

SUPPORTING SEX AND INTIMACY UNTIL THE END OF LIFE FOR OLDER ADULTS LIVING WITH DEMENTIA

Alisa Grigorovich, PhD^{1,2} and Pia Kontos, PhD^{2,3}

¹Recreation and Leisure Studies, Brock University, St Catharines, ON, Canada

²KITE Research Institute, Toronto Rehabilitation Institute – University Health Network, Toronto, ON, Canada;

³Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada



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Background

- The sexual rights of persons living with dementia in long-term care homes (e.g. aged care homes) are largely unsupported.
- Most research in this area has focused on micro-level factors, and in particular, professionals' perceptions and practices.
- Limited attention to macro-level factors (e.g. cultural norms, legislation, professional education/standards), or the interrelationship between these and individuals' perceptions and responses, which limits our understanding of how to better support sexual expression and intimacy in this setting.

Methodology

- An exploratory qualitative research study:
 - 27 participants: 21 professionals, 3 persons living with dementia and 3 family members.
- Combination of focus groups and interviews:
 - 12 professionals participated in a focus group, and interviews were conducted with a subgroup (n=7) + 9 professionals who were unavailable to participate in a focus group.
 - The same guide was used for the focus groups and interviews.
 - A series of stock images of diverse examples of intimacy and sexual expression were also used to prompt discussion.
- Drawing on a human rights approach, and analyses of public policies and professional standards with respect to sexual expression in long-term care in Ontario (Grigorovich & Kontos, 2018, 2019, 2020), all data was analyzed thematically (Braun & Clarke, 2005).

Findings

1. It's natural but prohibited
2. Dementia and being old: The double stigma
3. Discomfort, fear, and anxiety

It's natural but prohibited

I think ... as somebody ages, they don't lose that need for sexual expression and intimacy ... it's natural, it's part of being a human.

Oh, definitely. I think it's a part of everybody's life. At least intimacy ... I think it's very important because some people have these notions that once you're about 50 or past that, you're going down in the grave – and you're not.

It's natural but prohibited

What you often find is that what people perceive as normal sexual activity is much less likely to be perceived as inappropriate ... it's not going to be interfered with. A very good example of that would be, say, a wife who lives in a long-term care home, who has Alzheimer's, doesn't recognize anybody at all. Husband comes in on Sunday afternoons, closes the door, and everyone knows they're having sex in there. It's like, well, the husband, so I guess it's okay ... On the other hand, if it's ... outside of the norm, so it could be like anal sex, or gay sex, or something ... those activities are much more likely to be perceived as inappropriate for older persons living in ... long-term care.

It's natural but prohibited

[W]e're going to stop everything. I mean this is ... common practice ... I think there's a big difference between penetrative intercourse and handholding [but] if they're not married [to each other] then [we even] separate hands.

It's natural but prohibited

They wouldn't allow it....Because I worked in dementia care I know...it is very much tabooed ... and it should not be ... Because they still have feelings and they ... still need that connection.

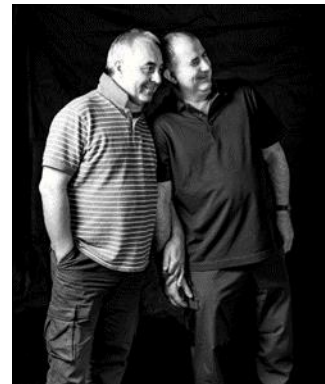
[I]n her long term [care home] everybody's like all separated and disconnect[ed] and I think it's something to do, I don't know, with staff or maybe it's at her floor because her floor is more designed for people with dementia ... I think the environment is awful there. The physical environment design is like a hospital ... if I'm in a hospital environment I don't think of sexuality or intimacy ... whereas if the environment was inviting, cheerful, that would create a different mood in the residents.

Dementia and being old: The double stigma

I live alone. I'm a widow, so I'm on my own. But [intimacy and sexual expression] it's still something that I think about, you know. I would like to have a companion, I would like to meet somebody. People around me discourage it. They think it's very risky, that I could get taken advantage of and, you know, that it's not – I've had someone say to me, "Well, it's not fair to have a relationship with somebody with your diagnosis, because they start to care for you and your disease progresses and that's not fair. You shouldn't do that to anyone." So, I really struggle with ... you know, I'm still a human being and I'm still very much alive...and, just because I have dementia doesn't mean that I still don't have that need and desire.

Dementia and being old: The double stigma

I can't help but when I look at these pictures I think about how these different kinds of touch would be interpreted in the environment of long-term care...it just seems so natural and normal that people should interact in this way [but it] gets twisted or pathologized.



Dementia and being old: The double stigma

*[S]he wants to ... do it [masturbate] like on her own and in her room ... it's becoming often in the day... **I don't know how you would define a normal frequency in masturbation ... Almost to a point where it would keep her up at night ... even though she's ... 75 or 80 years old ... I just don't expect [someone] at that age will still do that ... our main concern was around like interfering with sleep... like she doesn't sleep at night at times, because she's doing it and sometimes she doesn't want to eat, because she's doing it. So that's the problem ... we were looking [at] medications [for] dampening her sex drive... We worry about people being grumpy and irritable and then more **uncooperative with the care** that the nurses and staff need to provide."***

Dementia and being old: The double stigma

I think it's lumped in with behaviours because there's kind of a trigger for it. There's a need that's not being addressed and therefore it comes up as behaviour.

Never mind the stigma of dementia, there's also just the simple stigma of being old. And I'll confess that for most of my life the thought of my parents having sex ... was something that I was never going to want to contemplate let alone have a conversation about with them.

Discomfort, fear, and anxiety

I think it's just sort of all the morality, you know, the morality and the sort of ethical sort of dilemmas that come up around sexuality. People have a lot of very strong opinions, sometimes rooted in religion or culture or upbringing, that really influence the way that we think about things like that.

Discomfort, fear, and anxiety

[There was] this woman who comes to visit her mother at the nursing home and is astonished to discover at 8:00 in the morning that there's a man in her mother's bed, and her astonishment and dismay is in part because mother's husband, her father, is alive and well and living in the community and here's another man. This woman goes ballistic in the nursing home and starts screaming at people, "How can you let my mother lie in bed with that guy?" [and] saying her mother got raped.

Discomfort, fear, and anxiety

He developed a relationship with another female resident within the home that did develop into a sexual relationship; and this was reported ... and the wife was okay with it ... she was completely fine with the relationship proceeding but ... the staff ... wasn't able to kind of get over that barrier. So, they were constantly trying to redirect the resident away from this female resident and interrupting their intimate moments together and reminding him that he had a wife.

Discomfort, fear, and anxiety

I think we're all primarily concerned about whether we're meeting our responsibilities in caring for our [residents] and maybe in terms of the legalities of it ... What are the risks legally, for us as [an organization] and as an individual care professional? Because I mean there are high profile legal cases around sexuality and dementia ... you assume it would never get to that, but there's always the possibility. So, no one wants to be in that situation.

Discussion

- Consensus that intimacy and sexual expression are aspects that are important to the wellbeing and quality of life of persons living with dementia in long-term care homes.
- Despite this, intimacy and sexual expression were restricted rather than supported in practice. This was particularly so in relation to intimacy and sexual expression outside of a married heterosexual couple.
- Micro-level barriers to support of intimacy and sexual expression:
 - Fear of being perceived as failing to prevent sexual abuse.
 - Perception that cognitive impairment erodes all capacity for decision-making and intentional self-expression, and thus all intimacy/sexual expression is pathological.

Discussion – continued

- Macro-level barriers to support of intimacy and sexual expression:
 - Cultural imaginary of persons living with dementia as being incapable of purposeful and meaningful communication and the pursuit of life-enhancing relationships and activities.
 - Professional curriculum that links sexual expression in the context of dementia to pathology.
 - Professional standards and legislation that exclusively focus on prevention of sexual abuse; neglect of the duty to support safe and healthy intimacy and sexual expression.

THANK YOU! QUESTIONS?

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Contact:

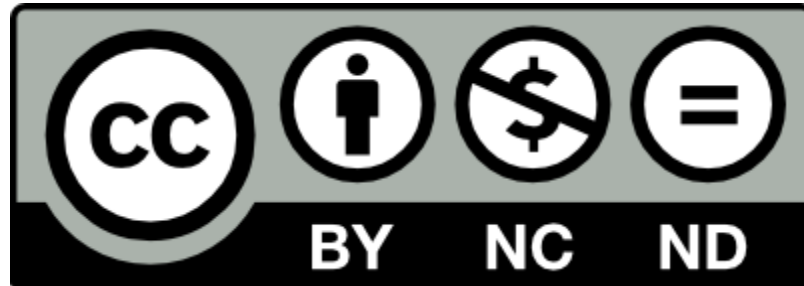


agrigorovich@brocku.ca
pia.kontos@uhn.ca



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