

Sexual Expression in Alberta's Continuing Care Homes

Perspectives from Residents and Family Members

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Executive summary

In this report, we outline the findings from Phase 2 of a multi-phase, Alberta-wide study on sexual expression in supportive living and long-term care homes. By “sexual expression,” we mean handholding, hugging, fantasizing, bed sharing, kissing, masturbation, grooming and self-presentation, forming intimate relationships, and engaging in physical sex acts. In what follows, we outline some of the key themes from the academic literature; briefly describe our methods for data collection and analysis; share key findings; and make recommendations for policy and practice. We conclude with a list of resources for family members and residents who are navigating sexual expression in continuing care homes.

In Phase 1 of this research, we interviewed continuing care managers and those with whom they consult (clinical ethicists, social workers, best practice/geriatric assessment teams, and others) about matters related to sexual expression. We asked about how residents’ sexual expression is navigated in congregate settings. In the absence of related provincial policies and practices, we explored how managers both support safe, healthy, and dignified expressions of sexuality, and respond to unhealthy, unsafe, or undignified expressions. The Phase 1 report is available here: <https://opus.uleth.ca/handle/10133/5253>.

In Phase 2 of this research, we interviewed 20 participants (12 residents and 8 family members). We asked them about how they define sexual expression, its place in continuing care, their experiences with/thoughts about sexual expression in continuing care homes, and suggestions for how to improve this aspect of resident life. We heard diverse accounts of what sexual expression can look like in continuing care homes, the importance of resident autonomy, how privacy matters, complex communication dynamics, and challenges with distinguishing between appropriate and inappropriate expressions. The Phase 2 participants represent urban, sub-urban, and rural communities across the province.

Residents told us about their wide range of experiences. For instance, some participants indicated that their sexual lives ended when their spouses died or became ill, some used sex toys nightly, one participant won an award for an



erotic film, and another came out of the closet for the first time in his long-term care home. Some residents regularly listened to romance novels on audiobooks and some cherished any non-clinical touch that they received. Their accounts provide insight into what it is like to be (or try to be) a sexual being in a care home environment; the joy, hope, frustration, and fear associated with living out this aspect of their lives under the gaze of care providers and family members.

Family members were generally supportive of, and simultaneously concerned about, sexual expression in the care home. They were concerned about staff making sexually disinhibited residents with dementia feel like “monsters,” about inadequate responses to unwanted sexual touching, about how easily a resident can be left out of discussions about their sexual expression, and about the views and actions of staff members.

This is a complicated, emotionally laden, and socially taboo matter. While all parties involved are making concerted efforts, there is opportunity for further discussion and strategic, coordinated action.

Background

Long-term care and supportive living demographics are changing and the demand for these services is growing.¹ This sector has historically been associated with care for older adults, but recent trends also indicate a growing need to support middle-aged adults with medically complex conditions.² Sexual expression is often overlooked in these populations despite ample evidence of ongoing need for intimacy, connection, and self-expression. Furthermore, “future cohorts of older adults are expected to have even higher sustained interest in sex, as well as higher frequencies of participating in sexual acts, as generational acceptance and perception that sexuality is normal for elders increases.”³

Over the last 30 years, this topic has become increasingly popular and pressing. There has been a fair amount of international literature dedicated to exploring the views, attitudes, and responses of continuing care staff and residents’ family members.⁴⁻¹⁰ Much of the research with family members indicates that there is support for “minor” or subtle expressions. Loving and caring expressions are more accepted by families than erotic ones.⁵ It is common for family members to feel the need to be kept informed about a resident’s sexual activities,¹⁰ but support for sexual expression varies considerably.

Several scholars in this field have indicated that we need more resident voices in this research. Unsurprisingly, residents’ views on the matter are diverse. Researchers from Spain examined residents’ attitudes towards physical sex acts such as intercourse and masturbation and found that internalized ageism and social stigmas around sexuality were barriers to healthy sexual expression.¹¹⁻¹³ In the UK, some

residents indicated that social intimacy is more important to them than physical intimacy.¹⁴ Scholars from the United States found similar results for men living in nursing homes, noting that increased non-sexual intimate interactions improved residents’ quality of life.¹⁵ Several international research teams have looked at residents’ attitudes towards sexuality and their perceptions of barriers to sexual expression.^{16,17} Many of these studies offer ways to categorize and understand sexual behaviours and expressions (e.g., solitary/dyadic, touch/talk/non-touch expression, etc.; and social, intellectual, emotional, and physical components of intimacy). Across this scholarship, staff attitudes and privacy consistently come up as key themes and significant barriers to residents’ sexual expression.

Residents and their family members are rarely informed about what types of expressions are considered acceptable in continuing care settings or what sort of privacy is available to them. Research from the UK revealed that only 2.1% of contacted care homes provide any materials that address love, sex, or intimacy.¹⁸ It is possible the lack of attention to sexual expression reflects societal attitudes about aging and diminished sexual interest, particularly for those with chronic health conditions. Furthermore, a growing amount of literature addresses the fact that sexuality in continuing care homes is often heterosexualized (Westwood, 2015).¹⁹ Members of LGBTQ2S+ communities across the world have expressed concerns about potentially having to hide their sexual orientation and/or relationships in continuing care for fear of harassment or discrimination.²⁰⁻²³

We wanted to see how these themes from the national and international literature play out in the current Alberta context. With this in mind, we posed the following questions to guide Phase 2 of this study.

Key Research Questions

1. How do continuing care residents and family members define sexual expression? What place do they think it has in continuing care homes?
2. What kinds of conversations have participants had related to sexual expression (with residents, families, staff)? What kinds of conversations do they think are needed?
3. For family members, how prepared do they feel to support this aspect of their relative/partner's care? What would help them to feel more prepared?
4. What types of resources or supports related to sexual expression would be most useful for residents and family members?

Methods

We received ethics approval for Phase 2 of this research from the University of Alberta Research Ethics Office and operational approvals from Alberta Health Services, CapitalCare, Carewest, and Covenant Health. We used a qualitative exploratory design to better understand sexual expression in continuing care from the perspectives of residents and family members.

Data collection took place between May 2018 and March 2019. We recruited residents and family members via posters in continuing care homes, e-mail list serves, caregiver support groups, and direct e-mails to recreation therapists and care home managers who then shared study information at resident and family council meetings. In order to participate, residents needed to have the cognitive capacity to consent to participate in research and be their own legal decision-maker.

We conducted semi-structured interviews with 20 participants (12 continuing care residents and 8 family members). Participants ranged in age from mid-40s to early 90s. We conducted the interviews in-person and over the telephone. We asked about how participants defined sexual expression, the kinds of conversations that they have had/think are needed related to sexual expression (with staff, families, residents), their preparedness for this aspect of life/care, and the types of supports that would be useful to them. The interviews were digitally recorded and lasted between 45–75 minutes. The transcribed interviews were coded and critically analyzed using Braun and Clarke's²⁴ approach to thematic analysis. In the following section, we describe our key findings.

Key findings

Our findings confirmed and extended the themes from the existing literature and highlighted experiences specific to the Alberta context. Key themes include: (1) diverse experiences of sexual expression in continuing care homes, (2) resident autonomy, (3) privacy matters, (4) communication dynamics, and (5) distinguishing between appropriate and inappropriate expressions.



1

Diverse experiences of sexual expression in continuing care homes

Our findings reveal that continuing care residents express their sexuality in diverse ways. Some of these experiences may not fall under everyone's definition of "sexual expression," but for our participants, they did. Their stories varied considerably. For instance, several residents indicated that their sexual lives ended when their spouses died, some told us that they use sex toys nightly, one participant won an award for an erotic film, another came out of the closet for the first time in his long-term care home.



"I've tried to show people that [though you may be] in the closet when you go into long-term care, it is okay to be yourself. You must be yourself. I've lived a lifetime of not being myself and my God, it feels so good to be yourself!" (Resident 2 – August 9).

We learned that for many residents, it is not just about being true to one's internal self, but also about the outward presentation of that authentic self. Residents wanted to look and feel good. A number of participants spoke about maintaining their appearance as part of their sexual identity.

"I wear makeup. I make my hair nice when I go out, because I want to present the world to meet who I am, and I am me...I'm going to be the best me I can be to the world" (Resident 12 – October 23).

"The girls do my hair, I brush my teeth, I put on my cologne... I always like to smell nice" (Resident 7 – October 23).

Participants spoke about residents' need for non-medical touch, the importance of emotional intimacy, individual and/or coupled sexual acts, and the ways in which sexual expression can

change over the life course. Several residents indicated that their expressions of sexuality have changed over time. This was the result of different stages in relationships, changes in their bodies, and other life transitions. Some of these residents described physical sex acts and/or dating as something that they were content to have left behind in earlier chapters of their lives. In several cases, these individuals still enjoyed and desired sensual touch, emotional intimacy, companionship, or reading romance novels.

“I’m happy with my life of self, because I’ve been a widow for eighteen years, and I’m happy with my life now. I’ll read a good book for a good tingle, you know, like, a good romance novel... If you want love, get it from a book. It’s a lot safer and you get a new guy every time, and you’re not breaking your heart or anyone else’s... I get the glow, the warm, fuzzy glow of love and intimacy through my books that I read. That’s kind of my sexual expression these days”
(Resident 12 – October 23).

“Probably at this point in my life, there isn’t a lot of sexual expression or intimacy there. There is more maybe friend relationships and I think that’s maybe what I miss more, like companionship and friendship” (Resident 6 – October 10).

“Somebody said, ‘well why don’t you get somebody else?’ I said ‘no, I had one and that’s all I needed’... I had it years ago and I don’t need anymore”
(Resident 4 – August 28)



Physical touch was also identified as an important part of residents’ sexual expression. One resident told us about how rarely he receives any non-medical touch and how meaningful that type of human connection can be.

“And [staff member] came into the room one evening and I was crying. And he said, ‘What’s wrong?’ I said, ‘I miss being touched.’ ‘You get touched all the time,’ he said. I said, ‘Yes, to be washed, to be bathed. Never just to be touched.’... [The staff member then hugged the resident in a long embrace]. And for those two minutes I was in heaven. Because you do that little expression. And at that time, it was an expression of sexuality, but also an expression of being human. ... Oh my God, it was glorious. I knew he had a partner. But I was crying tears of joy. Like I told him, ‘you don’t know what this means to me’” (Resident 2 – August 9).

The meaning of touch is often invisible to care staff who have come to know residents in a strictly medical setting. One participant noted that in other congregate living environments, we would be less surprised to see people form new relationships or express their sexuality.

“I think sexual expression has a really important place [in continuing care] because if you took away the disability and that, you could very much see continuing care homes would be like a college residence, where a lot of people are living close together. But you don’t often see people engaging in stuff like that because it is kind of reduced to being a medical setting. But this is where these people live!” (Family Member 5 – October 12).

Other residents indicated that physical touch, emotional intimacy, and sexual acts were still very much a part of their lives. For instance, we spoke with one couple who met and married



as residents in continuing care and continue to have an active sex life. Participants also spoke about general benefits of sexual expression. They told us about how touch and emotional intimacy can provide a sense of personhood, safety, and/or belonging.

“Well, I think just connecting with other people is the important thing, not so much the sexual part of life, but just having human connections... The emotional intimacy just makes me feel more as a person. Because I think without that, you can just sort of get lost in yourself.” (Resident 6 – October 10).

“My mom wasn’t a demonstrative person with hugs and saying, ‘I love you,’ even though we always knew that she did. But it was interesting to watch her [in continuing care] hold another lady’s hand and just stroke it... So, I think obviously, she needed that sexual expression in that case, to feel safe” (Family Member 7 – March 25).

“Right now [after recent breakup with a fellow resident], I’m just trying to be happy again. I want to feel like I belong. I want to feel like I belong to someone” (Resident 7 – October 23).

In sum, residents’ experiences of sexual expression in continuing care homes were nuanced and diverse. These expressions included overt and/or covert acts, identities, relationships, and ways of being in the world. By attending to human connection and physical touch, there is opportunity to support residents’ sense of belonging, personhood, safety, and authenticity. There are also opportunities to improve residents’ privacy and autonomy when it comes to decisions about their sexual expression.

2

Resident autonomy

Most of our participants indicated that retaining autonomy through personal choice is very important for residents' sexual expression. This includes making decisions about what to wear, how one's hair is styled, which social activities one participates in, and more. By making these choices, residents can retain a sense of identity beyond being a recipient of care.



“Because they have to get help, being changed and getting help to bed and that. Sometimes they can’t even dress themselves or do those little extra things that will make them feel attractive or keep spirits up, how they look... Because of that, I think they start to feel like they are losing their sexual expression” (Family Member 5 – October 12).

In other words, rather than solely being acted upon, residents expressed a desire to act within their worlds. Being able to make choices for themselves means being able to pursue possibilities. One resident told us about how it was disappointing to not have any say about with whom he sat at mealtimes. It was always the same dining room seating plan in his care home. He said that it can be exciting to sit and chat with new people and/or their visitors.

Our findings also reveal that financial independence can enable sexual empowerment. Residents who were in control of their own finances and had reliable internet access were better able to address their sexual needs without assistance from others. These residents purchased items like lubrication, sex toys, or erotica discreetly online.

“Sometimes staff would be like, ‘oh, are you sure you want to wear that? Because that’s a little more difficult [to put on].’ And it’s like, ‘yeah, she’s sure she wants to wear that. It makes her feel pretty’” (Family Member 5 – October 12).

Choice is not solely about maintaining identity; it is also about the feeling of empowerment that comes with being able to make choices at all.

“Let [husband] be strong. Let him do as much as he can for himself for as long as he can. That independence is part of our sexuality too” (Family Member 3 – June 19).

“I get books through the internet, so I can read whatever... I can download an e-book or audiobooks that I want to read, so I can read whatever I want... more explicit than I ever had read” (Resident 6 – October 10).

“[re: accessing lubrication] Oh, it’s no problem. I’ve been buying a lot of stuff from Amazon... I’m in control of my own finances” (Resident 1 – May 30).

Residents who did not enjoy the same degree of autonomy had to involve family members and/or staff in these purchases and practices.

“Because the [vibrator] that I had before, it broke on me. So I not only had to ask my sister if I could have the money for another one, but I [had to ask recreation therapist to order it online]. She just used a credit card and then I paid her back for it” (Resident 11 – October 23).



By nature, congregate environments require some limitations on autonomy. The residents we interviewed did not expect that they should be free to do whatever they want in a shared living space. That said, both residents and their family members indicated that sexual expression is an activity of daily living and that residents should have freedom to engage in certain expressions (privately and consensually). One participant suggested that respecting autonomy means recognizing that people will make different choices than you might make. She spoke about her experience with supporting her father’s pornography viewing habit and highlighted how easy it can be to exclude residents from decision-making about their sexual expression.

“His nurse, she’s like, ‘this is his choice and if he’s doing it, then here’s what we figure out to manage it, but you can’t actually force him to do what you want’... afterwards, I said to him, ‘I’m sorry. I probably should have come to get you’ and he was nodding. I think that’s the danger with continuing care settings. I’m probably someone’s who has a fairly high degree of consciousness around that and it was still so easy to just kind of steamroll in and not have him involved one of the more important meetings around how his life unfolds. So, when it comes to sexual expression, that those conversations have the potential to happen without the person is really scary... I want my dad to be able to watch porn. I mean, I don’t want him to be able to watch porn, but I want him to be able to do as much as he can in his space that is his space” (Family Member 1 – May 18).



As noted earlier, the extent to which other parties are involved in residents' sexual expression varies. Some residents told us that they want little to no family or staff involvement in their romantic or sexual lives. One participant told us that her care staff do not seem to recognize that her relationships with them are already intimate. She told us that she had never been naked as an adult in front of anyone except her late husband and now she has to do so in front of multiple care staff members. She wanted them to understand this vulnerability and to recognize their work as intimate moments for her.

“The staff should say ‘good morning... how are you?’ Don’t just come in, shut the door and start... They’re just [being] robots... When they come into our rooms, they come into our hearts [points to chest]” (Resident 8 – October 23).

Others residents indicated that they require or desire some assistance with their romantic or sexual lives. These residents indicated that they might need assistance with getting in and out of bed when they have a visitor, assistance with transportation to and from dates outside of the care home, or some emotional support following a break-up. Many residents indicated that, at times, they end up feeling like clusters of care tasks and are worried about being a burden. Some felt that their identities were reduced to their diagnoses and their medical care plans. These participants said that they feel a greater sense of personhood when their preferences are valued and they are treated as though they are deserving of choice.

3 Privacy matters



“I don’t feel that a long-term care facility is a very sexy place to be” (Resident 6 – October 10).

Our participants were unanimous that continuing care homes are not particularly ‘sexy’ environments. They did not suggest that care homes should be sexy environments, but rather, that they ought to feel like homes in which residents are afforded the privacy to have personal lives. Our participants spoke about several types of privacy. The first was spatial privacy. This refers to the physical care home environment. In some care homes, rooms are shared, doors do not lock, and couples cannot room together.

“I would like to see... more places in facilities where couples could be together. This would be especially for older couples that have been together for many years and now have to face being separated because one person needs more care than the other. After all those years with each other, they are now separated and cannot rely on the comfort that they have always received from the other one, be this sexual or not” (Resident 6 – October 10).

We were told many times about how limited privacy in continuing care can be. Residents indicated that there was limited space that was truly their own.

“If I had a girlfriend in here someone can always catch us. People come in the bedroom without knocking. There’s no privacy. I’ve been caught a couple times by the nurse without knocking” (Resident 7 – October 23).

“When they’re giving you a shower, you’ll be sitting there and lying there naked and they’ll be opening your room door to the hallway” (Resident 6 – October 10).

This resident expressed a concern about spatial privacy as well as how her modesty was respected within that space. Another resident spoke about how the structured nature of the care home environment put strain on his romantic relationship.

“I mean [having girlfriend visit] worked out for the most part, but she felt kind of nervous, shy kind of. Like if we decided to be – get a little romantic, you know, because the door doesn’t lock. So of course, you just come up with ways, and we did, but she still would feel kind of like she’s on the clock, you know, ‘They want me out of here by 11:00.’ Your times to be romantic are kind of cut into quarters and if they maybe had more – I don’t know, flexibility around like times of, you know, bedtimes and stuff like that. Like it’s so crazy this assembly line style living that I often feel like I’m kind of – I can’t keep up with a regular life” (Resident 3 – August 13).

In this instance, the heavily routinized environment left little room for spontaneity or relaxed intimate time.

Residents and family members also spoke about social privacy. This included privacy surrounding one's sexual interests or practices. One participant told us that care staff would inquire about her masturbatory habits, unrelated to concerns about her health and well-being.

"[I] have a personal toy that I like to use at night and sometimes the staff kind of embarrass me because they say they don't understand why I have to use it and stuff... not only do they not understand why I have to use it, but they always say they don't understand why I have to use it every night... And sometimes it makes me really, really mad and upset... I wish there was a way that I could get the staff to be a little more understanding" (Resident 11 – October 23).

In this instance, the resident used and cleaned the toy on her own, but required staff assistance with retrieving it from her bedside table once she was in bed. She said that she wished that they would just pass her the toy in its covering without any commentary or judgment. Similarly, a family member told us about how the staff at her mother's care home would tease her mom whenever she was getting to know a new man.

"Sometimes the care aides would later be like, 'Oh, you have a crush on that person?' or whatever. So that's really hard and with any relationship, even with your friends that you're trying to start a relationship with someone and they right away bug you about it. That can really just turn you off or make you shy. I know in her place that they jokingly try and set my mom up quite a bit. So she finds that kind of frustrating because it's okay to joke about it, but every time she goes and she talks to someone new, 'Oh, you should hook up with that person.' That's not necessarily a) how my mom is and b) it's not necessarily the intention of it" (Family Member 5 – October 12).

Residents indicated that privacy about their sexual and romantic lives was important, and added that general privacy of information was important as well. One participant said that when staff speak about her bowel movements in public spaces, she feels embarrassed.

"They'll be talking, 'oh, here you need a laxative, you're constipated.' Things like that in the middle of the dining room. It's just there isn't the modesty and privacy that you're used to. If you have company over, you wouldn't be talking about that type of thing... Getting asked about that everyday just really kind of removes the sexuality about you because you get reduced to, 'what time did I poop?'" (Resident 6 – October 10).

In sum, privacy matters. This includes privacy of physical and social space and of personal information. Whether residents do or do not have the privacy to express themselves, we heard that their expressions get mixed responses from staff and family members. Family members have indicated that they too get mixed responses from staff, which can make these scenarios challenging to navigate. We heard consistently that few people felt prepared to engage with this topic (in words or in action). This does not mean that there were no positive stories, but rather, that the positive experiences often resulted from individual instances of compassion and/or support, rather than a systematic, reliable, and consistent effort. This highlights the need for clearer and more consistent communication amongst residents, family members, and care home staff.



4

Communication dynamics

Our participants had a great deal to say about communication regarding sexual expression. The most common concern was about a lack of related communication in continuing care homes. Residents and family members felt that there were no clear expectations, policies, guidelines, opportunities for conversations, or information about what types of supports were available to them. Residents did not know that they could ask staff about opportunities to go on dates, have company over, or order items online. Similarly, family members did not know what to anticipate or with whom they could speak about an issue.



“[What] can help is developing a glossary or some kind of language... so we don’t have to say things like ‘dirty old man.’ Sometimes you just got to be like. ‘yeah I’m going to make some mistakes and this is going to be really kind of awkward and kind of uncomfortable and kind of funny, but we just need to kind of like move forward and talk about it’” (Family Member 1 – May 18).

“Nobody knows what the rules are... If everybody gets the same information... [about sexual expression] then isn’t everybody on the same page?... I think, you’d almost need something like a booklet or a manual or a pamphlet, saying ‘okay these things could be tolerated or could happen’” (Family Member 8 – March 21).

Many participants described a lack of preparation for sexual expression and an absence of clear, normalizing language with which to speak about it.

“One day I had a very awkward conversation with the front desk person who said ‘well we have an extra charge on your dad’s cable bill for a special channel’ and she was sneaking in euphemisms and it took me a minute to actually figure out what was going on” (Family Member 1 – May 18).

When staff do not address these matters directly, important details may be omitted, events may be misinterpreted or poorly understood, people may be stigmatized, and it contributes to the idea that sexual expression is taboo and something we do not speak about.

Another important concern was the ‘lack of unified voice’ within and between continuing care homes. In other words, there was considerable variation in staff language, attitudes, and responses. We heard that some staff members are very empathetic and compassionate, treating sexual expression as something that can be worked with and/or supported, and other staff in the same care home treat sexual expression as something distasteful and shameful that has no place in continuing care. This inconsistency is challenging for residents and family members.

Participants indicated that communication issues are complicated by the fact that information about sexual expression is not always easy for families to accept. We heard about family denial, fear of stigma, and being caught off guard by changes in a relative who has dementia.

“My mom really didn’t handle it well so she started to get mad at my dad and [say] ‘you dirty bastard’ and just arguing with him... One sister is like ‘well, what are those girls doing taking dad into the bathroom anyways?’ you know. And no one was being suggestive with my father, but my sister just could never – she idolized my dad and it always has to be the woman’s fault, unfortunately” (Family Member 2 – May 29).

“And, you know, there’s people [with dementia] there and, they’re having these behaviours and it’s really upset my aunt... It’s been explained to her that they can’t help it. It’s part of the dementia. And she said that she’s being lied to... She’s very cognitively intact but, there’s an impairment there for her to be able to accept that this is not something that’s being done on purpose... So, she’s even said to [her husband], ‘are you having an affair?’... And, he’s crying...” (Family Member 6 – February 7).

Lastly, participants reminded us that partners and spouses have different informational needs than residents’ children. Residents’ children were often unsure about what to do with information about their parents’ sexual expression and questioned whether it should have been shared with them at all.

“Once they see something, should they be telling us right away, ‘oh we found your mom with her top off in her room’? Like, should I know that? And then, when I know that, what do I do with that? I store that information. Am I supposed to act on that? Do I say ‘okay, now what?’... Nobody knew exactly how we should be told and how much” (Family Member 3 – June 19).

“But I think for maybe some other family members, they don’t necessarily want to hear about all those things about their family members. So, I mean I’m sure the staff do use discretion about who they talk about, but sometimes I feel like maybe they don’t” (Family Member 5 – October 12).

The boundaries regarding how much information should be shared, and with whom, remain unclear. Our participants have indicated that these discussions need to be navigated thoughtfully in effort to balance the benefits of sexual expression with safety/transparency and privacy/autonomy. Without clear and consistent communication about sexual expression, we also see challenges with distinguishing appropriate expressions from inappropriate ones. These are discussed in the following section.



5

Distinguishing between appropriate and inappropriate expressions

Because of personal views and varied understandings about cognitive impairment, it can be challenging for family members and care home staff to distinguish between appropriate and inappropriate expressions of sexuality. Our Phase 1 participants suggested that it might be helpful to think about this issue in terms of ‘wanted’ and ‘unwanted’ expressions. This helps to distinguish between expressions that may cause harm and those that staff may subjectively find distasteful. Phase 2 participants indicated that care homes tend to suppress sexual expression and only speak about it when there is a problem. Residents and family members often hear about inappropriate or unacceptable expressions, but they almost never hear about what is considered acceptable or appropriate sexual expression in continuing care. For instance, what can sexual expression look like for residents? Where are residents entitled to privacy? What is the protocol for indicating that they should not be disturbed? Can they expect or ask staff to assist them with purchasing items online? Residents expressed frustration and told us that they learn these things through trial and error.



“[Continuing care homes] discourage residents from getting too close. If you see a couple kissing or something like that, ‘ah, ah, ah, you got to stop that’... if you wanted to date somebody in a long-term care setting, it’s almost discouraged”
(Resident 2 – August 9).

“[I haven’t been told] very much at all and, again, it depends on the personality of the person that’s talking to you and their understanding of Alzheimer’s, but nobody has said ‘this is inappropriate, this isn’t’. There’s no guidelines as such”
(Family Member 8 – March 21).

Participants expressed concerns about how the behaviours of residents with dementia are pathologized. Several family members noted that staff sometimes shame and/or punish residents for their sexual disinhibition. These participants did not suggest that care staff or fellow residents ought to endure any unwanted expressions, but they also did not want their loved one’s identity reduced to those behaviours. They agreed that remediation was needed, but that it need not be stigmatizing and/or punitive. These participants suggested that we need to anticipate sexual expression and respond with compassion – and that we can still be firm and bounded in doing so.

One resident's wife told us that she and her husband had always enjoyed an active intimate life. When he moved into care, she would take him out of the care home to enjoy sexual time together. When the care staff became aware of this, they informed her that these outings could potentially be triggering some of his unwanted behaviours (e.g., sexual comments and/or groping care staff). As a result, she began to limit physical contact with him out of fear that he would be expressive towards staff.

"I'd love to lay down behind him and just put my arm around him, but I'm scared to in case it turns him on... I'm so scared to do anything, practically touch him... I'm so scared I'll turn him on and he'll get into trouble... I don't want him to do anything that's going to end up on a report and get everybody bent out of shape and make it more difficult for him" (Family Member 8 – March 21).

This participant indicated that she mourned the loss of their intimate life and what it provided for both of them. She did not see an alternative approach, and none were discussed with her. Similarly, we spoke with a daughter whose father had become uncharacteristically demonstrative since his dementia diagnosis. She spoke about the difference between two care homes' responses to his behaviour.

"Immediately [after an incident in which a naked woman was found in father's room] the next day... they sent my dad to [another care home] to the dementia care unit, which is men only. And, you know, we were pretty upset about that, they didn't ask us, there was no discussion, it was you sort of get caught in this thing where everybody treats you like you're a criminal... But it was only at [second care home] that they were really compassionate and they treated my dad with respect. And he still [was sexually disinhibited], but the staff just redirected him. 'Your father's really easy to redirect, he's very polite.' And they were just so much better at dealing with it. And this is a small part of my dad's personality, it's not like he was masturbating 24 hours a day. He wasn't just completely out of control. I mean, he was out of control, but 95% of the time he was just this quiet guy" (Family Member 2 – May 29).

Once again, we heard about the need to anticipate sexual expression and address unwanted expressions in strategic and compassionate ways. This can have tremendous benefit for residents and their family members.

"I think they need to have a much better plan than just hiring security guards and kicking you out in a crisis... Because it should be predictable that, you know, dementia in its many forms is many things. I don't think my dad's sexual expression was appropriate at all, but the way they handled it at [second care home] was to redirect and treat the man with respect. It removed the shame and allowed us to just – it helped us get through this crisis and just see our dad as dad again, as opposed to this sick monster, which everybody made him seem like" (Family Member 2 – May 29).

Families and residents are also unclear about mechanisms for preventing and responding to unwanted sexual attention. Two family members told us that they were concerned about their mothers' safety in the care home environment – especially in cases where residents have diminished capacity.

"...where's the line between criminal and non-criminal behaviour? And how do we even - are our laws adequate? Like yes, we could say it was a criminal act [when my mother was touched in unwanted, sexual ways by another resident], but really was it when his mind isn't much better than my mom's mind? And that's what - that's what was hard for me" (Family Member 3 – June 19).

"I truly wonder what went on there at night... because I know that people wandered in and out of rooms. People continuously wandered into my mom's room, which unsettled her a fair amount... People would come in and use her bathroom all the time. Steal things out of her room all the time. And then, as her disease progressed more, she was there longer and her friendships developed with different people, I found out that she wasn't even sleeping in her own bed at night. She was sleeping in a bed with another woman" (Family Member 7 – March 25).



Family members want assurance that their loved ones will be protected from unwanted forms of sexual expression. In instances where people may communicate their consent in covert or non-verbal ways, extra attention is needed to ensure that acts are consensual. This highlights a further need to find a balance between managing risks and supporting healthy sexual expression.

Summary Statement

Our research provides insight into residents' and family members' experiences with sexual expression in Alberta's continuing care homes. Participants had diverse experiences, and many of these reflect the inconsistencies that result from a patchwork approach to sexual expression. Our interviews reflect concerns about autonomy, privacy, communication, and the appropriateness of particular expressions. The findings are consistent with what is in the international literature, and shine a light on the specifics of the Alberta context. This report reflects experiences of particular people at particular points in time. It is not an exhaustive account that represents all opinions or all facets of this phenomenon.

Our findings suggest that sexual expression is an under-recognized activity of daily living, and yet people are surprised when it presents in residents' lives. There is an urgent need to proactively anticipate and compassionately respond to resident sexual expression; this includes creating a safe, welcoming environment for individuals from LGBTQ2S+ communities. On the following page, we provide recommendations that support an integrated approach to resident sexual expression.

We close with an observation from one participant that reflects the meaning that sexual expression can hold for residents.

“From my point of view, if you do not find the world tasty and sexy you are out of touch with the most important things in life; the kinds of things that are supremely important about being alive in the world, right? The world is a wonderful place and tastiness and sexiness are just part of what makes the world wonderful” (Resident 1, May 30).

Recommendations

For practice

- **Recognize sexual expression as an activity of daily living.** Care homes can normalize safe and dignified expressions by anticipating that this is a legitimate aspect of residents' lives and respecting their privacy and autonomy.
- **Residents need to know with whom they can speak if they want to have a conversation about sexual expression.** Our participants did not think that there should be a conversation at admission to assess their sexual needs, but that there should be some signaling to residents that certain expressions are acceptable in their home (e.g., "if you ever want to have an overnight guest, just let [person] know and we can make arrangements").
- **Families need conversations and resources.** Several family members indicated that a brochure or information package would provide them with some clear language about sexual expression and basic knowledge about dementia's potential effects on intimacy and sexuality. These materials would complement a site-level policy.
- **Develop a site-level policy** about resident sexual expression. This document should be developed by the care team in collaboration with resident and family councils. This policy can provide, among other things, a glossary of terms, clarity about arrangements that can be made for guests, clear guidelines that indicate types of behaviour that are unacceptable (unwanted touching, exhibitionism, harassment, etc.) and what the consequences for those behaviours may be.

- Care homes should **make visible the role of recreation and occupational therapists** in supporting sexual/self-expression through leisure and creative activities. These staff members have relevant training and are well positioned to access and adapt resources. Several participants indicated that recreation therapists were their allies in their efforts to have vibrant personal lives.

For policy

- **Integrating sexual autonomy and related rights into continuing care standards.** Formalizing the sexual rights of continuing care residents can create accountability for upholding privacy, autonomy, and freedom from discrimination.
- There should be **accountability to ensure that continuing care homes are, indeed, safe and welcoming environments for LGBTQ2S+ persons.** There should be inclusive language in site materials and residents should have confidence that there is zero tolerance for harassment or discrimination based sexual orientation or gender identity. Alberta Health Services (AHS) has already done some excellent work on this front and developed a suite of resources for staff: <https://www.albertahealthservices.ca/info/Page15590.aspx>
- Continuing care homes need a **sufficient level of staff and appropriate skill mix** to ensure that there is time and opportunity to support these recommendations and residents' quality of life.

Resources for residents and family members

Alzheimer's, Dementia, and Sexuality

Changes in Sexuality and Intimacy. Alzheimer's Association. (July 2018). Available at: <https://www.alz.org/media/Documents/alzheimers-dementia-sexuality-intimacy-changes-ts.pdf>

- This two-page resource provides insight into changes in sexual desire and sexual behaviour that may accompany progression in Alzheimer's disease.

Intimacy and Sexuality. Alzheimer's Society Canada. (October 2018). Available at: <https://alzheimer.ca/en/Home/Living-with-dementia/Understanding-behaviour/Intimacy-and-sexuality>

- This resource provides helpful advice and tips for people with Dementia, partners of people with Dementia, and health professionals.

Sexuality and people in residential aged care facilities: A Guide for Partners and Families. Australian Centre for Evidence Based Aged Care. Available at: <http://dementiakt.com.au/wp-content/uploads/2016/08/SexualityConsumerGuide.pdf>

- This booklet discusses the importance of sexuality, sexuality and living in a care facility, sexuality and dementia, how changes might affect family members, and tips for communication with staff.

Sex and Intimate Relationships. Alzheimer's Society. (July 2015). Available at: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/factsheet_sex_and_intimate_relationships.pdf

- This booklet provides information on adapting to changes with dementia, practicalities of sex in care homes, consent, what to do in cases of suspected abuse, forming new relationships, maintaining healthy relationships, and sexual health.

National Institute on Aging. (2017). Intimacy and Sexuality: Resources for Dementia Caregivers. Available at: <https://www.nia.nih.gov/health/intimacy-and-sexuality-resources-dementia-caregivers>

- This site from the United Kingdom provides a list of resources for family caregivers of people with dementia. The resources include: Changes in Intimacy and Sexuality in Alzheimer's Disease (2017), Changes in Sexuality and Intimacy (2016), Dementia: Emotional Changes (2014), LGBT Caregiving: Frequently Asked Questions (2015), Sex and Intimate Relationships (2015), Sexuality and Dementia (2014), and Sexuality in Later Life (2013).

Alzheimer's Society of Canada. Conversations about Dementia, Intimacy, and Sexuality. Available at: https://alzheimer.ca/sites/default/files/files/national/brochures-conversations/conversations_intimacy-and-sexuality.pdf?utm_medium=301&utm_source=alzheimer.ca

- This information sheet provides information on how to address the intimacy and sexual needs of people with dementia and their partners as dementia progresses.

Other health conditions

Sex and sexuality after brain injury. Headway: The Brain Injury Association (2017). Available at: <https://www.headway.org.uk/media/4995/sex-and-sexuality-after-brain-injury-e-booklet.pdf>

- This booklet was written for brain injury survivors who have issues with sex after brain injury, and their sexual partners. It describes how sex can be affected following brain injury, offers tips for managing sexual issues, and gives information about where to seek professional support.

Intimacy and sexuality in MS. Multiple Sclerosis Society of Canada. Available at: https://mssociety.ca/en/pdf/MS_Intimacy.pdf

- This booklet discusses some of the ways in which multiple sclerosis can affect intimacy between partners and provides tips for how to work around them

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