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Sexual Expression in Alberta's Continuing Care Homes

Perspectives from Managers and Leaders

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Page 5: Laurence Butet-Roch: Harriette and her sweetheart, Denis, enjoy spending some time together ahead of lunch. Harriette's daughter, Therese, says they've been together for about 2 years. Bloomington Cove Care Community. Withchurch-Stouffville, Ontario. May 11, 2018.

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Executive summary

In this report, we outline the findings from Phase 1 of a multi-phase, Alberta-wide study on sexual expression in supportive living and long-term care homes. 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 practice, policy, research, and education. We conclude with a list of resources for those navigating sexual expression in continuing care.

In the first phase of this research, we interviewed 28 participants including continuing care managers and those whom they consult (clinical ethicists, social workers, best practice/geriatric assessment teams, and others). 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, and undignified expressions. In Phase 2 of this study, which began in May 2018, we are interviewing residents and family members. Broadly, our aim is to encourage productive and informed conversations, and support compassionate resident-centered responses to sexual expression. The Phase 1 participants represent urban, sub-urban, and rural communities. We spoke with them about: how they define sexual expression, its place in continuing care, challenges and facilitators in navigating sexual expression, and suggestions for how to improve this aspect of resident care.

It was evident that there was appetite for conversations about sexual expression in continuing care. The interview participants provided a rich definition of sexual expression that includes a broad range of identities, practices, acts, and relationships. Participants were unanimous that sexual expression has a place in continuing care, though the boundaries remain undefined. It was acknowledged that the demographic profiles of continuing care residents and staff are changing and with this shift, there is an increased urgency to address matters of sexual expression. However, there are considerable gaps in knowledge and a lack of preparedness about how to anticipate,



navigate, and respond to diverse expressions of sexuality. Participants identified challenges related to values, dementia, consent, privacy, family and community dynamics, education, and consistency with approaches across the sector.

At the same time, we heard a strong commitment to safety, health, and quality of life for residents and those who are engaged in their care. This was supported by leaders who destigmatized sexual expression to foster a culture of compassion. Moving forward, we hope the content of this report is useful for raising awareness, starting conversations, and thinking differently about sexual expression in continuing care.

Background

Long-term care and supportive living demographics are changing and the demand for continuing care services is growing.¹ This sector has historically been associated with care for older adults, but current 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.³⁻⁶ When we do not attend to this aspect of care, we cannot ensure that expressions of sexuality are safe, healthy, and dignified.

Ours is not the first study of sexual expression in continuing care homes. Similar research has been conducted in Australia, New Zealand, the United Kingdom, and elsewhere around the globe. Broadly, the international scholars of sexual expression in continuing care explore resident and staff attitudes,⁷⁻¹⁰ dementia and consent,¹¹⁻¹³ policy challenges,¹⁴⁻¹⁷ LGBTQ2S+ needs,¹⁸⁻²¹ assessment tools for sexual health concerns,^{11, 22-23} and education development.²⁴⁻²⁵ This literature often focuses on the challenges associated with resident sexual expression. These challenges include varied staff attitudes and training,²⁶⁻²⁷ lack of privacy,^{25, 28} divergent views of family members and fellow residents,^{3, 30-31} and sexual behaviour that is considered inappropriate.³²⁻³⁴

Other Canadian scholars have explored sexual citizenship and rights,³⁵ LGBTQ2S+ needs,³⁶ and ethical approaches to determining consent in the context of continuing care.³⁷ We wanted to understand if and how these themes operate in the Alberta context. In Alberta, there are no province-wide policies or guidelines to support continuing care managers in navigating residents' sexual expression. With this in mind, we posed the following questions to guide Phase 1 of this study:

Key Research Questions

1. What are the current practices around sexual expression in Alberta's continuing care homes?
2. What are the biggest challenges sites have identified? When and how have they seen sexual expression navigated well?
3. What types of resources or supports related to sexual expression would be most useful for managers, direct care workers, family members, and residents?

Methods

We received ethics approval for 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 identify how managers navigate resident sexual expression in continuing care settings.

In the presence or absence of policy, managers coordinate decision-making and shape the culture of a care home. These individuals have the authority to shape site level responses to sexual expression. For this reason, we recruited continuing care managers and those whom they consult (clinical ethicists, best practice/geriatric assessment teams, social workers, and others). Participants were recruited at regularly scheduled managers' meetings and through Alberta Health Services (AHS) administrative assistants who disseminated the invitation via e-mail. Prospective participants contacted the research team to indicate their interest. Our sample included participants from each of the five provincial health zones, with a mix of urban, suburban, and rural care homes. Participants were employed through AHS, its wholly owned and operated subsidiaries



(Carewest and CapitalCare), and/or Covenant Health. Participants represented a diverse array of communities from across the province.

Data collection took place between December 2017 – July 2018. We conducted semi-structured interviews with 28 participants over the telephone or in person. The interviews were digitally recorded and lasted between 45-75 minutes. We asked participants about existing policies and practices, challenges, exemplary cases, and supports that may be useful for navigating sexual expression. The transcribed interviews were coded and critically analyzed using Braun and Clarke’s approach to thematic analysis.³⁸ 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 context of Alberta. Key themes include: (1) broad definitions of sexual expression and its place in continuing care homes, (2) structural features that influence how managers navigate residents’ sexual expression, (3) interpersonal dynamics that create the context for sexual expression, and (4) exemplary cases of support for healthy sexual expression.

Key findings

1. Broad definitions of sexual expression and its place in continuing care homes
2. Structural features that influence how managers navigate residents’ sexual expression
3. Interpersonal dynamics that create the context for sexual expression
4. Exemplary cases of support for healthy sexual expression

1

Defining sexual expression and its place in continuing care homes

We asked participants how they defined “sexual expression.” The managers and those whom they consult described sexual expression in continuing care settings as both inherent to resident well-being and laden with values. It was noted that sexual expression in continuing care can include a broad range of identities, practices, acts, and relationships. Specifically, this can include handholding, hugging, bed sharing, kissing, masturbation, enjoying privacy, grooming and self-presentation, forming bonds and relationships, and engaging in physical sex acts.



Many remarked on the importance of sexual expression for both mental and physical well-being. Participants described it as part of who we are as people, a basic need of human beings, and a deeply meaningful aspect of life inextricably linked to dignity.

“It’s just part and parcel of who we are as people. I think it should have the same place as getting up and washing and dressing and eating your meal. It provides a deeper meaning to life” (January 12th Interview).

“It encompasses things like sex, gender identities, sexual orientation, eroticism, pleasure, intimacy, and reproduction and it’s experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships” (March 1st Interview).

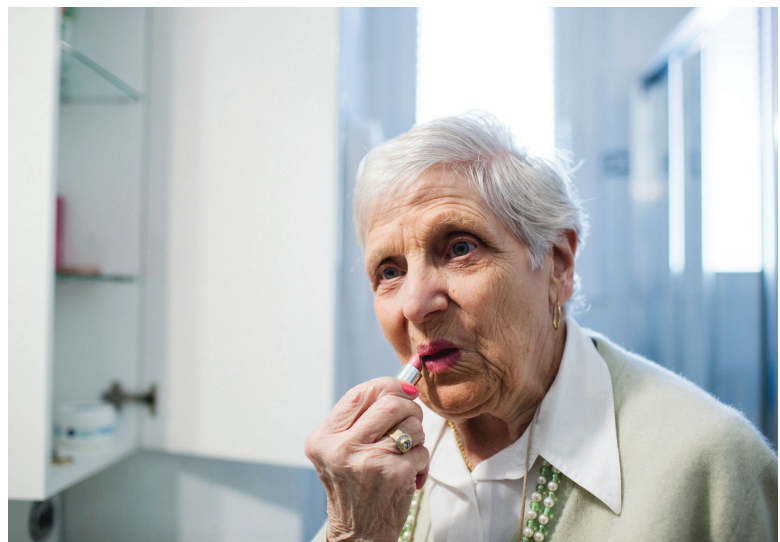
“This is a healthy part of being a human. Our residents who come in with us are still human beings and part of that, for most human beings, is having an intimate life of some kind or a sexual identity” (February 15th Interview).

Some participants presented it as a human right and this was operationalized through a proprietary organizational policy from one of the AHS subsidiaries. Participants described the place sexual expression should have in continuing care, but most of them agreed that it was complicated to navigate and often only spoken about when things became problematic.

“When it gets to me we’re seeing it as a misbehavior, rather than as a healthy part of being a human being” (July 4th Interview).

“The world is not quite prepared to talk about sexual expression, [but] seniors – and people generally that are in long-term care – are pushing that issue. Our residents don’t fit in the boxes or with the myths out there about seniors as asexual beings, or even that same-sex LGBTQ+ [sic] doesn’t happen in care homes. So, it’s our job to calm people down about this because it is all normal!” (January 25th Interview).

The majority of participants spoke about sexual expression as a healthy and necessary part of life. It was emphasized that the systems, strategies, and practices in place are not sufficient for supporting this view. Overall, participants agreed there was opportunity to strengthen leaders’ capacity to support resident sexual expression. This requires strategic, integrated changes to both structural and interpersonal features in continuing care.



2

Structural features influencing how managers navigate residents' sexual expression

Participants spoke to the limited availability of policies, standards, or education; feasibility of resident privacy; centrality of risk aversion with regards to sexual expression of persons with fluctuating/diminished capacity; and ambiguity about the boundaries between appropriate and inappropriate sexual behaviors. The combination of these factors contributed to the participants' experiences of 'just winging it'. To this end, participants expressed a need for a proactive and resident-centered approach.



(A) Policy, standards, and education

With few exceptions, such as the rare case where a site-specific policy was in place, participants identified a need for a principle-based, system-level policy on resident sexual expression. Several participants identified how a broad group of stakeholders could undertake such an endeavor and noted that the product should be flexible for site-specific considerations. We heard that standards of practice to support safe and healthy sexual expression would be beneficial. Such standards could guide educational programming, normalize sexual expressions, provide a safe environment to discuss the topic, and facilitate compassionate responses.

“There should be some standards that are set so that if you are a long-term care provider, it is clear that this is a fundamental aspect of care. You need [tools] to be able to address it in a compassionate and a forthright manner. I think the provincial health authorities could give us some guiding principles, and then a policy and some training for people on the practical aspects of this”
(June 29th Interview).

“There should be a policy with clear principles behind it. It’s out of respect for the resident’s autonomy and understanding that sexuality is a very important part of human expression. That would be the principle. Education can’t be one-dimensional either. There should be opportunity for participants to explore values, to develop vocabulary, and to come away with an ability to have a conversation that is guided by a set of principles to navigate the situation”
(March 9th Interview).

There was agreement that there is currently discomfort, fear, and lack of preparedness among staff when it came to following through on recommendations about resident sexual expression.

“Yes, policy. But it still requires understanding, rapport and communication. We need to make it safe for staff to have these conversations and education for all parties could help that”
(January 11th Interview).

Many participants acknowledged there was some education about sexuality and dementia through the Supportive Pathways program. Overall, participants agreed it was important to develop additional resources to address the broad spectrum of needs as well as to provide ongoing education about sexual expression.

“A policy is effective if we use it. I also think it’s the education and awareness piece that needs much more focus in continuing care, not only for staff and other residents, but also for family members” (March 6th Interview).

Across all interviews, there was positive regard for the Supportive Pathways program specialist teams and clinical ethicists. It was widely acknowledged that these resources could be augmented by a holistic approach that includes standards, principles, policy, and education. Furthermore, it was believed these kinds of structural features would increase the options available for those working at geographically dispersed sites.

(B) Privacy

Privacy was discussed extensively from both spatial and social perspectives. Many parties occupy the residents’ space for safety purposes, to provide treatment for managing medical conditions, and for assistance with activities of daily living. Participants described how the norms of a congregate environment influenced the nature, timing, and place for sexual expression.

Because health providers work where residents live, there was a juxtaposition between residents’ right to privacy and the demands of care provision. For instance, several participants highlighted how a resident’s privacy could be constrained by care routines.

“This is going to be quite a challenge in facilities that are so institutional in terms of privacy – that’s like non-existent for, you know, conjugal anything – and where the routines are set, and where it’s a top-down approach to people. The time’s ten o’clock, lights out, you know? ‘What’s John doing in with Mary? We can’t have this. We can’t do this. We can’t let them do that, because we have to do this, this, and this, and this by midnight” (April 5th Interview).

Even when residents and staff have established an understanding (e.g., by providing an hour of privacy for the resident and their spouse), staff have the additional task of ensuring the entire team understands the arrangement. As a result, coordination among the staff is essential for ensuring privacy.

Participants gave examples of challenges associated with providing time and space for privacy. This required scheduling around care routines, communicating at a staff huddle/team meeting, and/or posting a ‘do not disturb’ sign on the resident’s door. The prevalence of shared rooms complicates matters of privacy even further. Most of the residents’ rooms do not have locks on the doors and as a result, there was a consistent concern that staff, roommates, or visitors may walk in at inopportune moments. To alleviate spatial constraints on privacy, some facilities experimented with allocating a couples’ room to accommodate these types of resident requests.

Not only was there limited availability of physical spaces for privacy, there was also ambiguity related to the boundaries of private-public spaces.

“You know, the amount of really meaningful privacy that some of our residents have is pretty minimal... what’s at play is a difference in how people understand the space. So, especially for our residents who are a little bit younger or are more cognitively capable, do they see their room as essentially their home, like an apartment almost, like a little bachelor suite? Or is it a bedroom in a larger house? Or is it neither of those things – is it actually just a room and a bed in a health facility?”
(February 15th Interview).

Collectively, the architectural constraints of shared accommodation, the environment’s fixed schedules, the resident’s reduced independence, and the ambiguous boundaries between personal and public space increase the complexity of managers’ work in supporting an environment for sexual expression.

(C) Dementia, consent, and resident safety

Our findings highlight the participants’ intense deliberations related to capacity determination and protection for persons in care. They carefully weigh the benefits and harms of sexual expression for residents with cognitive impairment such as dementia. Participants expressed concern about whether a resident



with dementia is capable of consenting to sexual activity, what consent would look like, and whether there would be unpredictable changes in their disposition during sexual activity.

Part of creating an environment for safe and healthy sexual expression requires prevention of unwanted, uncomfortable, or aggressive expressions. Participants highlighted the importance of risk aversion, but also noted that, at times, people with cognitive impairments have their sexual expression restricted when there is no indication of physical or emotional harm to themselves or others. This nuanced assessment is challenging for care staff, but is essential for protecting vulnerable populations and retaining their agency over nourishing aspects of their lives. Many participants acknowledged that there is a greater need for sexual intimacy in continuing care because of the cumulative losses of other relationships, social roles, and activities. Touch and intimacy can be a primary source of joy, pleasure, and connection – particularly when life in a continuing care setting can be routine, task-oriented, and focused on clinical, biomedical needs. The difficulty for most participants arose from navigating the personal and legal risks associated with vulnerable persons of fluctuating or diminished capacity.

“If an individual has a mild or even a more moderate cognitive impairment, the response from the clinical team has been profoundly conservative when it comes to sexual behavior”
(June 29th Interview).

“It would be restrictive to prevent that resident from engaging in sexual expression when they seem to be pretty happy to do [it]”
(February 15th Interview).

Given the imperative to protect residents from harm and mitigate staff concerns about legal reprisal, participants were under pressure to make decisions that may limit the resident’s sexual autonomy.

“I think certain facilities have a fear of legal complications. So we’re not going to allow any form of intimacy between these two people because there might be a threat of lawsuit”
(March 20th Interview).

Matters of consent and capacity were complicated by situations where the cognitively impaired resident's spouse/partner, who was also the resident's agent, would visit and engage in sexual behavior.

"If [visiting husband who is the agent] wants a Do Not Disturb sign, we don't know what he wants to do at that point. And, I'd like to say it's none of our business, but if he's causing stress to our resident who's going to be upset and have trauma and behaviours later, are we giving good care? So, there would be quite a lot of discussion and might even become an ethical consult" (December 1st Interview).

"Well, it becomes hard because – many of the people I deal with have questionable or lost capacity. And they look to this partner as the one thing that makes sense in their world. It sort of anchors them in an otherwise very confusing experience of the world. And they express that sexually ... and then, you know, we look at it from a legal perspective, "where's the consent? Can she consent?" (March 9th Interview).

Participants highlighted an important tension between safety and autonomy. There was strong agreement that determining consent requires a nuanced approach. The participants acknowledged that this process requires advanced assessment skills and time for ongoing resident monitoring. Additionally, they noted that care staff should receive education related to dementia and consent, as well as training to identify behaviours associated with assent/dissent.

(D) Distinguishing between 'appropriate' and 'inappropriate' expressions of sexuality

Participants noted that the distinction between appropriate and inappropriate expressions of sexuality were a matter of perspective. For example, there was widespread agreement that unwanted groping was inappropriate, but there was less agreement about whether or not residents should be permitted to view pornography in their bedrooms. Typically, sexuality is only addressed when family, staff, or

other residents consider particular expressions to be inappropriate. This means that there are few exemplars of appropriate or healthy ways for residents to express themselves in continuing care settings. A consequence of the environment only recognizing inappropriate expressions of sexuality is that sexuality can be pathologized and stigmatized.

When a resident is sexually disinhibited because of cognitive impairment, we heard about an increase in verbal and/or physical advances directed towards staff. In some cases, staff can redirect the resident. However, there are instances where participants had to intervene when staff felt offended, disrespected, and/or uncomfortable.

"There was a resident with dementia who had a long history of being really touchy. He was always touching the female staff, like putting his hand on their back, or rubbing them and saying 'hey, sweetheart', or trying to be touchy and affectionate. This attention wasn't welcomed or wanted" (April 5th Interview).

Participants identified forms of sexual expression conducted in public areas of the care home that can be problematic for staff and make other residents uncomfortable. This can include sexual comments, public masturbation, and overt use of pornography.

"The resident was using pornography in a public space and talking about their sexual preferences in ways that weren't the most appropriate for the setting and were making their fellow residents very uncomfortable" (February 15th Interview).

When navigating ambiguous boundaries of sexual expression, many managers framed behaviors in terms of 'wanted and un-wanted', and aimed to ensure that sexual expression did not compromise the safety or comfort of residents and staff. This highlights a need to find a balance between managing risks and supporting healthy sexual expression.

3 Interpersonal dynamics that create the context for sexual expression

In addition to structural features, participants spoke about interpersonal dynamics that support or constrain expressions of sexuality. These dynamics include the role of families and agents in decision-making, cases where the staff's personal values and beliefs are not conducive to supporting sexual expression, and the diverse ways in which residents understand and express sexuality.

(A) Family and agent involvement in decision-making

Participants agreed that family and agent involvement is an important part of resident-centred care. However, when it comes to sexual expression, families and agents tend to be unprepared for related conversations and decision-making. Relatives are not often aware of the sexual desires, practices, and preferences of their kin and navigating this aspect of their lives can be challenging. Each family's distinct dynamics can complicate matters even further.

"Family members can be really, really stressed about their mom or dad showing sexual expression that they have never, ever seen before"
(January 25th Interview).

"Family can be a big thing. Because some families have guilt. Maybe they don't feel good about how their relationship went with their parents. They're either trying to make up for it now or they're trying to punish the parent now... and often, overstepping their bounds. What many people don't realize is because you may be someone's guardian, that doesn't mean that you can tell a physician or a nurse how medication is going to be administered. And so, care providers often allow that to happen [with sexual expression] because, 'Oh, they're the family.' And so the boundaries of what can [family] legitimately have an opinion on is an issue as well" (March 9th Interview).

There are few resources available to prepare families for how dementia and other neurocognitive conditions can affect sexual desire and behaviours. Many participants noted that family members often find it difficult to accept uncharacteristic changes in their loved one's behaviour. These changes can include handholding with someone who is not their spouse, forward or public displays of sexual interest, engaging in public masturbation, starting a new sexual relationship, verbal expressions, and more. These expressions are particularly difficult to accept when staff present them as problematic.

"There were a number of incidents that were happening that the staff found disruptive and that families were saying, "This was never my family member. This was not how they acted before"
(July 4th Interview).



“We have to try and be patient with [families] for sure because it’s a lot to wrap your head around and it’s very emotional and it’s very difficult. Although, from the health care side, this is something that we’ve seen many times before and it’s sort of a normal situation, perhaps it’s not normal for the family” (March 1st Interview).

Participants also mentioned difficulties associated with making decisions on the basis of how someone presented themselves prior to having dementia. In these cases, participants spoke about agents who want to make decisions in the resident’s best interest, but do not recognize that sexual desires and preferences may change with dementia. We were told that this sometimes meant that expressions of sexuality were restricted because they did not reflect the person’s prior identity.

“And so, the agent may be going back to that previous experience, but not being very respectful of the current experience” (June 29th Interview).

“A case I recently had, the daughter was the patient’s agent... It obviously was hard for her, but she said, ‘My mother would be horrified to see herself behaving like this, but that person is no longer here. And for the woman here, my mother that’s here in the facility, sex is very important for her.’ And so that’s a rare daughter that can so thoughtfully and generously understand the needs of her mother. So often families will say, ‘I’m not going to let my dad do that. I’m not going to let my mom do that.’ And they hold them to standards that they knew when the person was fully competent” (March 9th Interview).

Most participants had experience with cases in which married residents begin relationships with a fellow resident who is not their spouse. This common scenario becomes even more difficult

to navigate when the spouse is the legal agent. Spouses may neither understand the effects that dementia can have on someone’s sexuality, nor see how the new relationship contributes to their partner’s quality of life. As a result, spousal agents may push to ensure that the expression ceases; for instance, by having the residents in the new relationship kept apart. This separation can be very hard on residents who have formed a close bond and do not understand why they can no longer spend time together. A couple of participants told us that when residents are separated like this, they often respond with challenging behaviours (e.g., anger, aggression, misdirected sexual advances, etc.), which is quite hard on direct care staff.

Several participants noted that rural families face an additional layer of complexity because of limited anonymity. In small towns where “everybody knows everybody else” and there are concerns about the resident’s reputation in the community, families and staff experience further challenges.

“And if you’re in a small town, in a small town care facility, word gets out. Oh, you know, Frank’s dad – oh my God, you should see him. And it affects the family. So they have a lot invested in managing the resident’s behaviour” (March 9th Interview).

“Perhaps the mother of somebody wants to have a relationship with a resident in this facility, but her husband still lives in the community and she doesn’t realize she’s still married. So, in a small community those things present more difficulty because everybody talks at the post office and, you know, maybe the daughter or the son actually work here and that makes it a little bit more difficult to navigate” (December 13th Interview).

‘Being known’ in a rural community can also be an asset. Staff members may have a shared history or current relationship with

the resident and/or their family that can create an understanding and supportive environment. Additionally, there can be cultural and/or religious traditions in rural Albertan communities that contribute to the interpersonal dynamics in a continuing care home.

“In my experience and the cases that I’ve heard of from colleagues, generally in the cities, in the larger centres it’s a little easier... People are a little less uncomfortable to talk about it and the prevailing social attitudes tend to be more conducive to that. That being said, it depends on the facility as well” (March 1st Interview).

As a result, rural dynamics can complicate or facilitate discussions related to sexual expression. To summarize, our participants highlighted the importance of family and agent involvement in resident care, while also recognizing how fraught family and community dynamics can be.



(B) Tensions related to staff’s personal perspectives

As noted in the background section, much of the literature on sexual expression in continuing care looks at the attitudes and beliefs of health care providers. Our data confirm the significance of this issue. The participating managers and advisors identified challenges associated with supporting care teams in which there is no consensus about best practices. They expressed concern with the fact that there is no formal

preparation related to sexual expression in the education curricula for RNs, LPNs, or HCAs. This means that there are varying degrees of knowledge about the sexual health care needs of older adults and continuing care residents with complex chronic conditions.

“When it happens in our congregate settings – and some of our staff, when they see this, it’s suddenly alarming to them, because how do they handle it? And they handle it in a way of reporting it as inappropriate behaviour, without recognizing that maybe we have to open this up for discussion.” (January 11th Interview).

In the absence of related policies, standards, and staff education, care staff foreground their personal views. Most participants suggested that, even though they may not always be comfortable, conversations about staff’s attitudes and beliefs are crucial for addressing this aspect of resident care and recognizing multiple perspectives.

“Depending on the staff assigned to work in that unit, it goes back to their cultural or religious norms. Are they comfortable in implementing their strategies? If it is regarding the female who wants to pleasure herself in a room, are they comfortable with that instead of thinking, ‘that’s disgusting. No, I’m not going to give her any lubrication. I’m not going to clean her finger nails. Why should I have to do this? And I don’t think it’s appropriate” (March 20th Interview).

“I think because we have quite a diverse cultural staffing group is I think having them actually have conversations about what their beliefs are with regards to sexual expression and what their biases are. And how that either interplays with the work and what they’re seeing and how they recognize other people’s beliefs and differences as well. We don’t do that” (July 4th Interview).

When responses to sexual expression come from personal convictions, we heard about inconsistent approaches between staff members and across facilities. Without a coordinated effort, responses risk becoming more staff-centred than resident-centred – with a focus on what staff are most comfortable with, what they have time for, and what they deem to be appropriate. This can create barriers to realizing the health-promoting benefits of sexual expression and can sustain

an environment of shame and stigma. This type of environment shrinks the spectrum of “appropriate behaviours” and can make residents feel uncomfortable or ashamed.

“What else would make it easier? Certainly the attitudes of the staff would make it easier for the residents. If they were very encouraging and compassionate about how that expression was to take place and facilitate it, it would make it easier” (December 1st Interview).

“There were two residents in this facility both young, maybe 30’s, that each had disabilities, which was the reason they were there. But this is a couple of unattached, straight, young people and the facility was really concerned that they were holding hands in public and they were asking these people to sign something to agree that if that they were in the same room together they wouldn’t close the door and this sort of thing because they were unwed” (March 1st Interview).

Sexual expression is not the first health care matter in which there have been conflicting values and perspectives. Three participants drew parallels between sexual expression and medical assistance in dying (MAID). They spoke about MAID as a successful example of systematically broaching a sensitive topic that is laden with many values, beliefs, laws, and standards.

“This is like MAID except that [sexual expression] doesn’t die and you can’t conscientiously object. The topic of sexual expression has many of the same features as MAID related to values, operational practices, education, and involvement of staff, family, and residents” (March 9th Interview).

“So, the basic tone is – look, we’re not looking to hide anything, we’re not saying that this is wrong or inappropriate. We’re not trying to make those moral judgements. It might be inappropriate in my estimation, it wouldn’t maybe be my moral narrative or compass, but we’re trying. ‘We’ – meaning sites that I’ve dealt with – we’re not trying to impose one person’s moral narrative about sexual expression on somebody else’s. We are trying to recognize that are a number of narratives involved and sometimes there’s tension” (January 12th Interview).

The references to MAID reflected an optimism about our collective ability to navigate this complex terrain of sexual expression in continuing care. Without a formal foundation upon which to make decisions, care providers defer to their own views and preferences. The complexity of this decision-making layered on top of a heavily scheduled workday presents a tremendous challenge for care staff. Without attention to their own values and biases, staff can overlook the ways in which these elements influence their professional practice. This is particularly important when it comes to caring for marginalized populations, as discussed in the following section.



(C) Diverse expressions of sexuality

A one-size-fits-all approach to sexual expression cannot adequately account for residents’ diverse needs. We heard from participants about the need to account for diversity and experiences of prejudice or marginalization. For instance, many participants referred to ageism and stereotypes about asexuality in older adults.

“So, some young staff find senior sexuality distasteful, or they don’t understand that this is still a very important part of a senior’s wellbeing, to have healthy sexual expression. And so it’s like – I have heard statements from HCAs where... they find it distasteful” (April 5th Interview).



“I mean we do think of seniors as asexual. I think society views them like that, despite how wrong that thought is” (January 22nd Interview).

Since many care staff do not expect to see sexual expression from this population, these expressions may be pathologized and seen as disgusting or perverse. There was a sense that societal attitudes about older adults as asexual have led care providers to overlook this aspect of their care.

“We graduate, we go and we see our clients, maybe we have our own ageism built into the whole scenario, right? ... and that is not something that I was ever encouraged or instructed to talk about with my patients when I graduated” (January 12th Interview).

Some managers and continuing care leaders took the opportunity to address this issue with existing and incoming staff, by reminding them that sexuality can be an important part of people’s lives across the life course. Many participants also highlighted stereotypes associated with disability. They spoke to popular assumptions that people with physical and/or cognitive disabilities do not have sexual lives and desires.

“We often think of disabled people as neutered or somehow – that they’re not sexual beings” (March 9th Interview).

“It’s like if you’re disabled or you’re a senior, sexuality is something that just dissipates, it disappears because those people disappear. We put them into homes, we put them into congregate living, and they’re out of sight out of mind, but they’re not ... But the idea of sexuality, because it’s so taboo, it’s still taboo in North American western culture, so you talk about a hidden population and a hidden part of a hidden population, and it’s a hard thing to bring to the forefront and to have a productive conversation about” (June 29th Interview).

In addition to older adults and people with disabilities, we heard about the need to consider the cultural context(s) for sexual expression when it comes to Indigenous persons. A culturally safe continuing care home should recognize the effects that colonization can have on residents’ experiences of sexuality and their relationships with their bodies – knowing that these experiences will be diverse. One participant spoke to these effects.

“So, at the residential school, things were very hard on [students]... and I think that’s where a lot of the sexuality was... You know, the nuns were the ones that were taking care of them and they told them, ‘you don’t look at the other boys’ and they were separated and you never – you’re never in the same room with the boys. Everything was the junior boys, the junior girls, the senior girls, the senior boys. They were never intermixed. So, it was always, the opposite sex is bad. So, you know, things probably took a change on how sexuality was spoken about, like moving from the sacredness to feeling our bodies are dirty” (May 28th Interview).

“So, I think maybe just in broader terms... it’s rather taboo to talk about sexuality. So, I wouldn’t be one to bring it up. I would allow the person to bring it up. But yes, it’s very taboo. So, if we were to have a policy, we would have to be very careful with how we would word it and we’d have to include some of our elders in on that” (May 28th Interview).

When developing facility-level policies and strategies, staff and management should attend to cultural contexts and consult with local leaders to ensure that their policies and responses are appropriate.

Participants also spoke about supporting residents from LGBTQ2S+ communities. There was agreement that continuing care homes should be inclusive spaces, but there are varying degrees of familiarity with LGBTQ2S+ history, needs, and appropriate terminology. Several participants mentioned that there will be much more visibility of these populations in incoming cohorts. While this may spark more open discussions about related needs and supports, care staff should also be aware of the work that is needed to create a space that actually feels safe and inclusive for LGBTQ2S+ residents.

“We’re hearing from folks as well, ‘well, the incoming cohorts will have lived through the sexual revolution. They’ll have been through the hippies and love movement. They’ll have been through the legalization of same-sex marriage.’ There’ll be much more open, vocal, social norms. So, there just might be different conversations” (March 20th Interview).

“We’ve had conversations with LGBTQ people on site, but as an individual practitioner going in and helping them either come out or become much more comfortable in the space, a lot of LGBTQ people are very fearful of being open in a long-term care setting, vulnerable. And a lot of LGBTQ elders have experienced extraordinary amounts of discrimination. In Canada, it’s only been legal since 1969 or so, I think. So, an 80 year old gay man or lesbian or transgendered person is going to have some very close traumatic experiences about that. When you’re coming in and someone’s providing you with intimate care or someone’s providing you with care that you require to live, like your insulin, you’re scared” (June 29th Interview).

There was widespread acknowledgement that support for same-sex relationships in continuing care is a ‘work in progress’. We heard about some promising developments, but also heard that many educational or supportive efforts are done covertly, to avoid controversy. Some facilities identified that community and/or leadership support was lacking.

“Well, I think what we’ve got in practice is we do have couple suites. So again, we’re just beginning the conversations of what defines a couple. Is it a heterosexual couple? Or is it a same-sex couple as well? I don’t think we’re having conversations about that. I don’t think we’ve moved to that direction where we would actually admit that same-sex couple into that particular suite. However, there is opportunity for couples to be together. So in terms of defining sexual expression, we’re moving it forward with regards to couples. Now when you don’t have a couple but you’re actually an individual, how do we navigate that? I think it’s tolerated for people who are in their rooms and alone. It is not tolerated when it’s publicly displayed and particularly, if they’re not married” (July 4th Interview).

“I think [if we supported a same-sex couple holding hands in public] there would be a component of judgment there and probably the facility would come under attack too for, you know, ‘Why are you allowing that? What’s going on?’” (December 13th Interview).

As the participants noted, there is no one way to approach sexual expression. The principles of cultural safety provide a good framework to support care planning. However, current individual efforts to support sexual expression operate independently of unit or institutional practices or policies. Therefore, there is limited accountability to ensure that efforts are integrated into practice and sustained as part of daily care.

4

Exemplary cases of supportive efforts

Throughout the interviews, we witnessed a firm commitment to safe, healthy, and dignified resident care. Managers spoke to the value of individual consultations with physicians, social workers, or clinical ethicists; specialty team assessments and recommendations; as well as inpatient units for complex behavioral care planning. Several participants shared examples of cases where they have seen sexual expression navigated well. Distinguishing features of these exemplars include: active leadership in creating an accepting environment, seeking to understand the motivations underlying sexual behaviours, supporting collaborative decision-making that respects the autonomy of residents as well as the rights of others, and assessments that ensure that sexual encounters are safe. We highlight these success stories to recognize and share the productive outcomes of targeted efforts.



A) Managers taking an active role in destigmatizing sexual expression

We heard from a few managers who leveraged their roles to set a tone for how sexual expression is discussed and supported. A couple of participants shared anecdotes of exemplary cases in which site leadership established an open and accepting culture that normalized sexual expression while also creating space for diverse experiences and opinions.

“I think [manager’s] leadership was a big part of [the successful efforts to support two residents getting married] ... I’m thinking back to it where the families on both sides were like, ‘oh my god, this can’t happen, how is this going to work, you know, what about this, what about that?’ And I think, working through all of that to say, ‘yeah, why can’t it work? Yes, we are a care facility, but this is definitely workable and doable.’ I think that whole navigation from then to now, it’s kind of funny to look back at those conversations, because people were having immediate reactions to the logistics. But I mean, it’s been very natural – it’s not really any different than any other couple. Yes, they live in long-term care, but it’s worked very, very well.” (March 6th Interview).

“Yeah, so privacy, intimacy and sexuality education will be provided to our staff at orientation and on an ongoing basis, so the [importance of] sexuality and intimacy as part of our normalized life experience, regardless of age or disability and sexual orientation is recognized. Staff will be expected to offer supportive care to residents.” (January 31st Interview)

In these cases, managers and other continuing care leaders took the initiative to have conversations about sexual expression and then to normalize it. While these were single events, they contributed to the development of a culture that speaks openly about human sexuality and where continuing care staff are adequately prepared to support residents in the pursuit of romantic and sexual lives.

B) Looking to understand the motivations that underlie behaviours

Managers told us that redirection strategies can be a great tool for responding to sexual expressions that are unwanted, uncomfortable, or aggressive – particularly for residents with dementia. Interdisciplinary, collaborative redirection efforts can include leisure activities, personal grooming, social opportunities, and individual comforts. In some instances, managers collaborated with staff and families to explore historical and contextual factors that might contribute to a resident's behaviour. There was an appreciation that these behaviours may manifest because of unmet needs. Some examples include a need for attention, touch, social connection, privacy, and others.

*“So, is it groping or is it just intimacy? Is it reaching out? Is there something that she is missing and that we need to support her with? So having a clearer definition of what's going on.”
(January 25th Interview).*

“So again, it would be – you're expressing this need, so other than approaching staff and people who are not going to be responding to your advances, what can we do to help you? Is there something?... Open up that conversation” (January 11th Interview).



C) Balancing individual autonomy with the rights of others

Participants shared exemplary cases in which there was a thoughtful balance of individual residents' needs with the realities of a congregate living setting. In order to strike this balance, managers needed to be explicit about the heart of the tension and facilitate conversations among all parties. In these cases, managers worked with residents and staff to find compromises that left everyone feeling heard and respected.



D) Assessing that sexual encounters are safe and healthy

Participants spoke about efforts to ensure the safety of sexual activity through physical inspections or “safety checks”. This strategy can support various forms of sexual activity from masturbation to sexual intercourse. The aim is to ensure that there are no injuries, no apparent harm, no bruising, no signs of force or struggle, etc. Having a safety check protocol can alleviate some staff and family concerns about potential physical harms associated with sexual activities. These checks would accompany other efforts to assess capacity to consent and interest in sexual encounters.

“We had a gentleman that wanted to view pornographic movies. The staff were very upset by that. So, we had to get the team together and decide how we would go about this – allow him to have his freedom in his home, which was now the facility – and still manage to respect the rights of the other residents and the staff... So, in doing that we need to find a balance and what we did was, we talked to him and had a contract with him where he was allowed to watch [these movies], but he needed to let the staff know in advance that that’s what he was doing by pulling his curtains or closing his door so that anybody coming in would know what they might be walking into” (December 1st Interview).

“In cases where the family would say things like ‘well, stop them. How could she? She’s married, etc.’, I take a little bit more of an involved approach to talk about the extent to which we think this is contributing to mom’s wellbeing ... see if there’s some way to help the family along. Or come to a compromise where we can preserve the resident’s ability to sexually express him or herself, or themselves and not just that, but also not take away something that is a source of comfort for them or a joy or a pleasure or a security or whatever” (February 15th Interview).

“Does she have a bed that’s going to take the weight of the two of them? Because these are the issues that come across. You know, does she have a catheter? Is there going to be pain? Like what other things, other than a ‘Do Not Disturb’ sign are also required to make this safe and good for both of them?” (January 25th Interview).

“So, a female that we recently had was [masturbating]. So, the staff [were not initially supportive] but their concern went beyond that and included worries about infection control. So [once staff were on board], we talked about trimming the nails, keeping the nails clean, giving her lubricants and again, doing that visual inspection and make sure everything’s okay” (March 20th Interview).

“So, if you see [the couple] wandering down the hallway together, just keep an eye on them and make sure the door’s closed, kind of listen. Make sure no one’s fallen. If you hear a thump or you hear an expression of something’s hurting them, but you don’t need to linger there the whole time [sic]. And then after, they come out, gently guide the lady to the washroom just to kind of do toileting check to make sure everything’s safe, there’s no injury, there’s no harm, no bruising. Just kind of do a body inspection and make sure there’s no signs of force or struggle. So having that in place for the staff made them feel a little less at risk, or feeling like they weren’t fulfilling their jobs, or they could be in danger or something” (March 20th Interview).

These exemplary cases reflect participants' cumulative efforts to have normalizing conversations about sexual expression, to appreciate the underlying motivations for sexual behaviours, to balance multiple parties' needs and interests, and to ensure that sexual activity is safe.

Summary statement

Our research provides insight into the experiences of managers and those whom they consult with navigating resident sexual expression in Alberta's continuing care sector. Participants were unequivocal that diverse sexual expressions enrich residents' quality of life. Our findings are both optimistic and fraught. There is urgent work to be done. While there is tremendous interest to ensure residents' sexual expression is safe and healthy, and there are system-level assets for consultation and education, it is clear the existing resources are insufficient for supporting a comprehensive, person-centered approach. In this project, we engaged with a variety of stakeholders who provide services in Alberta's continuing care sector, but our findings are not an exhaustive representation of all leaders' experiences. These findings confirmed the challenges identified in the literature and indicate a need and opportunity for Alberta health care providers to implement the recommendations outlined on the next page. The resource page and recommended readings provide concrete tools for developing an integrated, comprehensive, flexible, and person-centered approach to sexual expression.

Recommendations

Below, we outline strategic recommendations to support immediate and lasting effects at various levels as part of an integrated approach.

Practice at the care home level

- Creating a **culture that proactively destigmatizes sexual expression** and prepares for compassionate conversations and responses. This can include creating opportunities for staff to have safe, facilitated, evidence-informed, and honest discussions with each other on this topic.
- Develop a **site-specific policy or policy amendment regarding sexual expression** that includes all stakeholders. The policy should include a principle-guided approach to navigating sexual expression (e.g., balancing the needs of safety and autonomy, consent, self-determination, cultural safety, human rights, and diverse perspectives regarding the place of sexual expression in continuing care homes – with consideration of the cultural and geographic contexts of the sites). This policy should be addressed in the resident handbook, family admission package, and onboarding materials for new staff and contracted providers.
- The site-specific policy should **identify who is responsible** for upholding the tenets of the policy, what their respective roles are, and related accountabilities.
- **Initiating conversations with residents and/or family members** following admission with ongoing follow-up in care planning. Using appropriate language, understanding that sexual expression and identities are dynamic and differ from person to person. Recognizing these conversations as fundamental to person-centeredness. Challenging assumptions that the person's history is irrelevant or predictive of present or future wants and/or needs.

- If care homes wish to designate themselves as **affirming spaces for LGBTQ2S+ persons** (e.g., safe or positive space signage at entrances), then this should be validated by residents, staff, and family members. There should be demonstrable features in the environment that reflect this commitment. Potential examples can include inclusive language in site materials and clear policies related to harassment and discrimination.

Policy (at multiple levels)

- **A commitment to a standard of resident-centred care that supports safe, healthy, and dignified expressions of sexuality**; that recognizes sexual expression as a natural, normal, aspect of human experience across the life course. This commitment would also recognize overt and nuanced features of sexual expression in vulnerable populations (e.g., persons with neuro-degenerative disorders). It also comes with a responsibility to ensure that individuals are free from unwanted and unpleasant expressions of sexuality.
- Sharing of decision-making and supportive resources at all levels. Taking a close look at proprietor-ship of policies and resources. **Consolidating existing resources and making them available** on a platform that is accessible for paid care providers as well as family members and agents.
- Construction or renovation of continuing care homes should **include space for conjugal encounters**, private rooms, and couples suites.

- Implement a **personal care line item related to sexual expression** in the budget in order to reduce risk of harm/pain, to promote safe and comfortable sexual practices, and to ensure dignity (e.g., lubrication, sexual aides, contraception, and barrier devices for the prevention of sexually transmitted infections).

Education

- Assessment of **staff's individual values and beliefs** about sexual expression; engaging with diverse views and values (between care providers and recipients, between personally held views and professional codes of practice).
- Improve understanding about sexual expression, aging, disability, culture, and dementia.
- Discussion of sexuality as part of the formal **staff orientation**.
- Ongoing and regular staff development opportunities/**continuing education** regarding navigating sexual expression.
- Incorporate sexual expression into health care provider curricula.
- Interpersonal **communication skills training** that supports the discussion of sexual expression and introduces appropriate language.

Research

- Explore related areas in need of further research: dementia and consent, LGBTQ2S+ populations' needs and wants, Indigenous perspectives on sexual expression, the role of agents, comparative analyses with other jurisdictions, and more.
- Interventional research to assess the effectiveness of education and/or practice changes for sexual expression.
- Inclusion of other stakeholders such as residents and family members/agents (this is underway in our current research for Phase 2) and direct care providers, such as HCAs.

Resource page

We encourage continuing care staff to consult the AHS Continuing Care LGBTQ2S+ Tip Sheets for staff, physicians, and volunteers (2018) hosted by the AHS LGBTQ2S+ / Sexual and Gender Diversity website (available at: <https://www.albertahealthservices.ca/info/page15590.aspx>).

We understand that managers have distinct networks and varied access to provincial level organizational resources. Some of the following resources are immediately available to support managers and advisors.

- **The last taboo: A guide to dementia, sexuality, intimacy and sexual behaviour in care homes.** (2011). The International Longevity Centre – United Kingdom. http://ilcuk.org.uk/wp-content/uploads/2018/10/pdf_pdf_184.pdf
- **Supporting Sexual Health and Intimacy in Care Facilities: Guidelines for Supporting Adults Living in Long-Term Care Facilities and Group Homes in British Columbia, Canada.** (2009). Vancouver Coastal Health Authority. <http://www.vch.ca/Documents/Facilities-licensing-supporting-sexual-health-and-intimacy-in-care-facilities.pdf>
- **Intimacy and sexuality in long-term care a guide to practice: resource tools for assessment and documentation.** (2010). Lanark, Leeds and Grenville Long-Term Care Working Group, Ontario. <http://brainxchange.ca/Public/Files/Sexuality/Sexuality-Practice-Guidelines.aspx>
- **Sexuality and people in residential aged care facilities: A guide for partners and families.** (2016). La Trobe University, as represented by the Dementia Collaborative Research Centre, Australia. <https://privacy.org.nz/assets/Uploads/Bauer-M.-Featherstonhaugh-D.-2016-Sexuality-and-people-in-residential-aged-care-facilities-A-guide-for-partners-and-family.pdf>
- **Intimacy, sexuality and sexual behavior in dementia: How to develop practice guidelines and policy for long-term care facilities.** (2002). Shalom Village, Hamilton, Ontario. Ontario. <http://brainxchange.ca/Public/Files/Sexuality/Intimacy-Sexuality-and-Sexual-Behaviour-in-Dementi.aspx>
- **Sexualities and Dementia: Education Resource for Health Professionals.** (2014). Dementia Training Study Centres, Australia. <https://privacy.org.nz/assets/Uploads/Jones-C.-2014.-Sexualities-and-Dementia-Education-Resource-for-Health-Professionals-Manual2.pdf>
- Bauer, M., Fetherstonhaugh, D., Nay, R., Tarzia, L. & Beattie, E (2013). **Sexuality Assessment Tool (SexAT) for residential aged care facilities.** (Available from the Australian Centre for Evidence Based Aged Care, La Trobe University, Melbourne VIC 3086). <https://privacy.org.nz/assets/Uploads/Sexuality-Assessment-Tool-SexAT.pdf>

Recommended reading

Doll, G. A. (2012). *Sexuality and long-term care: Understanding and supporting the needs of older adults*. Baltimore: Health Professions Press.

- Rationale for recommendation: practice-ready. A user-friendly book set up like a manual to walk the reader through many aspects of sexuality in long-term care (physical space, LGBTQ2S+ residents' needs, social dynamics, aging and sexuality, etc.). It also includes reflective activities, quizzes, and case examples. Importantly, it provides guidance for developing a facility-level policy related to sexual expression – with tips and exemplars.

Doll, G. (2013). Sexuality in nursing homes: Practice and Policy. *Journal of Gerontological Nursing*, 39(7), 30-37. doi:10.3928/00989134-20130418-01

- Rationale for recommendation: provides background on the range of activities associated with resident sexual expression as well as the staff and family responses. Makes recommendations for policies and staff/family training and education to respond to residents' intimacy needs.

Lichtenberg, P. (2014). Sexuality and physical intimacy in long-term care. *Occupational Therapy in Health Care*, 28(1), 42-50. doi: 10.3109/07380577.2013.865858

- Rationale for recommendation: includes case examples and suggestions for health providers to discuss sexual expression with older adults. Includes practical considerations regarding capacity and intimacy.

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