Intimacy and Sexuality in Residential Aged Care Facilities

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Introduction

- Introduction
- Issues
- Research
- Responses
- Legal issues
- Conclusion
- Discussion
Intimacy, sexuality and dementia can raise complex and difficult issues

- What is intimacy? What is sexuality?
- What are the roles of intimacy and sexuality in our lives?
- What are our personal and social stereotypes of sex and older persons?
- What gender role stereotypes do we have?
Issues (cont’d)

– What is ‘competence’?
– What is sexual exploitation?
– What rights to privacy and pleasure do people have in various circumstances?
– What do we think of sex outside of marriage (especially when the marriage still exists)?
– What about same-sex and transgender sexuality?
• Issues (cont’d)
  – What do we think of masturbation? Pornography?
  – What do we think of paid sex work?
  – What do we believe about the right to intimacy and sexual activity of people with disabilities?
  – Do our private opinions differ from our professional/workplace policies and practices? How do we reconcile those differences?
• Our responses to these issues are profoundly informed by our individual, social and cultural experiences (including religious values)
• Can we separate the personal from the professional?
• Intimacy is a little less threatening than sex, but is often confused with it

• Sexuality “relates to the private dimension in which people live out their sexual, intimate and/or emotional desires”

(Dunk-West & Hatfford-Letchfield, 2011, p. 2)

– The place of sexuality is contested; some authors propose that this ‘private’ dimension must be understood in cultural and socio-political contexts as well as at the individual level
• The professional literature doesn’t define intimacy, but rather assumes a shared concept
  – Dictionary definitions include ‘closeness’, ‘familiarity’
  – Intimacy can be emotional or physical
  – ‘Intimacy’ is often conflated with ‘sexual behaviour’ as a euphemism
Sex is surrounded by an array of social and cultural constructions and taboos which change from culture to culture, and in any culture over time.

- We have learned
  
  “Sex is dirty, disgusting, and dangerous, and we should save it for the person we love!”
  
  (Parents everywhere)
Our first task, then, at this moment, is to become aware of the personal values and expectations we have about intimacy and sexuality, because we will bring them to discussions, trainings, client relationships, policies, etc.

- By being aware of them we can manage how our personal values influence our professional lives
- We can also help others (such as families) to manage their own values and expectations about their seniors
Some of the practical questions we face include
- Is intimacy a need, a right, or ‘just nice to have’?
- Are physical touch and sexual expressions needs, rights, or ‘just nice to have’?
- Do residents of aged care facilities (RACF) have the right to make their own decisions about intimate, romantic or sexual relationships?
- What is the role of families, including spouses who are not in care?
- Should RACF have on demand access to sexuopharmaceuticals?
- Should RACF provide access to sex workers?
• The population aged 65 years and over in Aotearoa New Zealand is expected to increase from 13% of the total population in 2009 to 21% by 2031

Ministry of Social Development/Te Manatu Whakahiato Ora, n.d.)

– Clearly the number of residents of RACF will also increase
• Take a moment to consider these questions:
  – Older people should face the fact that their sexual lives are finished
  – I cannot think of a way I could justify a person with dementia having sex
  – I would always agree with the opinions of family members about whether their elders should have sex
  – The question of providing access to sex workers for residents in care isn’t even worth thinking about
• We must be aware that most research in this area is international, and little has originated in NZ
  – For instance, while Māori are approximately 2% of RACF residents, there are far larger numbers in caregiver, nursing and managerial roles
  – Many caregiver staff are new settlers, bringing their own cultural and religious values to caregiving, sexuality and intimacy
• We must now to think through these issues carefully, ethically, legally and compassionately in an NZ context
There has been a quiet explosion of international research in intimacy, sexuality and dementia over the last four years.

- Let’s consider some of the key findings
There is a clear consensus that sexuality is an intrinsic part of human identity (Elias & Ryan 2011).

Intimacy and sexuality in aged care is a troubling, misunderstood and frequently contended issue (Bauer et al, 2013; Gilmer, 2010; Shuttleworth et al., 2010).
• There is no age limit on sexual responsiveness or the need for intimacy (Benbow & Beeston, 2012; Lindau, 2007)

• Sexuality and intimacy contribute to the quality of life of RACF residents, their families and carer (Benbow & Beeston, 2012)
  – Future cohorts will have even higher sustained interest in sex (Hillman, 2008)
  – Sexual minorities constitute a significant ‘invisible minority’ in RACF (Callan, in Elias & Ryan, 2011; Frankowski & Clark, 2009), and thus relationship and intimacy needs remain unknown and unacknowledged
Residents of RACF (in Australia; n=16) saw themselves as sexual beings, with a continuing need and desire to express their sexuality

(Bauer et al., 2013a)
• Sexuality in residents with dementia are a particular challenge since the ethical and legal expectation of consent can be difficult to ascertain (Ehrenfeld et al., 1999; Hajjar & Kamel, 2003)

• Reports of inappropriate sexual behaviour (ISB) vary between 1.8% and 17.5% of residents (Hayward et al., 2012)
  – This wide variation is attributed to the lack of definition and clarity around this issue
  – ISB is invariably subject to staff/reporter perceptions
Negotiating the sometimes competing interests of residents, staff, families and regulatory bodies (and public opinion) is not simple. In the absence of specific guidance staff will draw on their own values and experience (Elias & Ryan). Few of 198 RACF in NSW had policies or training programmes in place (Shuttleworth, 2010).
Staff attitudes towards sexual relations in RACF were characterised by ‘confusion and ignorance’ and residents were mistreated and humiliated around issues of sexuality (Tabak & Shemesh-Kigli, 2006).

Staff responses towards sexual relationship are characterised as ‘extremely cautionary’ and ‘patronising’ (Frankowski & Clark, 2009; Villar et al., 2014)

– Health providers don’t see supporting sexuality as part of their jobs.
• American studies have found negative attitudes in staff, including embarrassment, confusion and helplessness (DiNapoli et al., 2013)
  – Staff reactions to resident expressions of love and care were positive,
  – Reactions to romantic behaviour were mixed, and included humour and infantilising attitudes
  – Erotic behaviour aroused strong reactions of anger and resentment
    (Tabak & Shemesh-Kigli, 2006)
• Frankowski & Clark (2009) found:
  – RACF have minimal policies about sexuality
  – Facilities/Family compete with residents’ autonomy and privacy
  – Facility responses to sex and intimacy are context-related
  – Staff only deal with the issue of sex when they have to
  – Residents’ children are the primary consumers
The good news is staff education works! “[Workshop] Participants’ attitudes and beliefs towards older people expressing their sexuality in long-term care, including same sex couples and people with dementia, were more permissive following education” (Bauer et al., 2013b)
The ethics literature is broadly divided into (1) principles, and (2) care

- ‘Principles’ literature focuses on
  - Autonomy, informed consent, privacy
  - Beneficence, QOL
  - Nonmaleficence, duty to protect
  - Justice, anti-discrimination, anti-ageism
• Ethics (cont’d)
  – ‘Care’ literature focuses on
    • Care as ethical concept (care is rooted in the receptiveness, relatedness and responsiveness of the caregiver to the one cared for)
    • Holistic approach
    • Singularity (people are different), historicity (what is the context of the relationship), relationality and intersubjectivity (does the relationship depend on the vulnerability of one partner)

(Mahieu & Gastmans, 2012)
• **Summary:**
  – Sexuality and intimacy needs are real and an essential part of care
  – ISB is as much about staff perception as resident behaviour
  – Helping professions in general don’t do a very good job about attending to the sexuality of any of our clients
  – This issue is going to become even more important to address over the next few years
• Our responses need to fall into three general areas
  – Attitudes: We need to examine our personal and workplace attitudes about sex and ageing, sex and dementia
  – Caregiving: If we understand people as sexual beings with intimacy needs throughout their lives, then we need to find ways to support those needs throughout their lives in safe and compassionate ways
  – Institutional policies: We must adopt person-centred care, rather than institutional-convenience care
...We need to examine our personal and workplace attitudes about sex and ageing, sex and dementia

- We must start to think and talk about sex openly in healthy ways
  - We need to break open the silence and anxiety about sex that is supported by fear, judgment and disapproval
  - We must examine our own attitudes and test them against current research and knowledge
  - Sex can actually be pretty funny!
Examining attitudes (cont’d)

- We need to educate ourselves and our colleagues
  - Such education should be respectful, research-informed, and interdisciplinary
- We need to educate families and involve them in case planning
• ...We need to find ways to support those needs throughout their lives in safe and compassionate ways
• Revisit traditional legalistic and exclusively risk-management approaches to decision-making
• A salutogenic orientation builds on how older people naturally use their resources for health and wellbeing
  – Focuses on resilience and strengths, rather than deficits
  – People have been living with their sexuality longer than their dementia
A salutogenic approach must reconsider:

- Privacy
- Competence
- Access to trained sex workers
  - It is happening in Australia (Jeffreys 2008) and elsewhere
  - It is happening in NZ, although few agencies are talking openly about it
• *We must adopt person-centred care, rather than institutional-convenience care*

• Intimacy and sexuality are part of person-centred care
  • Do policies and practices around these issues support the resident? Or the facility convenience?
  • Do auditing standards merely manage risk or ensure the overall well-being of residents?
  • Are we simply managing demented residents until they die, or do we take a life-enhancing approach?
• Person-centred care (cont’d)
• There is no current consensus about when someone with dementia (or any cognitive disability) loses the right to decide about sex
  – There is an emerging consensus about the right to intimacy and a sexual life
• RACF need to address staff who treat residents like children, through language, manner, amusement
  – Policies and inservices should ensure staff respect all diversity groups: age, culture, sexual orientation, religion, (dis)ability, etc.
Legal issues are both clear/not clear

- A vulnerable adult is a person unable, by reason of detention, age, sickness, mental impairment, or any other cause, to withdraw himself or herself from the care or charge of another person.
- Health professionals have a duty of care to patients in their care or charge, and patients have a right to services that comply with legal/professional/ethical standards.
- There are legal, civil and professional consequences for negligence or misconduct (by commission or omission); includes sexual assault (Sec 195A).

*With thanks to Iris Reuvecamp*
• Liable persons under Sec 195A include
  – Reside in the same household as the victim or are a staff member of any hospital, institution or residence where the victim resides; and
  – Have frequent contact with the victim; and
  – Know that the victim is at risk; and
  – Fail to take reasonable steps to protect the victim from the risk

• This seems clear, but as we’ve seen, it can be very unclear
  – To what extent does someone have ‘diminished capacity’?
Conclusion

• This discussion is happening internationally
  • RACF and policymakers in New Zealand are not the first in the world to deal with these issues...
    – ...they also do not need to be the last
• Our responses can be three-fold:
  1. We need to examine our personal and professional attitudes about sex and ageing, and sex and dementia
  2. If we understand people as sexual beings throughout their lives, then we need to find ways to support their sexual and intimacy needs in safe and compassionate ways
  3. We must consider adopting person-centred care models, rather than institutional-convenience models of care
• Responses should be
  – Interdisciplinary
  – Iterative (gradual)
  – Generalisable to all populations and residential care facilities
    • There’s no reason these issues are limited to aged persons, but also include any dependent person of any age or (dis)ability

• It is good that we are engaging in the conversation
Thank you!


