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Recommendations for sexual expression management in long-term care: a qualitative needs assessment

Maggie L. Syme, MPH, PhD,

Assistant Professor, Center on Aging, Kansas State University, Manhattan, Kansas, USA

Peter Lichtenberg, PhD, ABPP, and

Director/Professor of Psychology and Physical Medicine and Rehabilitation, Institute of Gerontology, Merrill Palmer Skillman Institute, Detroit, Michigan, USA, Wayne State University, Detroit, Michigan, USA

Jennifer Moye, PhD, ABPP

Geriatric Mental Health Clinic Director/Associate Professor, VA Boston Healthcare System, Brockton, Massachusetts, USA, Harvard Medical School, Brockton, Massachusetts, USA

Abstract

Aims—To conduct a qualitative needs assessment of Directors of Nursing regarding challenges and recommendations for addressing sexual expression and consent.

Background—Sexual expression management among long-term care residents is a complex issue for nursing home staff. Little guidance is available for those wanting to follow a person-centred approach. Policies and procedures are needed, and must be usable across long-term care settings.

Design—Qualitative design for in-depth exploration.

Methods—Semi-structured interviews were conducted with 20 Directors of Nursing in the spring and summer of 2013, representing a range of regions, facility sizes and resident populations. Interview questions prompted them to identify recommendations that address challenges to improving sexual expression management in long-term care settings.

Results—Comparative thematic analysis resulted in several codes, which were grouped into eight overall categories. Recommendation categories that addressed key challenges included: address the issue, make environmental changes, identify staff expertise, provide education and training, assess sexuality initially and recurrently, establish policies/procedures for sexual

Correspondence to: M.L. Syme: msyme@ksu.edu.

Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
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expression management, develop assessment tools for sexual expression and consent, and clarify legal issues. The recommendation to develop national guidelines was observed across categories.

Discussion—Directors of Nursing report several challenges to sexual expression management in their facilities, and perceive their current methods to be ad hoc. A proactive approach to policy and procedure development is needed.

Keywords

long-term care; nurses; nursing; older people; policy; sexuality

Introduction

In long-term care (LTC) facilities, where approximately 40% of residents have dementia (Harris-Kojetin *et al.* 2013), it is challenging to provide quality dementia care that protects personhood, enhances remaining capabilities and supports diminished capability (Murray & Boyd 2009). The person-centred care movement in LTC highlights the short-comings of traditional dementia care – unmet needs, loss of autonomy, extremely limited choices – while exploring the challenges of supporting quality dementia care, quality of life and choice for all residents (Zimmerman *et al.* 2014). Although social interactions are integral to quality dementia care, a potential limitation remains the lack of attention to intimate and sexual contact as a resident need and right. Sexual expression in older LTC residents is complex, particularly given consent issues; however, sex remains important and beneficial for many throughout life (Syme *et al.* 2015). Balancing challenges of supporting sexual and intimate expression with residents' rights and autonomy is an ongoing struggle for homes. The purpose of this study is to explore both the challenges LTC facilities face in addressing sexual expression and consent and their subsequent recommendations for improving care via a qualitative process.

Background

Intimacy and sexual expression in later life is taboo in Western society. Ageist myths (e.g. older adults are asexual) have often barred older adults from the 'charmed circle' of sexuality and led individuals, healthcare providers and older adults themselves to believe that sexual activity is not for the aged (Bouman *et al.* 2006, Hinchliff & Gott 2011, Hillman 2012). In contrast to these pervasive stereotypes, the need for physical closeness, intimacy, and sexual contact does not diminish with age or loss of cognitive capacity (DeLamater 2012, Doll 2013) and continues to provide psychological and physical benefits throughout life (Nay 1992, Syme *et al.* 2015). Sexual expression represents a spectrum of activities across the life-span, often emphasizing intimate activities (e.g. hand holding, cuddling) into older age to accommodate preferences and physical limitations (Doll 2013). However, older adults continue to engage in a range of sexual activities throughout life, which includes oral, anal and vaginal intercourse, masturbation, and foreplay-related activities (DeLamater 2012).

Older adults in LTC settings are also engaging in sexual/intimate activities, although frequency and type of activity may change (Spector & Fremeth 1996, Archibald 1998,

Roelofts *et al.* 2015). For example, a study on LTC facilities in Kansas (US) found the majority of administrators reported that residents engage in some form of sexual expression (e.g. sexual acts, sexual talk, romantic activities) (Doll 2013). Yet, there are several individual barriers to sexual expression for LTC residents, including lack of a willing/able partner, physical and mental health problems, and medication side effects (Hajjar & Kamel 2003, Villar *et al.* 2014).

Sex becomes a double- and triple-barrelled taboo for older adults living in LTC with dementia, and unfortunately, sexual rights of older LTC residents are often unacknowledged (Roach 2004, Frankowski & Clark 2009). This is partially due to the difficulties reported in managing sexual expression among LTC residents (Elias & Ryan 2011, Lester *et al.* 2015). Challenges to managing sexual expression in LTC include lack of privacy, restrictive/negative staff and family attitudes, lack of education/training in sexual expression, and balancing autonomy with protection from harm (Hajjar & Kamel 2003, Roelofts *et al.* 2015). Another significant challenge for facilities is navigating sexual expression with cognitively impaired residents, which may compromise older adults' ability to consent to sexual activities (Lichtenberg & Strzepek 1990, Wilkins 2015). Sexual consent capacity – ability to decide to voluntarily engage in sexual activities – has been largely ignored in ageing research, and is an unresolved clinical and ethical issue in LTC facilities (Tarzia *et al.* 2012).

There is a notable lack of policy, procedures, and understanding of resident sexual expression and consent in LTC facilities in the US (Lester *et al.* 2015). A recent study on a convenience sample of long-term care facilities ($N = 175$) in the US showed few facilities have policies related to sexual expression (~23%) and consent (~8.5%) (American Medical Directors Association [AMDA] 2013). This is also demonstrated internationally with lack of policy and failing to address sexuality with LTC staff (Shuttleworth *et al.* 2010, Villar *et al.* 2014). Thus, facilities and their staff are often left to their own devices to regulate sexual expression and consent, which may or may not comply with legal and ethical standards for sexual consent (Lyden 2007, Everett 2008).

Supporting sexual expression in LTC is daunting for nursing homes. There are few, isolated homes addressing sexual expression comprehensively and proactively (e.g. Hebrew Home at Riverdale; River Spring Health 2011) but this has not been widely recognized or adopted across LTC facilities in the US (Lester *et al.* 2015) and is limited in other countries (Shuttleworth *et al.* 2010, Benbow & Beeston 2012). Little guidance is available for administrators of LTC facilities needing assistance in managing complex, sexual situations (Elias & Ryan 2011, Bauer *et al.* 2014). The few policies that exist locally in the US are often universally applied and may miss the nuance of sexual situations (Lester *et al.* 2015). The need for sexual expression policies in LTC has been identified (Benbow & Beeston 2012, Lester *et al.* 2015); however, there is less empirical research on what those policies should incorporate, especially from multiple stakeholder perspectives. One integral perspective is nursing home staff, as understanding their needs and recommendations will help ensure resulting policies are practical and usable in LTC settings.

The study

Aims

To determine a range of challenges Directors of Nursing (DONs) in the United States face in addressing sexual expression and consent in LTC facilities and their subsequent recommendations for addressing them through clinical practice and policy.

Design

The aims of this study were consistent with a basic interpretive qualitative study (Merriam 2002). The goal was to identify patterns for specific, practical applications in nursing home care. Thus, thematic analysis methods were used (Braun & Clarke 2006), which allowed for depth and breadth of information regarding challenges and unmet needs of DONs addressing sexual expression in LTC facilities.

Sample

Directors of Nursing (DONs) were selected for this study due to their supervisory role with staff, direct resident care, and their ability to comment on policies and procedures in LTC facilities. A convenience sample of DONs ($N = 20$) were recruited via an email sent in the spring and summer of 2013, which was facilitated through the National Association of Directors of Nursing in Long-Term Care (NADONA-LTC). Thus, all participants were either an active or former DON in a LTC facility in the US. The email provided a brief description of the study, duties of participating, voluntary nature of the study, and research team contact information. Thirty interviews were originally planned, based on suggested sample sizes for qualitative studies (Mason 2010). However, data saturation was continually evaluated throughout interviews and it was determined that saturation was achieved after 20 participants, as no novel themes and very few additional codes were generated in the final two interviews.

The majority of participants were middle aged (mean = 55.84 SD 6.35), White ($n = 18$) females ($n = 19$) with an average of 8.31 (SD 6.27) years of experience as a DON and 20.21 (9.82) years working in LTC. Educational background was split evenly between Associates ($n = 7$, 35%), Bachelors ($n = 6$, 30%) and Masters Degrees ($n = 7$, 35%) in nursing. Participants represented facilities from several regions in the United States (East and West Coasts, Midwest, Northeast, Southeast).

Data collection

Data were obtained via in-depth, semi-structured interviews. Interviews were designed to assess four domains of sexual expression and consent in LTC: knowledge, actions, attitudes, and challenges/recommendations. Questions were developed based on research literature and consultation with experts in LTC and consent capacity (co-authors names blinded), and prompts were identified to use as needed (see Appendix 1). This was reviewed by two expert consultants (co-author names blinded), revised, and piloted for clarity. This study focused exclusively on the interview questions related to a) perceived challenges/barriers to patient-centred sexual expression management and b) recommendations for resources, policies, and procedures to aid sexual expression management (#7 and #8).

The principle researcher – experienced in qualitative methods – conducted all interviews for reliability and continuity. Telephone interviews were audio-recorded with participant consent. To develop rapport with participants, the interviewer provided additional information about the study and asked initial questions about their facility before beginning questions about sexual expression. At the end of the interview, participants were invited to ask questions. Interviews typically lasted 45 minutes – 1 hour. They were also asked to provide additional background information (e.g. gender, age, education, years of experience) in a brief, online survey. To ensure confidentiality of responses, participants were assigned a unique, numerical identifier to match their interview and survey data. They were given a \$50 gift card for their participation.

Ethical considerations

Study procedures were approved by the Institutional Review Board at San Diego State University. Identifying information was de-identified during transcription to protect interviewees' privacy.

Data analysis

Twenty interviews were transcribed by the principle researcher (female) and several trained research assistants (both male and female). Thematic analysis was employed to discover emerging patterns among the data (Boyatzis 1998), facilitated by the use of Dedoose software (2014). Codes were initially identified and refined by the principle researcher who read through and compared the data within and between interviews. Relationships between codes were continually assessed, producing categories among the codes, which were discussed with the research team. The categories were inductively identified, although the process was guided by prior research on sexual expression in LTC. Thus, exploratory and theory-driven processes were combined within an interpretive paradigm.

Rigour

During the data collection and analysis process, initial categories were presented to DONs participating in the study as a member-checking procedure to ensure credibility (Lincoln & Guba 1985). This was conducted individually at the conclusion of each interview, presenting a brief summary of the themes discussed in the interview and key emerging categories/themes from previous interviews. In addition, quotations were selected from several participants to ensure representation of the sample (Granheim & Lundman 2004). To address dependability, a trained research assistant examined randomly selected transcripts to establish agreement on codes and categories with disagreements resolved through discussion (Burla *et al.* 2008).

Findings

Recommendations were represented across eight categories, corresponding to several key challenges DONs faced in managing sexual expression and consent.

Category 1: Address the issue

DONs frequently cited the need for local facilities and national organizations (e.g. Centers for Medicare and Medicaid Services (CMS), NADONA-LTC) to become aware of and address sexual expression and consent directly. This was related to the challenge of stigma and their perception that sex is ignored in LTC. One DON (#022) indicated this need by stating:

Sometimes I get so provoked with them [national organization] that unless it's something that's quick simple and easy to address that nobody wants to wrap their hands around it and take ownership and say hey, let's get together a representative from different districts and let's see where we can take this or what can we do with this?

In terms of stigma, DONs often recommended addressing sexuality in conjunction with the need for attitude changes about resident sexuality. For example, one DON (#010) stated: 'Everybody has to change their mindset and embrace the fact that people are sexual beings and they deserve to be able to express themselves.' They often suggested creating buy-in for administrators and national organizations by tying it to person-centred care. 'This naturally segues into culture change...If I were wanting to implement that here I would present it as part of culture change, which is already being mandated (#002).'

Category 2: Make environmental changes

Several challenges related to environments in LTC were identified (e.g. time, staffing, privacy), which led DONs to recommend changes. Recommendations included having easily implemented changes that would facilitate sexual expression management, such as a 'knock-first' policy, do-not-disturb signs, wider beds or pushing beds together, and well-delineated procedures for sexual situations for expediency. Intimacy needs were often considered as the impetus for changing spaces. For instance, one DON (#004) stated:

I think that level of connection with another human being changes a lot about your demeanor and how you move through life and long-term care is so isolating to begin with. You've left your home, you've packed just enough belongings in a box to take up half of only an 80 square foot room and so, so many things are lost and disconnected. But if we had a better way to maintain intimate relationships with people, that would change the perception of long-term care to some.

Category 3: Identify staff with expertise

Recommendations were related to the type of staffing available at facilities. Ombudsmen were mentioned as a recommended resource for patient advocacy in complex situations (e.g. family involvement). Several DONs also mentioned potential benefits of having expert behavioural health staff – in addition to social work – readily available, particularly consent issues (e.g. #014 'A psychiatrist or psychologist, just to come up with capacity'). Notably, one DON (#008) who felt sexual expression was being addressed well in her facility mentioned excellent behavioural health staff as a major part of that process. She stated: 'I think in issues like this it's a must, it's an absolute must, to have the psychologist and the medical director involved...you gotta have an expert.' However, other DONs indicated that a

psychologist and/or psychiatrist are not necessary if support for sexual expression and consent management were available to existing staff. One DON (#009) stated: 'I think a decent social worker in any facility that has a proper policy and proper training can do that.' This was a more common response among DONs as many operated in smaller- to moderate-sized facilities or remote areas with contract psychology services. As one DON (#002) stated: 'I have to contract with people that may or may not provide appropriate services anyway.'

Category 4: Provide education and training

This category was dominant among recommendations. All DONs reinforced the importance of ongoing sexuality education (e.g. #006 – 'Oh-ho yeah! Education, education. It's the biggest thing'). This coincided with challenges around negative attitudes of staff, family and administration towards sexual expression in LTC and a general lack of knowledge about sexual expression and consent among LTC staff. An education priority for DONs was increasing staff awareness of their own attitudes. One DON (#027) captured this by stating: 'I think the first thing is just an awareness and acceptance, and then education. If you have those three things, everything else falls into place.' Recommended education involved discussions with staff about their own values, emphasizing residents' rights and intimacy needs across the lifespan, and providing factual information about ageing sexuality (e.g. physical/emotional benefits, rise of sexually transmitted infections). Many DONs indicated comfort with discussing attitudes towards ageing sexuality with their staff; however, they consistently identified a need for education and training resources on sexual expression and consent from experts: 'I would need someone that is well-versed and educated to come in (#030).' This was further illustrated by one DON (#018) stating: 'We would need somebody to really help us process this and give us the tools and say what we're all going to do.'

Education/training was also recommended for administration and family. Most often, recommended content related to changing negative attitudes and emphasizing intimacy needs continue across the lifespan. For example, one DON (#006) stated she would tell family and administrators: 'These people are not dead...sexual feelings are still there.' Family member education was key, as one DON (#030) stated: 'Because if the families don't buy it, it's gonna fail miserably.'

Category 5: Assess sexuality initially and recurrently

Several DONs recommended formalizing sexual assessment processes in LTC, both at intake and recurrently to monitor resident needs and behaviours. For instance, one DON (#011) mentioned: 'I'd like to see more upfront discussion on admission or having it much more detailed by social work in their intake and ongoing counseling with the resident about the resident's feelings about these things.' This directly related to DONs' challenge with approaching complex situations of consent and sexual expression with little information about the residents' sexual needs, attitudes, and behaviours. Some also mentioned the importance of involving family in assessment at intake, and suggested it may reduce backlash from family if addressed up front. For example, one DON (#019) mentioned having a 'consent' form for family addressing resident sexuality at admission. Notably, there was an emphasis on supporting the patient and educating the family about residents' rights

and the role of the facility to act in the best interest of the resident. This was captured in a recommendation by one DON (#004) who stated: 'I think developing and really having the conversation when people are admitted that we support relationships and the continuation of those relationships.'

Category 6: Establish policies/procedures for sexual expression management

The majority of DONs reported lack of formal procedures or policies that addresses sexual expression management and consent, and very few felt confident in their 'informal' procedures. Several cited this as a barrier to effective management of sexual expression and compounding the difficulty of managing complex, sexual situations that often involve consent. A DON (#019) spoke about these challenges by stating: 'How do we, and when do we say enough is enough? Or what kind of presenting mechanism or measures should we have?...So those are the types of things that it kills us to deal with.'

Notably, a key challenge frequently cited by DONs was approaching sexual expression situations ad hoc, versus proactively. One DON (#004) indicated most are: 'waiting "till it actually catches fire"' and another (#019) suggested: 'A lot of times we are thrown into a situation...either sink or swim attitude, you know? I think we should be proactive and looking at healthy people's need.' Many recommended a centralized policy and/or set of procedures to guide sexual expression management and consent issues in LTC. Most often, this was suggested as a top-down strategy, with national organizations providing policy and support. One DON (#018) illustrated this by stating:

Somebody has to give me the process because we do everything from DPH [Department of Public Health] and CMS. They guide us in what we can do and care and everything. And from my knowledge, there's nothing about this. So we're on our own...But, we all keep saying 'why reinvent the wheel?'

Recommended components of policy to address sexual expression included: providing educational resources, being adaptable to individualized sexual situations, providing specific guidance for working with families, being integrated into care planning/documentation, and having more specific guidelines to assess sexual consent. For working with the family, this addressed a common challenge cited throughout the interviews. Specific procedures for negotiating this were recommended, as one DON (#018) stated:

We need a process with how to talk to the families. And even just some words, how do you talk about this with them? I mean that poor three to eleven supervisor that that makes that first phone call. What words is she saying to the family?

Category 7: Develop assessment tools for sexual expression and consent

There were several DONs that strongly recommended facilities adopt some form of structured tool or guidelines to assess sexual consent (e.g. #030 – 'It is imperative!'). This was directly linked to having few to no guidelines or tools at their facility to manage complex, sexual consent situations. One DON (#014) captured this by stating:

If one of them [resident] had memory issues, as a mild as it can be, that's where I would struggle. Where do I go with that and how do I do that? I'd like to have a

standard assessment to tell me, yes, this individual understand the risks or the benefits or probably does not.

This included a general lack of confidence in existing tools (e.g. cognitive screeners) to provide quality information in making difficult determinations about sexual expression. 'I'm not a big fan of the BIMS [Brief Interview for Mental Status]. I think nine times out of ten that doesn't tell me diddly. But it's the one the government says I have to use, so it's the one I use.' Even those DONs who were either positive or neutral towards using a cognitive screener to determine consent often recommended a more specific tool for sexual consent assessment, although they were unaware of existing tools specific to sexual consent (e.g. Lichthenberg & Strzepek 1990).

Among the recommendations for tools to guide the decision- making process, ease of use was repeatedly emphasized. Ease of use was defined by several elements: time efficient, usable by several levels of staff expertise, and that it should easily fit in a larger team discussion/process. Time was a key challenge for many DONs, as one (#020) recommended: 'A very simple thought process is what people are looking for. They don't have time to sit down and read four chapters.' Many DONs also reported that decisions about sexual expression would require a team discussion. Thus, a tool would need to facilitate the team in gathering evidence for guidance, as one DON (#022) illustrated: 'Yeah, you could weigh the issues, the evidence, and then make a team decision about it.'

This decision-tree tool was described as an 'if this, then do that' guideline, and likened to other tools available for suicide assessment, falls, and other issues. One DON (#030) labelled them 'idiot lists' and exclaimed that she 'loves them'. Several echoed this sentiment as they often help guide the decision-making process, make it more standardized, and provide evidence that the facility followed a valid process. They were often compared with a typical, paper-pencil assessment, which was frequently identified as rigid and not allowing for complexities inherent in these decisions. As one DON (#003) stated: 'One size doesn't fit all with situations like that. It has to be individualized.' Further, they indicated that traditional assessments may require expertise to administer and interpret that may not be readily available at every facility. One DON (#017) emphasized the need for use with staff, stating: 'I think to have something like that at the ground level for your direct care workers...So they could make some good, healthy decisions on the unit.'

Although they did not recommend a more formal, standardized assessment, they did emphasize the need for a valid, recognized tool to give 'credence' to their decisions. To illustrate, one DON (#030) stated: '...at least you'd have a piece of paper...saying, okay look, we did everything. We assessed this person, using the best form that's available out there...that should be safe for them.' Several who mentioned needing a recognized tool underscored the importance of national recognition or 'best practices' (#014) designations by governing organizations (e.g. #026 '...the regulatory bodies having that acceptance would be the one I'm looking for here.') The majority of DONs regarded this top-down dissemination as the gold standard for establishing practices.

Category 8: Clarify legal issues

Legal issues were emphasized throughout the interviews, with each DON making some reference to their importance. Most often legal issues were cited as a key challenge to managing sexual expression and navigating consent issues, and were related to facilities restricting sexual expression, ‘scrambling’ when sexual expression issues were presented, and following family wishes to regulate sexual expression (versus advocating for patients). One DON (#009) summed up the challenge of legal issues and fear of litigation as a motivator. ‘The majority of the people opposed [to sexual expression] are scrambling or are terrified because they are terrified of lawsuits.’ Consequently, the recommendations based on legal issues were often to have more specific legislation or improvements in existing laws that would provide guidance for sexuality in LTC. This was often tied directly to having policies for sexual expression and consent, which was captured by the same DON (#009) stating:

The policy would be better to be more specific, but to be specific we need to have a specific legislation when it comes to this. More specific law can address the inner policy. But the law is almost nonexistent, very generic, to say the least. Then the policy follows the same route.

When considering legal challenges, DONs also recommended the use of ombudsmen for patient advocacy and additional ‘backup’ to strengthen the evidence of their decision to allow or not allow the intimate activity.

And having them [ombudsman] understanding the situation and being there with us...the resident having an advocate in the conversation...it’s certainly the best way to go. Because then if it becomes an issue that the state wants to look at, we have a backing of a mutual person or a neutral person who has been aware of the situation throughout the course (#004).

Although policy and assessment recommendations by DONs were often aimed at addressing legal challenges, some remained sceptical policies would be able to keep facilities ‘safe’ from legal action. One DON (#009) citing legal challenges stated: ‘...you follow your policy, and you hear people commenting, ‘So what? You go in a court and the lawyer is going to throw your policy through the window and you’re going to get in trouble.’” This illustrates the importance of agreement between existing law and local policy when addressing sexual consent, and also highlights the need for improved laws to support. One DON (#013) discussed the importance of synchronicity between policy and law to support residents’ rights to sexual expression.

We have to realize that the residents that we have are our primary focus. Family is second. We have to stand our ground when it comes to what the residents wants versus what the family wants. And at facilities we have to have that ability to stand our ground. To know that, even if somebody took us to court, we have a better chance of winning because we are meeting the needs of the resident.

Discussion

The purpose of this study was to explore the challenges and recommendations of DONs related to managing sexual expression and consent with their older adult LTC residents. The results confirm previous findings that managing sexual expression and consent in LTC facilities is complex and challenging for LTC staff (Spector & Fremeth 1996, Villar *et al.* 2014, Wilkins 2015). As DONs contemplated what they would need to be successful in managing sexual expression and consent, they cited multiple challenges. Expanding on previous research (Hajjar & Kamel 2003, Villar *et al.* 2014), the challenges identified included: (a) the built environment in LTC (e.g. privacy, institutional quality); (b) protective/prohibitive attitudes of family and staff; (c) lack of knowledge and training resources for sexuality; (d) managing complex sexual situations (e.g. cognitively intact and impaired resident pairs); (e) determining consent and how that affects sexual and intimate expression; (f) stigma of addressing sexuality; (g) legal worries; and (h) an ad hoc vs. proactive approach to sexual expression management. These challenges were often exacerbated by the lack of structure and/or guidelines around sexual expression that have been reported previously (Lester *et al.* 2015, Roelofts *et al.* 2015), and which DONs acknowledged remains a key problem.

Despite numerous challenges identified, all DONs interviewed in this study were supportive of sexual expression, and they had many suggestions to successfully tackle these challenges, both locally and system-wide. First and foremost is the need to address sexual expression and consent openly in LTC, which has been largely ignored due to issues such as stigma and legal worries. This may be best facilitated by leaders of national organizations – such as NADONA/LTC, AMDA and CMS in the United States – putting this on their agenda. Although some organizations have begun address sexual expression in LTC (e.g. AMDA), many are behind the curve and lack a centralizing force. Acknowledging the widespread need by convening a national working group or task force of experts and stakeholders to discuss key issues is an initial step in addressing sexuality, with consideration of DONs' recommendations. Notably, a cohesive approach to sexual expression management has been attempted by individual homes (e.g. Hebrew Home at Riverdale) in the US, and there are various international models of sexual expression policies and procedures that can be consulted as well (Vancouver Coastal Health Authority [VCHA] 2009, International Longevity Centre – UK 2011, Bauer *et al.* 2014). By learning from and adapting existing successful processes, a working group could move towards creating best practices in this area and providing LTC facilities in the US with much-needed policy development and management tools to help guide sexual expression management.

In terms of tools, DONs have given specific recommendations for utility. Of primary importance was providing educational resources to facilities. This was frequently suggested to be compiled by those with expertise and integrated into programming required by governing organizations (e.g. CMS). Resources could include suggested environmental changes (e.g. do-not-disturb signs, wider/expandable beds), which were recommended by DONs for homes to be more conducive to intimacy. For policies, DONs often recommended that the policy or guidelines for sexual expression management be adaptable to the highly individualized situations that they encounter. However, they also requested specifics, such as

ways to discuss sexuality with family and functional assessment tools to help guide the team's process. One clear message about an assessment tool was its utility for the entire team and its ability to provide step-by-step guidance, especially when considering sexual consent. This may include multiple levels of assessment, beginning with entry-level staff who are likely to encounter the sexual situation first, the supervisor, the DON, the social worker, and the medical director. This is opposed to existing tools (e.g. cognitive screeners, psychological assessments such as Lichtenberg and Strzepek (1990) that require more 'expert' staff to use. A decisiontree or algorithm tool was most frequently cited as useful, in that it would be adaptable, could guide evidence gathering, and be a tool to unify a team discussion. Ease of use, including the ability to document and incorporate into a care plan, was perceived as important to the process. Another strong message was for guidelines to be valid or widely recognized to ensure they are following standard and/or best practices and provide evidence of that if they should be sued.

These could all be compiled into a 'tool kit' of educational resources, skill-building exercises, and policy and assessment guidelines that can be disseminated broadly. There are well-established methods for developing this type of resource, which have been rolled out internationally (e.g. VCHA, 2009) and also in the US to address other medical needs (e.g. AMDA, n.d.). Certainly it is integral to base any tools developed on the best evidence available, in conjunction with consulting experts and stakeholders who may have essential knowledge and resources to aid the process. A working group could then pilot and disseminate their findings, which is a potentially fundable initiative.

Limitations

This qualitative study allowed for description, but limited in ability to draw causal or predictive conclusions. Also, selection bias is present as this was a convenience sample of DONs, and participants may over-represent certain groups or characteristics (e.g. more engaged with sexual expression issues). The sample was primarily White women, although the nursing profession itself is predominantly White (83%) and female (93%) (Budden *et al.* 2013). The sample size was also a potential limitation, as only 20 individuals participated; however, 30 interviews were originally planned and reducing the number was based on discontinuing after achieving saturation. The recommendations identified may not represent the unique needs across LTC facilities in the United States, such as homes that exclusively provide care to a younger, rehabilitation population or other specialized care. However, the LTC facilities represented in this sample were diverse in geographical area, facility size, and populations served (e.g. individuals with dementia, individuals with HIV, temporary and long-term residents).

Conclusion

Sexual expression and consent among LTC residents can no longer be ignored. Not only due to the expected increase in residents from future generations, who consistently cite sexual well-being as integral to quality of life (American Association of Retired Persons, 2010), but also because it has recently received increased attention, professionally and publicly (e.g., Belluck, 2015). To illustrate, in the US the AMDA responded to media attention of sexual

incidences in LTC by conducting the aforementioned study on policies and procedures in LTC and have continued to highlight research in this area (AMDA, 2013; Lester *et al.* 2015).

This surge in attention can serve as a catalyst for change. Instead of putting out fires, a proactive, standardized approach to support facilities and residents in sexual expression can and needs to be implemented. Existing tools that take a fluid approach to sexual expression have been used successfully at a local level (River Spring Health 2011) and can serve as a basis for broader initiatives. More effort is needed to develop, test, and adopt similar guidelines and conduct trainings that are highly visible and accessible to all LTC facilities. Finally, the resident should not be forgotten. Inviting older adults and LTC residents who are willing and able to serve as stakeholders in this process is imperative. From development to implementation, it should be conducted with person-centred care in mind, to support the choice and autonomy of residents while minimizing potential harm.

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Appendix

Semi-structured interview protocol

Note: * marks the questions of focus for this study

Knowledge

- 1 What are some of the key issues you face when addressing sexual behaviors among older adult LTC residents?
Prompts included: staff, administration, families, residents
- 2 What is your understanding of sexual consent for older LTC residents?

Actions

- 3 Do you provide staff training and or educational support for sexual expression?
Prompts included: initial and/or ongoing, resources used
- 4 Do you have formal procedures for sexual expression management among residents?
Prompts included: initial/ongoing sexual assessment, strategies/skills, ever updated, informal policy/usual practice

- 5 Do you have training, policy, procedures specifically addressing sexual consent, or sexual decision-making?

Prompts included: general decision-making assessment, informal policy/usual practice, staff/specialists available

Attitudes

- 6 How would you describe the general attitudes towards sexuality and intimacy among your residents at your facility?

Prompts included: staff, administration, family, residents; methods for addressing

Challenges and Recommendations*

- 7 I would like to hear your thoughts about the potential barriers to being able to address sexuality in long-term care in a way that supports the organization, the staff and the residents.

Prompts included: staff/family/organization attitudes; knowledge of sexual expression; existing strategies to manage sexual expression; sexual consent; strengths of facility

- 8 I would like to hear more about what you think can be done to improve our ability to address sexuality in LTC, and specifically how we can better address sexual consent capacity.

Prompts included: resources needed; tools needed; policy suggestions; 'wish list' items

Why is this research needed?

- Supporting sexual expression in long-term care is a difficult task for many nursing homes. Unfortunately, this often results in prohibitive practices wherein long-term care residents' sexual rights and needs remain unaddressed.
- There is little to no guidance available for those wanting assistance with person-centred approaches to sexual expression among residents, as few policies exist.
- To develop policies that are usable in a long-term care setting, an integral perspective to consult is nursing home staff and administration.

What are the key findings?

- Directors of Nursing want sexual expression addressed from the top-down, with national organizations taking the initiative to provide resources, training and policy that conform to regulatory standards.
- Traditional paper-pencil assessments for sexual consent are not recommended. Instead, a decision-tree tool/process that is usable across staff levels and is conducive to team decision-making should be developed.
- Legal issues are most challenging and any policy moving forward needs to address potential legal problems to support nursing homes in person-centred approaches to sexual expression management.

How should the findings be used to influence policy/practice/research/education?

- Residents' sexual rights can and should be seen as important by nursing homes.
- Sexuality should be openly addressed across long-term care facilities via education and training that is disseminated from the top-down.
- Stakeholders should advocate for more specific legislation for sexual consent among older adults as its ambiguity presents a challenge for policy development.