggie Sawatsky, Graduate Student, Faculty of Social Work, University of Regina, 306-270-5301, sawamegh@uregina.ca

Supervisor: Dr. Randy Johner Faculty of Social Work, 306-585-4549, randy.johner@uregina.ca

Purpose(s) and Objective(s) of the Research:

- The purpose of this research is to better understand the experiences of younger residents, ages 18-64, living in long term care attempting to access a sexual life.
- This research may help to guide policy development, and staff education.
- Data will be collected for a thesis report written by the researcher. The final report may be submitted for publication with recognized peer reviewed journals.

Procedures:

- If you volunteer to participate in this study, you will be asked to take part in an initial screening interview, and up to two or three more interviews. During the interview you will be asked to discuss your experience related to the research question. An interview guide will be used by the researcher to guide the discussion. The results of the interviews will be used to write a thesis report.
- Each interview will take approximately 30 - 45 minutes and will be conducted at a time and a location that is convenient for you. The interview will be audio-taped, and the researcher may take notes during the interview process to ensure that the data gathered will be reported accurately. Please feel free to ask any questions regarding the procedures and goals of the study or your role.
• You are free to decide to not answer any question during the interview. No negative repercussions will occur if you decide to terminate the interview, do not want your interview to be used, or decide not to participate in this project.

• You are welcome to invite a support person to the interview should you feel more comfortable with their presence.

Potential Risks:

• There are no known or anticipated risks to you by participating in this research. There is no physical risk from taking part in the interview. However, if you need help dealing with issues raised during the interview, you will be given a resource list with contact information for a variety of telephone crisis resources available to you at no cost. You may contact these service providers in the event that you could benefit from discussing these issues with a professional counselor. If you choose to be referred by the crisis service to a counseling agency or program in your community, you are responsible for any costs that may be incurred upon accessing these services.

• You are free to withdraw from the research project at any time and this withdrawal will not affect access to, or continuation of, services provided by public agencies such as hospitals, social services, schools, etc.

• The researcher will not provide any information to authorities unless required by law. For example, if anything you tell the interviewer indicates that a person under the age of 18 is in need of protection, the interviewer shall have to report this to Child Welfare authorities.

Potential Benefits:

• There are no direct benefits to you by taking part in this study. However, your participation may help with providing future guidance to policy development and staff education.

Compensation:

• No remuneration is provided for participation in this project.

Confidentiality:

• All of the data collected will be kept in strict confidence. The digital audio recording and any other data will be kept in computer files that are protected by a password and a firewall on a secured computer. All of the paper data will be kept in a locked filing cabinet.

• Your name or other information that could tell others who you are will not be recorded on the interview audio tapes, computer or paper files. Only the researcher and the course instructor will
be allowed to view the transcript data. The computer files will be labeled with a number code that only the researcher will see. The consent forms will be stored separately from other data collected so that it will not be possible to associate a name with any given set of responses. Please do not put your name or other identifying information on any documents except the consent form.

- When the final thesis is written, your name or any other information that could tell others who you are will not be used. Although direct quotations from the interview may be used, you will be given a pseudonym, and all identifying information such as the name of your home will be removed.

- Because the participants for this research project have been selected from a small group of people, it is possible that you may be identifiable to other people on the basis of what you have said.

- The computer files and any other information or data collected will be securely stored in a locked cabinet in the thesis supervisor’s office at the University of Regina and will be destroyed after five years.

There are several options for you to consider if you decide to take part in this project. You can choose all, some or none of them. Please put a check mark on the corresponding line(s) that grants me your permission to:

I grant permission to be audio taped: Yes: ___  No: ___

The pseudonym I choose for myself is: ____________________________________________

You may quote me using only my pseudonym: Yes: ___  No: ___

**Right to Withdraw:**

- You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort. Should you wish to withdraw, your data will be deleted from the project and destroyed, if desired.

- Your right to withdraw data from the study will apply until the data has been analyzed. After September 30, 2018 it is possible that some of the data will have been written into the final thesis and it may not be possible to withdraw your data.
Questions or Concerns:

- Contact the researcher(s) using the information at the top of page 1;
- This project has been approved on ethical grounds by the U of R Research Ethics Board on April 12, 2018. Any questions regarding your rights as a participant may be addressed to the committee at (306-585-4775 or research.ethics@uregina.ca). Out of town participants may call collect.

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.

List of community supports:

Saskatoon Crisis Intervention Services 306-933-6200

Mental Health and Addictions Services 306-655-7777

Family Service Saskatoon 306-244-0127