LOVE

THE LAST CHAPTER

DISCUSSION GUIDE FOR PROFESSIONAL FRONT-LINE CAREGIVERS

Overseen by: Dr. Theodore D. Cosco, PhD, Assistant Professor and Undergraduate Program Chair, Department of Gerontology, Simon Fraser University
Written by Student: Lucy Kervin
In Consultation with: Arianna Mailloux, Registered Practical Nurse, Care Manager
Written to accompany the feature-length version of "Love: The Last Chapter" (2021, Keller Media and the National Film Board of Canada).

INTRODUCTION

Healthy ageing means more than the absence of sickness or disease but involves the promotion of mental, physical and social aspects of well-being (WHO, 2020a). Taking this comprehensive view of healthy aging recognizes that sexuality and emotional and physical intimacy are important factors contributing to our self-worth and quality of life from the younger to later years of life. For many people, however, these factors may be overlooked or avoided as they grow older, even though age, disease, and physical and psychological decline don't necessarily reduce our desire or ability to be intimate or engage in sexual expression (Taylor & Gosney, 2011). This kind of challenge may be particularly common for people as they enter a long-term care or assisted living residence and a part of their lives that was once private and personal (their sexuality and sexual expression) must now be addressed in a less private environment. The complicated topic of older adult sexuality and intimacy in long-term care settings is further complicated by the varying attitudes of family members, residents and staff. Although some health authorities and residential care organizations have developed guidelines and policies regarding sexual behaviour and intimacy for care facilities, many care staff do not receive education or training on how to respond to resident sexual expression in care homes (Bauer et al., 2009). As a result of inadequate training, frontline care staff responses to sexual expression can be impacted by inaccurate and/or negative beliefs, values, and biases, and lead to outcomes that harm residents, frustrate care workers and family members, and damage relationships (Schwinn & Dinkel, 2015).

Learning about later-in-life intimacy and sexuality in care settings is very important to ensure the best care possible is provided to older residents. Research suggests that providing frontline care professionals with training about later-in-life intimacy and sexual expression can improve their response to sexual and intimate behaviours in the care setting, and reduce the likelihood that they will hold negative attitudes about this topic (Bauer et al., 2013). While not all older adults will want to maintain sexual or intimate relationships after they transition into long-term care or other care facilities for older adults, these institutions and frontline caregivers have a responsibility to respond to resident sexuality and intimacy in a way that is consistent and respectful of the rights and needs of both older residents and staff (Lichtenberg, 2014).

The documentary '**Love: The Last Chapter**' provides important insights into how older adults encounter and navigate challenges regarding their intimate relationships in the long-term care and retirement setting, including challenges that result from the actions and attitudes of care staff and family members, as well as organizational policies. As you watch the film, think about the care organization you are affiliated with and how older adult residents may come up against similar challenges.

SOCIAL EXCLUSION AND THE MEDICALIZATION OF SEXUALITY

Sexuality and intimacy have many dimensions and meanings to different people from romance, companionship and relationships to sensuality, sex, sexual identity, sexual orientation, and more. However, when we think about sexuality there is often a strong focus on sexual function, performance, and intercourse as being the 'gold standards' of sexual expression. Emphasis on sexual dysfunction both inside and outside of healthcare settings is a feature of what is known as the **medicalization of sexuality** (Štulhofer, 2015). From this perspective, the loss of sexual desire or function, at any age, is considered 'abnormal' and requiring medical treatment. Perspectives like this contribute to negative and inaccurate beliefs i.e. due to physical disabilities and age-related decline, older adults are 'sexless', and therefore, sexuality and intimacy are irrelevant for them (Marshall, 2012). Although physical function can be an important part of intimate relationships, focusing only on physical sexual function neglects the wide range of other forms that sexual expression may take across a lifespan. Taking a 'one size fits all' approach to sexuality may **exclude** older adults from engaging in an important part of social life and discourage them from having relationships that can promote improved quality of life and well-being. It also may keep them from asking their healthcare providers questions about their sexual health (Gewirtz-Meydan et al., 2018).

INTIMACY AT THE END-OF-LIFE AND PALLIATIVE CARE

Palliative care is defined as, "an approach that improves the quality of life of patients and their families experiencing life-limiting illness…(palliative care) aims to prevent and relieve suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual, and is designed to offer support to patients to help them live as actively as possible until death" (WHO, 2020b). **Palliative approaches** to care not only treat physical symptoms, but also involve meeting practical and psychosocial needs and provide bereavement support, all in consideration of the individual's choices and desires. Supporting quality of life through **palliative care** may also involve helping patients to maintain sexual or intimate companionship (Redelman, 2008).

Even though sexuality has been recognized as an important part of the **palliative approach**, sexual and intimate needs are rarely assessed in **palliative care** environments or included in **palliative care** plans, and are frequently avoided as a topic of discussion by health practitioners (Hjalmarsson & Lindroth, 2020). This neglect might be due to sexuality and death being seen as 'incompatible' and due to the medicalization of sexuality mentioned earlier, which considers physical illness or decline to be associated with a loss of sexuality. In actuality, the experience of terminal illness does not automatically mean the need for intimacy and sexual expression disappear; sexual and intimate connection may be especially important for couples near the end of life, as it may contribute to the palliative patient's quality of life and strengthen their sense of self and/or bond with their partner (Hordern & Currow, 2003).

SEXUAL SELF-DETERMINATION AND PERSON-CENTRED CARE

Person-centred care refers to an approach to providing and planning care that is built around the unique and multi-dimensional needs of the individual. Rather than providing care based on what is most efficient or convenient for staff, a person-centred approach to care looks to the 'selfhood' of the person receiving the care, including their values, beliefs, goals, desires, and so on (Ekman et al., 2011). **Self-determination**, defined as the ability to make personal choices and control one's own life freely, is one of the main principles of the **person-centred approach** to care. Promotion of self-determination in the care context extends beyond just the right to making one's own treatment decisions. It is particularly important for situations in which frontline caregivers, staff and/or family members' personal beliefs or attitudes may negatively influence their actions and responses, such as in the case of older adult sexual expression and intimacy (Syme, 2017).

Taking a **person-centred approach** to addressing older adult sexuality and intimacy in professional care settings acknowledges that older adults have a right to engage in sexual and intimate behaviours that are safe for themselves and others. Personal Support Workers, Health Aides, and caregivers working in long-term care and retirement communities with older adults have a key role to play in both assessing the capacity of older residents to safely and consensually participate in sexual and intimate relationships, and in creating a supportive environment and positive organizational culture in which older residents feel comfortable expressing themselves and voicing questions or concerns regarding their sexual health and relationships (Franowski & Clark, 2009).

QUESTIONS & ACTIVITIES

PRE-SCREENING QUESTIONS

1. Consider and describe your own thoughts on older adult intimacy within and beyond long-term care settings as you answer the following questions:
   a. In what sense do you think the expression of sexuality and intimacy is important for older people?
   b. In what ways do you believe there are positive links between health, well-being, and sexual expression for older people?
   c. How would you agree with the statement that most people as they age become less interested in sex or sexual expression?
   d. How do you think residents should be allowed to express their sexual needs in care homes?
   e. As a Personal Support Worker, Health Aide, and/or caregiver working in long-term care and retirement community, what do you think your role should be in allowing residents to express their sexuality?

2. How do you think older adult sexuality and intimacy are viewed within the organization(s) you are involved with? Think about and describe the perspectives you believe to be held by the following groups:
   a. Care home management
   b. Administrative staff
   c. Direct care staff
   d. Family members/informal caregivers
   e. Residents/care recipients

3. What is your opinion on the perspectives you've just described? How do you think they are accurate? Inaccurate? Consider this for all the groups identified above.

4. Thinking about the training and education you've received as a care worker, describe the training that pertains to older adult sexuality and intimacy in the following ways:
   a. How was the topic presented?
   b. Were psychosocial (i.e. related to emotional, psychological, and social functioning rather than physical functioning) components of sexuality included in the training?
   c. What was your opinion of the training/education? Do you think it was adequate? Accurate? Appropriate?
   d. Do you think there are ways that the training/educating of care professionals on older adult sexuality and intimacy can be improved? If yes, describe them.

POST-SCREENING QUESTIONS

1. After watching the documentary film "**Love: The Last Chapter**", revisit your responses to some of the earlier questions; has your perspective changed after witnessing the experiences of these older adults?
   a. In what sense do you think the expression of sexuality and intimacy is important for older people?
   b. In what ways do you believe there are positive links between health, wellbeing, and sexual expression for older people?
   c. How would you agree with the statement that most people as they age become less interested in sex or sexual expression?
   d. How do you think residents should be allowed to express their sexual needs in care homes?
   e. How do you think care homes should play a role in allowing residents to express their sexuality?

2. Think back to the training and educational experiences you described in pre-screening question number four. Has your opinion of the training/education changed through watching the film?
   a. Why or why not?
   b. Do you think there are ways that the training/educating of care professionals on older adult sexuality and intimacy can be improved? If yes, describe them.

SCENES FROM THE DOCUMENTARY FOR DISCUSSION

1. **"Love: The Last Chapter" Timecode Scene Select: 08:20 – 10:20**:
   Consider the circumstances of this older couple.Why do you think she's concerned about his relationship?
   a. Why do you think it was important for them to be together during this time?
   b. Do you think consideration and support for sexual and intimate companionship should be a part of end-of-life care? Why or why not?
   c. How might being able to live closely together at this stage affected the older adult's partner in his grieving process once she passed away?

2. **"Love: The Last Chapter" Timecode Scene Select: 42:25 – 45:00**
   Consider this intimate scene of the older adult couple.
   a. Both older adults are living with physical limitations. Do you think that these limitations make their intimate partnership less valid than couples who do not have physical limitations? Why or why not?
   b. Do you think these older adults would have been as comfortable being intimate when they were living in the long-term care residence as opposed to their own apartment? Why or why not?

3. **"Love: The Last Chapter" Timecode Scene Select: 27:45 – 28:54**
   Think about this scene when the woman's partner isn't allowed to go into her room to get her belongings. What do you think about this scene?
   a. Why do you think the care staff didn't allow the older adult to retrieve his partner's belongings for her while she was in the hospital?
   b. How do you think this may have made the older adults feel that their relationship wasn't recognized by the care staff?
   c. How do you think you would have felt and responded if you were one of the older adults in this couple?

ADDITIONAL READING

NON-ACADEMIC SOURCES

Abeykoon, H., & Lucyk, K. (2016, January, 26). *Sex and seniors: A perspective*. Canadian Public Health Association. **https://www.cpha.ca/sex-and-seniors-perspective**

American Psychological Association. (2008, September 2). *Aging & human sexuality resource guide*. **https://www.apa.org/pi/aging/resources/guides/sexuality**

Canadian Research Network for Care in the Community. (n.d.). *Keep on rockin': Sexuality and aging*. Ryerson University. **https://www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/SexualityandAgingInFocusDec09.pdf**

Clay, R. A. (2012, December). *Sex in long-term care*. American Psychological Association. **https://www.apa.org/monitor/2012/12/sex-long-term**

Manduca-Barone, A., Brassolotto, J., & Howard, L. (2021, May, 09). *Seniors have a right to express their sexuality in long-term care homes, but staff need guidance*. The Conversation. **https://www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/SexualityandAgingInFocusDec09.pdf**

Ontario Human Rights Commission. (n.d.). *Ageism and age discrimination (fact sheet)*. **http://www.ohrc.on.ca/en/ageism-and-age-discrimination-fact-sheet**

PalliAGED. (2021, June, 11). *Intimacy and sexuality*. **https://www.palliaged.com.au/tabid/5734/Default.aspx**

ACADEMIC SOURCES

Bauer, M., McAuliffe, L., & Nay, R. (2007). Sexuality, health care and the older person: An overview of the literature. *International Journal of Older People Nursing*, 2(1), 63-68.

Benoot, C., Enzlin, P., Peremans, L., & Bilsen, J. (2018). Addressing sexual issues in palliative care: A qualitative study on nurses' attitudes, roles and experiences. *Journal of Advanced Nursing*, *74*(7), 1583–1594. **https://doi.org/10.1111/jan.13572**

Malta, S., & Wallach, I. (2020). Sexuality and ageing in palliative care environments? Breaking the (triple) taboo. *Australasian Journal on Ageing, 39*(1), 71–73. **https://doi.org/10.1111/ajag.12744**

REFERENCES

Bauer, M., McAuliffe, L., Nay, R., & Chenco, C. (2013). Sexuality in older adults: Effectof an education intervention on attitudes and beliefs of residential aged care staff. *Educational Gerontology, 39*(2), 82-9 https://doi.org/10.1080/03601277.2012.682953

Bauer, M., Nay, R., & McAuliffe, L. (2009). Catering to love, sex, and intimacy in residential aged care: What information is provided to consumers? *Sexuality and Disability, 27*(1), 3–9. https://doi.org/10.1007/s11195-008-9106-8.

Doll, G. (2013). Sexuality in nursing homes: Practice and policy. *Journal of Gerontological Nursing, 39*(7), 30–39. https://doi.org/10.3928/00989134201304 18-01

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I. L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L.E., Rosén, H., Rydmark, M., & Sunnerhagen, K. S. (2011). Person-centered care-ready for prime time. *European Journal of Cardiovascular Nursing: journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology, 10*(4), 248–251. https://doi.org/10.1016/j.ejcnurse.2011.06.008

Frankowski, A. C., & Clark, L. J. (2009). Sexuality and intimacy in assisted living: Residents' perspectives and experiences. *Sexuality Research and Social Policy Journal of NSRC, 6*, 25-37. https://doi.org/10.1525/srsp.2009.6.4.25

Gewirtz-Meydan A., Hafford-Letchfield T., Benyamini Y., Phelan A., Jackson J., Ayalon L. (2018) Ageism and Sexuality. In: Ayalon L., Tesch-Römer C. (Eds.), *Contemporary Perspectives on Ageism. International Perspectives on Aging* (19 ed., pp. 149-162). Springer. https://doi.org/10.1007/978-3-319-73820-8_10

Hordern, A. J., & Currow, D. C. (2003). A patient-centred approach to sexuality in the face of life-limiting illness. *The Medical Journal of Australia, 179*(6), S8. https://doi.org/10.5694/j.1326-5377.2003.tb05567.x

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

Marshall, B. (2012). Medicalization and the refashioning of age-related limits on sexuality. *The Journal of Sex Research, 49*(4), 337-343. https://doi.org/10.1080/0224499.2011.644597

Redelman, M. J. (2008). Is there a place for sexuality in the holistic care of patients in the palliative care phase of Life? *American Journal of Hospice and Palliative Medicine, 25*(5), 366–371. https://doi.org/10.1177/1049909108318569

Schwinn, S., & Dinkel, S. (2015). Changing the culture of long-term care: Combating heterosexism. *The Online Journal of Issues is Nursing, 20*(2). https://doi.org/10.3912/OJIN.Vol20No02PPT03

Štulhofer, A. (2015). Medicalization of sexuality. In The International Encyclopedia of Human Sexuality (eds A. Bolin and P. Whelehan). https://doi.org/10.1002/9781118896877.wbiehs297

Syme, M. L. (2017). Supporting safe sexual and intimate expression among olderpeople in care homes. *Nursing Standard: Official Newspaper of the RoyalCollege of Nursing, 31*(52), 52-63. https://doi.org/10.7748/ns.2017e.10906

WHO. (2020a, Oct 26). *Ageing: Healthy ageing and functional ability.* World Health Organization. https://www.who.int/westernpacific/news/q-a-detail/ageing-healthy-ageing-and functional-ability

WHO. (2020b, Aug 5). *Palliative care.* World Health Organization.https://www.who.int/news-room/fact-sheets/detail/palliative-care

DISCUSSION SHEETS MADE POSSIBLE BY

Impact Producer: Jackie Garrow
Project Lead: Lindsay Fitzgerald
Academic Advisor: Dr. Theodore Cosco, Simon Fraser University
Reviewers: Dominique Keller and Kelly Fox
Copy Editor: Lindsay Fitzgerald

'Love: the Last Chapter' is an NFB and Keller Media Co-Production.

'Love: the Last Chapter' can be licensed for educational use through
National Film Board of Canada at:
info@nfb.ca

Community Screening Requests:
communityscreenings@nfb.ca

Overseen by: Dr. Theodore D. Cosco, PhD, Assistant Professor and Undergraduate Program Chair,
Department of Gerontology, Simon Fraser University
Written by Student: Lucy Kervin
In Consultation with: Arianna Mailloux, Registered Practical Nurse, Care Manager
**Written to accompany the feature-length version of "Love: The Last Chapter"
(2021, Keller Media and the National Film Board of Canada).**