Ethical challenges in upholding sexual citizenship & a duty of care

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I acknowledge the many cultures
the prestige all here
the leaders among us
greetings to each of you
welcome to you all
I welcome you all twice
I welcome us all thrice
my past research: ageing & invisibility

- omission from STI prevention programmes
- stereotyping – sexually inactive
- delay from symptoms to consultation
- difficulty initiating questions
- increased risk of complications
- continued transmission to partners
Humanising living arrangements for older people to diminish loneliness & to enhance relationships, connections, dignity & reasons to live

elder justice
empowerment + duty of care

wellbeing
diversity
proxy decision-makers

ageism
consent
ethics
law
consent
rights
advocacy

‘then’ self & ‘now’ self

paternalism

proxy decision-makers

consent
risks
law

A nursing home should be a residence in which healthcare functions form the background rather than the foreground of the experience of daily life. In this home, encouraging relationships and providing privacy for sexual intimacy...are about allowing a profoundly human need to be met. The disabbling loneliness of nursing home residents is partly constructed by policies that diminish relationships (p.41)


social death or social citizenship?

- social death - people considered unworthy of social participation & deemed to be dead when they are alive.
- if carers believe that people are socially alive, what difference does this make to care? (Brannelly, 2011)
Grey area: The fragile frontier of dementia, intimacy and sexual consent

What happens when seniors who can’t recognize their own kids try to navigate the hazards of physical intimacy with one another? Zoëia Bick looks at the challenges for elderly people, nursing homes and families.

ZOÉIA BICK
Published 2017-11-21, 2015

Marjorie Drennan, 90, and her 65-year-old grandson Jayson Drennan, at Brookside Care Community in Chicago, Ill. Their relationship came as a shock to their families, though staff would rather have children be told than leave them in the dark about what was going on between the pair.

[YouTube video link]
Senior judge says it is 'inhumane' to separate elderly couples going into care

Sir James Munby says social workers should show 'common decency' in keeping couples together

Iowa Man Found Not Guilty of Sexually Abusing Wife With Alzheimer's

Henry Rayhons after his acquittal Wednesday on charges of sexually abusing his wife, who had Alzheimer's disease. Brian M. Higginbotham/Des Moines Register, via Associated Press
what is intimacy?
WHO (2006) definition of sexuality

We don’t see things as they are, we see them as we are

Anaïs Nin
motherwit & the golden rule

New Zealand residents’ ethnicities

- NZ Euro/Pākehā: 85%
- Māori: 2%
- Other: 13%

Total: 4.7 million
New Zealand RAC staff ethnicities

- Māori: 10
- NZ Euro/Pākehā: 44
- Other: 46
- Total: 4.7 million

discourses & sexuality in older people

What are the taken-for-granted societal stories that circulate about intimacy, sexuality, relationship needs & ageing?

What are the effects of these stories?

discourses – ‘it’s complicated’

https://www.youtube.com/watch?v=n_KCKGUAKEw
discourses about ageing & sexuality
*Curmudgeons* directed by Danny De Vito
Hebrew Home for the Aged

https://vimeo.com/77166281

New York Times 12/7/16

http://www.programsforelderly.com/documentaries-gay.php
Marriage Amendment Act
2013
Prostitution Reform Act
2003
Homosexual Law Reform Act
1986
Marital rape became a crime
1985
legislation

- Human Rights Act 1993
  - The right to freedom of expression
  - The right to religious belief
  - The right to freedom of movement
  - The right to be free from discrimination

- Crimes Act (1961) Crimes Amendment Act (No.3) 2011
  - S151 Duty to provide necessaries & protect from injury
- Protection of Personal & Property Rights Act (1988)
- NZ Bill of Rights Act (1990)
- Privacy Act (1993)
Health & Disability Services (General)  
Standard 8134.1.2008

- 1.3 Consumers are treated with respect & receive services in a manner that has regard for their dignity, privacy & independence.
- 1.3.1 The service respects the physical, visual, auditory & personal privacy of the consumer & their belongings at all times. (MoH)
- G1.3.5 Sexual health information is readily available.
- 1.3.5 Consumers’ intimacy and sexuality are supported in a manner that ensures the rights of the individual are protected & intervention only occurs to maintain balance between personal rights and/or wellbeing of the consumer and those of others.

What does obtaining informed consent mean?  
A competent person making a voluntary choice about information communicated effectively which is sufficient to make an informed decision.
...but people with diminished competence retain the right to make informed choices to extent appropriate to level of competence...

......I don’t need to be able to count backward from 100 by sevens to know Miss Piggy is hot!
POLICIES AND PROCEDURES
CONCERNING SEXUAL EXPRESSION
AT THE
HEBREW HOME AT RIVERDALE

Supporting Sexual Health and Intimacy in Care Facilities: Guidelines for Supporting Adults Living in Long-Term Care Facilities and Group Homes in British Columbia, Canada

Vancouver Coastal Health Authority,
July 16, 2009

SUPPORTING SEXUAL HEALTH AND INTIMACY IN CARE FACILITIES: A POCKET REFERENCE GUIDE
May 2013

content analysis: themes
duty of care
respect, diversity & dignity
well-being
narrative approaches
rights
sexual consent capacity

- basic sexual knowledge
- understand possible consequences to self & others
- understand appropriate locations & times
- express personal choice & resist coercion
- recognise distress/refusal in partner & stop

intervention in residents’ sexual activity

- risk must be significant
  - interference must be:
    - effective
    - not generative of other/greater harm
    - mildest possible
    - not discriminatory
    - thought justifiable


no policy?

- risk aversion – misuse of notion of duty-of-care violates people’s rights
- situations seen as crises = ad hoc processes in too-hard basket
- hide away from realities
- see a policy as dangerous precedent
- No guidance for proxy decision makers – blended family & family dynamics
best practices

- clear policy & protocols based on legal & ethical considerations & commitment to elder justice
- bringing policy to life – early discussion with potential residents & families
- role-modelling & leadership from the top down
- no room for shaming
- care team planning
- clear plan for implementation: includes staff education & case consultation processes

these steps keep us from the ethical quagmire

Staff education works!

Workshop participants’ attitudes & beliefs towards older people’s expressions of sexuality in long-term care, including same sex couples & people with dementia, were more open & supportive following education (Bauer et al., 2013b)
pilot study key qualitative results

1. mediated intimate relationships & everyday ethics in RAC
2. self-referential morality
3. knowing the person then and now
4. juggling ethical priorities

mediated relationships
We had one married couple in particular, the health care workers would go into their room and they’d be laying on the bed and all she had was her continence pants on and a frilly apron and he’d be naked. It was sort of like staffroom talk and they used to sort of laugh and snigger and stuff like that and I guess talking about it – and I actually did use them as an example – that it is not staffroom joke kind of stuff. But maybe that would have been a way of them dealing with it as well. Sort of overcoming their own embarrassment. So okay, be prepared for it, you know this is going to happen...

(RAC manager)
In my opinion it is really not appropriate to have a sexual relationship in any kind of facilities – dementia, rest homes or hospital, because there is no privacy in this area. Even if they put some room for this kind of thing, it is still not appropriate; it’s embarrassing to some people (caregiver, residential aged care).
knowing the person then & now

juggling ethical priorities
sexuality & intimacy needs = real & ethical part of care
‘inappropriate’ sexual behaviour - whose perception?
everyone benefits from education & flexible policies
adult children not always ideal proxy decision-makers
decisions based on care ethics, narrative ethics, biomedical ethics & law
staff must differentiate own personal morals & residents’ rights
over-emphasis on risk & assumptions about ‘then’ self may impinge on rights & wellbeing of ‘now’ self

reflect privately:
• what stood out to me is...
• something I hadn’t considered is...
• what might be relevant in my workplace/role is...
• one step I could take is...

& then in groups:
• what might we do better to support our residents & their families?
• what support might be needed to develop a policy and education package in my area?
References


References


Tenenbaum, E (2009). To be or to exist: Standards for deciding whether dementia patients in nursing homes should engage in intimacy, sex and adultery. Indiana Law Review 42(3).