Investigating sexuality and consent in New Zealand's residential aged care

Professor Mark Henrickson, Dr Catherine Cook, Dr Vanessa Schouten and Ms Sandra McDonald interrogate conceptualisations of consent in the domain of sexuality and intimacy in residential aged care. Their main goals were: 1) to analyse how people are making decisions in practice about sex and intimacy in aged care; and 2) to use this information to contribute to the existing literature on ethical theory and discourses on consent and wellbeing.

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Sexuality is an intrinsic part of an individual's identity. However, intimacy and sexuality in residential aged care (RAC) are often contested issues, particularly in the case of people living with different types of dementia (Bauer, Fetherstonhaugh et al., 2013; Gilmer et al., 2010; Shuttleworth et al., 2010). Gender and sexually diverse people are an invisibilised minority in residential aged care in general.

Aged care residents and staff in New Zealand are culturally diverse, and their ethnic identifications include European (known as as 'white' or 'Caucasian' in some countries), Māori, and Pasifika. Another important aspect in this context is generational culture, which is frequently omitted as a cultural consideration (Gentile, Keith Campbell & Twenge, 2014). The existing theoretical work on the ethics of sex and intimacy highlight the importance of consent, an issue which has also been prevalent in public and legal discourses. However, attempts to protect older adults can lead to their vulnerabilisation, depriving them of their agency and increasing their social isolation. Here we look at Professor Henrickson and his team's work, which examines how aged care stakeholders (residents, families, and staff) make sense of consent. The authors investigate 1) how people are making decisions in practice about sex and intimacy in aged care and 2) how these findings can inform ethical theory and discourses on consent and wellbeing.

METHODS

Professor Henrickson and team used a mixed method study to analyse care home settings cross-sectionally (at a specific point in time), using a concurrent triangulation design. The study took place in residential care settings in Aotearoa New Zealand, a country with legal bicultural arrangements between indigenous Māori and the Crown, and is a diverse, multicultural nation of five million people on two main islands in the southwestern Pacific Ocean. The study used both quantitative and qualitative research methods. The researchers categorised care settings into large facilities with more than 100 beds; medium-size facilities with 50-100 beds; and small facilities with fewer than 50 beds.

Quantitative methods in their research consisted of a survey questionnaire focusing on knowledge, attitude, and behaviour (KAB). Surveys were distributed to staff at routine staff meetings, and were anonymous and self-administered. The estimated response rate was 62.5 percent and

The majority of respondents agreed that intimate relationships are a lifelong human right.

While there is a consensus that sexuality is an intrinsic part of human identity, intimacy and sexuality in aged care remain misunderstood and contested issues.

433 staff surveys were collected from 35 RAC across the country. Nearly half of the survey respondents identified themselves as European (n=151, 48.7%), followed by Asian (n=84, 27.1%), Māori (n=29, 9.4 %), other (n=24, 7.7%), Pacific (n=15, 4.8%) and Black African (n=7, 2.3%). Just over half (n=209, 54.0%) of respondents said their country of origin was New Zealand, and 239 (61.6%) said that English was their first language. Project staff also conducted 61 semi-structured interviews with 77 staff, residents and family member participants recruited from the participating RACs.

FINDINGS

From the survey it appears that staff are familiar with the language of consent and the fundamental moral importance of consent in the context of sexual intimacy. There was still a significant level of confusion and disagreement about consent, particularly in situations involving residents with diminished cognitive capacity. This may be related to a lack of education and training in sexuality and consent.

Less than half of staff survey respondents (n=200, 46.2%), said they had received education from their employer on intimacy and sexuality for residents. More than half (n=239, 55.2%) agreed that sexual activity may improve the wellbeing and mood of older persons, and nearly three-quarters of respondents (n=314, 72.5%) felt that they were able to make ethical decisions that balance residents' rights and safety. Two-thirds of respondents (n=289, 66.7%) said they were interested in further professional education about intimacy and sexuality in residential aged care. Interview participants felt that education on ageing, intimacy and sexuality was very important for staff, and might also be useful for residents, and possibly even family. Few facilities have a policy regarding sexuality, and for those that do, there is still little if any education to support staff effectively to implement those policies.

ATTITUDES TO ETHICAL AND LEGAL ISSUES

Only 125 staff respondents (28.9%) agreed with the statement 'I know enough about the law and about ethics to deal with sexual issues in aged care', and a nearly equal number (n=129, 29.8%) said they did not know enough; 179 (41.3%) responses were neutral or missing. This strongly suggests that survey respondents both wanted and needed more professional education on sexuality, although they reported feeling confident that they knew enough. Only 90 (28.9%) respondents said that it was easy to tell whether a person with dementia consents to sexual intimacy with another person just by looking at their behaviour. A third of staff do not know whether the behaviour of a resident living with dementia should be understood as implying consent. The study found that staff were over-consulting with family members about resident relationships even when such consultation was not necessary or was inappropriate.

Nearly two-thirds of respondents (n=281, 64.9%) agreed that intimate relationships that involve pleasurable touch are a lifelong human right. Responses suggest that only 22.2% of staff rely on workplace or professional education when making essential decisions about resident expressions of sexuality. There was a lack of clarity over whether residents who are mildly affected by dementia should be allowed by staff to engage in sexual activity. The results also indicate staff inconsistency and a lack of confidence on issues related to dementia and consent. However, nearly half of the respondents would consider a casual sexual relationship between two residents as acceptable. Similarly, there was a lack of consensus over whether sex workers should be allowed for residents who want this service. While staff in some facilities appear to be prepared to respond to resident requests for sex workers, several staff were not, and were looking to policies and management to provide guidance (sex work is legal in New Zealand; this issue is explored further by the authors in Henrickson et al., 2021).

DIVERSITY, ETHICS AND RELIGION

Over half of the staff respondents appeared to accept the idea of same-sex relationships. However,

the study suggested that there was a generational difference in New Zealand-born respondents in their support for same-sex activity, with younger respondents, born in the era of homosexual law reform and marriage equality legislation more likely to support same-sex marriage (Henrickson, Cook & Schouten, 2021).

Respondents were quite divided about the statement: "My main responsibility is to ensure that people in my care are well and happy, even if this means allowing them to engage in sexual behaviours that their family members might not approve of". This question was designed to assess staff opinions about who holds the real power of consent for resident sexual intimacy: 161 (37.2%) agreed, and 106 (24.5%) disagreed with the statement; 166 (38.3%) were neutral or missing. Staff are largely comfortable with their own ability to make decisions in the best interests of patients, and are generally familiar with the need to leave their own personal values and religious beliefs behind when making a decision on behalf of someone else in a professional setting.

Religiosity was important in the lives of many people who participated in this study: staff, family members, and residents. Religion was also co-mingled with ethnicity. Religion was raised by interview participants mostly regarding issues of legal behaviours and relationships which remain difficult or contentious for some religions, such as sex work, private masturbation, access to pornography, or same-sex relationships.

Another important aspect of the research was focused on constraints and limitations to sexual and intimate freedoms of the residents. Staff emphasised that although efforts were made to uphold privacy, the routinisation of care meant that individual privacy was constrained. The ability of staff to provide person-centred care is compromised by busy routinised care practices, limitations of the built environment, and the ethos of facilities that may prioritise efficiency and physical safety over wider considerations of wellbeing.

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Furthermore, residents often felt that the care environment was a liminal space, neither entirely their own home nor completely a work environment. The transition to care had a profound effect on their sense of self and (dis) connection from significant people, places, and lifetime artefacts, and involved a process of grieving. Participants were aware of an existential loneliness that most residents had to navigate and accommodate in order to live with a reasonable quality of life (Cook et al., 2021). Loneliness and liminality were key themes in people's narratives about sexuality. This highlights an importance of this study, as practical arrangements should be put in place to help older adults cope with these feelings.

Loneliness and the liminality of spaces were also key issues identified by residents and staff.

IMPLICATIONS OF THIS STUDY

This study sheds new light onto the issues of sexuality in care settings, which has been an underexplored topic for a long time, although there is increasing interest in the literature. It proposes a shift in focus from managing risk and meeting minimum obligations to a focus on caring for the whole person and considering a person's overall wellbeing and quality of life.

The researchers make 20 practical recommendations for care providers to take into account when considering an older adult's wellbeing. These regard consent, intimacy, and sexuality, and should be available in plain language to staff, residents, families, and visitors. Policies should be put in place that relate to the questions of education, access to sex workers, consent, and they should clearly outline when an Enduring Power of Attorney should (and should not) be invoked. The management in residential settings should organise tailored training for the staff on a regular basis both formally and informally. Such training should be available to all staff, including administrators, kitchen, cleaning, maintenance, gardeners, casual staff and contractors, etc. Gender and sexually diverse residents should be sure to have advanced directives or other written instructions in place in the event they become intellectually compromised, so that their wishes are clear.

Behind the Research

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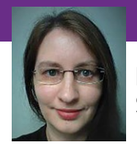

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Research Objectives

Professor Mark Henrickson and his team investigate the attitudes of residential aged care staff, residents and family members towards sexually diverse persons, based on data from the first national study of its kind in Aotearoa New Zealand.

Detail

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Bio

Mark Henrickson is Professor of Social Work at Massey University, Auckland, New Zealand. He has published extensively on HIV, sexual and gender diversity, vulnerability and marginality, and on research ethics. He is a registered social worker, and principal investigator on *What counts as consent? Sexuality and ethical deliberation in residential aged care.*

Catherine Cook is a senior lecturer in the School of Clinical Sciences AUT University, Auckland. Her clinical background is in nursing, midwifery and counselling. She has for many years had clinical and research interests in the areas of sexuality, sexual health and sexual identity, particularly as these issues relate to marginalised and vulnerablised populations. The main questions driving her research are as follows: how do health professionals optimise healthcare, quality of life and wellbeing for potentially vulnerable and marginalised populations, balancing both a duty of care and upholding rights? How does cultural diversity in teams shape ethical assumptions and communication about healthcare, quality of life and wellbeing for potentially vulnerable and marginalised populations?

Vanessa Schouten did her BA and MA at Victoria University before moving to Princeton, New Jersey in 2007 to begin her PhD. Schouten graduated in 2015, a few months after she started working at Massey University as a philosophy lecturer. She spent five years working on the Auckland campus before moving down to the Palmerston North campus in July of 2020. Schouten's research focus is the ethics of sex and sexuality – in particular on the value (and role of) consent, and the insights theory can gain from the knowledge held by those who grapple with difficult ethical decisions in this domain in their everyday lives.

Sandra McDonald contributes to the development of inclusive models of care that improve the health status of Māori in Aotearoa New Zealand. She is also quantifying and documenting gains made to increase the number of Māori nurses and the pedagogy used to achieve this.

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Collaborators
- The researchers acknowledge project manager Nilo Atefi, PhD, RN.

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Personal Response

How do ideas about sexuality/consent vary according to respondents' gender, ethnic origin and race?

"Our qualitative data showed that it was important for all residents to be able to express their sexuality. One female resident in particular expressed how much fun she was having in a new sexual relationship with a fellow resident. In the quantitative data, staff of European descent and those born in NZ were more likely than staff of different origins to agree that same-sex sexual intimacy was a right of residents, and that residents who consent should be able to have casual sexual relationships. A significantly higher proportion of Asian staff and staff born outside NZ believed that people with dementia could not reliably consent to sexual intimacy.

What could intersectionality theory contribute to your work?

This was effectively an interdisciplinary and intersectional study. The research team came from backgrounds that included social work, nursing, and philosophy, and drew on theories and practice experience from those disciplines. Three of four members of the core research team have extensive practice experience with vulnerabilised and marginalised communities and populations, and our research is informed by that experience. Aotearoa New Zealand has had a formal treaty relationship with the indigenous Māori since 1840, so all research is expected to include a consideration of the implications for Māori. Social work and nursing are also intersectional disciplines that intentionally reflect on power and privilege in an ongoing way. Too often older persons are dismissed as powerless or irrelevant in some cultures, and their lives become almost caricatures; valuing the multidimensionality and the lives and relationships of our elders is core to this project."