

A new way to think about dementia and sex

July 5 2017, by Alisa Grigorovich And Pia Kontos



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Persons living with dementia don't have sex. Or they have weird sex. Or they have dangerous sex, in need of containment.

When it comes to dementia and sexuality, negative language and apocalyptic warnings abound. The aging population has been described



in the media as a "<u>rape case time-bomb</u>." Health practitioners often respond in punishing ways to sexual activity in <u>residential care</u>. And the sexual rights of persons living with dementia are largely ignored within residential care policy, professional training and clinical guidelines.

As critical social researchers, we argue that <u>a new ethic of dementia care</u> is urgently needed, one that <u>supports the facilitation of sexual expression</u>

Our research at the University of Toronto and the Toronto Rehabilitation Institute-University Health Network investigates embodiment, relationality, ethics and dementia. We are motivated by a shared concern about the reductive focus of dementia care on basic physical needs, and our desire to foster a more humane and life-enriching culture of care. We have explored how the sexualities of persons living with dementia are poorly supported in long-term residential care settings such as nursing homes.

Sex and dementia in the media

When we see persons living with dementia and sex linked in the media, it tends to be in high profile cases of alleged abuse. One example is the <u>legal trial of Henry Rayhons</u>, an Iowa lawmaker found not guilty of sexually abusing his wife who at the time was living with dementia in a nursing home. Another example is the wider <u>investigation into sexual</u> <u>assaults in nursing homes</u> in Ontario.

Vital as such investigations are to the safety of residents in long-term care, we rarely see sexual <u>expression</u> valued or as <u>fundamental to human</u> <u>flourishing</u>.

Our research has explored how these negative representations of the sexualities of persons living with dementia are also found within long-



term residential care settings such as nursing homes.

Practitioners and administrators often hold negative and judgmental attitudes about dementia and aged sexuality. When faced with <u>sexual</u> <u>activity</u>, they can intervene in threatening and punishing ways. And long-term care policies, professional training and clinical guidelines tend to ignore the sexual rights of persons with dementia.

The problem with biomedical ethics

The sexualities of persons living with dementia are considered troubling partly because long-term care polices are shaped by <u>biomedical ethics</u>. This ethical approach relies on four core principles: autonomy, beneficence, non-maleficence and justice. These principles support intervening in residents' sexual expression if it will cause harm to themselves or cause harm or offence to others.

However, this approach sets the bar for practitioners' interference excessively high. It can restrict voluntary sexual expression by residents living with dementia in nursing homes.

Biomedical ethics also ignore the performative, embodied and relational aspects of ethical reasoning. It assumes that people are rational autonomous beings. It also assumes that self-expression, including sexuality, results only from cognitive and reflective decision making. Given that dementia involves progressive cognitive impairment, persons living with dementia may be unfairly discriminated against by this approach to sexual decision making.

A duty to support sexual expression

We use a model of relational citizenship to create an alternative ethic in



which sexuality is seen as embodied self-expression. It is an ethic that recognizes human beings as embodied and embedded in a lifeworld. And one that views sexuality as an important part of being human.

This new ethic broadens the goals of <u>dementia care</u>. No longer do health professionals just have the duty to protect persons with dementia from harm. There is also a duty to support their right to sexual expression.

We argue that institutional policies, structures and practices must also support sexual expression. These should facilitate sexual rights. We must also introduce education for health professionals and the broader public —and policy initiatives to counteract the stigma associated with sexuality and <u>dementia</u>.

Social and leisure activities that are supportive of sexual expression and the development of intimate relationships are also essential within <u>nursing homes</u>.

Of course, protection from unwanted contact or sexual harm is still important. However, freedom of sexual expression should only be restricted when necessary to protect the health and safety of the individuals involved.

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