Journal of Aging Studies 53 (2020) 100849

Contents lists available at ScienceDirect

Journal of Aging Studies

journal homepage: www.elsevier.com/locate/jaging

"If you do not find the world tasty and sexy, you are out of touch with the most important things in life": Resident and family member perspectives on sexual expression in continuing care

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ARTICLE INFO

Keywords:
Sexual expression
Continuing care
Residents and family members
Alberta
Canada

ABSTRACT

Over the past three decades, there has been growing attention to sexual expression in continuing care homes. However, resident perspectives continue to be underrepresented, particularly in the Canadian context. In this article, we share findings from a qualitative, exploratory study looking at the experiences of residents and family members in Alberta, Canada. As continuing care demographics and social norms about sexuality shift, it is increasingly important to understand these perspectives. We asked participants about how they define sexual expression, its place in continuing care, their experiences with/thoughts about sexual expression in 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. These findings foreground the voices of residents and family members and highlight key areas of opportunity for policy and practice change.

Introduction

Over the past three decades, there has been growing attention to sexual expression in continuing care homes. However, resident perspectives continue to be underrepresented, particularly in the Canadian context. As continuing care demographics and social norms about sexuality shift, it is increasingly important to understand these perspectives. The term "sexual expression," refers to a wide range of sexual identities, practices, and relationships (Doll, 2013). This can include kissing, hugging, bed sharing, fantasizing, emotional intimacy, sexual acts, and more. The sexuality of people living in residential care homes is often overlooked. When this aspect of their lives is not addressed, there is potential for infringement on human rights, unmet needs, and missed opportunities for social connections and for residents to feel good in and about their bodies. In this article, we discuss findings from the second phase of a province-wide study on sexual expression in continuing care homes. In Alberta, Canada, continuing care includes supportive living (SL) and long-term care (LTC) residential homes. SL homes provide support services for residents who have a range of needs and levels of independence. LTC homes provide 24-h nursing and personal care for residents with more complex needs.

In Phase 1 of this research, we interviewed continuing care managers and those with whom they consult about matters related to sexual expression (e.g., clinical ethicists, social workers, best practice/geriatric assessment teams, and others). In the absence of related provincial policies, we explored how managers navigate matters of resident sexual expression [blinded for peer review]. In Phase 2, we interviewed residents and family members. We asked them about how they define sexual expression, its place in continuing care, their experiences with/thoughts about sexual expression in 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 distinguishing between appropriate and inappropriate expressions. This paper provides the much-needed perspectives of residents and family members. The research findings highlight areas of opportunity for policy and practice change to support residents' diverse sexual expressions, as well as their need for the physical and social privacy to ensure that such expressions are dignified.

Background

Continuing care demographics are changing (Demographic

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https://doi.org/10.1016/j.jaging.2020.100849
Received 18 December 2019; Received in revised form 23 April 2020; Accepted 29 April 2020

Planning Commission, 2008). This sector has historically been associated with care for older adults, but recent trends indicate a growing need to also support middle-aged adults with medically complex conditions (Suter et al., 2014). Sexual expression is often overlooked in these populations despite ample evidence of their ongoing need for intimacy, connection, and self-expression. Furthermore, it is expected that with changing social norms and increasing generational acceptance, future cohorts of older adults will have greater interest and more frequent participation in sexual activity (Hillman, 2008). We can also anticipate that upcoming continuing care cohorts will have a higher proportion of residents who openly identify as lesbian, gay, bisexual, transgender, queer, or two-spirited (LBGTQ2S+). Thus, there is a need to hear from continuing care residents and their family members about their present experiences and priorities for the future.

The majority of research on sexual expression in continuing care comes from the perspectives of clinicians and/or care providers. 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 (Bauer et al., 2014; Doll, 2013; Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999; Gibson, Bol, Woodbury, Beaton, & Janke, 1999; Roelofs, Luijkx, & Embregts, 2015; Rowntree & Zufferey, 2015; Wiskerke & Manthorpe, 2018). Much of the research with family members indicates that there is support for "minor" or subtle expressions of sexuality. Loving and caring expressions are more accepted by families than erotic ones (Bender, Burgess, & Barmon, 2020; Ehrenfeld et al., 1999; Wiskerke & Manthorpe, 2018). It is common for family members to feel the need to be kept informed about a resident's sexual activities (Bauer et al., 2014), but their support for sexual expression varies considerably. Family members' perspectives are important because these individuals are often consulted about matters of residents' sexual expression by staff or by residents themselves. As a result, they have intimate involvement as residents' partners, children, advocates, and/or substitute decision-makers (known in some jurisdictions as 'surrogates' or 'health care proxies').

In a systematic review of the literature on sexual expression in nursing homes, Aguilar (2017) found that few studies include resident perspectives. This is particularly true in the Canadian context. 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 (Villar, Celdran, Faba, & Serrat, 2014; Villar, Faba, Serrat, & Celdran, 2015; Villar, Serrat, Celdran, & Faba, 2016). In the United Kingdom, investigators noted similar features in their research and described the importance that residents and family members attached to a variety of forms of sexual expression (Bouman, Arcelus, & Benbow, 2006; Simpson, Wilson, Brown, Dickinson, & Horne, 2018). Scholars from the United States found that increased non-sexual intimate interactions improved male residents' quality of life (Bullard-Poe, Powell, & Mulligan, 1994), yet noted similar challenges as the aforementioned studies (Bender et al., 2020) and called for a person-centered approach to resident sexual expression (Cornelison & Doll, 2013; Syme, Johnson, & Fager, 2019). Research teams from Israel and Australia looked at residents' attitudes towards sexuality and their perceptions of barriers to sexual expression (Aizenberg, Weizman, & Barak, 2002; Bauer et al., 2013; Bauer, Haesler, & Fetherstonhaugh, 2019). Many of these studies offer ways to categorize and understand sexual behaviors and expressions (e.g., solitary/dyadic, touch/talk/non-touch expression, etc.; and social, intellectual, emotional, and physical components of intimacy). A meta-ethnographic synthesis of resident perspectives on sexual expression revealed six key themes: residents' definitions of sexuality, sexuality as something not to be discussed, sexuality as a distinct aspect of the self, hopes and fears for the future, the impact of the care home environment, and adapted sexuality (Hooper, De Boos, Nair, & Moghaddam, 2016). Across this scholarship, staff attitudes and residents' privacy consistently come up as key themes and pose significant challenges for resident sexual expression. The current lack of policy and procedures related to sexual expression appears to be a pervasive problem across Western jurisdictions, often leaving staff to respond to these matters on an ad hoc basis (Steele, 2017; Syme, Doll, Cornelison, Yelland, & Poey, 2017; Syme, Lichtenberg, & Moye, 2016; Tabak & Shemesh-Kigli, 2006).

Continuing care 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 United Kingdom revealed that only 2.1% of contacted care homes provided any materials that address love, sex, or intimacy (Bauer, Nay, & McAuliffe, 2009). It is possible that the lack of attention to sexual expression reflects stereotypical attitudes about aging (de São José & Amado, 2017) and assumptions about 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, 2016). 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 (Furlotte, Gladstone, Cosby, & Fitzgerald, 2016; Mahieu & Gastmans, 2015; Nay, McAuliffe, & Bauer, 2007; Sharek, McCann, Sheerin, Glacken, & Higgins, 2015).

There is limited Canadian research on sexual expression in continuing care (Dyck, Kontos, Angus, & McKeever, 2005; Kontos, Miller, & Kontos, 2017) and none from the province of Alberta. We designed this study to understand how the themes from the extant literature play out in the current Alberta context.

Methods

We undertook an exploratory qualitative study (Creswell, 2013) to understand residents' and family members' perceptions of sexual expression in continuing care homes. An exploratory approach is well suited to this research because there is limited scholarship on residents' and family members' perspectives, and we wanted to clarify the specific nature of the problem(s). We received ethical approval from our institutional ethics review board and operational approvals from participating health service agencies.

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?

Participant recruitment

We used purposive sampling to recruit adults who either lived in or had a family member living in a continuing care home for at least six months and had experience related to sexual expression in continuing care. We only included residents who were their own legal decision-makers and had the cognitive capacity to consent to the research. The care homes were managed by Alberta Health Services, Covenant Health, CapitalCare, or Carewest. These operators represent urban, suburban, and rural care homes across the province. All of these continuing care homes are publicly owned and operated and the health care services are publicly funded at no cost to residents. Residents pay for accommodations (rooms, meals, housekeeping, and maintenance) at a government-set maximum of $2074/month (Government of Alberta, 2020). All care homes in Alberta are regulated by the Long Term Care

Accommodation Standards (Government of Alberta, 2010) and the Continuing Care Health Services Standards (Government of Alberta, 2018).

We recruited potential participants through e-mail invitations sent via care home listservs, print invitations circulated at resident-family council meetings and caregiver support groups, and posters placed in high traffic areas at care homes. Prospective participants contacted the investigators directly, by e-mail or telephone. Either the primary or secondary author described the research project, discussed the study activities, and answered questions. We reviewed and completed consent forms with participants prior to each interview. Participants were made aware of how they could withdraw or modify their participation in the study.

Our sample of 20 participants included 12 residents and eight family members. Seven of the residents were women and five were men. The resident participants ranged in age from 42 to 91 years. They also ranged in their physical and cognitive functional ability. Seven of the eight family members were women. These family members were the spouses or children of continuing care residents. The family members ranged in age from 27 to 81 years.

Data collection

The primary and secondary authors collected data between 2018 and 2019. Participants in the local geographical region had the option to participate in the interview in-person or over the telephone. Participants from elsewhere in the province took part via telephone. We conducted in-depth, semi-structured interviews that lasted 45–75 min. We asked participants about how they define sexual expression, its place in continuing care, their experiences with sexual expression in continuing care homes, and their thoughts about how to improve this aspect of resident life. All interviews were digitally recorded and transcribed verbatim. Our research team assessed the interview transcripts for accuracy and annotated them with observations made from the interviews.

Data analysis

The data were analyzed by the two co-principal investigators, a research associate, and two research assistants. We analyzed the interview data using Braun and Clarke's (2006) approach to thematic analysis. The research team independently familiarized ourselves with the data and identified preliminary codes. The research team met and discussed coding, reviewed codes for consistency, and then grouped codes into patterns and themes. We collected and analyzed the data concurrently until the themes were replicated across multiple cases and we had reached saturation. We then defined and named the themes. After about 14 or15 interviews, participants' accounts were consistent with the same, repeating themes about what sexual expression can look like, autonomy, privacy, communication, and distinguishing between appropriate and inappropriate expressions. In other words, the experiences and examples were diverse, but no new themes were generated.

Findings

Across our data, we identified five main themes. These include: 1) diverse experiences of sexual expression in continuing care homes, 2) resident autonomy and the involvement of others, 3) privacy matters, 4) communication dynamics, and 5) distinguishing between appropriate and inappropriate expressions.

One size does not fit all: nuanced and diverse experiences of sexual expression

We heard diverse accounts of what sexual expression looks like in continuing care homes. Our participants' experiences 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 years ago for an erotic film he created, and another came out of the closet for the first time during a resident council meeting. These accounts offer insight into the vast range of what sexual expression can look like for continuing care residents.

We learned that for many residents, sexual expression included a desire to look and feel good. Maintaining one's physical appearance was described as a way of being true to one's self and outwardly presenting that self to the world.

> I wear makeup. I make my hair nice when I go out, because I want 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, female).

> The girls do my hair, I brush my teeth, I put on my cologne… I always like to smell nice (Resident 7, male).

Most 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. Some 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, 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, female).

> Somebody said, 'why don't you get somebody else?' I said 'no, I had one [spouse] and that's all I needed'… I had it years ago and I don't need anymore (Resident 4, female).

For other residents, physical touch was identified as an important part of 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. 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. I told him, 'you don't know what this means to me' (Resident 2, male).

The meaning of touch is often overlooked by care staff who have come to know residents in a medical capacity. Some 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:

> The emotional intimacy just makes me feel more as a person [sic].

> Because I think without that, you can just sort of get lost in yourself (Resident 6, female).

> My mom wasn't a demonstrative person with hugs and saying, 'I love you,' even though we always knew that she did. 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, female).

> 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, male).

In sum, our participants' 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 these diverse expressions, there is opportunity to support residents' sense of belonging, connection, personhood, and safety. A standardized or "one size fits all" understanding of sexual expression in continuing care cannot reflect the breadth of residents' needs.

Many cooks in the kitchen: sexual autonomy and the involvement of others

In order to actualize the diverse expressions described above, residents act on their own and/or with the assistance of others. Several of our participants indicated that having 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 sexual identity and autonomy:

> 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, female).

Being able to make choices for themselves meant being able to pursue possibilities, which can be exciting. 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.

Residents who were in control of their own finances and had reliable internet access were better able to address their sexual needs independently. These residents purchased items like lubrication, sex toys, or erotica discreetly online.

> 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, female).

> [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, male).

Other residents 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, female).

In cases such as this one, there were additional steps required and additional parties involved in order for residents to actualize their sexual expression. By nature, continuing care environments require the involvement of others for the activities of daily living. However, not all residents are comfortable with having other parties involved in their sexual lives and this adds a layer of complexity to decision-making.

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.

> So, when it comes to sexual expression, it's easy to just steamroll in and make decisions for him…that those conversations [between myself and the staff] 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, female).

In sum, 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. Other residents indicated that they require or desire some assistance from others in order to actualize their sexual autonomy. These residents indicated that they might need assistance with getting in and out of bed when they have a visitor, assistance with arranging transportation to and from dates outside of the care home, or some emotional support following a break-up. The involvement of others was not described as inherently good or bad, but as adding a layer of complexity to sexual expression in continuing care. By nature, congregate living environments require some limitations on sexual 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, our participants were unanimous that residents should have sexual autonomy to engage in certain expressions privately and consensually.

The intimacy of congregate living: privacy matters

Several participants pointed out that although continuing care homes are not particularly 'sexy' environments, they should feel like homes where 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. Residents indicated that there was minimal 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, male).

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

In these instances, the lack of physical privacy and 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…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, female).

The resident in this example 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 when 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, 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, female).

Several residents indicated that privacy about their sexual and romantic lives was important, and added that general privacy of information was important as well. One resident 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… 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, female).

In sum, privacy matters in congregate living environments. This includes privacy of physical and social space and of personal information. Whether or not residents have 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.

Tackling the taboo: communication dynamics around sexual expression

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 whether 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.

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, female).

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, female).

[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 awkward and kind of uncomfortable and kind of funny, but we just need to move forward and talk about it' (Family Member 1, female).

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. In some instances, residents and family members perceived biases and stereotypes about resident sexual expression.

So, I just wish that staff approached it in a more sensitive way …If residents want to watch porn on their own time…then the care aides are like, 'oh, she's watching porn again'… It's like well if there was a system where [residents] could have this private time and not feel so bad about a natural way to express their sexuality… I just find the staff are not as sensitive or as understanding (Family Member 5, female).

I'm chair of resident's council [and sexuality] seems to be a subject you cannot bring up. It'll almost clear the room if you bring it up….When you reach a certain age, that part of your life is supposed to end. Why?… If you wanted to date somebody in a long-term care setting, it's almost discouraged. Why? (Resident 2, male).

Another important concern was the 'lack of unified voice' within and between continuing care homes. The considerable variation in staff language, attitudes, and responses meant 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.

Lastly, several participants indicated 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, female).

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, female).

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.

Walking the fine line: distinguishing between appropriate and inappropriate expressions

Because of (1) personal beliefs and (2) varied understandings about

cognitive impairment, it can be challenging to distinguish between appropriate and inappropriate expressions of sexuality. Several of our Phase 1 participants suggested that it might be helpful to think about this in terms of 'wanted' and 'unwanted' expressions. This helps to distinguish between expressions that may cause harm and those that some may subjectively find distasteful. Many Phase 2 participants indicated that the boundary between appropriate and inappropriate expressions is ambiguous. 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. Several participants spoke about restrictive environments in which sexual expression is discouraged and a lack of clarity about what was considered acceptable.

> [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, male).

> [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, female).

Some participants expressed concerns about how the behaviors of residents with dementia are pathologized. Several family members noted that staff sometimes shame and/or punish residents for 'sexual disinhibition' without distinguishing whether the expression is wanted or unwanted (e.g., 'it's inappropriate that he is masturbating' vs. 'it's inappropriate that he is masturbating in the dining room'). None of our participants suggested that care staff or fellow residents should endure any unwanted expressions, and they also did not want residents' identities reduced to their inappropriate behaviors. 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 behaviors (e.g., sexual comments and/or groping care staff). As a result, she began to limit wanted 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, female).

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 there was no discussion about 'appropriate' outlets for her husband. Similarly, we spoke with a participant whose father had become uncharacteristically demonstrative since his dementia diagnosis. She spoke about the difference between two care homes' responses to his behavior:

> 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, and 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… it should be predictable that 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 helped us get through this crisis and see our dad as dad again, as opposed to this sick monster, which everybody made him seem like (Family Member 2, female).

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. In navigating the ambiguous boundary between 'appropriate' and 'inappropriate' expressions, there is a need to balance resident autonomy and sexual rights with the safety and well-being of others. Because it is unclear what is appropriate or inappropriate, we heard that many care homes err on the side of suppressing resident sexual expression. Unfortunately, this can result in discouraging wanted expressions and insufficient preparation for or stigmatizing responses to unwanted sexual expression.

Discussion

Our research offers rich data about the profundity of particular individuals' experiences, while also providing evidence that these themes have global resonance. Some participants' accounts have stretched our understanding of what sexual expression in continuing care can include. This emphasizes the importance of having resident voices included in the generation of recommendations for changes to policy, practice, and education. Consistent with themes identified in the existing literature, our findings reinforce the importance of autonomy, privacy, and communication regarding sexual expression in continuing care and extend our conception of what support for sexual expression can look like in these settings. Our findings provide further evidence of the challenges associated with inconsistent responses to resident sexuality ([blinded for peer review]; Cornelison & Doll, 2013). In absence of a strategic, coordinated approach, there are missed opportunities for connection and for residents to express their sexuality in safe and dignified ways.

Similar to other studies on this topic, our research identified diverse interpretations of sexual expression among residents in continuing care homes and their adult children or spouses (Bauer et al., 2014; Frankowski & Clark, 2009; Mahieu & Gastmans, 2015). We noted many residents' ongoing interest in sexual expression, which is consistent with theoretical perspectives of older persons' sexuality (Barrett & Hinchliff, 2018; Doll, 2013) as well as studies in continuing care contexts (Aguilar, 2017; Aizenberg et al., 2002; Villar et al., 2015). Our resident participants identified that it is important they have autonomy and privacy with their sexual expression. We provide further evidence that resident's physical or cognitive abilities, the care home routines, the building layout, and the involvement of others can make it challenging to realize this ideal (Bauer et al., 2013; Roelofs et al., 2015; Wiskerke & Manthorpe, 2018). Our findings make visible the complex interplay of informational, physical, and social privacy and the influence that these have on resident sexual autonomy. With the exception of rare instances, our participants described reticence, discomfort and lack of knowledge on the part of care staff about sexual expression in the care home. Similar findings have been reported in other studies, and we add evidence to the case for care home staff development in this area (Bauer et al., 2013; Doll, 2013; Howard, Brassolotto, & Manduca-Barone, 2019; Roelofs et al., 2015; Villar et al., 2016).

Our participants had diverse experiences, some of which reflect the inconsistencies that result from a patchwork approach to sexual expression. There are currently no provincial policies or sector level standards in Alberta related to sexual expression in continuing care – nor is this a required component of health care staff training and education. As a result, many staff members are insufficiently prepared to support this aspect of resident care and often default to their personal views about how these matters should be handled (Howard et al., 2019). Residents and their family members are then left unclear about when and where residents can expect reasonable privacy, what sexual expression could look like in a residential care setting, and how sexual

behavior might change when a resident experiences changes in their cognitive function.

Our findings reflect the experiences of participants from Alberta, Canada at particular points in time. We acknowledge that this does not provide an exhaustive account of all facets of sexual expression in continuing care homes. All of the care homes represented in this study were publicly funded and there was no recruitment from private or for profit agencies. As a result, we know little about experiences in those settings. We recruited people to participate voluntarily and, given the nature of the topic, those who were uncomfortable with sexual expression likely opted not to participate. There are presumably residents and family members who hold less favorable perspectives on sexual expression, but these perspectives were not directly reflected in this study. We recognize that people are constituted of multiple and intersecting identities and that these can produce distinct experiences related to sexual expression. Although our sample had range in terms of geographical location, age, and functional ability, our participants were predominantly Caucasian and heterosexual. There is merit in doing research specifically to explore the impact of ability, race, gender identity, sexual orientation, and/or socio-economic status on sexual expression in continuing care homes.

Recommendations

There is much work to be done. We believe that this work begins with the development of care home policies on sexual expression. The policy should reflect the mission and values of the health service agency (for instance, person-centered care) as well as the ethical codes of the staff's professional bodies. The policy should broadly establish the place of sexual expression in the care home, feature inclusive language, outline the consequences for unwanted expressions, and indicate where residents or family members can turn for further information. In addition to the sectoral level recommendations we have made elsewhere (Howard et al., 2019), continuing care staff can also take action to address the concerns that surfaced in our data. Our participants offered suggestions for what could improve their lives. As a result, we offer the following recommendations to address matters of sexual autonomy, privacy, communication dynamics, and distinguishing between wanted and unwanted expressions.

Autonomy

- Encourage staff to support resident choice and autonomy where possible.
- Honor preferences about personal appearance (e.g., wearing particular clothing or styling hair in a preferred way).
- Respect resident choices about sexual expression, even if they are different from one's own (e.g., if a resident is watching pornography, using a sex toy, or engaging in a sexual relationship outside of wedlock).
- Seek out ways to offer flexibility from the “assembly line living” of continuing care and create opportunities for spontaneity or intimate connections. Make use of the expertise of Recreation Therapists in these endeavors.

Privacy

- Respect resident privacy. Knock before entering a room, avoid sharing personal information in public spaces, and be judicious about what information is solicited or shared with others.
- Assess the physical space of the care home and consider how it could be best used to support resident privacy. If there are many shared rooms, seek out or adapt spaces where residents can visit in private.

Communication dynamics

- Indicate to residents and family members what are considered reasonable accommodations in the care home (e.g., overnight visits for partners).
- Offer residents and family members brochures or documents that discuss how dementia, Multiple Sclerosis, Parkinson's, traumatic brain injury, or other conditions can affect sexual expression.
- Develop a glossary of related terms and add it to the care home policy and any related print or digital materials.
- Provide indication that the care home is a safe and welcoming space for LGBTQ2S+ residents (e.g., inclusive language on forms and print materials, no default assumption of heterosexuality, take up the work of the AHS task group (2019) on safe and welcoming environments).
- Recognize the challenges and discomfort that family members often experience related to this topic. Be judicious about what information is shared with them and clear about why they should know it and what they are expected to do about it (if anything). If there is uncertainty, consult management or seek out an ethics consult.

Appropriate vs. inappropriate expressions

- Reflect on personal values and beliefs and consider how these might impact care work.
- Respond with compassion to residents who have diminished cognitive capacity. Remember to help de-stigmatize sexual expression by implementing redirection strategies when needed.
- Discuss these matters as a care team (in ways that respect resident privacy) and develop a consistent approach.
- Request a consult from a clinical ethicist or social worker when there is uncertainty about the ethics of a particular case.

Conclusion

One resident poignantly said:

> 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, male).

Sexuality is not something that disappears when people move into continuing care. Although sexual expression may take on new forms over the life course, it continues to be a fundamental part of human life and flourishing for many residents. However, staff are not well prepared to anticipate or respond to resident sexual expression, nor are care home environments designed to accommodate opportunities for intimacy. Our research demonstrates how residents persist in their endeavors to express themselves as sexual beings in the face of interpersonal and structural challenges that come with living in a care home.

Funding sources

Alberta Innovates and University of Lethbridge Research Fund.

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