

Intimacy and Sexuality in Residential Aged Care

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Goal

- The goal of this presentation is to encourage you to think about some of the ethical complexities of this issue, and to present some key issues and findings from a pilot study on intimacy and sexuality in residential aged care
 - It is *not* my goal to provide answers, but to invite you to think more about the questions

Questions

- What happens...
 - if a couple moves into a residential facility, but there are no shared rooms?
 - if a single woman with moderate cognitive decline initiates a relationship with another resident? What if the family wants staff to intervene?
 - if a widower asks to pay for the weekly visits of a sex worker?
 - if a resident who has always cross-dressed at home wants to continue the practice in residential care?
 - if a widower with children changes the expression of his sexuality and begins a relationship with another man?
 - if a resident living with HIV becomes sexually active with another resident?

WHO definition of sexuality

- “...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.” (WHO, 2006)

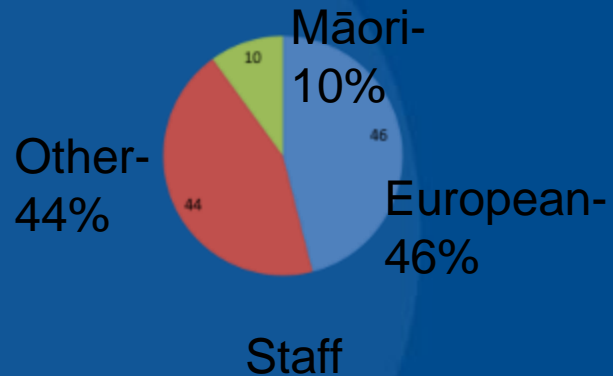
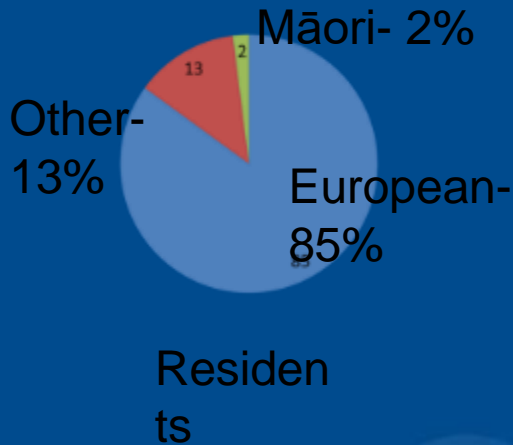
Background

- Even though intimacy and sexual is integral part of human identity (Elias & Ryan, 2011), intimacy and sexuality in aged care remains a troubling, misunderstood and frequently contentious issue (Bauer et al. 2013; Gilmer et al., 2010; Shuttleworth, et al. 2010)
 - 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
 - Our responses to these issues are profoundly informed by our individual, social and cultural experiences (including religious values)

- In other words, “ We don’t see things as they are, we see things as we are” (Anaïs Nin)

Background

- In NZ, 85% of residents are 'NZ-European' while 56% of care staff are other than NZ-Euro; this has the potential for conflicting values



Background

- 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

Background

- 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)
 - Thus their relationship and intimacy needs remain unknown and unacknowledged

Background

- Sexuality in residents with dementias is a particular challenge since the ethical and legal expectation of consent can be difficult to ascertain (Ehrenfeld et al., 1999; Hajjar & Kamel, 2003)
 - Negotiating sometimes competing interests of residents, staff, families and regulatory bodies is not simple
 - Decisions are usually made to manage risk, not to care for residents
- 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- staff rely on their own subjective interpretation

Background

- Staff attitudes towards sexual relations in RACF are characterised by ‘confusion and ignorance’ and residents 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

Background

- International 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)

Ethical issues

- 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)

Background

- In short, this is a fraught and complex area that many staff (particularly direct care staff) feel unprepared to talk about, and consequently institutions take a ‘risk management’ approach
 - Risk management is usually a very conservative approach
 - It ‘vulnerabilises’ residents and treats them as agents incompetent to make their own decisions

Legal issues

- ✓ Crimes Act (1961)
- ✓ Protection of Personal & Property Rights Act (1988)
- ✓ NZ Bill of Rights Act (1990)
- ✓ Human Rights Act (1993)
- ✓ Privacy Act (1993)
- ✓ Code of Health & Disability Services Consumers' Rights Regulation (Code of Rights) (1996)
- ✓ Common Law
- The legal environment can be conflicted and unclear

Ethical issues

- In April 2015, global media reported the case of a 78-year-old Iowa man, Henry Rayhons, who was charged with felony sexual abuse because he allegedly had sex with his wife, Donna
- Donna was in an RAC facility because of severe dementia, and had been judged by staff (at the request of Donna's daughter) to be incapable of consenting to sex
- Although Rayhons was found not guilty at trial, the fact that this arrest and trial took place is a clear signal of the confusion and public anxiety about the issue of sexuality and consent

Ethical issues

- The dominant position in the theoretical literature on the ethics of sex and intimacy is that consent is of fundamental importance
- In particular, there are three claims about sex and consent which describe the views most commonly argued in the literature
 - that non-consensual sex is morally wrong
 - that what makes it morally wrong is the fact that it is non-consensual
 - that in order to give morally valid consent, a person must meet standards of cognitive competence

Ethical issues

- The emerging concept of *sexual citizenship* argues for the rights of people living with dementia to maximise their autonomy, enfranchisement, belonging, equity, and justice, which then frames institutions' risk-aversion toward sexual expression as a violation of these rights
- The literature on citizenship redirects ethical attention from standardised assessments of an individual's global capacity to give consent and managing institutional risk, towards the facilitation of self-governance and overall wellbeing
- Vulnerabilisation of older persons in order to protect them, however well-intended, effectively robs them of possibilities to exercise self-governance, depersonalises them, and increases their social isolation

Ethical principles (Nursing)

- Beneficence
- Non-maleficence
- Veracity
- Advocacy
- Fidelity
- Justice
- Autonomy

Ethical Principles (Social Work)

- Treaty of Waitangi
- Human rights and human dignity
 - Self-determination, right to participation, integrity of the whole person, focus on strengths
- Social justice
 - challenging negative discrimination, recognising diversity, equitable distribution, challenging injustice, inclusiveness

Ethical approaches

- Become aware of and reflect on our own personal values and expectations of intimacy and sexuality
- Critically reflect on how personal values influence our professional lives, values and decisions
 - In becoming aware of and reflecting on our own values we make them available for inspection, make intentional decisions, and we can help others (e.g. colleagues, residents, families) reflect on their values and decisions

Ethical interventions

- When we intervene in residents' lives
 - The risk must be significant, and must be focussed on the person, not the institution
 - The intervention must be
 - Effective
 - Non-maleficent (does not generate greater harm)
 - Non-discriminatory
 - Justifiable
 - The mildest possible

(Everett, 2008)

Pilot study

- We carried out a first pilot study on intimacy and sexuality in one residential aged care facility
 - Two-arm mixed method study
 - Staff survey (quantitative)
 - Interviews with staff, residents and family members (qualitative)
 - A full human ethics review was undertaken, with a view to continuing it for a larger national study
- An expanded pilot at five facilities is now under way

Pilot study

- 14 of 30 staff participated in the 53 question survey (46.6%)
- Four interviews were carried out
 - 2 staff, one resident, one family member
- In this sense, the pilot proved that target participants would accept such a study and participate in it

Pilot study

- Great variation in quantitative data, with large standard deviations on most questions (suggests wide diversity of thinking)
- Staff support more education
 - “I would like to know more about change in sexual functioning in older years” $M=4.21$, $SD=1.188$ (range 1=disagree strongly to 5=agree strongly)
 - “I feel I know all I need to know about sexuality in older people” $M=3.07$, $SD=1.385$
 - “Staff of RACF should be trained about sexuality in older people” $M=4.14$, $SD=1.351$

Pilot study

- That staff want more education is excellent, because we know that 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., 2013)

Pilot study

- Interviews

- [Sex] does happen, I've seen it happen and nobody talks about it and as you say, we've got to make a judgement call which I have done on a few occasions and it's something that's to be brought up, especially with our generation coming up next which are more open to something the last generation... I think if they opened up a bit more there wouldn't be all this secrecy and whatever going over. (Staff)
- I think if I saw a bloke who was good looking and about fifty I'd go for him. Definitely. *While you were living here?* Yes. I'd get out...we should be able to get away. Yes, I'd have a bit of fun. Why not? (74 y.o. Resident)
- ...Being the daughter, I don't really want to reflect on it too long or too much. But he certainly was very tender with her, and was always stroking her arm and wanting to hold her hand, and would give her kisses on the cheek. He was very loving and very attentive. (Family member)

Pilot study

(Could you have a sexual relationship in this facility?)

- I think you could do what you wanted to do but within reason. I don't think they'd have any sleeping round going on in here. I haven't tried it so I can't tell you [laughs]. (Resident)
- Oh definitely, no. Couldn't do anything here because if the door opened and somebody like [manager] walked in I'd be mortified. There are no locks on the door, as you notice, and the old dear next door is really deaf so she doesn't know if I'm in the [shared] toilet or not and she just swings open the door and says, "oh, sorry". So there really is no privacy here at all I don't feel like I'm home. (Resident)
- When we go into the room we always knock and then tend to open the door. I suppose we should wait for – but sometimes I don't always hear it and I remember going in, because he's on injections as well, going in, and he quickly closed the laptop. (Staff)

Pilot study

- I'd hate anybody to come [to me in my life] and say "Hey, you can't do that". So I've been very liberal in that area Not all caregivers are as liberal as what I am but I'm just a free spirit and I believe everybody should live the most well as they are able to and enjoy the pleasures of life that are offered Everybody has the right to explore their own life story, journey... (Staff)
- [Healthcare assistants] will be coming from... different cultures so it's a matter of being able to freely discuss [ideas] as opposed to just putting your point of view, to say, "this is what we think and this is what we would like to see happening"... I've worked at [prison] for fifteen years, I learned a hell of a lot there. Caregivers will be coming from quite a different perspective and may feel quite uncomfortable so it's about perhaps talking about it [sexuality] openly, respecting that each is different and what's best for the resident to make them feel comfortable because it's about the resident being comfortable as much as the health care assistant or whoever is supporting them. (Staff nurse)

Conclusions-1

- Sexuality & intimacy needs are a real and ethical part of care
- ‘Inappropriate’ sexual behaviour – inappropriate to whom?
- Staff benefit from education and flexible policies
- Adult children not always ideal proxy decision-makers
- Staff must differentiate own personal values and residents’ rights
- Decisions must be based on personal reflection, professional ethics, and law
- Person-centred care (rather than institutional-convenience care) is the best approach (Henrickson & Fouché, 2017)

Conclusions-2

- Responses to sexuality and intimacy should be
 - Interdisciplinary and consultative
 - Iterative (gradual)
 - Generalisable to all populations and residential care facilities
 - These issues are not 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!

