WHAT COUNTS AS CONSENT?

Sexuality and ethical deliberation in residential aged care

Final Project Report
19 November 2020

MARSDEN FUND
TE PŪTEA RANGAHAU A MARSDEN

ROYAL SOCIETY
TE APĀRANGI

A ROYAL SOCIETY MARSDEN FUND PROJECT

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(Community Advisory Board with the project team. L-R: C. Cook*, J. Marsden, O. Mortera, J. Jang, N. Atefi*, M. Boyd, J. Watson, S. Johansen, M. Henrickson*, S. McDonald*, J. Buddendijk, V. Schouten*. Missing from photo, A. Miller. *Project team)

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[1] Where they are included, organisations are for identification only; inclusion does not imply organizational endorsement of this project or report.

Executive Summary

BACKGROUND

This report is intended as a summary of the three-year Royal Society Marsden Fund-funded project "What counts as consent: Sexuality and ethical deliberation in residential aged care" (MAU-1723). The project was funded for the period March 2018 to February 2021. The aim of the project is to interrogate and inform conceptualisations of consent in the domain of sexuality and intimacy in residential aged care. The project completed and exceeded all recruitment and participation goals.

While there is a general consensus that sexuality is an intrinsic part of human identity, intimacy and sexuality in aged care remain misunderstood and contested issues. This is particularly so in respect of older persons living with dementia. Gender and sexually diverse communities constitute a significant invisible and invisibilised minority in residential aged care (RAC), and that invisibility means their intimacy needs remain largely unknown and unacknowledged. There are cultural issues in aged care unique to New Zealand: for instance, while 85 percent of residential aged care facility (RACF) residents identify as European and an estimated 5.5 percent are Māori, 44 percent of staff identify as other than European, including 10 percent who identify as Māori, and 10 percent Pasifika.

The dominant position in the theoretical literature on the ethics of sex and intimacy is that consent is of fundamental importance. Consent has dominated not just the theoretical discourse but also public and legal discourses about the ethics of sex and therefore carers and staff make decisions based on the management of institutional risk rather than the wellbeing of the resident. 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. How sexual consent in particular is conceptualised has significant ethical implications for the growing number of elders in Aotearoa New Zealand who are living with degrees of cognitive decline.

The specific contribution of this project is to interpret how aged care stakeholders (residents, families, and staff) make sense of consent, to contribute substantively to ethical theory around consent, sexuality, and intimacy, and to inform practice and policy in aged care environments. The project interrogates and intends to inform conceptualisations of consent in the domain of sexuality and intimacy in residential aged care. Our 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 inform the literature on ethical theory and discourses on consent and wellbeing.

METHODOLOGY

This study is a two-arm mixed method cross-sectional study using a concurrent triangulation design. The study received approval by the Massey University Human Ethics Committee Northern, number NOR18/25. Recruitment of sites was stratified by region and by size proportionate to the number of RACFs throughout the country. We classified large facilities as more than 100 beds; medium-size facilities as 50-100 beds; and small facilities as fewer than 50 beds. For various reasons, we had 29.6 percent success rate in recruiting sites. For the quantitative arm, the research team developed and validated a knowledge, attitude, and behaviour (KAB) survey (Cronbach's alpha for the entire survey was α=0.81). Surveys were distributed to staff at routine staff meetings; 433 surveys were completed and returned from 35 RACFs through New Zealand. The survey was anonymous and self-administered. The estimated response rate was 62.5 percent. Composite scores were developed for each domain and assessed. The data collected from the surveys were cleaned and coded, entered into statistical software for analysis, and the probability threshold set at α=.05. Data were checked for accuracy, missing data, outliers, and normality before statistical analyses were conducted. Missing items were coded with a neutral response.

The second arm consisted of semi-structured interviews recruited from these sites. Project staff conducted 61 interviews with 77 participants recruited from the 35 participating RACFs. Interviews were completed as follows:

- staff, 19 individual interviews, and four groups with 17 additional people, for a total of 36;
- residents, 26 interviews with 28 people;
- family members, 12 interviews with 13 people.

The length of the interviews depended on participant engagement and fatigue; the shortest was 20 minutes, and the longest several hours over two days.

QUANTITATIVE RESULTS

We achieved our goal of recruiting participating sites nationally proportionate to the size of the facility. There were only 40 missing item responses (out of a possible 8,660 responses, 0.4%) on the survey. Age groups were roughly equally represented in the survey respondents, with the greatest number (n=97, 25.1%) being recorded in the 51-60-year-old age group. Half (n=217, 55.9%) of the respondents identified their role as health care assistant (HCA); 35 (9.0%) were managers, 66 (17.0%) were nurses, and 70 (18.1%) identified their roles as something else (social worker, occupational therapist, diversional therapist, etc.). Nearly half of the 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 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.

Knowledge: Less than half of 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. Only 125 respondents (28.9%) said they knew enough about law and 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, despite initially 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 activity 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 can imply consent. Responses were also very divided on the more complex legal and ethical question of whether consent to sexual activity and agreeing to sexual activity are the same thing; 152 (35.1%) disagreed with this statement, 125 (28.9%) agreed, and 156 (36.0%) were neutral or missing. The composite knowledge variable (cKNOW) score was 23.40 (SD± 3.76), out of a possible composite score of 35.

Attitude: Nearly two-thirds of respondents (n=281, 64.9%) agreed that intimate relationships that involve pleasurable touch are a lifelong human right. The responses to the statement "I rely on my personal values more than anything else to guide me when I make decisions about sexual issues that arise in my workplace" were similarly divided: 191 (44.3%) agreed with this statement, 96 (22.2%) disagreed, and the rest (n=146, 33.5%) were neutral or missing. These responses suggest that only 22.2 percent of staff rely on workplace or professional education when making essential decisions about resident expressions of sexuality.

On the question "Staff should allow residents who are mildly affected by dementia to engage in sexual activity", 107 (24.7%) agreed, 127 (29.3%) disagreed, and 199 (46.0%) were neutral or missing. These responses indicate a lack of clarity on this issue by respondents. Further, 145 (33.4%) of respondents agreed, and 115 (26.6%) disagreed with the statement "People living with dementias can never reliably consent to sexual intimacy with another person. These responses suggest inconsistency and a lack of confidence on issues related to dementia and consent.

However, 207 (47.8%) respondents agreed and 81 (18.7%) disagreed with the statement "A resident of an aged care facility should be able to have a casual sexual relationship with another resident who consents", suggesting that casual sex between two consenting residents would be acceptable to nearly half the respondents. Since 250 (57.5%) respondents agreed with the statement "People over 65 have little interest in sexual activity", and only 65 (15.2%) disagreed with this statement, the perceived risk of such casual sexual intimacy would appear to be low.

Responses to the question "My workplace should allow access to sex workers for residents who want this service, provided the resident is the one paying" were about equally divided: 131 (30.2%) agreed, 157 (36.3%) disagreed, and 145 (33.5%) were neutral or missing. Opinions about residents' using the Internet in private to meet their legal sexual interests (effectively asking about access to on-line pornography) were also equally divided: 148 (34.2%) agreed, 133 (30.7%) disagreed, and 152 (35.1%) were neutral or missing. It is not possible from the question to determine whether respondent attitudes were related to pornography in general or resident use of the Internet to gain access to pornography. Still, 245 (56.6%) of respondents agreed and only 58 (13.4%) disagreed with the statement "Two male (or two female) residents have the right to be sexually intimate with one another"; 130 (30.0%) were neutral about same-sex couples. 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. The composite attitude (cATT) score for was 32.18 (SD±6.97), out of a total possible composite score of 50.

Behaviour: Less than half the respondents (n=208, 48.1%) agreed that they have all the communication skills to work with sexual issues that may arise in their workplace; 64 (14.7%) disagreed, and 161 (37.2%) were neutral or missing. Nearly half of the respondents (n=216, 49.8%) agreed that "Residential care facilities should provide rooms to allow residents to engage in sexual behaviour without fear of being watched or interrupted"; 73 (16.9%) disagreed, and 144 (33.3%) were neutral or missing. Less than one third of respondents (n=118, 27.2%) agreed that "Staff should prevent a relationship between residents if family members object to the relationship"; 131 (30.3%) disagreed, and a surprising 184 (42.5%) were neutral. This suggests that staff are clear about who holds primary responsibility for resident decision-making, and are unsure about what they would do if faced with this situation. These responses suggest that less than half are able to talk about or prepared to act when faced with a situation of resident sexual activity. The composite behaviour (cBEH) score for the overall sample was 9.99 (SD±2.29), out of a total possible composite score of 15.

A significant positive moderate correlation was found between cKNOW and cATT scores and a positive moderate correlation between cKNOW and cBEH scores. A significant positive moderate correlation was found between cATT and cBEH. Participant knowledge about intimacy and sexuality appears to be moderately related to behaviour and their attitude in relation to intimacy. A multiple linear regression analysis found a higher cKNOW score was associated with a higher cATT score, and a higher cATT score was associated with a higher cBEH score. All of this suggests the importance of employer-provided staff education and training for staff on intimacy and sexuality.

QUALITATIVE RESULTS

Qualitative themes were grouped into four clusters.

Cluster 1: Decision-making

- Need, right or privilege?
- Consent
- Decision-making and Enduring Power of Attorney (EPoA)
- Role of the family and the primacy of children
- Māori

Cluster 2: Management, Policy and Education

- Leadership and the role of management
- Policy
- Education
- Misdemeanours

Cluster 3: Physical and emotional space

- Privacy, physical space, furnishings, and homeliness
- Home space or Workplace?
- Transition to Care
- Loneliness and the management of relationships

Cluster 4: Diversity

- Religion
- Gender and sexual diversity
- Sex work

Qualitative data are presented to support these key themes within each cluster. The Discussion section is also organised by cluster.

> *The specific contribution of this project is to interpret how aged care stakeholders make sense of consent, to contribute substantively to ethical theory around consent, sexuality, and intimacy, and to inform practice and policy in aged care environments.*

Cluster 1

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. It is not clear to family members and residents who will be kept informed, and when, and there is substantial disagreement about who should be involved in the decision-making process. Ethical issues which arise are difficult, overlapping, unexpected, and sometimes really context specific.

Staff, family members and residents did not necessarily have a shared view about their roles, and in particular their capacity to influence residents' lives. Staff and residents were both exposed to mixed responses from family about decisions about resident wellbeing.

Recruiting Māori kaumātua, whānau, and kaimahi was difficult, which was expected given the relatively small percentage of Māori engaged in the RACF sector and their reticence at discussing topics of this nature. Greater understanding of the complexity of Māori understandings of these issues could be achieved by a more focused exploration of te ao Māori in relation to intimacy and sexuality in residential aged care. Where people have grown up, who has been involved in their life learning, and what their journey through life has been all will mean assumptions cannot be made about the worldviews of kaimahi or kaumātua.

Cluster 2

Managers set the tone for the facility, either by talking or not talking about sexuality and intimacy, by providing training for staff, or not, and by their attitudes towards resident expressions of intimacy. Residents also experience the attitudes of managers, either directly or indirectly. Few facilities have a policy regarding sexuality, or if they have, there is little if any education to support staff effectively to implement those policies.

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. Although more than half of staff survey respondents at smaller facilities said they had not received education on intimacy and sexuality, at least two-thirds of respondents, regardless of size of facility, said they wanted more.

Staff and residents at times witnessed and responded to degrees of unwanted sexual behaviours. These data add to evidence of the importance of having leadership around interventions for unwanted sexualised behaviours, and policies and education for staff, residents, and families.

Cluster 3

Residents and family members gave accounts of how the lack of privacy and the limitations of the built environment meant that residents did not have access to the sexual and intimate freedoms they had in their own homes. Staff highlighted that although efforts were made to uphold privacy, the routinisation of care meant that privacy practices easily slipped. The ability of staff to provide person-centred care is compromised by busy routinised care practices, limitations of the built environment, and the ethos permeating facilities that may prioritise efficiency and physical safety over wider considerations of wellbeing.

Staff, residents, and family members highlighted that the transition to care commonly, but not always, resulted in a period of significant grief and adjustment for residents and family members.

Some of the loneliness of older age is a fundamental challenge for older people. Residents held back from intimate relationships because they imagined that there were unwritten rules that would become apparent it they crossed on invisible line. Given the legal authority held by the person with the EPoA, staff were sometimes aggrieved by family members' decisions and yet had no power to intervene.

Cluster 4

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

We refer again to the specific section on tangata whenua in this report. It may be difficult to separate the expectations of cultural tikanga from missionary religion, in both Māori and Pasifika communities. The sacredness of tinana, the mana of the individual, and the tapu of the relationship between individual, āwhai, whānau, hapu, and iwi are essential aspects of Māori wairua, particularly in kaumātua and kuia. Each whānau will have expectations of how these are managed.

There are strongly held views on many sides about gender and sexually diverse residents. Gender and sexually diverse persons, including trans persons, are not theoretical notions, but are already residents. Some staff felt that asking residents about important people in residents' lives was considered intrusive or too difficult. Staff also face unexpected ethical and practice dilemmas in this area: a resident with dementia identified as a trans person, and family members insisted on treating their family member as if they still identified as their sex assigned at birth, using their 'dead name'.

Access to sex workers is happening in RACF in New Zealand, if not in all facilities, at least in a number of them around the country, in urban, suburban, and rural areas. While staff in some facilities appear to be prepared to respond to resident requests for sex workers, a number of staff are not, and are looking to policies and management to provide guidance. Many participants observed that residents have a right to privacy, and as long as residents are competent to make financial decisions elsewhere in their lives, they have a right to spend their own money on sex workers without the need for the facility to notify the family or EPoA, or to seek their permission. Both staff and family members often have a hazy understanding of EPoA as this relates to residents' sexual expression.

DISCUSSION

It is clear that staff, family, and residents 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. It was common for staff to take the behaviour of a resident as indicating consent. While staff were comfortable with the language of consent, and aware of its moral importance, they were also sensitive to the fact that they were operating in a particular context and that they had to balance risk to residents with promoting resident wellbeing. Staff also had to manage family expectations about being involved in the decision-making process. Residents were aware that their decisions were being monitored by staff and sometimes by family, which affected the extent to which residents felt comfortable engaging in sexual intimacy. Understanding the kinds of decisions which get made in the context of residential care has important implications for the ethics of sex. Consent matters but it is not the only value that matters. Relationships, particularly intimate relationships, are important for most people's wellbeing, and a complete ethics of sex should recognize this.

We created the axiom that if a facility gets care right in the areas of intimacy and sexuality, it will get care right in all areas.

> *It is clear that staff, family, and residents 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.*

Cluster 1

Decision-making around sex and intimacy was a source of confusion and struggle. Policies and procedures with regards to residents' decision-making around sexual intimacy were frequently absent, or not well understood. It was often not clear to staff when and to what extent family should be involved. The extent to which Enduring Power of Attorney holders had a right to be involved in the process was a particular source of confusion. One result of this confusion was that staff frequently engaged in risk-averse decision-making: they consulted with family members and EPoA holders when it was not necessary to do so, or they intervened in situations where it was not necessary to do so to protect residents. This approach may expose staff to risks associated with privacy violations.

Cluster 2

If there is a single finding from this study that requires immediate and universal attention at all facilities, it is the importance of regular education about intimacy and sexuality. Larger facilities were more likely to provide education than smaller ones, but two-thirds of staff at facilities of all sizes expressed a desire for more education. Half of staff at smaller facilities said they had never received education on resident intimacy and sexuality; this may be because the education had never been provided, or was simply unmemorable. The need and demand seem quite clear to staff and to us, and in our view the sector must heed and respond by providing education specifically related to intimacy and sexuality.

Cluster 3

Intimacy and sexuality in the RAC context can only be fully comprehended through scrutiny of contextual influences. We identified four components that shaped the (im)possibility of residents' experiencing intimacy and sexual expression related to the physical and emotional context of RAC. Firstly, the extent to which residents, staff and family members perceived that residents were entitled to real rather than tokenistic privacy had a major impact on residents' sense of being at home. Secondly, residents' felt the experience of being at home, or not, was influenced by the built environment and furnishings; the environment was a liminal space, neither entirely their own home nor completely a work environment. Thirdly, the transition to care had a profound effect on residents' sense of self and (dis)connection from significant people, places, and lifetime artefacts, and involved a process of grieving. Fourthly, 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.

> *...the importance of regular education about intimacy and sexuality.*

Cluster 4

Diversity is a theme that emerged in every aspect of this study. Diversity comprehends a wide variety of differences. In this context, diversity refers especially to differences that are marginalised, hidden, ignored, or otherwise devalued. There are four areas that we believe are critical to consider: tangata whenua; religion; gender and sexual diverse persons; and sex work. In every area, staff education, and in some cases resident and family education, is urgently needed in facilities of all sizes.

Consent for Māori in the aged residential care context embraces another layer of complexity. In-depth understanding of te ao Māori both of kaimahi and kaumātua and their whānau is required in each facility to ensure that tapu and noa of te ao Māori are not breached. This would have an impact far wider impact than the mana of the kuia or koroua in care. This study found that the lenses through which these groups view the world are strongly based in te ao Māori. However, there is not a unitary understand of te ao Māori: where people have grown up, who has been involved in their life learning, and what their journey through life has been, all mean that within this world kaimahi and kaumātua will have a rich diversity of perspectives. It is important to engage meaningfully with Māori, particularly in respect of intimacy and sexuality. Further research specifically in the area of Māori working and living in residential care will be useful, particularly given the anticipated increased life expectancy of Māori, and the ever-increasing diversity of Māori. Understanding how whānau and RACF manage cognitive decline in kaumātua will be an important area of further research and planning.

Religiosity (and non-religiosity) is important in the lives of many people—staff, residents, and family—who participated in this study. While the impact of religious beliefs on residents may be indirect— for instance, the owners/managers or new settler staff drawing on their beliefs or religious values toward what is considered acceptable behaviour in a facility—there is still an impact.

Facilities and their staff must be prepared for same-sex couples, widows, and widowers, and trans persons. Since we live in a cis-heteronormative society, gender and sexually diverse residents must be provided with specific and welcoming opportunities to disclose who they are and who their important relationships are. Silence forces residents to hide in plain sight, and reinforces oppressive cis-hetero norms. Maintaining or enforcing silence about relationships, sexuality, and identity is not respectful: asking questions of every resident about their important relationships, with a genuine openness to whatever the replies are, creating opportunities for disclosure (or not), and respecting the answers is respectful.

A facility policy on access to sex workers and staff education to that policy are essential. The reactions of many participants indicated that the topic of sex work was beyond their imagination in the context of RACF. Preparation may pre-empt a crisis when the unimaginable occurs.

RECOMMENDATIONS

The report makes 20 practical recommendations for facilities to consider. These are grouped as policy, leadership, education, physical and emotional space, and pastoral care. These are ranked in a priority order, where facilities can begin with the most urgent. We direct the reader's attention to the full Recommendations section of the report.

- It is critical that facilities have comprehensive policies in place in respect of consent, intimacy, and sexuality, and should be available in plain language to staff, residents, families, and visitors. Policies should address education, access (or not) to sex workers, consent, and when an EPoA should (and should not) be invoked. Facility leadership should create and implement appropriate policies, and organise regular and routine staff education, beginning with the staff interview and orientation, and sustained for all staff both formally and informally. Education about intimacy and sexuality should not be limited to regular direct care staff, but should include all staff—administrators, kitchen, cleaning, maintenance, gardeners, casual staff and contractors, etc. Residents, family, and managers may wish to consider developing advance directives in respect of intimacy and sexuality.
- In-depth understanding of te ao Māori of kaimahi, kaumātua, and whānau must be routinely sought. It is essential that local and individual contexts be considered thoughtfully, with aroha, and where necessary in consultation with local cultural advisors. We encourage respectful conversations with whānau, kaumātua, and kaimahi about how intimate relationships will be managed early in the move into care.
- Managers must be prepared to listen and talk openly and frankly about sexuality and intimacy with staff and to create an environment where staff can talk with them about difficult and often complex issues. They should themselves undertake regular education on these issues as they would on any other. Managers and clinical leaders need to work with direct care staff to ensure the ethos of the facility being a home is translated into practices that make people feel more at home, rather than a guest, or a patient.
- We strongly recommend that the residential aged care sector require, audit, and provide routine and regular education specifically related to intimacy and sexuality. If a facility, regardless of size, is unable to implement any other recommendation of this report, it should implement education for staff. The recommendations set out what such education may include. Education and training should allow staff respectfully to reflect on how they can navigate any dissonance or space between their religious (or non-religious) values and workplace expectations.
- We recommend preparation, planning, and staff training for interventions for unwanted sexualised behaviours. We encourage facilities to consider developing educational opportunities for residents about intimacy and sexuality. This will establish appropriate behaviours (providing some first-line protection for staff), and may address resident concerns and questions about ageing, intimacy, and sexuality, and about appropriate expressions of sexuality and intimacy in a community living environment.
- Questions about intimate partners and relationships should be routinely included as part of a standard intake assessment. No assumptions should be made about the sexual orientation or relationships of any resident.
- We encourage managers and leaders in residential care to be active in their contribution to facility design, working with architects in the early stages of any new build.
- We recommend that particular attention be paid to residents who are transitioning into care, and that transition management be a specific area of support. We encourage facilities to consider providing clear statements about diversity as part of routine orientation to the facility. Senior staff should consistently role-model and require from all workers a philosophical commitment to residents' right to privacy, translated into practice. Residents should have an opportunity to discuss their sexual and intimacy needs and desires with appropriately trained staff. Explicit discussion of policies and guidelines would alert residents to their rights and responsibilities, and also inform prospective residents and their families of issues they might not otherwise address until a crisis occurred. Resident wishes on gender presentation (including clothing, hairstyle, make-up, jewellery, etc.) should be prioritised over the wishes of the family, even if the resident's capacity to assert their wishes becomes diminished and an EPoA comes in force.

> *Questions about intimate partners and relationships should be routinely included as part of a standard intake assessment. No assumptions should be made about the sexual orientation or relationships of any resident.*

WHAT COUNTS AS CONSENT?

Sexuality and ethical deliberation in residential aged care

Introduction

This report is intended as a summary of the three-year Royal Society Marsden Fund-funded project “What counts as consent: Sexuality and ethical deliberation in residential aged care” (MAU-1723). The project was funded for the period March 2018 to February 2021. The aim of the project is to interrogate and inform conceptualisations of consent in the domain of sexuality and intimacy in residential aged care. The project completed and exceeded all recruitment and participation goals, as will be evidenced in this report. This report, however, is only one outcome of a project that has generated an extensive amount of quantitative and rich and complex qualitative data, and the research team anticipate continuing to work and publish from this dataset for some time to come. We will also remain available to respond to requests to present the findings to facilities and other parts of the sector. Other less documentable outcomes include the discussions that we have generated within the sector during the course of the research. There is little doubt that sexuality and intimacy in residential aged care is a controversial, and for some people a difficult, unspeakable, or even unimaginable, topic. We have little doubt that our findings and recommendations will generate public debate and controversy. It is clear from the data, and from informal but widespread discussions, that this has been the right project at the right time, and the researchers are proud to have been a part of the project. We have carefully considered our findings and make no recommendation without awareness of the debate and controversy it may cause both within the sector and in the public arena more generally.

BACKGROUND

An estimated 32,000 people currently live in residential aged care facilities (RACF) in Aotearoa New Zealand (IBISWorld 2019), and has been estimated that as soon as 2026 between 12,000 and 20,000 ‘extra’ residents will require residential care (GrantThorton, 2010). Although the rate of growth in the numbers of people entering care has been debated (Broad et al., 2015; Broad et al., 2011), it is clear that the number of people in care will increase in actual numbers as the population grows. As the number of Baby Boomers (people born between 1946 and 1964) and GenXers (born between 1965 and 1980) increases and considers entering care, they will bring with them very different understandings and expectations of sexuality and relationships than previous generations (Risman et al., 2018). Improved medical care means a longer active lifespan, and the increasing availability of sexuopharmaceuticals, the ubiquity of the Internet and access to sexually explicit websites, dating, and hook-up apps, and increasing legal and social acceptance of gender and sexual diversity all contribute to the expectation of Boomers and ensuing generations—even those in residential care— that they will both expect and be able to remain sexually active longer than previous generations. However, Alzheimer’s New Zealand estimates that in 2016 there were 62,287 people living with dementia in Aotearoa New Zealand, of which 18,929 were in residential care (Deloitte, 2017). The number of people living with dementia is expected to rise to 170,212 by 2050 (Deloitte, 2017). This trend means that partners, children, and care providers for people in RACF face increasing ethical challenges in supporting people in care to live their relational, intimate, and sexual lives.

While there is a general consensus that sexuality is an intrinsic part of human identity (Elias & Ryan, 2011), intimacy and sexuality in aged care remain misunderstood and contested issues (Bauer et al., 2013; Gilmer, 2010; Shuttleworth et al., 2010). This is particularly so in respect of older persons living with dementia (Elias & Ryan, 2011; Hayward et al., 2012; Price, 2012). Gender and sexually diverse communities constitute a significant invisible and invisibilised minority in RAC (Callan, 2006; Elias & Ryan, 2011); that invisibility means their intimacy needs remain largely unknown and unacknowledged (Cronin et al., 2010). There is no age limit to the need for intimacy or to sexual responsiveness (Benbow & Beeston, 2012), a point affirmed by RACF staff to the current research team in workshops they have led or spoken at around Aotearoa New Zealand, and is a consistent theme in the data in the present research project. The international literature on sexuality in older persons, sexuality and cognitive impairment is growing (Chen et al., 2017; Cook et al., 2018; Cook et al., 2017; Di Napoli et al., 2013; Mahieu et al., 2014; Mahieu & Gastmans, 2012; Robinson & Davis, 2013; Simpson et al., 2017; Simpson et al., 2018; Tabak & Shemesh-Kigli, 2006; Thys et al., 2019; Villar et al., 2014; Villar et al., 2018). Members of the present research team have contributed to the limited New Zealand research to date. There are cultural issues in aged care unique to New Zealand: for instance, while 85 percent of RACF residents identify as European and an estimated 5.5 percent are Māori (New Zealand Labour Party, 2010), 44 percent of staff identify as other than European, including 10 percent who identify as Māori, and 10 percent Pasifika (GrantThorton, 2010; we were unable to identify more recent data on the entire workforce)). Among health care assistants (HCA), an entry level role requiring minimal formal education who comprise about half the RACF workforce, 59 percent identify as New Zealand European, 22 percent as Asian, 12 percent as Māori, 11 percent as Pacific peoples. (Meagher, 2016). Ethnic disparities between residents and the workforce, and within staff groups, are important because sexuality and culture are intrinsically linked (Aggleton et al., 2012).

The dominant position in the theoretical literature on the ethics of sex and intimacy is that consent is of fundamental importance (Schouten, 2015). In particular, there are three claims about sex and consent which describe the views most commonly argued for in the literature: (a) that non-consensual sex is morally wrong (West, 2010); (b) that what makes it morally wrong is the fact that it is non-consensual (Archard, 2007; Estrich, 1986; Gardner & Shute, 2000); and (c) that in order to give morally valid consent, a person must meet standards of cognitive competence (Alexander, 1996; Hurd, 1996; Kelly & Innes, 2013). The 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 a violation of these rights (Kelly & Innes, 2013; Simpson et al., 2017). The specific contribution of this project is to interpret how aged care stakeholders (residents, families, and staff) make sense of consent, to contribute substantively to ethical theory around consent, sexuality, and intimacy, and to inform practice and policy in aged care environments.

The literature on social citizenship redirects ethical attention from standardised assessments of an individual's global capacity to give consent in order to manage institutional risk, towards the facilitation of self-governance (even when a person is not fully autonomous) and the overall wellbeing of older persons. The exploration of such nuanced conceptualisations is important ethically because historical and prevailing understandings of citizenship emphasise the self-governance of a fully autonomous self (Brannelly, 2011; Sweeting & Gillhooly, 1997). These historical narratives, focussing on the lack of autonomy rather than the facilitation of self-governance, give credence to organisational risk-averse beliefs and practices, and emphasise residents' vulnerability; this focus eclipses attention given to the maximization of residents' opportunities for self-governance and their wellbeing (Birt et al., 2017). The resulting effect can be a kind of 'social death', that is, the assumption that some people are unworthy of full social participation (Brannelly, 2011; Sweeting & Gillhooly, 1997), or must have decisions made for them. This '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. How sexual consent in particular is conceptualised has significant ethical implications for the growing number of elders in Aotearoa New Zealand who are living with degrees of dementia, and cognitive decline from other causes.

Decision-making by care workers, residents and family members around sex and intimacy in RACF provides a useful way of interrogating the majority view of consent in the literature. Consent has dominated not just the theoretical discourse but also public and legal discourses about the ethics of sex (Benbow & Beeston, 2012) and therefore carers and staff make decisions based on the management of institutional risk rather than the wellbeing of the resident (Henrickson & Fouché, 2017). In our previous work on this issue (Cook et al., 2017) we found that proxy decision makers (both carers and family members) drew on tacit moral understandings which conflated wellbeing with consent in order to make complex decisions about intimacy and sexuality, implying that concern about wellbeing and citizenship were guiding their decision making in practice, even though they still thought about these issues in terms of consent and risk.

The overall aim of this project has been to interrogate and inform conceptualisations of consent in the domain of sexuality and intimacy in residential aged care. Our 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 inform the literature on ethical theory and discourses on consent and wellbeing. Specific objectives in this research and the methods used to consider them are iterated in Figure 1.

Figure 1: Funded project objectives

Objective	Method
To assess the knowledge, attitudes, and beliefs of RACF caregiver staff about sexuality and intimacy in older persons	Surveys
To determine how personal values, education and training of caregiver staff inform workplace decisions about intimacy and sexuality in older persons, and particularly about residents who are intellectually compromised	Interviews with staff
To analyse how caregivers make ethical decisions in respect of residents' intimate and sexual relationships, the ethical underpinnings of their decision-making, and how staff negotiate conflicts among residents, families/whānau, and institutional expectations	Interviews with staff
To understand how carers, family/whānau and/or surrogate decision-makers interpret the issue of consent, and how consent is assessed	Interviews with residents and family members
To make a significant contribution to conceptualisations of consent and wellbeing in the literature of ethical theory, and in practice in the RAC sector.	Final report and published articles and presentations

Our primary research question was: What kinds of ethical decisions are being made about expressions of intimacy and sexuality in residential aged care in Aotearoa New Zealand?

THE PRESENT REPORT

The key elements of consent are: (1) that the individual is fully informed about the nature of the activity; (2) the decision is voluntary; and (3) that the individual giving consent is competent to make a decision. If we take these three requirements as our starting point, then we can make some statements about what counts as consent in respect of sexuality and intimacy in residential aged care, and by extension residential care in general.

Fully informed

A fully informed decision is one in which an individual has knowledge about all of the relevant features of the activity they are engaging in. In the case of sexual intimacy, the person making the decision needs to know the kind of information that is relevant to that decision: who they are engaging in sexual intimacy with, the nature of the acts they are engaging in, and what (if any) risks there are. Of particular importance in the context of an RACF setting is whether residents are aware of risks such as sexually transmitted diseases or other possible risks to their physical safety. A more complicated issue is when a resident is mistaken about the person they are engaging in sexual intimacy with: a resident with dementia for example may mistakenly believe that the person they are engaging in sexual intimacy with is a spouse or significant other, and in a case like this cannot be held to be fully informed about a relevant feature of the activity.

Voluntary

Whether an individual is capable of voluntary consent is a critical and dynamic area of law, protection, and pastoral care. A voluntary decision is one where there is no overt or covert threat or coercion to make a decision in a particular way. Of particular importance in an RACF setting is that residents are in a relationship of dependence with care workers, and sexual relationships in this context are at risk of being (or being perceived as) coercive even in the absence of specific threat.

Competence

In an RACF environment, it may not be clear whether or not a resident is competent to make a decision. For this reason, RACFs are an excellent environment for testing this criterion. In particular staff working in this environment have practical experience making decisions with and for people who may not be entirely cognitively competent. In this report we will also challenge the notion of *competence* as the primary determiner of decision-making in the realms of intimacy and sexuality, and instead will focus on the notion of *wellbeing*. Nevertheless, it is useful to review notions of competence in current understandings, if only to demonstrate their limitations.

Assessing whether a person is capable of consenting to sexual or intimate activity is different from assessing whether they are competent to make decisions about medical care, personal care and grooming, finances, or even what and when to eat. Applying a single competency template across all areas is problematic: a person may well be competent to make decisions in one domain, but not another. Intellectual impairment in the case of conditions such as dementias is rarely stable: residents with dementias will have better and worse days, and times of day, and the dynamic nature of a person's capacity to consent must therefore be carefully considered.

The complexity of competency raises issues of staff training, and staff abilities to support resident autonomy and privacy. Staff must be educated and trained to assist residents to make their own decisions as far as possible, but also to recognize that promoting autonomy is not the only goal of person-centred care.

This study is mindful of an array of complex issues that arise from these issues. For example, one response to dealing with people with diminished competence is to maximize what autonomy they do have, but this may be a mistake. Autonomy over one's life choices is important in part because we expect that autonomous individuals are better judges over what would make their own lives go well than other people are.

But if a person's competence to make decisions is severely compromised, the right thing to do might not be to focus on maximizing what little autonomy they do have, but instead to focus on other ways of ensuring their lives go well. A person who is not deemed competent to make decisions about sex and intimacy at all may nevertheless desire and benefit from engaging in intimacy.

We acknowledge that these issues will be considered quite differently through a cultural lens, and for Aotearoa New Zealand particularly from worldviews that sit within te ao Māori and the diversity that encompasses.

Wherever possible a residential care facility should make every effort to accommodate residents and their partners, even when those partners are temporary; in some facilities this may require radical reconsideration of architecture, design, furnishing, and staffing patterns. We hope that this will be taken into account in future designs and renovations of existing facilities. To design facilities along panoptical hospital models and for the convenience of staff may discount the needs and desires of residents who do not need such close observation.

The RACF should also have policy(ies) specifically related to intimacy, sexuality, and consent to these; we do not propose what those policies should be, but only that policies exist and are regularly reviewed. These policies should be fully endorsed at all levels of governance.

These policies should be cognisant of cultural diversity and also gender and sexual diversity, applicable not merely to cisgender heterosexuals, but to trans persons and sexually diverse peoples, including lesbian, gay, and bisexual persons, both single and in relationships, and the RACF should inform residents, potential residents, staff, and families about those policies as part of a mutual goodness-of-fit assessment process, where a potential resident assesses whether the facility is right for them, and the facility staff also assesses whether the resident will be a good fit within the facility;

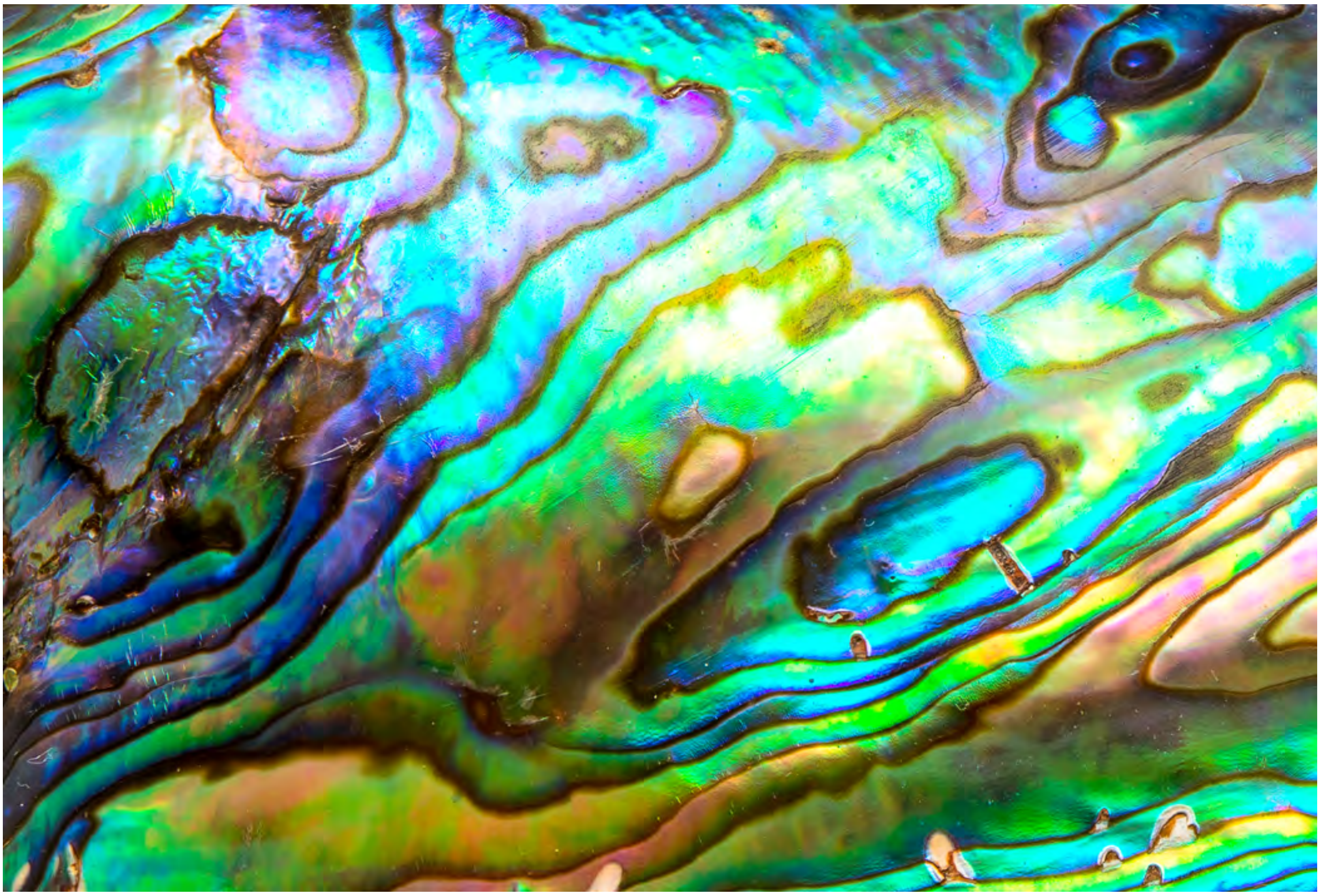
Simply having policies in place does not guarantee that the fully informed and autonomous decisions of residents and their privacy will be respected. Residents must be able to implement their fully informed decisions. Staff must also be fully competent and confident to raise and discuss questions of intimacy, sexuality, and relationships with residents and with each other. Therefore, the RACF should induct staff to institutional policies and regularly provide meaningful education to staff about those policies so that those policies are implemented. We address the content of that education in this report, but training should at least include current law, regulations, and institutional policies; and reflection on personal values and how to navigate differences between personal values, religious (or other) beliefs, and professional values.

The RACF should also assess resident expectations in respect of sexuality and intimacy with residents (and where relevant, with their families/whānau) at the time of transition to care, preferably within the first few weeks. This assessment should include at a minimum gender and sexual diversity, and advanced directives related to sexual behaviour.

Finally, The RACF should offer regular educational opportunities to residents and their families on those policies, as well as on sexuality and ageing/disability in general.

We are convinced that if residential care staff are supported to make good decisions about resident intimacy and sexuality they will be able to provide good person-centred care in other aspects of a resident's life. As one staff participant put it,

> *...[A]ge related care is not as old-fashioned as it used to be, and I think there's so much room for us to be supportive in a modern and non-institutional way about all aspects of people's lives, and really not be afraid to talk about them.* (S6F)



Methodology

DESIGN

This study is a two-arm mixed method cross-sectional study using a concurrent triangulation design. We used qualitative interviews to understand and explain the findings of a quantitative survey. The first arm of the study was an anonymous, self-administered survey completed by 433 staff in 35 RACFs throughout New Zealand. Recruitment of sites was stratified by region and by size (see Table 1), proportionate to the number of RACFs throughout the country. We classified large facilities as more than 100 beds; medium-size facilities as 50-100 beds; and small facilities as fewer than 50 beds. The second arm consisted of semi-structured interviews recruited from these sites: staff, residents, and residents' family members were canvassed and invited to contact research team members if they were willing to be interviewed. Project staff conducted 61 interviews with 77 participants recruited from the participating RACFs. The study arms were conducted independently, so it is possible that some survey respondents were also interview participants.

Although the project was not fully funded and we planned to reduce the number of participating sites to 32, proportionate to funding, we were able to continue to recruit the originally planned number of sites by reallocating budget resources. Table 1 (Appendix 3) sets out our target sampling strategy.

Initially we hoped to randomise selection of the sites (by stratum). However practical and recruitment challenges required us to modify this strategy. Practical environmental challenges included the lifting of name suppression and January 2019 trial of a Massey University academic for sexual assault of a resident with dementia at an RACF in Wellington, which made recruitment of facilities in the Wellington region extremely challenging; the Pigeon Valley Fire in the Nelson-Tasman District in February-March, the largest wildfire in New Zealand history, which resulted in the evacuation of large numbers of people in the region the same week we planned to launch the study in the district; and the shootings at Masjid al-Noor and the Linwood Islamic Centre in Christchurch on 15 March which occurred the day we planned to launch in that city. In each case we delayed recruitment by four to six months before we returned to the region. Other recruitment challenges were facilities whose managers said they were too busy to participate, were facing staff shortages, or had very recently participated in research (there is indeed a great deal of current research in this sector). We found the decision-making process at individual facilities owned by some (but not all) the major national syndicates complex (some managers of nationally owned facilities did provide access). Some facility managers were reluctant to participate in sexuality-related research, because they did not see the point, they did not want the issue raised with staff, or believed such study would conflict with their own individual values. In the end, 118 facilities were contacted and 35 participated, giving an overall response rate of 29.6 percent (most of the facilities that declined were in Wellington). These participation challenges also meant that managers who were less inclined to talk about sexuality and intimacy were less likely to be included in the project, meaning our results might depict a more positive picture of the sector than would be found by the probability sampling we originally planned.

While we cannot claim randomisation of facilities because the sample is somewhat self-selecting and therefore not strictly speaking representative, we believe that our sample of 35 facilities out of a total possible 648 (5.4%) identified at the time of the launch, and 433 staff who participated in the study (1.6% of the usually estimated 27,000, including 5,000 nurses and 22,000 facility caregivers (New Zealand Immigration, n.d.), fairly represents the opinions of staff throughout the country.

INSTRUMENTS

The survey instrument comprised three sections:

- Section I: The first section assessed the demographic data of the respondents. Optional demographic questions included: age, ethnicity, qualification, years of experience, role, religion, and country of origin.
- Section 2: The research team developed a knowledge, attitude, and behaviour (KAB) survey to assess staff KAB related to intimacy and sexuality in RACFs. The KAB instrument was adapted from the Aging Sexual Knowledge and Attitudes Scale (ASKAS: White, 1982) and had been tested in previous pilot studies. The adapted survey comprised 20 questions related to the three domains, knowledge (7 items), attitude (10 items) and behaviour (3 items) with responses scored on a five-point Likert scale containing responses ranging from strongly disagree (1) to strongly agree (5). A score of 3 represented a neutral response. Four negatively worded items were reversed and re-coded during the data analysis process. Composite scores for the three KAB domains vary according to the number of items. Composite median scores were identified by multiplying the mean score (3) by the number of possible responses.
    - Composite knowledge (cKNOW) ranged from 5 to 35, median (7*3)=21; with higher scores representing higher level of knowledge and lower score representing low knowledge,
    - Composite attitude (cATT) scores ranged from 10 to 50, median (10*3)=30; with higher score representing positive attitude and lower score representing negative attitude,
    - Composite behaviour (cBEH) scores ranged from 3 to15, median (3*3) =9; with higher score representing positive behaviour and lower scores representing negative behaviour.

- Section 3: This section consists of two questions that asks respondents opinion about a practice-based scenario.

Content validity for Sections 1 and 2 of the survey was established by giving a survey draft to a panel of twelve expert professionals in the field. The survey instrument was pilot tested on 53 staff of five different RACFs who were not included in the actual study. The internal reliability assessed by Cronbach's alpha for the entire survey was α=0.81, which we assessed as a satisfactory level of internal reliability. The survey instrument is found in Appendix 2.

The qualitative arm of the study consisted of 61 semi-structured interviews with 77 different individuals. Semi-structured interview questions were created after an extensive review of the relatively limited literature in the area, and had been field tested in pilot studies.

DATA COLLECTION

Quantitative data

As noted above, 118 eligible RACFs were recruited as a stratified sample by region and number of beds (<50, 51-100, and >100), of which 35 managers agreed that their facilities would participate, yielding a recruitment success rate of 29.6 percent; the highest rate of declining to participate was in Wellington.

Researchers contacted the managers from the identified facilities and obtained permission to attend a regular day staff meeting, bring a morning (or afternoon) tea, and to distribute surveys. Eligibility criteria for participation in the survey included being a RACF staff member who provided any kind of direct care to residents: these roles included managers, nurses, health care assistants, social workers, diversional (recreational) therapists, psychiatrists, and psychologists. An estimated 693 surveys together with consent forms and information sheets were distributed to eligible staff members (some extra surveys were left with managers to provide to absent or on-duty staff, or staff on other shifts) and 433 completed survey were returned, yielding an estimated response rate of 62.5 percent. (Although we know how many surveys were left at the facility for managers to distribute to absent staff, we do not know exactly how many were actually distributed or taken up by staff on different shifts). Surveys were deposited into a sealed collection box and were collected two weeks later by one of our research team members, or in the case of remote areas placed in envelopes and posted back to the research office.

Qualitative data

Semi-structured interviews were conducted between October 2018 and October 2019. Staff, residents, and family members of residents were recruited to participate in the study. We posted flyers within facilities, and obtained manager support to invite residents and residents' family members to volunteer for interviews. Participation was voluntary, and all participants were assured of confidentiality, and anonymity in the report and publications. All interviews took place at a time convenient for the participants and in a safe and quiet venue in the RACFs that provided privacy and relative comfort. Interviews were completed as follows: staff, 19 individual interviews, and four groups with 17 additional people, for a total of 36; residents, 26 interviews with 28 people; family members, 12 interviews with 13 people. Staff groups consisted of people who asked to be interviewed together for cultural reasons, to which we agreed; residents and family interviews with more than one person were also carried out in response to requests from those persons who were partners/spouses, family or whānau. The length of the interviews depended on participant engagement and fatigue; the shortest was 20 minutes, and the longest several hours over two days. In this report quotations are identified only by an initial letter indicated staff (S), resident (R) or family member (F) and the serial number by which the transcripts were returned from the professional transcriptionist. The gender of the participants completes the quotation identification (e.g., S1F is the first staff interview returned by the transcriptionist, and this participant was female). No assumptions can or should be made about where these interviews took place or the size of the facility where the resident lived, or staff worked. Table 2 (Appendix 3) sets out the regional distribution of the interviews.

DATA ANALYSIS

The quantitative and qualitative data sets were analysed separately. At the conclusion of the separate analyses, quantitative and qualitative results were integrated to develop the analysis of the knowledge, attitude, and behaviour of respondents.

Quantitative data

The data collected from the surveys were coded and entered into the Statistical Package for the Social Sciences [SPSS], version 25.0 (IBM Corporation, 2017) for analysis, and the probability threshold set at α=.05. Data were checked for accuracy, missing data, and outliers before statistical analyses were conducted. The data cleaning procedure began by examining each variable using frequencies; rare errors were found and corrected. Missing items were coded with a neutral response (Dodeen, 2003). There were a total of 40 missing responses on 13 questions, or a missing response rate of 0.4 percent; only three questions had more than three missing responses: "My main responsibility is to ensure that the 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" (n=4 missing); "Residents should be able to use a facility's internet in private to meet their legal sexual interests" (n=5 missing); and "Consent to sexual activity and agreeing to sexual activity are the same thing" (n=13 missing). These three questions were the final three (questions 18-20) on the survey before the scenario-based questions; the final question was possibly the most difficult on the survey as it required advanced knowledge of legal distinctions.

We assessed assumptions for statistical analysis. The data distribution was checked for normality and the Kolmogorov-Smirnov statistic for each variable indicated that all variables had a significance of $p \geq 0.05$, indicating normal distribution. We could not ensure that no staff person completed more than one survey, but we consider this extremely unlikely. Therefore, we used standard parametric tests in this study. In addition to descriptive analyses, one-way between-groups analyses of variance (ANOVA) were performed for comparison of response means. Pearson correlation coefficients were calculated to evaluate correlations among cKNOW, cATT and cBEH scores, and effects were reported as a correlation coefficient (r). Logistic linear regression analysis was further conducted to identify the factors associated with cATT and cBEH scores.

Qualitative data

Audio recorded interviews were transcribed by professional transcriptionists. Data analysis began with data collection. Each transcript was then reviewed and initially coded by five research team members. Thematic analysis, guided by Braun and Clarke's (2006) six steps of data analysis, was undertaken to identify key themes. This process involves identification, generating initial codes, and searching for themes, reviewing themes, and defining and naming themes. Each team member was then allocated a set of themes to develop further into report sections, and these written sections were again reviewed by each other member of the team.

Rigour

To facilitate credibility, convenience sampling of participants with a view to diverse characteristics of staff, residents and residents' family members was used. Transcriptions were reviewed by all researchers in this study for accuracy. To assess independence and interrater reliability of the analysis, five researchers viewed the data separately. The use of digital audio recordings ensured the accuracy of the data collected. All interviews were based on semi-structured interview questions. To address conformability, Braun and Clarke's (2006) six-step framework for analysis provides logical and accurate interpretation of the data. Validity was enriched by checking generated themes with five interdisciplinary research team members.

ETHICAL CONSIDERATIONS

The study received approval after careful review by the Massey University Human Ethics Committee Northern, number NOR18/25 (Appendix 1). For survey participants, anonymous completion and submission of a survey implied consent. Waiting for interested interview participants to contact the research team ensured that this latter group was voluntary; we obtained informed and written consent from the interview participants prior to the start of the interview.

Results

This project collected rich and complex data from 433 survey respondents and 61 interviews with 77 people. We therefore overperformed on all survey and interview objectives. We anticipate continuing to work with this qualitative and quantitative dataset for a number of years, and will continue to develop detailed publications. This results section is organised to present key overall quantitative findings consistent with the objectives identified in our funding application (Figure 1) and then findings from salient areas of interest that emerged from the data. To make reading this report easier, most data tables have been placed in Appendix 3. In this report we refer to survey *respondents* and interview *participants*. Variables are capitalised for clarity.

QUANTITATIVE FINDINGS

Respondents' characteristics

Details of the demographic characteristics of all the respondents are summarised in Table 3 in (Appendix 3). We achieved our goal of recruiting participating sites nationally proportionate to the size of the facility. Unfortunately, one of our casual staff did not record the source of the surveys collected in one region, so that 69 (15.9%) surveys could not be analysed by facility size. Age groups were roughly equally represented in the survey respondents, with the greatest number (n=97, 25.1%) being recorded in the 51-60-year-old age group This means that respondents were very experienced in their work, with 114 (29.5%) having ten years' experience or more. However, 61 (15.8%) had less than one year of experience working in RACF. Respondents were reasonably well educated, with only 27 (7.2%) having less than a high school education; 212 (56.2%) had some kind of tertiary education, of which 51 (13.5%) had some kind of postgraduate qualification. Just over half (n=217, 55.9%) the respondents identified their role as health care assistant (HCA); 35 (9.0%) were managers, 66 (17.0%) were nurses, and 70 (18.1%) identified their roles as something else (social worker, occupational therapist, diversional therapist, etc.). Nearly half of the 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 African (n=7, 2.3%). Ethnicities were not equally distributed within roles, nor roles within ethnicity (Table 4, Appendix 3). In the manager role, 25 (73.5%) were European, although 34 (60.7%) of the nurses were Asian. HCAs were more diverse: 69 (43.1%) European, 42 (26.3%) were Asian, 18 (11.3%) identified as Māori and 12 (7.5%) as Pacific; 19 (11.9%) identified as 'Other'. Table 4 shows the distribution of ethnicity within roles, and Table 5 shows the percentage of each ethnicity within a given role. The response rate on the ethnicity question (308/433, 71.1%) was particularly low, and we believe that respondents may have been concerned about being identified if they recorded their role on their survey. It is therefore likely that Māori, Pacific and Other respondents, and respondents less familiar with (or trusting of) research ethics, are under-recorded.

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 (Table 3, Appendix 3).

Slightly more respondents (n= 138, 36.5%) identified as No Religion than identified as Christian (n=121, 32.1%). Other religions (including Hindu, 5.0%; Muslim, 1.9%; Buddhist, 1.3%; all others 6.3%) accounted for 14.5% (n=55) of respondents. Sixty-four (16.9%) respondents said they belonged to some religious organisation but were not active (Table 3, Appendix 3). One of the interesting features of the Religion variable is that a majority of people who identified as Asian also identified as Christian, and the majority of Christians were Asian; similarly, the majority of Europeans identified as No Religion, and the majority who identified No Religion were Europeans (Tables 6 and 7, Appendix 3). As we attempted to model whether either Ethnicity or No/Religion were significant separate predictors of our composite variables we found it impossible to separate these two variables statistically; this may be an area for future research. Had we been aware of this strong alignment prior to the start of the study we might have explored them more specifically in our interviews, particularly since No/Religion was a significant predictor of composite scores (as we shall see below); however, exploring something that does not exist (No Religion) would have been difficult.

KAB questions

In order to improve the robustness of our statistical analysis of the survey responses, Strongly agree and Agree responses were grouped together, as were Strongly disagree and Disagree responses. Except where noted in the specific analysis, neutral responses were not reclassified. Missing responses were entered as item mean (Dodeen, 2003; Downey & King, 1998); this means that a large neutral response may be interpreted as ‘unsure’ as much as ‘no opinion’. There were only 40 missing item responses (out of a possible 8,660 responses). Missing responses are addressed more below. A basic summary of survey responses grouped by category (Knowledge, Attitude and Behaviour) appears as Table 8 (Appendix 3).

Knowledge: Less than half of respondents (n=200, 46.2%), said they had received education from their employer on intimacy and sexuality for residents. Nevertheless, 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. Still, two-thirds of respondents (n=289, 66.7%) said they were interested in further professional education about intimacy and sexuality in residential aged care.

Despite their feelings of confidence that they knew enough to make ethical decisions, only 125 respondents (28.9%) said they knew enough about law and ethics to deal with sexual issues in aged care, and a nearly equal number (n=129, 29.8%) disagreed with this statement (implying that they do not know enough); 179 (41.3%) were neutral or missing. This strongly suggests that survey respondents both wanted and needed more professional education on sexuality, despite initially 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 activity with another person just by looking at their behaviour; 203 (46.9%) disagreed and 140 (32.3%) were neutral or missing. This finding suggests that a third of staff did not know whether the behaviour of a resident living with dementia can imply consent. Responses were also very divided on the more complex legal and ethical question of whether consent to sexual activity and agreeing to sexual activity are the same thing; 152 (35.1%) disagreed with this statement, 125 (28.9%) agreed, and 156 (36.0%) were neutral or missing.

The composite knowledge variable (cKNOW) score was 23.40 (SD± 3.76), out of a possible composite score of 35.

Attitude: Nearly two-thirds of respondents (n=281, 64.9%) agreed that intimate relationships that involve pleasurable touch are a lifelong human right; only 33 (7.6%) disagreed, and 119 (27.5%) were neutral or missing. The responses to the statement “I rely on my personal values more than anything else to guide me when I make decisions about sexual issues that arise in my workplace” were similarly divided: 191 (44.3%) agreed with this statement, 96 (22.2%) disagreed, and the rest (n=146, 33.5%) were neutral or missing. These responses suggest that only 22.2% of staff rely on workplace or professional education when making essential decisions about resident expressions of sexuality. While disappointing, this finding is not surprising if only 46.2 percent of respondents had received relevant education.

On the question “Staff should allow residents who are mildly affected by dementia to engage in sexual activity”, 107 (24.7%) agreed, 127 (29.3%) disagreed, and 199 (46.0%) were neutral or missing. These responses indicate a lack of clarity on this issue by respondents, despite 55.2% having agreed that sexual activity may improve wellbeing and mood, and 64.9% having agreed that intimate relationships with pleasurable touch are a lifelong human right. Further, 145 (33.4%) of respondents agreed, and 115 (26.6%) disagreed with the statement “People living with dementias can never reliably consent to sexual intimacy with another person”; the balance (n=173, 40.0%) were neutral or missing. These responses suggest inconsistency and a lack of confidence on issues related to dementia and consent.

However, 207 (47.8%) respondents agreed and 81 (18.7%) disagreed with the statement “A resident of an aged care facility should be able to have a casual sexual relationship with another resident who consents”, suggesting that casual sex between two consenting residents would be acceptable to nearly half the respondents. Since 250 (57.5%) respondents agreed with the statement “People over 65 have little interest in sexual activity”, and only 65 (15.2%) disagreed with this statement, the perceived risk of such casual sexual intimacy would appear to be low.

Responses to the question “My workplace should allow access to sex workers for residents who want this service, provided the resident is the one paying” were about equally divided: 131 (30.2%) agreed, 157 (36.3%) disagreed, and 145 (33.5%) were neutral or missing. Opinions about residents’ using the Internet in private to meet their legal sexual interests (asking about access to on-line pornography) were also equally divided: 148 (34.2%) agreed, 133 (30.7%) disagreed, and 152 (35.1%) were neutral or missing. It is not possible from the question to determine whether respondent attitudes were related to pornography in general or resident use of the Internet to gain access to pornography, but there is no clear sentiment about this issue in either case. Still, 245 (56.6%) of respondents agreed and only 58 (13.4%) disagreed with the statement “Two male (or two female) residents have the right to be sexually intimate with one another”; 130 (30.0%) were neutral about same-sex couples.

Interestingly, 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. On this statement 161 (37.2%) agreed, and 106 (24.5%) disagreed; 166 (38.3%) were neutral or missing.

The composite attitude (cATT) score for was 32.18 (SD±6.97), out of a total possible composite score of 50.

Behaviour: Less than half the respondents (n=208, 48.1%) agreed that they have all the communication skills to work with sexual issues that may arise in their workplace; 64 (14.7%) disagreed, and 161 (37.2%) were neutral or missing. Nearly half of the respondents (n=216, 49.8%) indicated that “Residential care facilities should provide rooms to allow residents to engage in sexual behaviour without fear of being watched or interrupted”; 73 (16.9%) disagreed, and 144 (33.3%) were neutral or missing; as we found in the qualitative interviews, these rooms could often be the resident’s own room. Less than one third of respondents (n=118, 27.2%) agreed that “Staff should prevent a relationship between residents if family members object to the relationship”; 131 (30.3%) disagreed, and a surprising 184 (42.5%) were neutral. This suggests that staff are unclear about who holds primary responsibility for resident decision-making, and are unsure about what they would do if faced with this situation. These responses suggest that less than half are able to talk about or prepared to take action when faced with a situation of resident sexual activity.

The composite behaviour (cBEH) score for the overall sample was 9.99 (SD±2.29), out of a total possible composite score of 15.

Demographic characteristics and composite scores

Knowledge: A one-way ANOVA found that there were no statistically significant differences between socio-demographic characteristics (age, qualification, experience, role, religion, and ethnicity) and respondents’ cKNOW (Table 9, Appendix 3). We found this surprising and explore this in our modelling discussion below. One possible interpretation of this is that there is a low level of knowledge about intimacy and sexuality across all demographics.

Attitude: There were statistically significant differences between Experience, Role, Ethnicity, Country of origin, English as first language and No/Religion and cATT score (Table 9, Appendix 3). Several of these variables (Ethnicity, Country of origin, English as first language and, as we discovered, No/Religion) are associated with each other. A *post hoc* comparison using Tukey’s test showed that there was a statistically significant difference between the cATT of managers (37.97, SD±6.72, n=35) and other groups. Managers were clearly the most experienced of the respondents to the staff survey; most (n=23, 65.7%) had more than ten years’ experience in the field, were overwhelmingly European (n=25, 73.5%), and identified as No Religion (see below).

There was also a statistically significant difference between respondents with two to less than five years of experience (31.15, SD±7.09, n=84) and those with more than ten years of experience (34.11, SD±7.09, n=114, p<.05) on cATT scores. Perhaps not surprisingly, a higher proportion of respondents with more than ten years’ experience (n=61, 34.9%) had received education about sexuality and intimacy, compared with respondents with two to less than five years of experience (n=41, 23.4%), which suggests that such education is not a routine part of a staff induction process. Respondents who reported No Religion had a significantly higher mean cATT score (33.87, SD±6.45, n=202, *p*<.05) compared to respondents who identified as Christian (30.65, SD±7.37, n=121) and Other Religions (29.98, SD±6.79, n=55). This suggests that No Religion respondents had a more positive attitude toward sexuality and intimacy in RACF compared to respondents who identified as Christian or Other Religions. This is consistent with the literature on religion and sexuality. The results showed that the majority of European (n=115, 76.2%) and Māori (n=22, 75.9%) respondents reported No Religion.

There was a statistically significant difference between the cATT score of Europeans respondents (35.45, SD±5.94, n=151, p<.05) compared with Māori (31.93, SD±6.04, n=29), Asian (29.83, SD±6.92, n=84), Pacific (28.60, SD±6.31, n=15), and Others (31.58, SD±7.69, n=31). Respondents who were born in New Zealand had a significantly higher mean cATT score (33.73, SD±6.67, n=209) compared to those born somewhere else (30.62, SD±6.94, n=178, p<.05).

Behaviour: There were no statistically significant differences by experience, qualification, religion, role, ethnicity and respondents' cBEH score. There was a statistically significant difference between the cBEH score of respondents who were over 60 years old (10.65, SD±2.53, n=46) and those who 20 to 30 years old (9.38, SD±1.65, n=83, p<.05). This suggests that life experience (rather than work or role experience) is important in shaping how respondents behave toward expressions of sexuality and intimacy among residents. This may have to do with greater confidence in manage risk, greater life experience in responding to diversity of behaviours, or something else.

In our initial analysis we found no differences on any composite score by facility size. We had hypothesised that larger facilities would be better resourced to provide education, and therefore staff would have higher knowledge than smaller facilities. We then reclassified neutral and missing data together with Disagree responses to increase robustness, and did find a significant difference. We justify this reclassification by assuming that if a respondent agreed with the statement that they had received education from their employer then they remembered it, and if they disagreed, were neutral or disagreed, they had not received such education, did not recall it, or it was not significant to them. Staff of large facilities were more likely to say that they had received education. A higher proportion of staff of large facilities (n=31, 68.9%) agreed that they had received education compare to 65 of staff of medium facilities (41.1%) and 73 of staff of small facilities (45.3%). This finding suggests that large facilities are more likely to provide (at least memorable or meaningful) staff education and training on intimacy and sexuality than medium sized or small facilities. Since we did not ask facilities if they had provided such training, this difference may be due to a number of factors, including resourcing, staffing patterns, staff demand, having a designated staff person responsible for training, the (non)religious philosophy of larger facilities, or something else. This will be an area to explore further with facilities. There were no significant differences among respondents in having received education by formal qualification. This finding suggests that these qualifications may be less important than employer education, experience, or role in shaping attitudes and behaviours about intimacy and sexuality in staff who work in RACF.

Correlations between composite knowledge, attitude, and behaviour

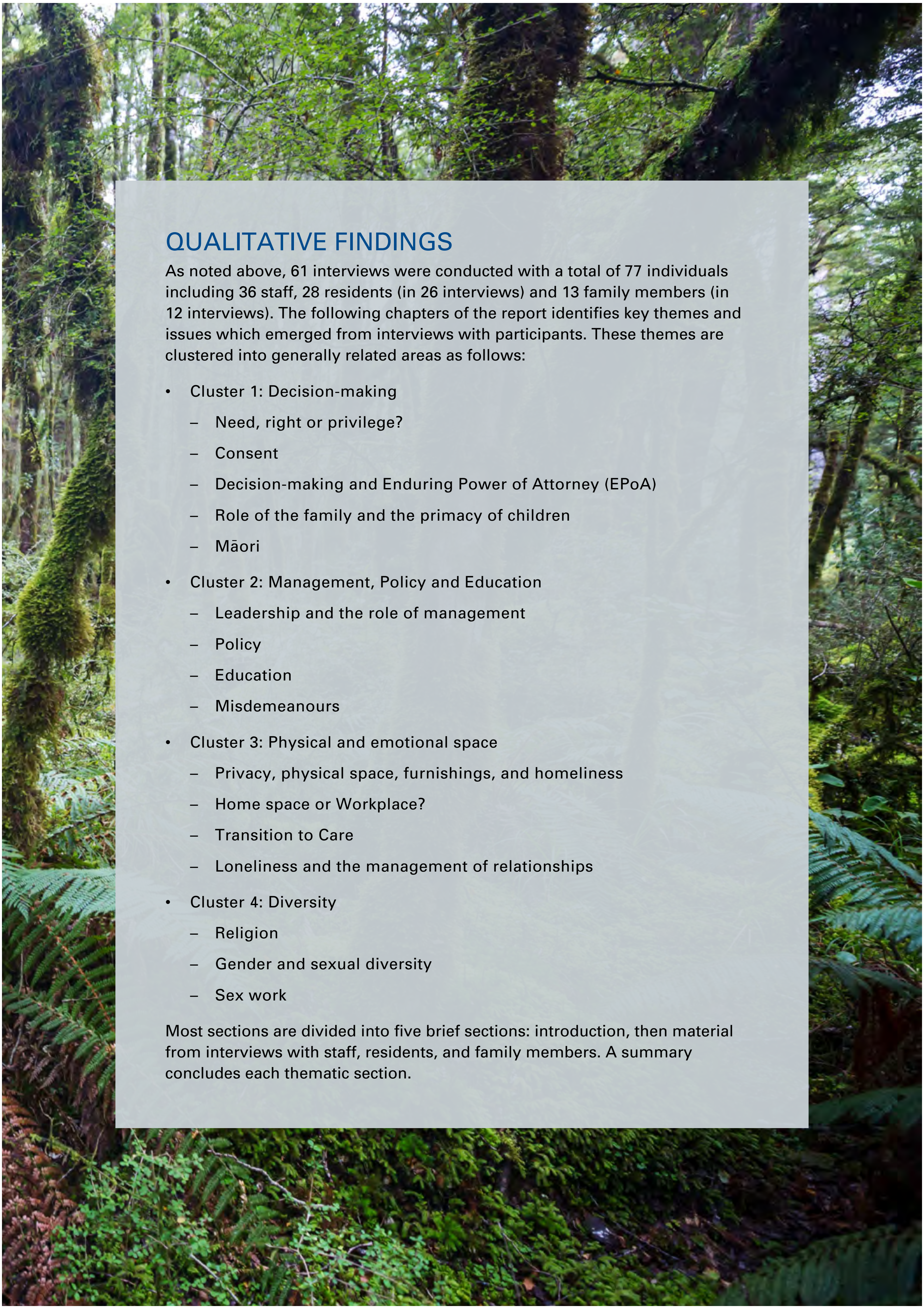
In this study r=-0.1 to 0.1 was considered to show no or very weak correlation, r=0.1 to 0.29 a weak correlation, 0.3 to 0.49 a moderate correlation and 0.5 to 1.0 a strong correlation (Schober et al., 2018). A significant positive moderate correlation was found between cKNOW and cATT scores (r=0.349, *p*=.001). There was also positive moderate correlation between cKNOW and cBEH scores (r=0.411, *p*=0.001). A significant positive moderate correlation was found between cATT and cBEH (r=0.486, *p*=0.002). Participant knowledge about intimacy and sexuality appears to be moderately related to behaviour and their attitude in relation to intimacy.

Multiple logistic regression

We explored the data in order to build a model to determine how personal values, education and training of caregiver staff inform workplace decisions about intimacy and sexuality in older persons, and particularly about residents who are intellectually compromised. In Table 10 (Appendix 3) we see that a multiple logistic regression analysis shows that HCAs were less likely to have higher score on cATT (OR=0.21, CI=0.06-0.69, *p*=0.01) as compared with the reference group, managers. Christian (OR=0.31 CI=0.15-0.64, *p*=0.00) and other religion respondents (OR=0.35, CI=0.01-0.82, *p*=0.01) were found to be less likely to have higher score on cATT, as compared with the reference group, No religion. Respondents with higher score on cKNOW score (OR=4.16, CI=2.24-7.71, *p*=0.001) were more likely to have higher score on cATT. In addition, respondents with higher score on cKNOW (OR=2.33,CI=1.40-3.86, *p*=0.01) were more likely to have higher score on cBEH as compared with the reference group, lower score on cKNOW. Respondents who had higher score on cATT were also more likely to have higher score on cBEH (OR=4.87, CI=3.00-7.91, *p*=0.01) as compared with the reference group. What this suggests is that role (and more specifically a manager role), reporting No religion (although most managers reported No religion) is likely to result in a higher cATT score. A higher cKNOW score was associated with a higher cATT score, and a higher cATT score was associated with a higher cBEH score. All of this suggests the importance of employer-provided staff education and training for staff on intimacy and sexuality; this education must specifically take into account staff personal beliefs, and in particular, religion.

...education by formal qualification... may be less important than employer education, experience, or role in shaping attitudes and behaviours about intimacy and sexuality in staff...

...the importance of employer-provided staff education and training for staff on intimacy and sexuality; this education must specifically take into account staff personal beliefs, and in particular, religion.



QUALITATIVE FINDINGS

As noted above, 61 interviews were conducted with a total of 77 individuals including 36 staff, 28 residents (in 26 interviews) and 13 family members (in 12 interviews). The following chapters of the report identifies key themes and issues which emerged from interviews with participants. These themes are clustered into generally related areas as follows:

- Cluster 1: Decision-making
  - Need, right or privilege?
  - Consent
  - Decision-making and Enduring Power of Attorney (EPoA)
  - Role of the family and the primacy of children
  - Māori
- Cluster 2: Management, Policy and Education
  - Leadership and the role of management
  - Policy
  - Education
  - Misdemeanours
- Cluster 3: Physical and emotional space
  - Privacy, physical space, furnishings, and homeliness
  - Home space or Workplace?
  - Transition to Care
  - Loneliness and the management of relationships
- Cluster 4: Diversity
  - Religion
  - Gender and sexual diversity
  - Sex work

Most sections are divided into five brief sections: introduction, then material from interviews with staff, residents, and family members. A summary concludes each thematic section.

Findings Cluster 1: Decision-Making

NEED, RIGHT, OR PRIVILEGE?

An important ethical question which has implications for policies around sex and intimacy in residential aged care is whether we should think of sexual intimacy as a need, a right, or a privilege.

If we think of sexual intimacy as a basic need, like the need for food or shelter, then we should treat it like we treat food or shelter – access to sexual intimacy must be provided, and those who are providing care have an obligation either to provide it or ensure it is made available. In the same way that a care facility must either cook food or provide outside catering to ensure the nutritional needs of the residents are met, the facility must either provide sexual and intimate services as part of everyday care or make use of outside contractors (e.g. sex workers).

If we think of it as a right (but not necessarily a need), then we might think that residential care providers have an obligation to ensure that residents who wish to pursue sexual intimacy are not prevented from doing so, but that care providers do not need to either provide it or ensure it is provided. By analogy, the right to get married is important (particularly for groups who have been denied that right in the past, such as members of the gender and sexually diverse communities). But the fact that I have the right to get married does not mean that any particular person is obliged to marry me, nor does it mean that the anyone is obliged to ensure I have access to a pool of marriageable partners.

If we think of sexual intimacy instead as a privilege, something to be earned, then the obligations of the care facility are significantly less. Sexual intimacy becomes a privilege reserved for those with privilege, such as access to social networks, private spaces, or sufficient funds.

How we conceptualize sexual intimacy therefore has practical implications. So how did our participants understand the status of sex and intimacy with regards to these three categories? And how did this impact their expectations for the role and responsibilities of the care facility?

From the quantitative survey, we know that significant numbers of staff in RACFs think of at least some aspects of sexual intimacy as having the status of a right. For example, 281 (64.9%) of participants agreed that 'Intimate relationships which involve pleasurable touch are a lifelong human right.' More than half of participants (56.6%, n=245) agreed that same-sex couples have the right to be sexually intimate with each other, though 58 (13.4%) disagreed with this statement.

In terms of the facility ensuring residents can exercise their rights in this domain, the results were less emphatic. Close to half of the participants agreed that facilities should provide a private space to allow sexual activity (49.9, n=216). Participants were fairly evenly split on whether facilities should meet the needs of residents who want to use shared internet in private (30.7% disagreed, 35.1% were neutral, and 34.2% agreed) and whether facilities should provide access to sex workers (36.3% disagreed, 33.5% were neutral, and 30.2% agreed).

It is also clear from the qualitative data that in general, participants think sexual intimacy has the status of a right, and for some people is a need. A number of staff, residents and family members expressed views which recognised the need for intimacy, the right to intimacy, and the role of the residential care facility to at least not actively prevent residents from engaging in sexual intimacy.

Staff

A number of staff did recognise that residents still had sexual and intimate needs:

> Q: *Some facilities enable residents to access sex workers or escorts if they want; what do you think of that practice?*
>
> A: *It's okay. I don't have a problem with that either. They have their needs as much as we do; young or old. Who are we to say, "No?" As long as it's done privately, and not tacky.* (S20F)

This included recognizing rights to sexual expression:

> Q: *If a man said to you, "Look I'd like to masturbate most nights; could you provide me with some cream?" or something like that; and he's just going to be alone in his room with the door shut. Would you facilitate that?*
>
> A: *Of course. I mean it's his right. It's his need. There's no reason why we would not be able to accommodate that one provided that it doesn't disrupt with the other residents.* (S12F)

One staff member also considered women's sexual needs, in the context of providing aids if necessary:

> Q: *And, if a person came and said, "I've run out batteries for my vibrator." You would help them get new ones, and things like that?*

A: *Yes, that's fine. We can't deprive them for that, because that's what they need; if that's what makes them feel better. Yeah, we just leave [them to it]. Yeah, as long as they're not going; I mean, to hire someone like a sex worker. We still let them do that. We should also give that to them.* (S2Group)

In general staff also recognised that residents had a right to sexual intimacy. "I don't see any problem, [with the resident's] intimate relationship with other people, because it's their right. If that will benefit them, and make them better and happy, then I don't see any problem with it" (S2Group).

This was true even in cases where staff members were themselves personally uncomfortable:

Q: *Again, you've spoken to this already; what are your thoughts about residents being able to access sex workers or escorts?*

A: *Personally, I don't feel that comfortable with it myself, but it's their right and so we are here to make sure that they are supported, happy and they have their rights.* (S24F)

Staff also recognised the need for education on these issues, and found policies addressing them useful.

Q: *Do you think somebody at the facility would assist them, like making the call, making a safe space available for them to see a sex worker?*

A: *Yeah, they would do. Totally education though, because some people they might think that kind of thing you're not allowed to do that. But, through education, through training, they would get to understand their needs as well.* (S19M)

One staff member in particular noted that re-reading the policy really helped her gain confidence, despite the fact that she was somewhat uncomfortable addressing these issues:

A: *When I re-read [the policy] today, yeah, I thought it was good, because it reminds you about everybody's rights to have that intimacy and feel that living connection with other people; it's so important-it's important for their happiness. It reminds you that it doesn't matter how old you are, you still have those needs and desires. But how I would approach...whether I'm meant to instigate a conversation with somebody about how do you...whether that became part of my questionnaire; I don't know how comfortable I'd feel or not about it... I probably wouldn't feel that comfortable about it, but I'm also quite a sensing, caring... I'm quite an intuitive person, so if that moment was there and it was in my policy and I was allowed to... Do you know what I mean? I don't think I would do it without it being appropriate, but if it was in policy and I felt like there was just that little bit more that needed to be drawn out there, I think I would be able to do it.* (S24F)

One manager described how education was used in her facility to help staff manage situations they may be uncomfortable with:

> *I teach all of the staff intimacy in the elderly. So, everybody is aware that if they go into a room and a gentleman is masturbating, they just quietly back out, close the door and go back in half an hour. That's his right and so you don't get shocked or, "Oh, he did such and such," you just walk away. A lot of these people have had a normal sex life; their partner dies and it's cut off, but that doesn't take away the urges, the feelings, or the need. It's not offensive, and it's not dirty; it's just natural and normal.* (S23F)

Another manager had an interesting perspective on the sexual and intimate needs of residents, describing meeting these needs as a kind of care, akin to other intimate cares performed by staff.

Q: *What about when you have a gentleman or a woman for that matter, who has a sexual need that can't be met within the facility; have you come across that?*

A: *We did have one in this other facility I was working in, and we actually paid for him... it was a male; he paid but we arranged for him to have a female visitor, and again 'Do not disturb sign;' same thing. It doesn't say why you don't want to be disturbed, it could be that you're having a sleep or whatever. Everyone had them, so you weren't unusual. You didn't draw attention to the fact.*

Q: *So, all doors have those on?*

A: *Every door had a 'Do not disturb,' sign, and some of them had, 'Care in progress,' so what it intimated was that you were being washed or showered in your room, so please do not enter, so that was even more discrete. Because it was kind of a care that was in progress.* (S22F)

Residents

There was a notable difference between how men and women thought about the need for sexual intimacy. A number of male residents expressed the desire for intimate touch. One male resident, when asked if he would like a sexual relationship, responded: “Would I like a sexual relationship? I’m not sure I’m capable of the same sort of sexual relationship I used to have then, now. I’m 86 now; I’m past it more or less but it doesn’t stop me thinking about it”. (R10M).

Another male resident put it this way:

> *Being a male, I like to be touched occasionally. I mean, I do have help in the shower, but nothing sexual. There’s absolutely nothing sexual at all. And, that’s a wee bit hard to take, because I’m still trying to regain who I am sexually. It’s not some person who I don’t want to touch me touch me; in other words, I’m making the choice of who is touching me, rather than not having had that choice.* (R8M)

When asked if he was able to make that choice, he responded:

> *Yes, but it’s costing a lot of money. In that regard, I don’t really know what the answer is. Men’s needs and women’s needs are different. It’s not something that I think they’re very comfortable with, the staff, talking about it.* (R8M)

It was common for women to express lack of desire or need for sexual intimacy. “I wouldn’t want a relationship, no. I’ve been there and done that, and can’t be bothered again” (R2F). Another female resident expressed the sense of freedom this gave her:

A: *[Being partnered is] not a need anymore.*

Q: *And, how is that, to have that not as a need anymore?*

A: *Freedom. The freedom of spirit. To have anything you want in life. To make decisions for yourself. This is part of those teachings. The freedom of spirit.* (R20F)

Some residents experienced staff as receptive to people’s needs around sexual intimacy:

Q: *Who makes decisions here about the relationships people might have; so, if there was a couple say, who got together, would that be their decision, or do you think family or staff would or should have a say in that?*

A: *I think it’s funny you say that. I don’t know. I haven’t been in that position. We’ve got staff generally are pretty receptive to everyone’s needs.*

Q: *When you talk about that, staff being receptive to people’s needs, do you think that includes people’s needs around intimacy and sexuality?*

A: *I do, definitely.* (R11M)

However, it was more common for those who wished to engage in sexual intimacy to experience frustration – access to sexual intimacy felt to them like a privilege they had lost when they lost access to the greater privacy living at home afforded them. Accessing sexual intimacy in the context of a care facility was difficult and often involved a lot of money, as a male resident described:

Q: *In terms of privacy you feel you have a lot of privacy?*

A: *Yes.*

Q: *How does that compare to when you lived in your own home?*

A: *When I was in my own home, I was by myself. My wife died ten years ago. Then after that, during the day, I was by myself; so I could have anybody around that I wanted to have around.*

Q: *Is that the same here or different?*

A: *The same here. I’ll be straight up front and say, to get any sexual touch I’d have to spend a lot of money and not here, but go out for it.*

Q: *And, why not here? What’s stopped you?*

A: *Because people would walk in while I was having a massage or something.* (R8M)

While it was the case that a number of women expressed lack of desire or need for sexual intimacy, it was also the case that some women’s expectations were that staff would generally be less receptive to women’s sexual needs than they would be to men’s sexual needs: “I don’t think the nursing staff would offer masturbation to women, but they might to men, just to ease them, if they needed it. If they do, I don’t know about it” (R5F).

I’m 86 now; I’m past it more or less but it doesn’t stop me thinking about it.

Family

Some family members we interviewed also recognised the need their relative in care had for intimate touch, though the family members tended to experience this as something awkward:

> *There were people who were very tactile with us; like when we visited there were particular older women who would want to come and give you a hug, or sit next to you and pat your hand. Physical touch was something they were obviously really craving. They would always want to come and give the kids a hug and the kids would be a little bit awkward about that sometimes because they didn't know this person.* (F5F)

One family member in particular was very much on board with the idea that sexual intimacy was a need that the residential care facility should have a role in facilitating.

> *It could be encouraged, like posters around, 'Don't be afraid to ask if your partner wants to come and have lunch with you and you feel a little bit... and you want to become intimate.' Something maybe a little bit more eye-catching. It would have to be typed. It would have to be said correctly, just a little bit of encouragement that it's actually okay because it's a human thing. Maybe posters or maybe when dad, we had a social worker talk to us about dad going into hospital and none of that came into the pre-rest home talk. They did not get mentioned.* (F10F)

There were of course family members who were very much against the idea of their loved one engaging in sexual intimacy in the context of a residential care facility. But even then, it was common for the family member to recognise that rights were important here:

> *Q: If you knew that there were people in the care home that were–for instance, not everybody allows sex workers into the care home, but they might facilitate people being put in a taxi and visiting, how would you feel about that?*
>
> *A: Like I say, if it was my mum, no way. But other people have their own rights. If their family is okay with it, then sure. If they're safe and all that sort of thing. Do they have someone beside them watching that they're okay? Not beside them in there, but they could be taken off premise and bad things could happen to them. That's other people's decision.* (F8F)

Another family member said about a new relationship her father had formed in the context of a residential care facility: "Yeah, and he needs that; everybody wants to be hugged. Everyone wants to feel loved, so why would I deny that? I do it every time I leave him. It's no different" (F7F). The same family member had had a good experience with the way the facility treated her father's relationship, but was of the opinion that this kind of positive attitude was unusual in RACF:

> *This is the only health group that has that they are actually individual people and they have individual rights, and they have individual needs. A lot of the rest homes try and blanket them all as they are just residents and they just have to do as they're told, because our plan is this. I think that's why there's so many miserable people in them to be fair; I really do. Like I say; they have of their rights and everything taken away, and they just have to toe the line really, and that's a blanket thing right across everything they do including if they wanted to be intimate.* (F7F)

Section summary

It was common for staff, residents, and family members to recognise that for at least some people in residential care, sexual intimacy was a need. It was also common for staff and family members to recognise that being able to do things to meet your sexual needs had the status of a right, but what this meant in practise for the facility was less clear. Most staff members appeared to be comfortable with allowing people to meet their sexual and intimate needs 'behind closed doors', but what role the facility had in ensuring these needs were met was not so obvious to staff in particular.

It is clear that even if guidance such as facility policies recognise the right to sexual intimacy, it needs to be clear to staff what this means in practice – the language used by the staff member who described a resident getting their intimate needs met as "a kind of care" could be a useful way of reframing these kinds of needs in the minds of staff, family and the residents themselves. Education and training for staff which includes information about policies and guidelines should also include discussion of particular scenarios (both hypothetical, and those staff members have come across themselves) would help to reinforce to staff that their judgment on these issues is important, and that their experiences working in residential care will be invaluable in helping them to work through what application of policies mean in practice in their everyday

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Everyone wants to feel loved, so why would I deny that?

CONSENT

Care workers in residential care facilities are sometimes put in difficult positions when it comes to the sexual and intimate activities of residents, particularly in the case of residents whose capacity to consent to sexual activity may be compromised due to dementia. Care workers have the ability to intervene, and may feel an obligation to intervene when consent may be in question. They also have an obligation to promote the wellbeing and autonomy of residents in the context of intimate behaviour so far as is possible.

In our staff survey, more than a quarter of staff (33.4%, n=145) agreed with the statement "People living with dementias can never reliably consent to sexual intimacy with another person". However, when we presented staff with a hypothetical scenario, the responses seemed to differ. We asked participants to respond to a scenario involving a woman called 'Carol' who is a resident with dementia and can no longer make her own decisions about her personal care. In the scenario, Carol has been married to 'David', her second husband, for 20 years. One day when David is visiting you find them having sex. Carol appears to be enjoying it. Her daughter from her first marriage holds Enduring Power of Attorney. We asked our participants what they would do in this situation.

More than half of the respondents (n=232) mentioned that they would leave them alone but report the incident to their managers; sixteen percent (n=66) would leave them to it but check up on Carol later; 58 respondents (14.6%) said they would do nothing because there is not a problem with this situation, 29 respondents (6.7.0%) would let Carol's daughter know; 13 people (23.1%) would tell David to stop.

Despite that fact that 26.6 percent of staff agree with the claim that people with dementia cannot reliably consent to sexual intimacy, it seems that only three percent would attempt to prevent a person with dementia from engaging in sexual intimacy.

A possible explanation for this is that in our scenario, Carol (by stipulation) appeared to be enjoying the sexual activity. When we asked staff whether they believed that consent to sexual activity and agreeing to sexual activity are the same, 152 (35.1%) disagreed, and 156 (36.0%) were neutral. So, it may be that staff responses to the hypothetical scenario reflect the understanding that while a person whose cognitive capacity is compromised may not be able to give consent to sexual activity, they may nevertheless be able to give assent – and this might be the thing that matters morally in these cases, along with wellbeing.

Behaviour by itself did not however seem to be a reliable guide to whether or not a person could consent to sexual activity. When we asked staff whether it was easy to tell whether a person with dementia consents by looking at their behaviour, 203 (46.9%) disagreed. Only 90 (20.8%) agreed; 140 (32.3%) were neutral.

The qualitative data mirrored the significant level of disagreement seen in the quantitative data. There was disagreement about whether consent is possible for people with cognitive deficits – some participants think that people who are not entirely competent may still be able to give consent, others think that residents who have dementia are therefore not mentally capable of making decisions for themselves. Those in the former group tend to think that we can look to people's actions to see what they are comfortable with in order to ascertain consent. A number of people in this group seemed to be equating willingness with consent.

A related issue is when the current desires of the resident seem to be in conflict with their past selves. For example, when they enter into new relationships of a kind that they probably would not have chosen in the past it is not clear here whether what matters most is what the person is agreeing to and enjoying in the moment, or what they would consent to, were they cognitively competent.

Given the confusion in this area it seems that training and education would be useful, and indeed this view was expressed by staff.

Staff

In the interviews, some staff felt that people with cognitive impairments may still be able to give consent, or that even in the absence of consent behaviour was a good indicator of whether the intimate contact was unwanted or not. One female staff member stated that:

> *Well really the person's own cognitive competency that can be relative as well, sometimes people can be not entirely competent but still able to give consent or not. Really, I think you've gotta do that on a case by case or sometimes a situation by situation on just ensuring that consent is there, that someone's not intruding on someone's space when they're not welcome.* (S1F)

The staff member also noted that "Cognitive impairment does not mean loss of sexual drive, so it is about assessing the situation and ensuring consent has been attained" (S5F). The idea that cognitive impairment does not necessarily entail lack of consent was also reflected in comments from a third female staff member, who described a relationship that occurred between two residents that the family of one resident did not approve of:

> *I think she probably pursued it a little bit more than he did. I don't know about that earlier on actually, before I came along, but they were certainly both quite capable of knowing what they were doing. I wouldn't say they were both fully compos mentis, but they both knew what they were doing, there was no question of that. It was definitely consensual.* (S1F)

Several staff members noted the importance of looking at behaviours to ascertain consent:

Q:	*So, in essence, when you're looking at the consenting, you're really looking at what behaviours the residents portray that gives you a sign, a clear sign of their consent or not?*
A:	*They're not able to verbally consent, and if you ask them they may give you one answer one day and a different answer the next, so you actually need to just be aware of people's expressions, their body language and conflict; that's the first thing. Their social graces are lifted, so if they don't like something, they'll often say straight away or there will be an action.*
Q:	*That's really clear.*
A:	*That's usually very... one thing you can be sure of with people with dementia is whether they're enjoying something or not.* (S22F)

Other staff members disagreed with the position that residents with cognitive impairments were capable of consent. In a group discussion with other staff, one staff member stated that, as most residents in the care facility had dementia, and they were not capable of making decisions about sexual intimacy, the staff relied on the wishes of the family rather than the wishes of the resident (S2, Group).

One female staff member, in describing a situation where the staff diverted the attentions of a male resident from a female resident, described why they took this approach:

Q:	*Because you didn't think that she was really consenting?*
A:	*No. She was too much dementia. That's what I'm saying, people with dementia and Alzheimer's, cognitive memory isn't like... they can't make simple decisions; they're not capable of making a decision like that. When you met her we're standing there saying, "Do you consent to having and intimate and sexual relationship with this man?" They wouldn't know what the hell we're talking about. You know, they could walk in the room with that going anyway* (S9F).

The same staff member went on to describe how they relied on non-verbal cues to assess the situation:

Q:	*So, how do you decide whether they...*
A:	*We just let it take its course. Keep an eye on them, like, just watch your facials, body language.*
Q:	*How did you know with that lady?*
A:	*After a while she was getting, like, facials, body language; it was okay for a little bit. I think he just went a bit too...And so she started pulling back physically.* (S9F)

This position – believing that people with dementia cannot consent, but looking to body language to ascertain assent – was shared by another female staff member. This staff member held strong views about the ability of residents with dementia to consent:

> *Well, personally; especially in the dementia unit, they are not of their own mental cognitive state, so to me they are not consenting adults. I don't think it's right, even though if we catch anybody in a situation, we're supposed to just close the door and leave them be. I just feel if their families came in and saw that going on, how would they feel? I wouldn't like it if it was my parents in that situation. I just do not agree with it. We've had people out there... just wide open in the lounge; she undoes her blouse and the old man's having a lovely play, fondle, and then trying to get the lady into his bed and things like that. But, mentally they are not able to make that decision for themselves at all, and I just don't agree with it. Also, out here in the rest home side; yes, they can make that decision whether they want to or not.* (S11F)

Nevertheless, while doing her job this staff member was able to focus not simply on consent, but also on *assent*: whether the person appeared to want the sexual behaviour or not. In order to do this, she looked to non-verbal cues:

Q:	*[Name], when you see something happen; what's going through your mind? How do you assess, this is safe, or this is not safe; what are the sort of cues your looking for? When you know the person can't cognitively consent; how do you work out if they want to be in that situation or not?*
A:	*This might sound silly, but I actually stand in the door; just leave the door open and I just watch for a couple of minutes for each of their reactions. If it's, you know just very quiet and calm; I walk away, but then I still go back, and just have another little peep. As I say; nice, calm, and cuddly situation or whatever; I just leave them be, but I still do check. So, I definitely keep checking if I come across anything like that; I don't leave it and say, "Oh I'll just let them get on with it". I will go back and just makes sure that it's a safe situation.*

> Q: *So, you're reading their body language as such?*
>
> A: *Yeah. For a lot of them, you can tell on their facial expressions. I pick up a lot from facial expressions, or... their bodies if they don't want it to be happening. If they're sitting there and letting one person do whatever, and there's no reaction from them, then I think no, that's not right.* (S11F)

One staff member described the difficulties around consent, noting the 'shady ground': "I mean, we're going to get, as people are dementing and living longer; we're going to get into some really shady ground about consent and people's ability to consent, and what consent actually is and isn't". (S1F).

Difficulty around reconciling the views of the family with the wishes of the resident was another common theme, with one staff member noting that they had received some education around this (though later on in the interview she also expressed a need for further training around this issue).

> Q: *Have you encountered a situation where a resident's wishes about their own sexuality differs from those of family and what did you do about it?*
>
> A: *Yes, we talked about this in education and it was in the staff survey. There are so many variables that come into this. Some people are really good about parents forming relationships and other people can't stand the thought of it. EPoA comes into this too and family get involved with this. Family can be very challenging over this. We encourage the EPoA to work in the best interest of their family member. We have to work alongside families on these matters. We encourage families to be respectful of their family's wishes and not take over. If there is no consent then we obviously would get involved. (S5F)*

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Residents

Residents were less likely than staff to express concern around the issue of consent – this may be because the residents interviewed were unlikely themselves to have diminished cognitive capacities, and they were also of course not in the difficult position of having to make decisions about the activities of people under their care.

One male resident however noted that in some cases the relationships older people enter into are less complicated than the relationships younger people have, and that there might not be a significant difference when it comes to consent.

> *Q: Do you think if there was the opportunity that residents would be interested in education about later life sexuality?*
>
> *A: Either they're interested or not interested would tend to be my feeling. Later life experiences have a different social level than private younger intimacy and the likes. There's less inhibition in older people and less complication in relationships. That just comes with old age or with maturity of life. Restriction and inhibition flew out the backdoor generally. There's a very fine line between old age experiences versus younger experience, being consent and involvement. That would be my feeling on that.* (R9M)

Another male resident was in the facility, as was his wife, who had dementia. It was his belief that it would be wrong for him to engage in intimacy with his wife, on the grounds that she could not consent:

> *Well I've been thinking about this since you came in here. My wife suffers from dementia. As far as I'm concerned, to the best of my knowledge, sexual relationships with me are not on. I don't know whether... I mean, some little while ago I woke up with[wife]by my bed crying. I asked her why she was crying, and she said, "I thought you were dead. You were cold and I hadn't seen you for four days". Then she got all gooey, if that's the right word, which I did not respond to, as I possible should have done, because I don't think that a person with dementia is in a position to make those sorts of decisions. The following day, when I tried to raise the question with her she said, "What's it all about?" and she'd forgotten all about it. So, if I had taken advantage of her, to put it that way, that would have been very wrong I think. I don't think that she's in a position to make those decisions. I'm only talking about [my wife], I don't know about anybody else.* (R12M)

Family

Some family members shared the view held by a number of staff members that what the residents want is important, even if there are cognitive impairments that might affect their capacity to consent. One family member (a former registered nurse) described a situation in the residential care facility where her husband was a resident, noting that feelings still occur even if "the mind is not all there":

> *A: Yes, there was one lady there who her husband had died some time ago. She obviously needed a sexual relationship because she used to chase all the men. Some of their families actually took them to another rest home because they didn't want [their] dad cavorting with this other woman who wasn't his wife. But, I mean, we're still people. Even if the mind is not all there we still have feelings. As long as the other resident was okay with it, I don't see why the family couldn't be okay with it as well.*
>
> *Q: I was interested in what you were saying in this example, but also when you were working as a registered nurse. You seem to be saying that even if someone has dementia, your understanding is that it's not about necessarily having the mental capacity to consent, but it sounds like you're reading their body language. Is that right? Is that what you're describing?*
>
> *A: This particular woman, and I think she's probably died now but she was alive the last time I went there. Her husband actually died before she did; but he used to come in rain or shine to see her. She would always be so glad to see him. She obviously wanted a cuddle from them. There were others who would sort of go for a cuddle with somebody who they thought was their partner* (F1F)

Another family member had a father with Alzheimer's who has formed a new relationship with a woman living in the same facility. This family member also recognized the value of intimate relationships for people with cognitive impairments, and described how she would ensure the safety of her father (and the woman) – by asking if they were happy.

> *Q: What intimate relationship issues might be of concern for you; if he did want to start having sex with [Name]; would that be an issue?*

A: I think the only thing you'd want to check—that because she has a mental issue as well, is that he's not coercing her into it, and I know that sounds really awful, but with their particular illnesses, they'll either become quite dominant or quite submissive. So, if dad happened to be the dominant and she was more of a submissive personality, he could potentially talk her into it. I'd hate to think that something like that happened; I'd like to think they were both happy doing it. I wouldn't like to think that he'd bullied her into it or made her feel like she had to or anything like that. And consequently, the other way around; I'd hate to think that the same happened to dad, that if he didn't feel it. So, it would be finding out that they were both happy with that, and that's probably a matter of having a conversation with them individually, and saying, "Hey look; are you sure you you're okay with this?" I think the biggest barrier for them is the judgement of other people within the rest home. (F7F)

Like staff, family members experienced the issue of consent in the context of residential care as a conundrum.

Q: What, if any, benefits do you consider might occur if staff, structures, and policies in residential care allowed for people to continue intimate relationships?

A: I just think it seems like a fundamental human right really, to have that physical touch and have the ability to kind of continue that part of your existence, even though you might have changed where you're living, or how you're living. I do understand that the issue of consent can become pretty fraught in an environment where people aren't necessarily always clear on their behaviour and why they're doing the things they're doing; so, I can understand that it's really difficult. It's a conundrum for where the boundaries are with that. But, for people within say a long-term partnership, if one partner has gone into care, it does seem really important that there would be the possibility that they could have conjugal visits-or however you would describe it. (F5F)

One family member also expressed the desire for clarity, noting that the issues were complicated and there were "two sides of the coin":

A: I guess really I think there needs to be some sort of a test or something, to see what kind of level a person is at, like as to whether they can make intellectual decisions for themselves. I don't know. The family has got to be happy about it as well, and every family is different. It might not be a drama for some families. My sister and I would be quite horrified if that happened to mum; although it did actually happen to my aunty who passed of Alzheimer's, but that was prior to her being in the home that she was preyed upon by a woman. She did end up that way. But, if it was mum it would definitely be quite bizarre for us.

Q: From what I'm hearing you say, you think that when it comes to making decisions about relationships, when someone is in a care home, that families should have a role to play?

A: Yeah, I think so to a degree. There's personal rights as well, isn't there–human rights. But, I think with our situation, he's only very early onset, so he could be quite active sexually. She's not bad enough that she wouldn't know what was happening or anything like that, but whether she would consent to it–maybe. I guess, we just want her to be happy for as long as she's got left. But, if it was like say he was really bad, because I guess some of them can get quite aggressive if they're having sex, and maybe could grab someone by the throat and not know what they're doing or something like that; so, I don't know. I think just to have some sort of guide as to what or where they're at, and how consensual it is, or is it the dementia. Like, they wouldn't know what they were consenting to. I don't know. To be honest, like I say, I haven't really thought about it; so, I'm in two minds, because they are their own person, but if it puts them in danger in anyway, then families should definitely be able to step in. If it's something they both want and it's safe for them, well I guess. I believe it goes on quite a lot in rest homes and things like that, from family friends who are nurses and they've seen a lot. Two sides of the coin really. (F8F)

One family member in particular experienced a lot of distress over the issue of consent, due in particular to a disagreement with staff about whether her husband (a resident in a facility for people with dementia) could consent to sexual activity with other residents. This family member's feeling was that her husband was simply not capable of consent, and the fact that he was not objecting to this behaviour did not constitute consent (contrary to what the staff appeared to believe):

> *This business of consent, my personal feeling is they're not in the right frame of mind to consent. A lot of them could think, not talking about my husband, but just A and B, if you like, male and female, they might just say, "Yeah, this is nice". But if they don't know, if they don't recognise their wife or their husband anymore, it's a new friendship to them, isn't it? It's something new and exciting perhaps. I don't know... So, now I have an added journey with my husband. I am somehow having to incorporate this woman, but wanting to place boundaries, saying to the staff, "I don't mind her sitting with him, I don't mind her talking to him". There's a limit. I've got to be reasonable. But I feel I have the right to say, "I don't want her getting into my husband's bed because you're saying he's consenting because he's not objecting." Well, that day she got into bed with him and he was asleep.* (F6F)

The same family member also raised the issue of legal difficulties arising from treating assent as consent, having consulted her stepdaughter (a lawyer) on this issue:

Q: *Your question underlying that really is that if he's in such a deep sleep that the RN is concerned about him, then how does consent work in that situation?*

A: *It doesn't. It doesn't. This is what's really upsetting me, and my argument is in those situations, how can they be consenting. It doesn't make sense. But they seem to be sweeping it under the carpet. I'm wondering actually if it's just too big an issue for them to handle... When I quoted my stepdaughter, who's a lawyer, she's in [Region], her mother-in-law's in care and I must talk to her about this because she said there have been a couple of court cases where families have taken the facility to, I suppose, where they have ruled categorically there is no such thing as consent in a dementia unit. One of the papers I looked up last night said this. The lawyer concerned said, "This is ludicrous. There can't be consent in a dementia unit". But I will follow through with saying at the end of that paper that was presented, this firm of lawyers said, "So therefore if you have any issues, we're happy". So, maybe that's their way of drumming up business. I don't know. But [Name] was quite emphatic about this and it was the one thing that she said after her visit here, "It can't be. Dad would not consent to this. In no way would he".* (F6F)

Section summary

What is clear from both the data and the interviews is that there is a lot of disagreement and confusion about a number of issues to do with consent in the context of residential care, particularly in cases involving residents with diminished cognitive capacity. There is disagreement and confusion about what consent is, how to tell whether a person is consenting or not, and when and why consent (rather than agreement or assent) matters. It is also clear that this disagreement and confusion is causing significant distress, particularly for staff and family members.

Some specific interventions which may be of help to staff, residents and family members would include clear and specific guidelines available to all, outlining (for example) that residents who have the capacity to consent have the right to make decisions about sexual intimacy without staff intervention and without consultation with family members. Where a resident's capacity to consent is in question, it needs to be clear to the family what procedures will be followed and when (and to what extent) they will be involved.

Specific education around consent for staff would also be useful. In particular, it should address the fact that residents whose capacity to consent to sexual activity may be diminished nevertheless may be able to make choices about sexual intimacy, and may benefit from engaging in intimate relationships. The role of staff in this context is to act as a guardian of a resident's welfare, rather than as gatekeeper of intimate relationships.

DECISION-MAKING AND ENDURING POWER OF ATTORNEY

In our staff survey, the majority of respondents (n=314, 72.5%) agreed that they felt confident in their ability to make ethical decisions that balance residents' rights and residents' safety. However, the qualitative data show significant disagreement about who should be involved in making decisions around sex and intimacy in aged care.

Staff generally saw their role as one of supporting decisions made by residents, regardless of their personal values. However, despite the fact that the majority of staff felt confident in their ability to make decisions, on the whole staff identified decision-making as a dilemma. On the one hand many staff felt they had a duty to involve the family in any decision-making, but on the other hand they felt they had an obligation to protect the residents' autonomy and privacy. Advanced directives were rarely mentioned, but one staff member expressed the view that they might prove useful in managing decisions. One particular issue which cropped up for a number of staff members was dealing with Enduring Power of Attorneys (EPoAs) – family misunderstandings about exactly what an EPoA meant often resulted in the family expecting more control over their relative's decision-making than was appropriate given the circumstances.

Residents were acutely aware of their lack of control in the residential aged care environment. This included the control the staff had over their environment, and the control their family were given when staff passed on information or included them in decision-making. Financial control was a particularly troubling part of this. While other residents did not exercise direct control, some residents expressed concern about other residents knowing their business or gossiping about them. Most residents felt that any decisions around sex and intimacy should be largely up to them, and that any decisions they made were not the business of staff, other residents, or their family (especially their children).

Family members differed quite substantially in their views on decision-making around sex and intimacy. While some family members of residents were entirely supportive of the resident being able to make their own decisions, other family members were deeply resentful of what they experienced as loss of control over their loved one's decision making, and felt displaced by the facility. Other family members had no wish to be involved or informed at all.

Staff

The importance of leaving personal attitudes at the door was a common theme in the interviews we did with staff. A male staff member who noted the importance of what he described as "putting away his own culture" had this to say about his role:

> *I'm not in the role to judge or this is wrong, this is right, but it's not me. My role here is as a nurse; my role is, I have to duty of care to look at the patient holistically, not just the medical needs, but of course you've got emotional needs, and that's what we are here for, is to enrich that.* (S10M)

He was not the only staff member we interviewed who mentioned the idea of putting aside one's culture. A female staff member who worked with a diverse team commented that similar discussions had been had in her facility:

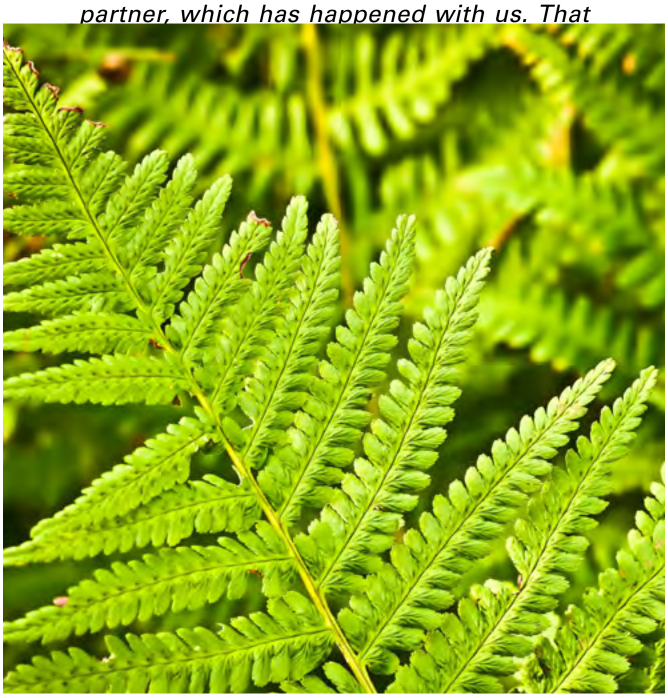
> *Yeah, that's quite funny, because we've got quite a diverse cultural range of staff here, of different ethnicities and religious beliefs, and some were like, "Oh my goodness," particularly with the first example [involving two people in the dementia unit sleeping in the same bed]... "This cannot happen; he's married, she cannot go near him, this is just not right." They would get quite physical and yell at her and things and say, "You can't do that; you have to leave your beliefs and standards at the door, and just remember your role here is to keep people safe and to care for them, and that doesn't mean making judgements about their behaviour". We did have talks about it, but once people saw that actually there was no harm being done, they were quite fine and they were like, "Oh, what's the big fuss all about?".* (S22F)

Another female staff member expressed similar sentiments, and also noted the role management plays in influencing the attitudes of staff:

> *I definitely think under this new management that it would be looked at quite differently. I can remember a discussion coming up in the old days about... there was someone here that might want to use prostitution services or something like that; that's fine, we have to facilitate. That's his choice and we don't make any judgement on it, kind of thing. My previous manager, she was always very business-like and official about things and rights were rights, and we had a neutral face about people's personal decisions and that whether we personally liked it or the idea or not; it was, like, up to them.* (S24F)

While staff were generally confident in their own decision-making abilities, and (as the examples above demonstrate) their ability to make decisions without their own values and culture superseding the wishes of those under their care, many of them still experienced decision-making as a dilemma. In describing this difficulty, a female staff member described attempting to protect all parties in a situation where the family was not on board with a new relationship:

> *Well protecting them and protecting everybody else. I mean nobody wants to see their mum do they...you don't want the kids to walk in go, "Oh my god!". So, there's that as well. Obviously the conversation about where relationships occur in the rest home, where the kids don't like attracted partner, which has happened with us. That*



A number of staff raised the issue of EPoAs causing problems, particularly when it came to family members with EPoAs expecting to have input in decision-making. In situations involving residents with dementia, things were a more clear-cut – the person with the EPoA was the "first line" (S2Group) when it came to decisions about sexual intimacy. However, family members with an EPoA often expected to be consulted even when their relative was still perfectly capable of making decisions for themselves. One staff member described saying the following to a family member who expected to be involved: "Look, both parents are still *compos mentis*. You may be appointed as Power of Attorney but at this stage you cannot overrule what Mum and Dad wants. We would have to respect that." (S12F)

The staff member dealing with the tricky situation described above emphasized the importance of getting the family onside, and building a good relationship with the holder of an EPoA:

> *I think for me it is very, very important for me to be build the rapport with the family. It makes it also easier when advocating for a patient. Because you're bound by the legality of, "No, you're not supposed to do that; we have an EPoA", you know? So, if there's a dilemma there, and for me it's like if the patient is fine, they are able to... it's the same thing as she can always ring, or if she wanted to let's say an outside contact or what have you; basically she can do it on her own. I can always facilitate that, but I don't have to do it myself, you see what I mean?* (S10M)

This same staff member was one of a few who also mentioned that advanced directives would be helpful in situations involving residents with dementia.

As well as family and staff interference in decision making, one thing that impacted residents' choices around sex and intimacy was the lack of privacy, or the feeling of being under surveillance.

Residents

Some residents were okay with staff being involved in their decisions. One female resident stated that while she felt comfortable with the relationships she had, she did not feel in control: "I do allow the staff to be in control and I am quite happy with that". (R13F)

One resident described family members being supportive, but stated that he would have been guided by their opinion had they not been supportive of his relationship:

Q:	*No, that's right. Who makes the decisions about relationships that you have, or might have; would that be you; would that be your family? Would that be staff?*
A:	*I'll just give you a little instance. It's a wee while ago now, but I was at a church meeting—it was in a house but it was a church meeting—and I met this lady and we got on fine together, and in my alternate way we're having a laugh, and I was saying goodbye and I kissed her, and she phoned somebody up and said (it was like a teenage thing again)"I'd like to go out with him." This person phoned me, and I thought, 'Oh well that's nice', and we had a couple of dates; and neither of us wanted to take it any further I don't think, but it was nice.* *So, I've got a son here, and a daughter; oh, and a sister who lives in [Town], and I put it to them, "What do you think? Should I go?" They said, "Go for it". I wanted the family to know that I've got this date because I didn't want them to be surprised by it. So I decided to say, "What do you think?" "Go for it, dad."*
Q:	*Yeah, great, and what if they had said, "No dad." What would you have done in that instance, if you had been really keen and they're not supportive?*
A:	*I think I would have probably let it drop.* (R10M)

A strong theme however was resentment from residents about what they perceived as interference from others, particularly from family. Male residents in particular seemed to strongly resent family interference. One male resident was particularly annoyed with the way both staff and family responded when he "rang a lady from the paper":

Q:	*The staff rang your family you mean?*
A:	*I said, "She's my daughter, not my mother." I got bloody annoyed about it.*
Q:	*So, in that situation you just mentioned, the staff informed your daughter that you had called someone in?*
A:	*I told them. I said, "You don't need to keep ringing my daughter all the bloody time; mind your own bloody business." It's nothing to do with them.*
Q:	*Was your daughter okay about it?*
A:	*That's what she wants; she wants to know what's going on all the time. I said to her, "You're not my bloody mother, for Christ sake shut up and keep out of my business."*
Q:	*So, you were very clear this is your decision and nothing to do with her?*
A:	*That's right, nothing to do with them.* (R3M)

Another male resident who was not currently interested in starting any kind of relationship in the context of a care home nevertheless had strong opinions about who should be making the relevant decisions:

Q:	*What about, I'm just wondering, say, you were interested in starting a relationship with someone or you just met someone that bowled you over, whose decision would it be for you to start a relationship? Would that be your decision or would your family or would staff have some sort of say in that?*
A:	*I'd bloody hope not. I'd hope it would be my own decision. I don't think it's got anything to do with anyone else.* (R24M)

As well as family and staff interference in decision making, one thing that impacted residents' choices around sex and intimacy was the lack of privacy, or the feeling of being under surveillance. In the context of a discussion about whether there would be sufficient privacy in a residential care facility for a resident to masturbate in their own bed, one resident stated: "You're very self-aware in a place like this. You don't do anything unless you double-check it. You're continually self-aware" (R9M).

Another resident noted that it was not just staff who contributed to a lack of privacy, but also other residents: "We don't have so much privacy. In here things travel very quickly between residents and staff, and management seems to know everything that goes on" (R22F).

Family

The family members we interviewed had quite divergent opinions about whether (and the extent to which) they should be involved in making decisions around sex and intimacy for family in residential care. Some family members felt that family and staff should have very little input:

> *Q: You wouldn't have any sort of objections to that. Who makes decisions about the relationships your relative might have? So, you're in the situation where your mum is in a married relationship, but say for example she wasn't and she did want to re-partner with someone, who would be...*
>
> *A: She would.*
>
> *Q: Do you think staff should have a role to play in that?*
>
> *A: I kind of think by 75 you're old enough to make your own decisions really; unless it was a destructive thing. No, I don't think they need to.*
>
> *Q: Do you see that you might have a role there in overseeing that it was okay?*
>
> *A: No, because I figure if anyone wanted a relationship with mum it would be her, because she's got nothing else; it's not like she's a millionaire or anything. It just would be her.* (F9F)

Another family member said that while he didn't expect to be involved, he thought his sister might want to be:

> *I don't know that the staff should have any say really. I wouldn't expect the staff to be on the phone to me saying, "[Name] did you know that?". I would have something to say about it, but mum's an independent woman and it's her life.* (F11M)

When asked if he would want to be kept informed about his mother's relationships (for example, if she was holding hands with another resident) the family member replied:

> *Actually no. I wouldn't want that level of information. Not because I'm not interested, because I probably would be interested; but I would feel uncomfortable if my mother was in a place where everything that she was doing was being noted and passed onto me. I don't require that level of scrutiny and I don't want it for my mother, to be honest. I wouldn't expect and I would discourage the staff from getting in touch with me saying that they had seen my mother with another man, or whatever. It's simply not my business. Nor is it theirs.* (F11M)

Some family members however felt strongly that they should be involved in the decision-making process. One female family member stated that while she thought that her view probably would not be taken into account, she felt it should be: “Because I would know what’s good for him [male relative in care] more than them [staff], so therefore I think I should be listened to if that should arise. But, I can’t see it happening” (F12F).

Another female family member we interviewed echoed the view that her being kept informed was important for monitoring her mother’s welfare.

> *Q: You’ve got power of attorney, which of course is either with property or personal care; but when it comes to relationships, who makes the decisions about who mother can have relationships with? Is it you? Is it her? Is it staff members, or other family members?*
>
> *A: You’d kind of think mum, but then it would have to be I guess that we would look at having some say in it, I guess, if we think that’s not right, or it’s not a healthy relationship. Would the staff? I don’t know. If they think it’s not a healthy relationship you would hope that they would say something to us at least. I mean, if it’s not good for mum, yeah, I would hope that they would say something.* (F2F)

One family member in particular found being left out of the decision-making process particularly painful. Her husband, a resident of a dementia unit, was involved in a relationship with another woman in the residential care facility in which he lived. From the perspective of the family member, this woman was targeting her husband, and having an extremely detrimental effect on her relationship with her husband. She experienced particular difficulties working with the staff of the care facility to manage the situations:

> *If I could just go back to that meeting with the clinical manager, and she has put it in an email to me because I put everything in writing to her initially. When she came back, she said she had been in and monitored the situation. I don’t know how long for. And in her opinion, everything my husband did was consensual. That made me go through the roof, because I do not believe such a thing exists in a dementia unit. I have heard a court rule that if a resident doesn’t have capacity in a dementia unit, then they don’t have the capacity to say yes or no to a physical situation. Now, I know that’s a huge argument at the moment because a lot of the research I’ve read to date this week online, says the opposite. It says although the resident doesn’t have capacity to run a bank account or do this or drive a car or what have you, they are still able to make decision over their emotions and their physical requirements.*
>
> *I don’t agree with that in my husband’s case. I can’t speak for any other resident. People in the early stages of dementia, maybe, I don’t know, because I know some forms of dementia, I think vascular dementia in particular, they do become more physical. We have one resident in the facility at the moment that just takes his clothes off. That’s fine. I usually spy him before he walks into the dining room at dinnertime so I can say to one of the staff, “I’ll do the dinners, you see to... he’s in the corridor with no clothes on”. And that’s something I’m happy to do. When I am here for those four hours, I do help. At dinnertime, I will help give the meals out and clear the dishes and do this and that. I don’t mind that. I’m not blaming the staff. But I feel a lot of the support I receive from them has gone, possibly because they feel things have settled down a bit. But they’re not in my position. They’re not seeing it from where I’m seeing it.* (F6F)

Section summary

It is clear that despite the fact that 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, decision-making around sex and intimacy is still the cause of tension between staff, family members and residents.

It is not clear to family members and residents who will be kept informed, and when – and there is substantial disagreement about who should be involved in the decision-making process. This not only has the potential to cause difficulties, it is clearly already causing substantial heartbreak and resentment for a significant minority of residents and family members.

At the very least, it should be clear to all involved how the decision-making process around these issues will work, who will be involved and when, and (most importantly) why this is the process in place. In particular, it needs to be clear to everyone involved exactly what an EPoA is, when it comes in to force, and what rights and responsibilities it entails. Such clarity would go at least some way towards mitigating the confusion and resentment that residents and family members are feeling in difficult circumstances, and would help staff manage relationships between all parties more easily as well.

Staff are frequently in the position where they have to exercise judgment about complicated cases, and manage the involvement of family members. As illustrated by the interviews, the ethical issues which arise in residential care are difficult, overlapping, unexpected, and sometimes really context specific. This in turn has implications for what kind of education would be the most useful – education that encourages staff to use their own judgment and moral reasoning skills to make decisions, rather than simply gives people a list of rules to apply.

ROLE OF THE FAMILY AND PRIMACY OF CHILDREN

This section describes findings about the role of the family and the primacy of children in relation to residents. Closely linked to this topic is family involvement in decision-making, which has been covered in the above section on decision-making. Analysis highlighted that families' engagement covered a spectrum, from intensely involved in the life of the resident to absent altogether except in some cases for significant events. The transition to care resulted in filial grief and guilt especially if the children had played a significant part of the decision about the move to residential care. Residents' loss of independence is covered in the section below on transition to care. However, there was a corresponding experience of loss for families and children of the person moving into care. This loss was sometimes reflected in something of a role-reversal, where the adult children took on an oversight role in decision-making. There was evidence of diverse experiences of the partnership between facility staff and family members. These relationships depended on whether staff and family members had a shared mental model of what was in the best interests of the resident. The default position for many staff was that they deferred to family members' decision-making around the resident's wellbeing often regardless of the resident's cognitive ability. From the residents' perspective, some tried to limit the role of the family by trying not to be a burden on their families. The data also highlighted tensions between families, especially if two residents formed a new friendship or relationship on the facility.

Staff

Often staff found themselves in the position of managing family relationships. Generally, any intervention was due to the impact staff were seeing on the resident. In this situation for example children were struggling with their estranged parents rekindling their relationship after many years of being apart.

> *Then when we had this family group meeting here one day, they were telling us, "They're not friends, they hate each other", and I said, "You know what? You have to let that go. You're putting that onto your parents. Somehow you have to go and have help and deal with what you're going through, because your parents in this very last stage of life, have found something together that maybe they didn't have from 60 years ago".* (S3F)

Often staff felt it was part of their role to help family members to adapt to having their relative live apart from them. One manager described how she advised a family member to limit their involvement for their own wellbeing.

> *I always say once or twice a week is plenty. This is with demanding high-needs people, because they're really not going to know whether you've been the next day or not, and you're totally basing your whole existence around this one person that is actually perfectly okay, and is not going to crumble to pieces if you don't turn up one day.* (S22F)

Although the manager may have considered her comments were freeing, this opinion may undermine a partner's moral view of loyalty, the pleasure of the moment-to-moment being with a person. The family member may not appreciate being told that their presence lacks meaning.

Filial guilt clearly impacts on relationships between staff, residents, and family members. The following staff member expressed the view that guilt could lead family members to be excessively critical of staff.

> *We get a lot of filial guilt, guilt from kids who are putting their mums in the rest home, or dad in the rest home; they feel crummy about it. Often we can be a scapegoat for them. How come you let mum fall etc. because they feel bad.* (S1F)

Staff reported maintenance of relationships between the resident and their family a challenging area. Several staff found the disconnection between family members and residents sad and were upset on the resident's behalf.

> *Some people here they don't see their children very often; some people don't see grandchildren [....] We have people here with seven children and only two of them have ever been here. I get the odd email and I'm asked to print it out and pass it on; things like that [....] I don't think I'm ever going to change, but there's been lots of things here that just make you cry. I just think the disconnection in people's lives is unbelievable.* (S3F)

In a rest home that had a mental health contract as well staff found it was difficult to foster family connections for the residents. This situation was especially hard if the resident was really missing their family.

> *[W]e know with our set-up here, [....] our rest home means we focus mainly as a rest home, but we do have mental health clients. Some of the mental health clients, their families don't want to have anything to do with them. They don't visit. There is no communication and no contact, so they are just on their own here.* (S19M)

A staff member described how she supported a mother and daughter through the initial transition process.

> *[T]he daughter had some sort of separation anxiety. So, she was looking after Mum for the past 15 years but she has was needing more advanced care. She has to have Mum in here. She asked me, "Can I please stay here for the next two weeks? I'm going to go to work but I would want to sleep right next to Mum". We accommodated that. It was very interesting the reaction from the staff; and they say, "Can we actually do that?" I said, "Why not?".* (S12F)

Of note it appeared that the staff member had to advocate for this plan; it was not routine for residents to be offered this sort of transitional support.

Staff recognised how difficult it could be for families and friends to maintain their relationships with a resident when the previous reciprocity was no longer possible in the relationship.

> *It does take a lot of effort in some cases for people just to participate in the life of someone who is in residential care. It is because you've got to be the one to come and see them, you've got to be the one to take them out shopping, and you know it's going to be a little bit more effort to do that. Not everybody gets that attention.* (S1F)

Challenges frequently escalated with family when intimacy and sexuality were involved as they often wanted to be the power holders over decisions on the residents' behalf regardless of the resident's opinion and cognitive ability.

> *Some people are really good about parents forming relationships and other people can't stand the thought of it. EPoA comes into this too and family get involved with*

> (S7F)

With other family members they couldn't be more supportive for example in this situation organising a sex worker where the niece would take the resident home so the sex worker could visit him there

> *His niece, if it got so that he really wanted this, and he was determined; they'd have to pay for it out of his petty cash, and that she [the niece] would have to take him home, and she'd [sex worker] come there, and that's how they'd do it.* (S8F)

However, the primary role from the staff perspective was of the family as decision makers in the residents' care. This situation often created a dilemma as the staff focus was the present wellbeing of the resident.

> *If family said under EPoA, "Stop" [a sexual relationship], then it would have to be investigated if they have a right to do that. Where does the person's desire fit in?* (S7F)

Staff noted that even when families were very involved in ensuring the resident's wellbeing, the consideration of sexual wellbeing was typically not in the mix.

> *Kids never want to know about parents' sexuality, it's an important part and they are usually the decision makers.* (S1F)

Residents

There were two main themes related to family within the resident interviews: the importance of the ongoing relationship with them and the decision-making role that families either held or wanted to hold on behalf of the resident. Some residents described what they perceived to be respectful, loving relationships, while other residents experienced their family members as controlling, and were keenly aware of their approval or disapproval.

Several residents talked about how they valued their relationship with their family. This connection was significant as their diminished social network made them much more reliant on their family for outside contact as well as assistance with resources.

> *I have daughters and I have grandsons that visit me reasonably well. I get regular reports on what's going on. I still have an interest in what they're doing. I'm interested, but I can't get out and go and watch them like we used to and things like that.* (R4M)

The following resident wanted to live in residential care as she perceived her family were busy. However, she was grateful that they were able to assist her financially at times. This support highlights the level of dependence on family that is wider than merely social connection.

> *It saves my kids looking after me, because they're all working. Bit short of money sometimes but the kids give me money if I need some.* (R6F)

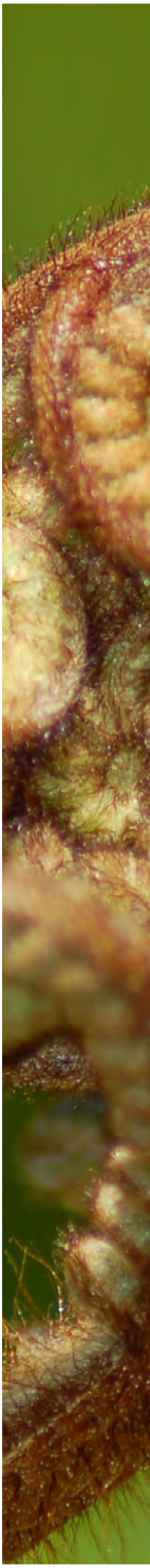
Residents for the most part appeared keen not to rock the boat with their family, on whom they depended for ongoing social connection. In the following quote a resident described seeking her sons' approval to embark on a new relationship.

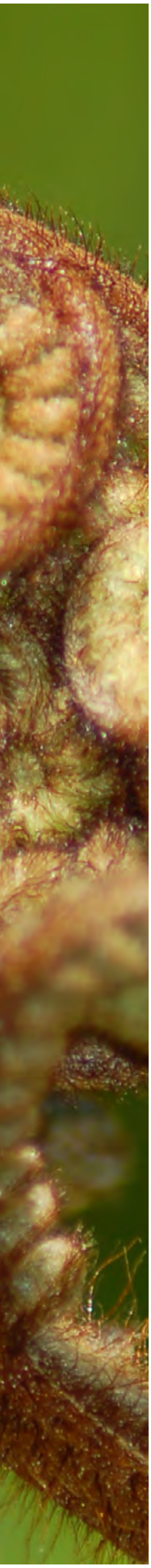
> *When I first met [male resident] I asked my sons if they minded if I had someone in my life and my son said that was the best news he had heard, he just told me to be careful.* (R16F)

The same resident described the reaction of the daughter of her new partner (another resident), who did not want the relationship to continue.

> *I have a rather nice relationship at the moment with one of the boys [another resident] in here. The daughter is against it and that has upset the relationship. [....] I said, "I have waited 50 years to go into a relationship and I would love to go into a relationship with you, if your daughter will allow it". I knew damned well she wouldn't. So, he said, "Let's just see what we can do". I agreed. I told his daughter that she had spoilt her dad's relationship with me. [....] I told her, if was about his money, I have probably got more than him. We share any expenses; I don't want him to pay for things. I don't look at it that way. Her dad and I would sit together, hold hands, have a good night kiss and a kiss in the morning. I told her I love it, I wait for that. I told him I hadn't been with man for many years and that I was not looking for marriage. I told her she has spoilt her dad's enjoyment. She did not speak about this in front of her father. He was shocked when I told him.* (R16F)

Data highlighted that it could be distressing for residents to maintain control over their lives due





to family members believing they knew what was right for the resident.

> *[My Daughter] gets very forthright about things; but I would have an argument with her. I know I always end up crying and she's saying, "Don't cry, you're always crying over things". Because I can't cope with her. She's so overpowering. I know she loves me and because of that later on she'll text me something nice.* (R13F)

> *My son was very good with the money and they got me into here. But having said that, because I am in here, I feel that they would feel resentful if they thought I was resentful that they have taken over. I feel that all my money has gone, on the other hand my son said, "Dad, what are you going to do with it? You are cared for there, you get your meals, they look after you, what you need to pay for?". I accept that in one way but in another way it is different, this is not what home was.* (R14M)

Although some residents commented that they trusted that family members had their best interests at heart, they found the loss of control a painful process.

Family

The family perspectives again were mixed in whether the role of family was a decision-making one or not. A sister expressed her view that she would have limited influence in enabling her gay brother to have a relationship in a Catholic-run facility:

> *I would know what's good for him more than them, so therefore I think I should be listened to if that should arise [possibility of a relationship]. But, I can't see it happening.* (F12F)

The wife of a resident described her discomfort at the power relations in her conversation with the facility manager when she expressed upset about a relationship her husband had formed.

> *Meeting with the clinical manager was akin to I suppose placing myself in the head mistress's office back at school. I was stunned at the lack of support I got from that meeting.* (F6F)

Family members were aware of the varying levels of support other residents received in terms of support from families.

> *I've seen these unfortunate ones there. It's like their family put them there, and then they forget all about them; out of sight, out of mind. That sort of thing, and I've seen that in about four different rest homes. So lucky with our children, and our great-grandchildren, our grandchildren. They're just marvellous, and they think the world of [Companion's Name] too.* (F3M)

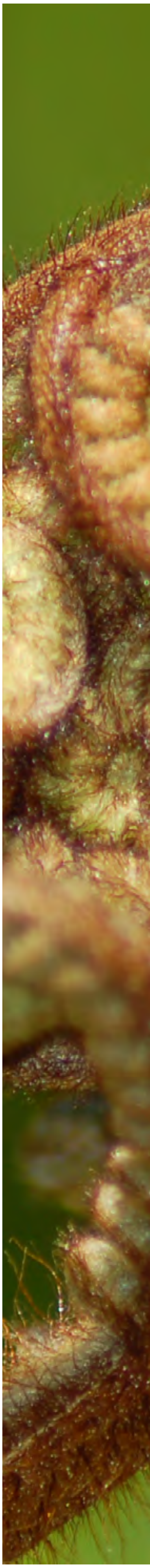
However, a resident's wife considered that she was judged because she did not have the same liberal view that she believed other residents' family members might have if their resident relative formed a new relationship while married.

> *I think some families take a backseat. Usually it comes from sons and daughters funnily enough. This is what I've read. "Oh, if mum or dad, if they're happy, look how happy they are together. This is their new friend. We'll just let it go".* (F6F)

Family members appeared to believe that in order for their relative to live within a facility they had to compromise at times on what they felt was best for the resident.

Summary

Data highlighted the considerable tension that occurred at times around the role of the family. Staff, family members and residents did not necessarily have a shared view about their role, and in particular their capacity to influence residents' lives. These discrepancies led to contention and in some cases a negative influence on the residents' wellbeing and created challenging situations for all parties to navigate. The key roles from all perspectives were firstly the ongoing relationship and inclusion of the residents in the lives of their family members; and secondly the tenuous role in decision making that family members held outside of the EPoA assignment. Staff and residents were both exposed to mixed responses from family about decisions about resident wellbeing. Filial guilt and the experience of loss from the family perspective impacted on relationships between the facility staff, the resident, and the family. The dataset highlighted that all parties would benefit from education about EPoA, and about the rights of residents, and about the scope and limitations of family members' rights to intervene in residents' lives.



Greater understanding of the complexity of Māori understandings of these issues could be achieved by a more focused exploration of te ao Māori in relation to intimacy and sexuality in residential aged care.

MĀORI

On the marae, mātua/koroua and whaea/kuia work in partnership/unison complementing each other's role. Neither one is more important. For example, it is whaea/kuia who karanga visitors onto the marae and koroua/mātua who do the whaikōrero. These are roles that are generally undertaken by kaumātua (koroua and kuia), Māori men and women senior usually in age and experience. Not all Māori achieve this status, especially those who are not connected to their marae. However, for those who are, as they get older the focus of their life becomes more about upholding the tikanga of the marae and supporting events like tangihana and marae-based celebrations.

Kaumātua relationships are often formed in a way that supports this part of their life. For example, an elderly man and woman may be seen as a partnership and have a strong relationship with each other that is based on respect for the roles they hold as protectors of the kaupapa rather than an intimate and personal relationship. An example of this is a couple who were well known to the author and were uncle (age 70) and niece (age 75). Many people thought they were husband and wife because they travelled to almost all hui together supporting the kaupapa o te rā teaching tikanga, modelling tikanga and upholding tikanga Māori for many years after they had both retired. Both had partners who had died several years before. The number of hui they attended or were invited to attend often wore them out, but they always considered what was important and saw each kaupapa to its natural end. They grew old doing this and being loved and supported by a huge and constantly growing supportive whānau and network. They constantly encouraged other elderly people to join them and the group attending grew. It also meant they set an example for attending other social functions like kaumātua hui, social gatherings and other kaumātua activity provided by community health providers.

For this couple, the roles they played on the marae and in their world as kaumātua defined their relationship. It was an intimate relationship based on their individual lives as Māori and their current status as holders and transmitters of tikanga and reo. They cared for and respected each other and all those who were around them. Their intimacy was based on their intellectual, spiritual and whānau connection rather than a physical, romantic, or sexual connection.

The concept of residential care for Māori is relatively new given the numbers in care throughout Aotearoa New Zealand. In November 2018 the *Aged Residential Care Quality Improvement Programme (Health Quality & Safety Commission New Zealand/Kupu Taurangi Haurora o Aotearoa, 2018)* report found that 1,868 (4.1%) of over 65 aged group in aged residential care and 0.24% of all Māori in New Zealand identified as Māori. By comparison those that identified as non- Māori were 42,803 (94.1%) of the over 65 aged group and 0.87% of all non- Māori in New Zealand and those identifying as Pacific 803 (1.7%) aged 65 years and over and 0.25 percent of all Pacific people in New Zealand. This shows firstly that there are smaller proportions of Māori and Pacific people reaching the age of 65 years, which reflects yet again the health inequities experienced by Māori. Secondly there is a lower percentage of Māori and Pacific people over the age of 65 years in aged residential care. In the disability sector it is clear that Māori have a different view of disability to non-Māori which leads Māori to care for their disabled whānau at home. This approach is similar for kaumātua who often prefer to be cared for by their whānau. In comparison, in 2010 10 percent of staff in RACF identified as Māori (GrantThorton, 2010; more recent statistics could not be located), which suggests that the sector is staffed by Māori at a ratio that could support more Māori kaumātua to be cared for by Māori kaimahi.

In this project, 29 (6.7%) respondents to the survey identified as Māori, 281 (64.9%) who identified as non-Māori and 123 (28.4%) who did not identify their ethnicity. Five kaimahi (staff) interviewed out of 24 (20.8%) identified as Māori kaimahi, and only one out of 26 (3.85%) residents (kaumātua) interviewed identified as Māori kaumātua. Despite our efforts, no family members interviewed identified as Māori.

Our analysis of the survey findings shows some interesting and statistically significant results that suggest a cautious approach by Māori to sexual intimacy as a right, a right to same-sex intimacy, and access to sex workers. We explore these findings below.

The survey asked respondents to respond to the statement "Intimate relationships with pleasurable touch are a life-long human right". Significantly fewer Māori respondents (19/29, 65.5%) agreed with this statement than NZ European (126/151, 83.4%; *p*=.04). Importantly, seven (24.1%) of Māori respondents were neutral about this statement, which could suggest a decision not to engage with the subject. A similar response profile emerged about same-sex sexual intimacy. Significantly fewer Māori respondents (13/29, 44.8%) agreed with the statement "Two male (or two female) residents have the right to be sexually intimate with one another", compared with NZ Europeans who agreed (116/151, 76.8%; *p*=.02). Likewise, significantly fewer Māori supported facilities' providing access to sex workers for residents (6/29, 20.7%) compared with NZ Europeans (61/151, 58.3%; *p*=.05). It is possible that the influence of Christianity through colonisation could be contributing to some of the reticence to discuss or acknowledge openly things of a sexual or intimate nature, although three-quarters of Māori respondents identified themselves as having 'No religion' (q.v.). However, there is also a deeper understanding of wairua for Māori which is related to the tapu or sacredness attributed to intimacy and sexuality. Within the spirituality and tapu constructs there is an understanding that there are greater forces than the individual and their individual 'rights' or personal desires. Decisions to engage with the intimacy and sexuality have impacts wider than the individual, and therefore what is important is wider than the individual.

Another area explored with staff in the survey that demonstrated a significant and, on the surface, surprising result, is wellbeing. Significantly fewer Māori (13/29, 48.8%) agreed with the statement "Sexual activity may improve older people's wellbeing and mood" than NZ Europeans (111/151, 73.5%; *p*=.007). However, a greater proportion of Māori (15/29, 51.7%) than NZ Europeans (35/151, 23.2%) scored this question as 'neutral', again suggesting that Māori might be unwilling to engage with the topic. Linking sexual activity to wellbeing may be similar to the privacy/tapu situation discussed above, or it could be that the binary choice 'agree/disagree' does not adequately reflect the complexity of how this issue is understood by Māori. Again, sexual activity is not generally discussed openly in Māori circles, and often opinions for Māori come from a collective or whānau perspective view rather that from an individual. If the subject is not openly discussed then there is no collective viewpoint to offer on an individual level. If an individual puts their own view forward, they could risk breaching tapu.

Responses to another wellbeing statement, "My main responsibility is to ensure that the 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" reflected a similar sentiment. Only eight (of 29, 27.6%) kaimahi agreed that this is a staff responsibility, compared with 88 (of 151, 58.3%; p=.006) NZ European staff. There is no doubt that wellbeing is important to Māori. However, the intent of the question was to force a decision about sexuality and wellbeing even in the face of family disagreement. Therefore, in analysing the response to this question, we must ask whether it is the wellbeing component or the whānau agreement component that kaimahi are responding too. It could be that this question, with the wording "family members might not approve", suggesting the whānau perspective could be being ignored, that was troubling to Māori respondents. This may not be the same as thinking that staff responsibility for wellbeing is important. From a Māori perspective the expectation could be that decisions around kuia or koroua wellbeing would be a whānau decision which would include the thoughts and opinions of the kaumātua, and may include some discussion and input from staff. It would then be the staff responsibility to act according to that collective decision. Whānau have much to contribute to this decision-making, since they would know the kaumātua for who they have been to that time, and on what basis they make their decisions. For example, if the kaumātua is an elderly kaumātua that has been very active in tikanga and marae they would have an innate foundation from which their personal decisions are made, a foundation related to the tapu of their wairua realm. They would have their own boundaries that would not be crossed, especially in relation to intimacy and sexuality. The whānau would know this and would have a responsibility to support the kaumātua to maintain their tapu or sacredness and in so doing uphold the mana of that kaumātua. It would be the responsibility of the kaimahi to respect that decision.

While initially, then, these findings may be surprising given the common assumptions that general wellbeing would be equally if not more important to Māori than tau iwi because of the emphasis on connectedness or whanaungatanga in te Ao Māori, we believe that much deeper exploration of these complex issues will be essential in order to capture the complexity and nuance of Māori understandings.

Staff

As we have set out above, it can be difficult for Māori to consider or link the ageing person and intimate relationships when kaumātua are leaders and often lead full lives centred on marae activity and their whānau leaving little or no room for private or personal relationships.

The interviews with kaimahi provided insight into how Māori kaimahi viewed caring for Māori kaumātua quite differently from non-Māori residents especially when they knew the person in their life previous to the residential aged care setting.

> *It's not so much a belief system, to me it's what I think is right. If their cognitive memory was working fine, would they do it? [...] It's like you'll be protecting that person, eh, because you're working with them all the time; sort of like they're your own, you wouldn't want them to.* (S9F)

Longitudinal relationships for Māori varied between facilities and localities. In one area where there was a high Māori population area, staff viewed their relationship with Māori in their care as a continuation of their being in the community both in how the kaumātua and the whānau engaged with facility.

> *Most of Māori don't lose the relationship with the whānau or their partners, whether they're here or not, they don't lose it. Whereas [for] Māori that whānau relationship never ends, it never ends. So, regardless of whether they're here or out there, it continues. They're always used to having someone there with them, with our culture, right to the very end. Māori don't lose the relationship with the whānau or their partners.* (S9F)

In another facility and location, the longitudinal relationship was enacted when the resident was nearing death. This was seen as a major difference between Māori and non-Māori and particularly with 'Caucasians'.

> *They don't always stay more connected while they're alive, actually, but when they're dying that's when you really notice a big difference in terms of that gathering and that support from a Māori family, from whānau, as opposed to where everybody gathers, no matter what – if you haven't seen Cousin X for the last 20 years, it doesn't*

> *matter if they're dying, you turn up. And that's another form of intimacy I suppose. Whereas generally for our Caucasian people you'll find that it's generally just one or two close people who hold that vigil.* (S1F)

In terms of transitioning to the care environment there was no reported difference between Māori and non-Māori (S9F). However, as shown above for some the relationship stayed the same with whānau; just the living space changed.

One facility was worried about a kaumātua who spoke te reo and they had no one that could korero with her. One of the senior staff was at a tangi and got talking to a kaumātua there and had the following conversation:

> *[H]e said, "You know, it's funny," he said; "I had an aunty," and he said, "I lost track of her and I could never find her, and the family now are scattered to the four winds couldn't find her." He said, "But someone told me she was in [region]," and I went, "Oh okay." So, I said; "What was her name?" And he told me. I said, "Oh she's one of my patients." So, it was excellent, so he would come through from [region] and stay with me a couple of nights and then he would come in and he would just speak te reo to her, but he would bless all our rooms and bless all our staff.* (S23F)

Another staff member (S15F) said that her facility didn't perceive any difference between Māori and non-Māori residents. She said the facility had only had two kaumātua; it was not clear how these kaumātua were identified.

Section summary

Recruiting Māori kaumātua, whānau, and kaimahi was difficult, which was expected given the relatively small percentage of Māori engaged in the RACF sector and their reticence at discussing topics of this nature. Greater understanding of the complexity of Māori understandings of these issues could be achieved by a more focused exploration of te ao Māori in relation to intimacy and sexuality in residential aged care. This is important to consider given the increasing life expectancy of all people including Māori and the ever-increasing diversity of Māori. Another layer of complexity is added with cognitive decline and who and how decisions are made around intimacy and sexuality when the mana of the kaumātua is perceived to be at risk.

It is important given these findings that in-depth understanding of te ao Māori of both Māori kaimahi and kaumātua is sought in each facility. Is their lens strongly Māori, or more diverse? These findings suggest that they are strongly Māori. Where people have grown up, who has been involved in their life learning, and what their journey through life has been all will mean assumptions cannot be made about the worldviews of kaimahi or kaumātua.

Managers set the tone for the facility, either by talking or not talking about sexuality and intimacy, by providing training for staff, or not, and by their attitudes towards resident expressions of intimacy.

Findings Cluster 2: Management, Policy And Education

LEADERSHIP AND THE ROLE OF MANAGEMENT

Managers were clearly the most experienced of the respondents to the staff survey; most (n=23, 65.7%) had more than 10 years' experience in the field, and were overwhelmingly European (n=25, 73.5%), followed by 'Other' (n=6, 17.6%) and Asian (n=3, 8.8%). There were no Māori or Pacific managers who responded to the survey. Of the 149 European survey respondents, 25 (16.8%) were managers; however, of the 31 'Other' respondents, 6 (19.4%) were managers. While the sample was self-selecting, and it should be noted that 127 people did not respond to this question, this demographic profile raises questions about who takes on managerial roles in RACF in Aotearoa NZ, and limits the conclusions we can draw.

Staff participants felt that managers needed to provide leadership in questions of sexuality and intimacy. Some staff also stated that they had not experienced this kind of situation before.

> *The sexual thing, I'm not actually a hundred percent. That one you'll have to ask [managers].* (S4F)
>
> *I think I would probably involve the manager or the family, or both. Certainly, straight to the nurse manager, or the CB nurse.* (S13F)
>
> *I would talk to my nurse manager first, definitely I wouldn't go ahead and do anything without talking to her and see what she suggests.* (S20F)

It is clear from staff participants' comments that consultation with managers and managers' support appear to be important elements for staff to support residents to continue their important connections.

Staff participants described how they usually talked and sought advice from their managers when they are faced with expressions of sexuality from residents. For example, the following female staff members mentioned that:

> *When they first got here they quite liked the younger staff to shower them and they made some quite strong comments about his royal parts; but we knocked that on the head pretty quickly. We first asked him to stop; either changed the subject or quickly asked them not to. But, we also took it to management and our nurse, which then in turn we had a discussion as a facility and it was made clear that he wasn't listening, so we got the owners.* (S4F)
>
> *If we have any concerns about anything, we have a form, an event form which we can fill out, and there's tick boxes whether it's an accident, a concern, whatever, and the managers door is always open, and so that would be your first port of call.* (S15F)

The above comments show that staff expect that one of the manager's most important roles is to be able to solve problems to support residents' sexual expression and address residents' sexual needs.

Addressing the sexual misbehaviour of residents in aged care is an important part of managing the facility. Managers are in a good position to provide their staff with ongoing education and training on how to recognize inappropriate sexual behaviour and intervene to protect themselves and other residents as well. One female manager also indicated that they have a responsibility for managing residents' inappropriate sexual behaviour in the workplace:

> *We were just actually having a conversation in the duty room about that; about one of the residents grabbing the boob of the diversional therapist is inappropriate. Certainly, that's a pretty obvious example of an inappropriate behaviour, but she had handled it pretty well,I all things considered. He was just being a ratbag; he wasn't actually doing it with harmful intent, if you know what I mean. But you do have to protect personal boundaries. Any time any of that intimacy was wrongly directly towards any of the staff, or in a disinhibited fashion, I think that would be where I would start to draw the line.* (S1F)

It is clear that managers wanted to offer support and to help people with issues related to their sexuality but, they also made it clear that they have also the responsibility to ensure residents have the capacity to consent to *sexual activity* as well. The following manager noted that:

> *Sometimes people can be not entirely competent but still able to give consent or not. Really, I think you've gotta do that on a case by case or sometimes a situation by situation on just ensuring that consent is there, that someone's not intruding on someone's space when they're not welcome.* (S1F)

While cognitive capacity is a significant issue within aged care, there can also be a danger of upholding stereotypical attitudes about residents' sexuality desires based on implicit assumptions about the lack of capacity of residents to make the right decisions. One of the female managers clearly mentioned her support of residents' rights to the intimate relationship while simultaneously acknowledging potential challenges such as protecting residents from any harm. When asked 'what would you consider harm?' she mentioned that she would act

> *When someone's being pursued that is not comfortable with that pursuit. When it's obvious that someone's getting into their space and there's anxiety and things like that being shown. To be honest, I've not really come across it that much. Its more often wanderers coming into people's rooms who don't have dementia and the invasion of their privacy; that's more often a problem and when female underwear ends up in a male's drawer; things like that, and the wife finds it; that's always awkward. I think just looking back on all the relationships since I've been doing this for eight years, and I've always had an element of dementia in that work. I think that unless someone is upset, and you can tell straight away whether someone wants them in their space or not, or if they're being pursued unhealthily; you just redirect them, give them something else to do. They're obviously looking for some love; there's an unmet need there, so we give them something else to care for. We've got cats, birds, and things like that.* (S22F)

Some managers believed that they have to look after their residents' emotional needs, address their sexual needs, and create a supportive environment for them so that they "*feel free to discuss" their* sexual desires. Two managers indicated that:

> *The thing there is, I'm not comfortable; for me it's the residents, it's his needs, her needs; my role I'm not in the role to judge or this is wrong, this is right, but it's not me. My role here is as a nurse; my role is I have to duty of care to look at the patient holistically, not just the medical needs, but of course you've got emotional needs, and that's what we are here for, is to enrich that. We've gone past the [era when] people who come here to die; now. I said, "That's what it is, they come here to live". Now, my role is to enrich that; by how? By meeting their needs as much as we can. And how far can we? (S10M)*

> *Creating a supportive environment and letting your residents know that they can talk to you if they're worried. That's one thing I enjoy here, is I've got an open-door policy, and I go and visit my residents every day and sit with them and talk, so I know pretty much how everyone's feeling. Every morning, first thing I do is I walk around, and that takes me about an hour and I just go around and get the lay of the land, see how people are doing; visit those that are ailing, but it really sets you up to maintain good relationships, so it's worth the investment. I've been taught that regime through a number of managers of my bosses, that they do it; it's a successful practice.* (S22F)

When managers were asked to what extent they feel they have a responsibility (or even an opportunity) to facilitate relationship, a male manager responded:

> *I think for us, for me as well, it is like we have to look as well at the condition of the resident; are they able to make that decision? Is it a genuine request? At the same time as well, and then we do assess the situation.* (S10M)

Residents

A small number of residents interviewed indicated that managers support, or at least tolerate, their intimate relationships.

> *I think the staff here are very tolerant. The manager here is very tolerant and sets examples for the staff. We run lots of training and interesting things here. Sometimes the residents present education to the staff and report back, especially regarding ideas for meals. Residents role-play to staff. The management trust us to present to staff which is a privilege.* (R25 M-F Couple)
>
> *I consider it when [Manager] found out about our relationship. She has a go at us every time she sees us, but she's really funny. We went around and the next minute we've got [Manager] with us. She's around and sat there with us. Of course, we ended up having hilarious fun. [Manager] told me one day when I was first here. I don't know what I did now or something, but she said to me, "Don't you dare change - don't you dare". She said, "From the minute you walked through that door, it was like a breath of fresh air," because we were laughing.* (R26 M-F Couple)

Positive attitudes and support from managers regarding sexual activity of residents could be essential in facilitating or opposing, sexual expression in nursing homes.

Family

Only one family member believed that managers are in a position to should make decisions about residents' intimacy in aged care.

> *I'm imagining the matron or the person who's the head nurse; that would be the person I would have approached about that. I mean, it does feel like you would be in a position of having to ask permission for that to happen. Not like that you could sort of say, "We want to make this happen?"*
>
> *Q: So, you would have felt beholden to what the manager said?*
>
> *A: Absolutely.*
>
> *Q: What if he had been very clear that, "No, I want this to happen."*
>
> *A: God. I still would have felt like... I'd just be going, "Well I can't make that happen. They have to say you can."*
>
> *Q: Is that right do you think?*
>
> *A: In some ways it does need a framework around it, just because it isn't an environment; especially in the dementia care setting, it isn't an environment that you can have that much privacy and control, so you are inevitably going to be affecting other people. I guess that's one of the most difficult things about that scenario; is that you aren't just making decisions for yourself anymore – you're part of a community.* (F5F)

The above comment indicated that the consideration of residents' sexuality can depend more on the managers' decisions and attitude than the wishes and needs of the residents.

Section summary

Managers set the tone for the facility, either by talking or not talking about sexuality and intimacy, by providing training for staff, or not, and by their attitudes towards resident expressions of intimacy. If the manager is not available, suppresses or avoids such conversations, staff are left to make decisions on their own, or to rely on their own values. Residents also experience the attitudes of managers, either directly or indirectly. It is essential that managers, as both the most experienced of the staff, but also as the legal and moral authority within the facility, be prepared to talk openly and frankly about sexuality and intimacy with staff, to support staff, and to create an environment where staff can talk with them.

POLICY

Both the quantitative surveys and the interview data indicate that the routine use of policy and education to inform practice is very limited in the area of residents' intimacy and sexuality. In the survey results, 96 of the respondents (22.2%) agreed that they rely on their personal values more than anything else when they make decisions about sexual issues that arise. Less than half of the respondents (n=200, 46.4%) agreed that they have received education on intimacy and sexuality and more than half of the respondents (n=289, 66.7%) agreed that they are interested in further education. Nearly half (n=216, 49.9%) of the staff respondents agreed that a facility should provide a private place to allow sexual activity, even for residents with mild dementia.

Staff

Some staff participants said that there was either no facility policy about residents' intimacy and sexuality, or if there were a policy they were not aware of it or did not know how to put it into practice.

> *I actually wanted to go back through the rule book, my licence book, to have a second look. That's one thing I have maybe glossed over. I'm sure there's something in the book. I know that if it's inappropriate it goes to staff and the most people to say in a kind way, or I think we can certainly be open to that. But, I'm not sure on the policy; I haven't read it as such in detail. Maybe I should have a quick look at the rule book. Everyone's got a contract on arrival.* (S4F)

> *My personal life, it's definitely my own values and things like that; but in a work scenario would have to be - the education around policy would have to be the guiding thing I would say, but where there was real conflict between them, I can't help it, I'd have to go and say, "I'm not comfortable with that", or, "What about this scenario?" I have to speak up.* (S24F)

A female staff member (S12F) highlighted the efforts the facility staff went to in order to support residents to continue important connections:

> *I think if we are able to actually have or if we would be able to highlight this particular need of the patient; I would say that it's actually being able to just close up the loop and say, "Yes we're actually able to provide a sense of home. Not just with the familiarity of the physical environment; having to invite family members to come as often as so". We have an open-door policy. We don't have any restrictions that you can't between seven and nine o'clock in the morning because we're doing morning cares. We don't do that. The families and friends from the community can come any time except if there's a specific instruction.*
> (S12F)

The above point was mentioned by most staff; that they were comfortable and confident in taking steps to support conventional relationships that had been established prior to the resident's move to a facility. The notion of an open-door policy was also discussed by a staff member:

> *We have an open-door policy; people can come anytime. We encourage family to stay for meals; we encourage family to celebrate things like birthdays. We have a ninetieth birthday on Sunday, but encouraging the family to celebrate with them. If we have little events here we always invite the families to come. Christmas, they're always invited to come and share Christmas lunch if they can't take their person home; they come here and have Christmas lunch with them. We try and keep them involved.*
> (S14F)

The following staff member realised as she undertook the research survey that there was a gap for her between policy and application. However, she went on to indicate that such a policy did not seem relevant to her workplace.

> *I think it would help everybody. Definitely once I saw the [research] survey today, I found some of the questions very difficult to answer, even though I have just read our policy on it. There's one thing reading something and living it day to day, but as I say; I don't think that too much has come up because it's been mostly just women on their own here, and no one's been indicating to me that they wish they could have a relationship. We might talk about it; if they miss their husband or something like that.* (S24F)

In the above account there appears to be the assumption that the single women living in the facility were heterosexual, and also that they would be able to initiate a discussion about their needs.

I think that we absolutely do need education on [intimacy and sexuality], because we're not sure. People aren't sure what they're meant to do, and people form their own opinions about things

Other participants said that there is a facility policy addressing residents' intimacy and sexuality which reminds staff of everyone's rights and desires. Staff in RACF usually come from different cultural, religious, and ethnic backgrounds where sexuality in older adults may be viewed in different ways. Therefore, having a clear policy may help provide a consistent response, and ensure that staff do not rely only on their personal values and beliefs regarding residents' expressions of sexuality. The following manager spoke of the balancing required in her role, allowing staff to express their views and also upholding residents' rights articulated within policies.

> *I do want people [staff] to have a voice and know I am here for them to talk with me. Everybody's opinion matters. They all have something to share and people leave their ego at the door. In my role I have to make good decisions and things do have to be done in accordance with policy and procedure so sometimes it's a balancing act.* (S5F)

The following staff member highlighted that is was helpful for her to be reminded of residents' rights:

> *A: When I re-read the policy today, yeah, I thought it was good because it reminds you about everybody's rights to have that intimacy and feel that living connection with other people; it's so important - it's important for their happiness. It reminds you that it doesn't matter how old you are, you still have those needs and desires. So, I would take from this that it's primarily the residents right first and foremost, but they obviously had it in the policy to advise families about things; I would say that's because of cognitive issues and things like that too.*
>
> *Q: What's your sense; what's your sense of that? Would it feel intrusive [to ask residents about intimacy and sexuality], or do you think it might be welcomed by some people?*
>
> *A: I probably wouldn't feel that comfortable about it, but I'm also quite a sensing caring… I'm quite an intuitive person, so if that moment was there and it was in my policy and I was allowed to… do you know what I mean? I don't think I would do it without it being appropriate, but if it was in policy and I felt like there was just that little bit more that needed to be drawn out there, I think I would be able to do it.* (S24F)

One staff person said that employer provided education was important to address not only staff reliance on their personal values when making decisions in the workplace, but also for residents.

The above staff member also made an important point; that if asking residents about sexuality was in a policy, she would feel more compelled to overcome her discomfort about asking questions in this area, because they were sanctioned.

In some facilities, there is also a policy that protects residents' privacy; residents are free to choose to have intimate and sexual activity in their private rooms.

> *We have privacy things in our policies for the staff to respect people's privacy, and just be aware. I mean, most people are aware if somebody's in a relationship, and to respect it.* (S15F)

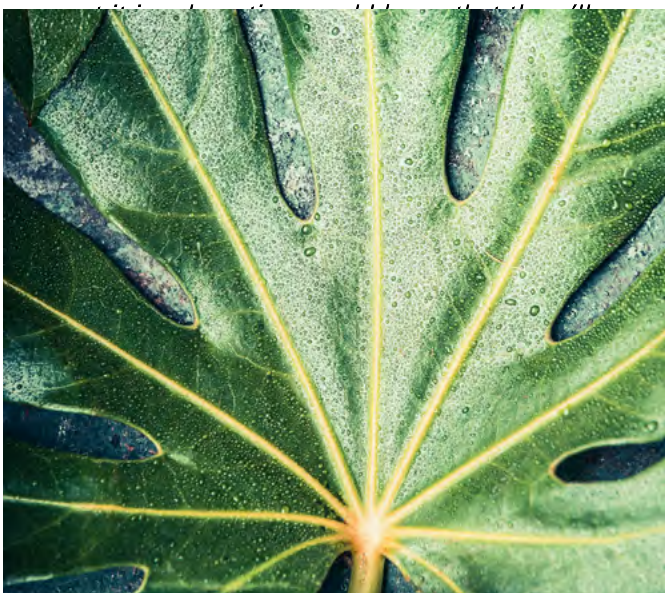
Policies need to be reasonably comprehensive, and address even difficult issues. For instance, three female staff noted that their facility's policy did not address the issue of resident access to sex workers.

> *They should make a policy; yeah, they should also include that one, because that's [sexual contact] a basic need. Those things like that to be addressed.* (S2Group)
>
> *A staff person reported that her experience was that different facilities handled policy toward sex workers very different, but that she didn't know what her current employer's policy was.* (S7F)
>
> *But to be honest, we don't have a specific policy in regards to sex workers.* (S12F)

The above statements suggest that staff need policies and look to them for guidance on all kinds of difficult issues, not only on sex workers. Staff may say that are looking to policies for guidance, but in fact they don't know what those policies are, or they are not looking at those policies.

Staff were asked if they were aware of any policies around sexual consent. One female staff member said that even though she perceived that consent for people with dementia was a significant issue she was not clear on the content of the policy:

> *I'm sure we've got a policy. I haven't looked*



(S19M)

The following quote is concerning: policies must reflect residents' legal rights and yet this staff person appears to indicate that residents may not be given the privacy to which they are entitled:

> *So, I would take from this that it's primarily the residents right first and foremost, but they obviously had it in the policy to advise families about sexual intimate relationships; I would say that's because of cognitive issues and things like that too.* (S24F)

Residents

No residents mentioned awareness of any policies pertaining to intimacy and sexuality. A few spoke of rules that they imagined existed, but that one would only know the rule if it were breached:

> *I think you'd pretty much have to ask management if that was alright, and I don't know what the rules are on that. I shouldn't imagine they would allow that.* (R22F)

The importance of making residents aware of policies was evident as a number of residents spoke of how other residents were often very conservative and judgmental in their views. It may make facilities safer for diverse residents if policies were made explicit prior to residents' entry.

Family

No family members interviewed indicated any awareness of policies pertaining to intimacy and sexuality. Having a clear policy and guidelines would help staff to make ethically justifiable decisions without unnecessarily breaching residents privacy with families. Policies may help staff to work with families when families insist on being unnecessarily involved in a resident's decision. Support should be provided to families who feel uncomfortable about a resident's sexual expression and rights.

> *I think probably the overarching policy, as far as I understand it, within the retirement village that my mother is in, is that you can have whoever you want in your little apartment thing; and that's up to you as the resident who is there.* (F11M)

Conversely, another family member said that:

> *I haven't seen or heard anything in regards to intimacy. Not a thing. Not of any documents. No. I guess if I was to go down that road, maybe I could find out, I guess because they're quite open there.* (F10F)

Section summary

Even though policies and procedures are essential in all aged care facilities, few facilities have policies regarding sexuality, or if they have, there is little, if any, education to support staff effectively to implement those policies. Policies are important because they are a fundamental guideline to help staff make appropriate decisions. Policies and procedures also allow staff to be consistent in their responses, rather than relying on their own individual values and beliefs. Staff may have more confidence to uphold residents' rights and to intervene if they understand the legal and ethical issues that underpin a policy. Policies manage risk by assisting staff in defending legal and ethical claims. Providing training and education to policies will improve the knowledge and attitudes of staff who work with older residents, reduce risk, and is essential in all RACF.

No residents in our study were aware of specific policies pertaining to their rights to intimacy and sexuality. Many residents imagined that having sex workers come to a facility was unthinkable (see the section on sex work below). Residents should have an opportunity to discuss their sexual needs with appropriately trained staff. Explicit discussion of such policy would alert residents to their rights and also inform prospective residents and their families of issues they might not otherwise consider until a critical event occurs.

EDUCATION

Less than half of staff respondents (n=200, 46.2%), said they had received education from their employer on intimacy and sexuality for residents, and two-thirds of staff respondents (n=289, 66.7%) said they were interested in further professional education about intimacy and sexuality in residential aged care. In the interviews we explored the issue further not only with staff but also residents. Almost all agreed that education would be useful, although not all agreed on what that education should look like.

We asked whether participants had received education about intimacy and sexuality at their workplace, and whether they were interested in further education. Of the 433 participants, 364 (84.0%) responded to these two questions. In the analysis of 'have received education' (Table 11, Appendix 3) we grouped disagree with neutral under the assumption that if a respondent were neutral then they did not remember having had the training, or that the training did not make much of an impact. In the analysis of 'would like further education' we left the neutral responses in because at least a quarter of each group were neutral, and these responses were a useful indication of attitude. A chi-square analysis found that there were significant differences by size of facility (p=.004) in having received education: survey respondents from facilities we classified as small or medium were significantly less likely to have received education about intimacy and sexuality than those in larger facilities (Table 11, Appendix 3). However, there was no significant difference by size of facility in whether respondents were interested in further education (Table 12, Appendix 3). This suggests issues of capacity and resourcing: larger facilities are more likely to provide training to their staff on intimacy and sexuality, although staff at facilities of all sizes were interested in further education.

Staff gave numerous examples of where residents made comments and jokes that involved sexual innuendoes directed at staff

Staff

Some managers were completely confident that training and education on sexuality and intimacy was essential, particularly to address the management of personal values and beliefs in the workplace:

> *We have a lot of education around sexuality and intimacy. We have it as part of our orientation for all staff, and then we have a course every year, but most of our staff are older woman; they're probably in their 40's or 50's. We do have quite an ageing workforce, and they've seen it all. So, there's not a lot that upsets them, but it's usually those with particular beliefs that find things difficult. And I just need to remind them sometimes, "You need to leave those [beliefs] at the door, because what happens in here is other people's beliefs and feelings". And they're all fine with that.* (S22F)
>
> *Absolutely, I think there needs to be education. There actually needs to be a module [...] I'm trying to remember [...] whether there was any kind of education around sexuality, and I think briefly it would have been touched on: "if you catch somebody doing something you just close the door and leave them to it"[...] I think education is going to have to expand, and I think they're going to have to get gays and lesbians and transgender people to come in and talk to staff to normalise it; I don't like that word normalise, but to make it not a big deal when it does happen.*(S7F)
>
> *I think that we absolutely do need education on [intimacy and sexuality], because we're not sure. People aren't sure what they're meant to do, and people form their own opinions about things. (S24F)*
>
> *I wish that we had more education or literacy when it comes to intimacy; for staff, intimacy, and sexuality. I wish we had [...] what you said, doing research. I'm really looking forward to that. What will come out [of the research you are doing, what] should be the best thing to do. It will be really good.* (S10M)

That same manager noted that staff education begins with staff interviews and induction:

> *[Education] starts with our onboarding. It starts with our interview. it starts with introducing different groups with different genders, different where you are at, what I experience when it comes to that. And during their onboarding I do a part there about cultural safety and Te Tiriti o Waitangi, as well LGBTTI—you've seen our Silver Rainbow [accreditation]. I do discuss that, and then I link into our values as well. So, that's where we start from there, and then going further to education.* (S10M)

One employer who was responsible for providing education was unsure how much good education and training on sexuality had done. However, she felt that it was the way the training had been delivered that was problematic.

> Q: *You have provided considerable staff training on sexuality and intimacy, so do you think this has been beneficial to your staff?*
>
> A: *I don't really. It can be hard getting staff to training. You have to have people/carers working in this sector who are passionate about care giving. It is trying to find and retain these people. I think the training needs to be more focused and with more interaction from the staff. Yes, there should be more training […] It can be hard getting some staff to speak at training, so that needs to be encouraged. Sometimes caregivers can be too shy or embarrassed to speak about sexuality. Telling staff about sexuality doesn't seem to work, they need to be involved in the training. Sometimes also staff can be intimated by other staff, so will not speak through fear of being ridiculed. Staff must have full training and an understanding of consent.* (S5F)

One staff person said that employer-provided education was important to address not only staff reliance on their personal values when making decisions in the workplace, but also for residents.

> *I think [education might change staff behaviour]. I mean, if you're working under a prejudice and a bias, it will. It'd be a really interesting thing to see happen. It's interesting you bring that up, because it's something that's never crossed my mind […] I'm a very, very liberal thinker, and the person sitting next to me might not be. It's all about your own beliefs and values, and stuff like that. Some residents might go, "Big deal", and [there are] others, especially with the age they are, coming from back where it was absolutely taboo, who might have huge prejudice against it. It'll probably take a generation or two before it'll be totally accepted in places.* (S14F)

Informal staff education

Several staff senior staff members pointed out that education is an ongoing process, and that much teaching and learning can take place outside of formal education and training workshops, and may be occasioned by particular events or incidents. We include some of these observations here.

> *Yes, the masturbation situation – if a staff member is really struggling with a resident and that was affecting their ability to care for that person. They would be provided education on this and talk with me, if they still weren't able to put their own thoughts aside, I would move that person out of that situation. I would rotate them somewhere else because why should the resident be judged by that person?* (S5F)

resident:

> *I used to give him a hug and used to have to [say], "Right, that's enough". He was quite sweet, but the girls [staff] did get a bit upset, my caregivers, because he used to brush himself on them and things like that, so I just explained, "You need to set your boundaries with him and let him know that was he's doing is inappropriate". He did respect that.* (S22F)

Another manager spoke of educating her staff to think of the facility as the residents' home:

> *As I always say to the staff, "This is the resident's home not yours; you're just here to assist them. You've got no place to judge; you're here to assist them in their home". Some things they [staff] just have to get over.* (S14F)

A manager also spoke of the way she intervened by giving corrective feedback if she heard staff making derogatory comments about residents' sexuality:

> *Certainly as the nurse in charge of the rest home, if I hear staff talking derogatory about a resident, or treating them in a disrespectful manner, then I definitely see it as my role to pull them aside and say, "Hey look this is what I've seen, and this is not what we do here".* (S7F)

A diversional therapist described re-visiting their staff intimacy and sexuality policy, and coming to the realisation that reading the policy alone did not provide the education she needed; she did not have the skills to put the policy into practice:

> *When I re-read it [policy] today, yeah, I thought it was good, because it reminds you about everybody's rights to have that intimacy and feel that living connection with other people; it's so important - it's important for their happiness. It reminds you that it doesn't matter how old you are, you still have those needs and desires. But how I would approach... whether I'm meant to instigate a conversation with somebody about how do you... whether that became part of my questionnaire; I don't know how comfortable I'd feel or not about it.* (S24F)

Residents

Some—but not all—resident participants said that they would find education about ageing and sexuality valuable.

> *Yes, [I] probably [would be interested in education about sexuality in later life]. For a while we had a lot of people with dementia and Alzheimer's, but I think that there's always people that would be interested in things like that. I don't know how many people would know what you're talking about.* (R14F)

A1: *Yes. A social work role would be great. Who do you go to talk to about issues? Some of these questions etc., are immediate. The sense of loss through grief is huge. It would be great if there was someone we could talk to about many things.*

A2: *Agency people could visit which could be helpful. Meetings are great, we bring everything up at meetings. If you had an emerging relationship, heterosexual or gay, it would be nice to talk to someone about it. You can't talk with family etc., or residents, talking about feelings etc.* (R25 M-F Couple)

Family

Even some family members said they might find education about sexuality and ageing useful.

Q: *Do you think older people would be interested in more education about later life intimacy and sexuality?*

A2: *I reckon they would.*

A1: *Yes, they most probably would, but it's not knowing how many men are up there, how many women are up there, unless they're going to invite some other men or some other women.* (F3, M-F Couple)

Section summary

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. Although more than half of staff survey respondents at smaller facilities said they had not received education on intimacy and sexuality, at least two-thirds of respondents, regardless of size of facility, said they wanted more education. The need and demand are evident, and in our view the sector must heed and respond by providing further education specifically related to intimacy and sexuality. For staff such training should include at a minimum an examination of personal values and beliefs, working with diversity, and training to policy (this of course means policy must be in place). Education should begin at the time of the staff interview by communicating facility or agency values, continue through induction (or 'onboarding'), and be updated regularly for all staff. The way these staff trainings are structured is important: education should be engaging, encouraging, respectful and empowering. We also acknowledge that senior staff, managers and supervisors are taking advantage of 'teaching moments' to address issues in the moment and to upskill staff on key skills and attitudes in working with residents. We also note from both the literature and our quantitative data that education to change attitudes may not be necessary or efficient, and may instead focus on desirable behaviour.

It also appears that RACF may wish to consider developing educational opportunities for residents about intimacy and sexuality. While not all residents will take advantage of the opportunity, it would appear that at least some residents are interested.

MISDEMEANOURS

This section highlights that residents' sexual behaviours, including those that were unwanted, unsolicited and that staff and residents deemed inappropriate were not uncommon. Staff boundaries regarding sexual activity are addressed in the section on sex work. It was not always clear in the interviews whether participants' accounts pertained to residents with some cognitive impairment. Of note, in interviews with staff it appeared that most staff were not unduly alarmed by unwanted sexualised behaviours, and for the most part did not feel unsafe. They spoke of the importance of having older, mature staff who were able to role-model de-escalation of the behaviours, typically through the use of humour and distraction, and sometimes cajoling and a degree of mild shaming were used to address the behaviours. Staff described teamwork in assisting each other with responding to unwanted behaviours. A minority of staff described situations where they had experienced a sense of being assaulted and fearful during a sexualised encounter with a resident. A significant feature of the data was that no staff appeared to have had any formal education on how to best respond to the range of unwanted behaviours, and therefore relied on the wider life experience and informal team de-briefing and planning.

Also, as addressed elsewhere in the document, through the interviews there was no indication of any induction process for residents in how to live communally, in such close proximity to many others, and the expected behaviours.

Staff

Staff gave numerous examples of where residents made comments and jokes that involved sexual innuendoes directed at staff:

> *I was asking resident, "Where are you going; are you going for a walk?" She said, "Yes, why don't you come with us?" I said, "No, I have to work". She said, "So, I could find some other guy out there, and we can do a threesome". That's what the resident said. I said, "No, you just go for a walk. Don't find any other guys there".* (S2F)

What is evident in the above quote is the staff member's low-key response; the staff member deflected the comment. In the following quote a staff member provided another account of an innocuous intervention that addressed the problem without shaming the resident:

> *We did have one lady who would, when the entertainers come in, she would be dancing with people and she'd put her hands all over people's bottoms and things like that, and many people resented that. Many of the residents resented that. What we would do, is one of the staff members would dance with her, so that she was occupied, and she wasn't behaving inappropriately with other people, and if you held her hands and danced, she was quite happy with that. So, it was only a matter of managing it so that it wasn't upsetting anybody.* (S13F)

Staff for the most part appeared not to attribute the same meaning to behaviours that, if they occurred in other social contexts with younger adults might be named as assault or sexual harassment. Instead they opted for descriptors that minimised intrusive behaviours and interventions that protected others while maintaining the dignity of the resident. This preference for the most part appeared to be the case whether or not the person was considered to be cognitively impaired.

The extended quote below is included as it is an example of the skilled leadership evident in the dataset. The context was that a nurse manager had been told by her staff of health care assistants that they were fearful of working with a resident because they felt harassed while showering him:

Many participants appeared to accept without question the diminishment of privacy; that the work of staff took precedence.

> *I thought, "We're not going to put up with that" [...] Anyway, he's in the shower and I knock on the door and say, "Hello, it's [Name] here. May I come in?" "Yes." I made sure he had a robe on and all that. I said, "Now look, we've had this problem. I know you'll understand what I'm going to say, but our lovely girls here are feeling a little concerned, because they would like to feel like when they care for you that they're caring for this lovely gentleman, who they like in the terms of dad or father; and the things that father does are quite different to things that a lover or a husband would do" [...] I said, "So, what I would like from you is the assurance, that as long as you're going to be here – and we love you and your family here – could you please make the effort to not bring your penis out and introduce it to the girls. You're perfectly capable of washing it yourself, and they don't want to handle it, and they don't want to examine it or anything else". This is how I said it to him. "Oh. I am still allowed to stay here?" "On the condition. [...] that this doesn't take place again." It never has. [...] The girls [staff] were so relieved. She [the HCA] was standing outside the bathroom door. She said, "Thank you, thank you".* (S3F)

Senior staff spoke of the importance of this leadership for protecting their staff and role-modelling how to intervene. They indicated that this protection was especially the case with their migrant workforce who were entirely unfamiliar with how to respond in such circumstances. Staff participants gave many examples of managing situations where a male resident had an erection. The erection *per se* did not necessarily mean staff felt threatened or uncomfortable, even if they associated the erection with an expression of sexual need, or undesirable behaviour, as in the quote below:

> *It's like our males, we being caregivers and we're cleaning around their private parts and that, they still have that feeling, and some of them can be rude but you learn to divert it somewhere else or you just ignore what they're saying and just carry on. You go and do [shower] a male and he gets an erection and you think, "Oh, my god". But he can't help it; he can't help it. That to me, so he's still got his sexual needs.* (S9F)

There were also many examples of staff managing their responses to women residents who approached them in a sexualised manner:

> *We've got a very charismatic male caregiver who everybody loves, and a lot of the female residents would fall in love with him, and he felt quite vulnerable at times being alone with those people, because at one stage, two of the female residents were having quite florid fantasies which sort of became real to them.* (S7F)

Significantly, participants appeared to have a very different response when the behaviour of concern was directed towards another resident. In the following quote a staff member described her immediate action when she was concerned about what she witnessed:

> *He was forcefully guiding her with her walker towards outdoors to get her on her own. I had alarm bells going off; I just raced downstairs and I felt like I rescued her from something that may have been inappropriate, because I had already observed that he had been trying to do things like that here; getting right up into people's personal space and wanting to touch them, and making sexualised comments. [...] Of course, I did overlook some things because of perhaps their cognitive function. They were very rare instances.* (S23F)

The above staff member indicated that she documented the incident and advised her manager. Again, there was no indication that there were any formal procedures to be followed after such an event where another resident was potentially at risk. The staff member made the point that she may have minimised some concerning behaviours due to viewing them as evidence of poor cognitive function rather than rational predatory intent.

Staff described situations where they continued to assess the safety of relationships, particularly where cognitive impairment featured:

> *She's got quite bad dementia, and she did have a sexual relationship with a man here. He also had a brain injury and that actually made him very sexual, so we thought, "where do you draw the line; this woman's going ahead with it, but does she really know what she was doing?". So, we let it happen to a certain extent and then it got a bit out of hand; he was very demanding of her, so that's when we did have to step in and talk to her. [...] We had to separate him, because he actually got very aggressive and possessive with her. It was a sickness with him; his whole sexual appetite, that's all he focused on. She was going along with it, but she was getting uncomfortable, so*

> *we did have to step in.* (S20F)

Staff described occasional circumstances where for safety reasons a resident was removed from the facility:

> *We've had a couple of incidents of male residents interfering with female residents, who can't speak for themselves. We've managed that by removing them [male residents] from the facility to a safer place for them, and for our residents really. I mean, the reason; safety comes first. We've had two that I know of, that we've sent to another facility away from here.* (S15F)

Staff participants typically described informal collaborative decision-making among staff as to how to manage sexual safety.

Residents

Residents only occasionally raised examples of having witnessed unwanted behaviours by residents. The following resident commented on the reaction of a staff member who was groped by a resident in the dining room:

> *He did it to the nurse one day; we were in the dining room she leant over to pass this person a plate of food and the man was sitting in a wheelchair, that same man; he put his hand up her dress, and she slapped it away, because it wasn't just a pat. He tried to put his hand up and she told him off in front of everyone - to a standstill. He was embarrassed as hell; he never did that again. He got a shock, because she's a really quiet woman. Her mother had just died, and this bloody bugger did that. Everybody just told him to stop it; yelled out, "Don't do that you dirty bugger."* (R6F)

Of note in the situation and the quote that follows, residents experienced themselves as having agency to react strongly when they observed or received unwanted sexualised attention:

> *We do have another male here who is crude and rude and disgusting to woman, we have taken this to staff. We started a card group and he asked if it was going to be a shagging club. He has been spoken to by staff and he has modified his behaviour. We complained to management which was acted on. We remove ourselves from him, we walk away.* (R25F)

It is clear in the above quote that this group of residents had the expectation that the senior staff in the facility had a responsibility to step in to manage a situation, and that they acted as a group to underscore their expectations.

Section summary

The data indicated that staff and residents at times witnessed and responded to degrees of unwanted sexual behaviours. From their descriptions it appeared that staff decisions were guided by their own moral compass rather than having reference points of policies and ongoing education; a minority made reference to such guidance. Nurse managers and senior staff spoke of a clear sense of responsibility for the wellbeing of their staff and described ways they role-modelled to staff and residents how to manage behaviours. Typically, what was described was a low-level intervention using distraction and humour. It is possible that an ageist view of desexualised older adults led to staff minimising behaviours of residents who were cognitively competent and not naming behaviours as harassment or assault. This ageist view appeared to be the assumption that because older adults are no longer fully sexual beings then any sexual expression, including inappropriate boundary-crossing (groping, touching, masturbation during care) did not carry the moral weight of such behaviours had they been enacted by a younger age group. This re-framing from a place that makes sense of these behaviours as holding less significance than had they been enacted by a younger person may impact on wellbeing for some staff and residents. These data add to evidence of the importance of having leadership around interventions for unwanted sexualised behaviours, and policies and education for staff, residents and families. The majority of residents will never have lived communally prior to moving to a facility and it may be of great benefit for the wellbeing of the communal group to clearly spell out guidelines pertaining to sexual freedom and sexual safety.

Findings Cluster 3: Physical And Emotional Space

PRIVACY, PHYSICAL SPACE, FURNISHINGS, AND HOMELINESS

The following data analysis explores how respondents conceptualised privacy in RAC settings. In the staff survey, almost half of respondents (n=216, 49.9%) agreed with the statement that facilities should provide rooms to allow sexual activity for residents, while 217 (50.1%) were neutral, or disagreed with the statement. In response to the statement that RACF should meet the needs of residents who want to use shared internet in private, only 148 staff (34.2%) agreed, while the remaining respondents were either neutral or disagreed. However, the interpretation of the latter statement is compromised, as staff may have been disagreeing to the provision of internet, rather than the right to privacy *per se*. Across the qualitative data, privacy was a key signifier of the distinction made between 'real' home and the facility as an ersatz home. The assumption of limited or absent privacy, along with a limited sense of entitlement meant that several residents could not begin to imagine attempting to foster intimate and/or sexual relationships or to engage in self-pleasure. Residents and family members were often acutely aware of the way the built environment impeded intimacy and reduced privacy. These factors diminished residents' sense that they did live in a place that was their home. It is useful to note that the right to domestic privacy is a relatively recent concept, linked to class and culture. The lack of privacy reported in the data may indicate differing conceptualisations of privacy and domestic space, rather than being the results of dehumanising actions. The notion of individual privacy developed in the mid-nineteenth century, associated with the development of the middle-classes in the global North. It is perhaps unsurprising that there is not a shared mental model of the concept of privacy in RAC, given the diversity amongst workers in terms of culture and class. In the staff survey, slightly under half of respondents (n=216, 49.9%) agreed with the statement that facilities should provide rooms to allow sexual activity for residents.

Staff

Some of the nurse managers spoke of a strong commitment to residents' physical privacy. In the following quote the manager made the links between the concept of home and upholding people's privacy:

> *We've been telling [staff] all the time; reminding them [staff] that [even though] this is a hospital that this is their home. We're invading their home, so all we need [to do is] to ask for consent to get into the room or whatever. (S10)*

The need for regular reminders to staff seems to imply that it was challenging for this manager to embed the concept of privacy into practice. Several other staff spoke of the importance of respecting residents' privacy. The key way this respect was shown was through ensuring that the residents' rooms were their private space:

> *If the other partner visits the other person [resident], we make sure that we provide them privacy; having to close the room. If they choose to go and lie in bed together; we would respect that. (S12F)*

One manager described the support they gave to ensure the privacy of two residents who formed a relationship subsequent to moving to RAC:

> *[We] maintained their privacy by giving them signs to put up on the door, and always respecting their privacy by knocking and waiting before you went into the room. (S15F)*

A manager spoke of efforts to create a home-like environment, but also described the effects of routinised care, due in part to staff shortages, where staff readily slipped into task-focused work, with the result of disrupted privacy and an imposed schedule:

> *I was doing some education with the staff..., and I said to them, "How often do we just roll into somebody's room, start undressing them and getting their stuff together for a shower, without any word or acknowledgement about what we're about to do?". Just step back, and it takes you half a second: "Hi, we're coming in, we're going for a shower now; are you ready for your shower?" Don't just haul them out and start doing stuff without any consultation. (S14F)*
>
> *Although your door can be shut and people might knock before they come in, I still imagine that if I was with my husband in a facility in a single bed and we were trying to be intimate, I would be constantly worried about someone just knocking and coming in without being invited in, or even that you would need to stop what you were doing to tell them to not come in. It would be on your mind that you are not in your own space. (S5F)*

Residents who had re-partnered were subject to being gossiped about within the facility.

Senior staff typically spoke of their role as a champion for privacy, and also highlighted that they had to continually reinforce to staff the importance of upholding privacy practices.

Residents

Participants repeatedly drew attention to a lack of privacy. This point was a key contrast they made compared to the benefits of living in their own home. Residents described the significant adjustment of moving from the privacy of their own home, compared to the much reduced, partial or absent privacy of their RAC room. The key issue participants raised about privacy was that residents could not lock their doors, and even if their door was shut, they knew at any time a staff member might knock and enter without pausing:

> *Sometimes they just knock on the door, and open the door, so if they did that, they'd catch you.* (R1F)

This resident's expression, "they'd catch you" appears to indicate that the resident anticipated a level of surveillance and monitoring. Being caught implies that expressing her sexuality in the privacy of one's room in the RAC context is problematic.

The staff practice of knock-and-without-pause-enter was commonplace and participants in their accounts appeared resigned to this practice. However, the lack of privacy was a key feature that residents cited when identifying differences between home and RAC:

> *When you're in your own home you've got privacy, as much as you want, and that isn't the same here, because for instance we're not allowed to lock our doors. Now, I'm fortunate in that I pay extra, I've got a toilet here, but quite a lot of the other people [don't]; so just a shared facility for showering and toileting. And as I say, I find it's worth the expense rather than touring the corridors. You know? So I get a modicum of privacy here. But it isn't available to other people. You know? But you go with it I think. It takes some getting used to when you first come into a facility like this, and there's no doubt you've got to adapt; but I've made that transition.... [Staff] always knock first but it's about a millisecond after the door opens.* (R10M)

Residents were aware that staff were busy and had tasks to complete, and appeared to perceive that it was their role to fit in to the task-orientated rhythm of the day, including interruptions to privacy:

A: *Well fundamentally no real privacy per se; people coming and out of your room all day being unannounced.*

Q: *Would people knock before they come in?*

A: *Yes, they always knock; they always let you know they are coming in.*

Q: *If it wasn't a good time for you, could you just tell them "Not now."*

A: *Sometimes you could say that, but they're on a pretty tight schedule most of the people here; they're quite busy. There's 140 rooms in here. You have to consider how busy they are and what the demands are upon them.* (R9M)

Another family member noted that a resident took umbrage at a new relationship her father had formed since he began living in the facility.

Many participants appeared to accept without question the diminishment of privacy; that the work of staff took precedence. Another resident dismissed the possibility of even engaging in self-pleasure, such as through masturbation, without careful planning:

> *I guess you would pick your times; that sounds awful doesn't it? That's all you could do. You wouldn't want to be standing in the middle of the room doing things, in case the staff came in.* (R23F)

The absence of a sense of having a private physical space was echoed by another resident when he spoke of feeling unable to have pornography in his room, with the implication he would be caught out by staff:

> *The funny thing is, a gentleman here said to me the other day at lunch time, "I've got some magazines here if you're interested". I thought they'd be about cars. He said, "They're about girls." Well, they were porno. This guy is 93. I took them back and said, "I've got nowhere to hide them. I can't even hide them to enjoy them." I went flick, flick, flick, and took them back as quickly as possible.* (R8M)

In the above two accounts the residents appeared to accept the extent to which residents' activities were dictated by staff interruptions and ready access to their rooms. Another resident metaphorically described the sense of regimentation and lack of privacy as a busy transport hub:

> *It's like Grand Central Station. You've got to work to their rules.* (R1)

One resident felt entitled to privacy and recounted rigorous efforts to have staff knock:

> *I had many a row with the staff for not shutting my door. In the end I told a couple of them, "Don't come back here unless you learn how to shut a door". So, I think finally they all got it.* (R13F)

From the accounts of residents and staff, it appeared that attitudes and access to privacy were part of the organisational culture of the facility. There were facilities where residents considered that staff actively worked to uphold their privacy. Several participants who were engaged in an intimate sexual relationship were supported by staff and had a 'do not disturb' sign for their doors. A female resident spoke of a staff member taking the initiative to support her privacy when she formed a new relationship:

> *I am friendly with [male resident] down the hall, that's only been in the last few months. [Staff member] appeared one day with a sign with 'do not disturb' on it. She said, "I brought this for you". [Resident] puts it on the door whenever the need arises, and we giggle away. I think everybody knows what we are up to. I don't care but I did to start with. We will be downstairs and [Resident] would come and sit beside me or others would tell him where I was, and he would come over to me. It was obvious that we two were walking out of the room together.* (R15F)

The resident above (R15F) highlighted that even with staff support, as a couple they had to manage the loss of privacy due to the nature of communal living, that other residents were aware they were going away to have intimate time together. When interviewers raised having a privacy sign on the door in facilities where this was not a routine practice, most participants thought it would be too embarrassing; that the sign would signal that something of a personal nature was happening behind the door and that this attention would be unbearable. One resident indicated that a privacy sign would only draw more attention to partnered sexual intimacy:

A: *Establishing a relationship in a place like this would be somewhat awkward to my knowledge at the moment.*

Q: *What would make it awkward or difficult?*

A: *To be seen to having your door shut. Knowingly not to be disturbed.... If you're a recognised couple that would be one thing. If you were just cruising around the building that would be a totally different thing. For some people that would probably be okay. I would tend to think so if you're a recognised couple.* (R9M)

The above resident (R9M) was adamant that people who entered the facility as a couple would be treated with respect, whereas developing a new relationship in the RACF would be seen as very problematic by other residents.

Residents mentioned bed size as one of the key signifiers that they were no longer in their own home, and a disadvantage of moving to RAC. One resident described the discomforts of the covering on her mattress:

> *The only thing I don't like is the mattresses, because they're rubber- covered and they make me sweat something terrible; even though I've got something on top of it. I just get so hot. I wake up and I'm wringing wet. I think, 'Oh dear'. Because my health doesn't help me that way either.... It's just the rubber on it; the rubber layer over the top is zipped up. It's to keep the mattresses clean, which is only natural... I'm used to a king-sized bed, and then I went to a queen-sized bed. Going into a single bed, I feel as if I've got no room to move.* (R7F)

The above resident indicated she would speak up about the bed issue and likened it to making a complaint in a hotel, that she would "get her bearings" first.

Family

Family members indicated they were aware that residents did not have the privacy they would have at home. A family member commented on the discomfort of walking past someone's room and seeing the person in bed:

> *There's definitely times where even just going to visit him [resident], I would feel really awkward that I could see into someone's room when they were in bed. It was just like that feels like a real invasion of their privacy. They're just in their bed and they've got some random stranger walking past and looking in the door.* (F5F)

In the above example the family member appeared to reconcile the felt discomfort by focusing on safety; in effect for her it was reasonable for risk management to trump privacy.

A daughter (F7F) spoke of the impossibility of her father attempting to commence a new relationship:

> *In dad's situation, no, because he's in a single room where he has a single bed and he opens straight out onto a corridor. The nurses just knock and basically go straight in, so they would have to have a system. Obviously, he can't lock his door, because if something happens, they can't get into it. There would have to be a system in place, like in a hotel you have a do not disturb sign.* (F7F)

It is interesting in the above quote that this relative proposed having a system like a hotel, which perhaps implies the status of guest, rather than the RAC being viewed as a home (where one might also knock on a door and give privacy and receive privacy).

The limited physical space in residents' rooms also reduced a sense of being able to do what one would do at home. The same family member above (F7F) also recounted the difficulties for her father in attempting to be physically close to the resident he had re-partnered with:

> *Even when they're watching TV together, the room's so small. Dad's only got one chair, so [partner] sits on the chair and he lies on the bed and watches TV, so they're not even sitting close to each other to do that much. It would be incredibly difficult, and being that they're older, trying to be contortionists is not going to happen either.* (F7F)

Another family member spoke at length about the disrupted intimacy for her and her resident husband due to lack of privacy combined with restrictive furnishings:

> *Unfortunately, rest homes that are not set up for that [partnered intimacy], there is very little chance for couples to enjoy any sort of sexual relationship. Even holding hands is sort of sniggered at by everybody in the room. Most of the rooms have got single chairs with arm rests in between and you can't sit close. You can't sit and have a cuddle, and if you do people are laughing at you.* (F1F)

Both residents and family members spoke of the discomfort of having an audience to expressions of intimacy.

Section summary

Residents' accounts differed depending on the culture of the facility in which they lived. A number had mentally relinquished privacy, resigned to the fact that this loss was one of the many losses that came with the move to RAC; an ersatz home. Residents and family members gave accounts of how the lack of privacy and the limitations of the built environment meant that residents did not have access to the sexual and intimate freedoms they had in their own homes. Staff highlighted that although efforts were made to uphold privacy, the routinisation of care meant that privacy practices easily slipped. In the staff interviews, it was apparent that staff worked within the limitations of the built environment. Although aware of couples who had been separated due to different care level needs, no staff interviewed expressed dismay at this practice, and nor did they express concern at the obstacles the furnishings posed to intimacy. Data in this section underscore that the ability of staff to provide person-centred care is compromised by busy routinised care practices, limitations of the built environment, and the ethos permeating facilities that may prioritise efficiency and physical safety over wider considerations of wellbeing.

HOME SPACE OR WORKPLACE?

The theme entitled 'Privacy, physical space, furnishings and homeliness' drew attention to RAC as a contested space; part workplace, part home, and explored the implications for residents' privacy and the extent to which they had a felt sense of being at home. The present theme provides additional data to extend the consideration of RAC as a liminal space with implications for intimacy, sexuality and wellbeing. The workplace – home-space tension contributed to the sense of liminality. Also, many residents had views about boundaries of permissible activities with implications for intimacy and sexuality.

Staff

The views of staff varied widely. Some took a strong advocacy role about the facility being people's home first and foremost:

> *We try and make it a sort of home atmosphere for them too; they're not coming into a facility, they're coming into their dad's home, their mum's home. It's hard in age care because we are the poor cousin in health. Although the caregivers are paid a lot better now, but the registered staff are not paid that well compared to the DHB's and all that sort of thing. We're still task focused. We can't get enough staff to move away from the task focus, and more on person-centric care..* (S14F)

Others clearly identified the facility as a workplace and from this position their views followed on about what should happen or not within the space. One staff manager described an ambivalent position; expressing ageist and objectifying perceptions about older adults' sexuality, yet with the expectation that staff must accept people's rights despite their disgust:

> *The thought of looking at some of these people [residents] and thinking of them engaging in any sort of sexual relationship 65 above, and 65 below, for me; I just think is yuk, that's yuk, I just think the whole thing's yuk, but I work very hard at not letting that influence my care or my relationships with anybody, because I mean, I know that people are sexual beings and that they're out there having sex; just because it's revolting to me, doesn't mean that it's revolting to everybody else. I mean, we'll joke in the nurses station about how in the old days the nun would hit it [a man's erection] with a ruler, and we'll joke about that, and what happens inside the nurses station stays in the nurses station, but certainly out there I encourage the staff to be a little bit more open-minded and tolerant in their views.* (SF7)

The staff member above did not appear to be aware that her role-modelling in the nurses' station, treating older adults' sexuality as a dirty joke, might undermine her call for tolerance.

Residents

The lack of at-homeness was particularly apparent when people were asked about the possibility of re-partnering. A common response from residents was to first wonder if relationships of this nature would even be allowed in a facility. This response was particularly the case when the facility was linked to a religious organisation. The following participant indicated there should be some degree of sexual permissiveness:

> *People should be allowed to have sex if they want it here. I mean, it's not my cup of tea. I wouldn't do anything like that in a place like this. But I think they should be allowed because they're living here, it's their homes, as long as it's not grotty or running a prostitute room or something.* (R24)

The above resident's comments were in keeping with those made by a number of other participants; that they wanted other residents to have what they believed was 'normal' sexual relationships that were unobtrusive and did not encroach on the sensibilities of other residents. Residents were very aware of the views of other residents. Residents who had re-partnered were subject to being gossiped about within the facility. A number of residents interviewed only wanted existing married couples to live together in the facility and were concerned about the reputation of the facility and/or their personal safety if there were overt indications of sexual expression, including re-coupling:

> *By the time you get to our age you sort of think those two are going off down the hall to have a 'bonk' or something – that's crude. But, if they were married and respectful and they've got their own bedroom well that's alright, that's their business. I think there's a time and place for everything. I don't fancy it here. You wouldn't want the place to get a bad name, thinking it's a bit of a brothel up the hill there..* (R2F)

For the most part, residents appeared not to question their present-day reality – that they had traded freedom and privacy in order to secure physical safety, and assistance with activities of daily living where they were no longer capable of full independence:

> *You're very self-aware in a place like this. You don't do anything unless you double-check it. You're continually self-aware.... you're quite unlimited in your restrictions in your own private home, whereas here you have to abide by certain rules, which is part of the mode of operation.* (R9M)

Resident 10 also described the role of residents; to fit in to staff schedules and relinquish preferences:

> *Routine is part of it. Whereas, when you're living on you own you can just say, "oh sod it, I'm not getting up this morning". It's constricting to an extent, but you've got to fit in with the routine, and you get used to it. That's what happens in a place like this. You can't go and change the system; you've got to fit into the system here.* (R10M)

In the above two quotes, the residents' sense of life being shaped by rules and routines not of their own making underscored the sense of the facility being an ersatz home. Of note, few resident participants appeared to express any sense of entitlement or expectation of a different type of experience; they were resigned to the pre-ordained organisational culture.

Family

Family members expressed some relief that their family member was being cared for, while acknowledging that people may not feel entirely at home living in a facility. One family member noted the differences between the advertisements and her observations of reactions of her brother and friends to living in residential care:

> *If you go by the advertisements they all have, all these various homes, they guarantee that you're going to be comfortable; and there's other people who participate that you're going to get on with, and start enjoying having more company than you had maybe for eight or nine years before that. But, that doesn't work for everyone. Some people I have met over the years don't like being in a home; but they really haven't got a choice at that stage. I think the feeling of being in an institution is probably the strongest feeling against it.* (F4F)

Family members echoed the views of some residents about what should and should not occur within the walls of a care home. One family member could not countenance the idea of a sex worker visiting the home:

> *I wouldn't like that. No. I guess here, this is our first time dealing with a rest home, and because [facility] is so little and it is like a home. It's just so lovely here. I couldn't imagine that happening here.* (F2F)

The sentiments expressed in the above two quotes were noted across the dataset; that although participants commonly baulked at the institutional aspects of RAC, they did not want an unregulated living environment either. Another family member noted that a resident took umbrage at a new relationship her father had formed since he began living in the facility. The family member perceived that any sexual expression would not fit with the resident's view of what a care home should be:

> *There is one lady in there that keeps telling [father's new partner] she's cheating on her husband. Yeah, there's a perception that they're up to something. It would be like if there were a couple of gay gentlemen in there; she would be absolutely horrified, she'd be mortified, this woman, and it would just be a massive "no" for her. So, I would imagine she would make that very difficult for those people.* (F7F)

The above quote highlights a point evident across the dataset; that people may feel unsafe in RAC, exposed to a level of scrutiny not associated with being 'at home', and at times being alienated by other residents, even when staff might be supportive.

Section summary

These findings indicate that making something of a home in a residential care facility is complicated. The communal nature of the living situation in RAC creates an intimate neighbourhood that may not reflect individual residents' beliefs, values, and preferences, giving rise to anxiety and gossip. Residents wanted the homeliness of RAC to be expressed through relational rather than merely functional care from staff. Although staff commonly expressed that they wanted the facility to be experienced as a home, staff expressed ambivalence about residents having sex at home. The results indicate the importance of leaders in residential care providing clarity in the form of ongoing education and information to staff, residents and family members about what is permissible in this communal living context. Leaders also need to work with direct care staff to ensure the ethos of the facility being a home is translated into practices that make people feel more at home, rather than a guest. Due to a desire to fit in and not be shamed or seen as a problem, residents assumed a more restrictive climate than might actually be the case within the facilities in which they lived.

TRANSITION TO CARE

This section covers the findings in relation to the transition from home to living in a care setting. Related to this shift are a myriad of emotions as well as the practical and physical changes. Some residents and family members experienced significant grief and loss. Staff identified that funding barriers impacted on their ability to provide person-centred care through this time. Residents' experiences often depended on their reason for entry to care; whether the decision was forced on them by others' concerns about their physical or cognitive decline; or whether they experienced some sense of control in the decision. Other influential aspects included whether the resident had friends already living in the facility; whether the move dislocated them from their community; other recent major changes such as bereavement; and whether the move involved separation from a partner.

Staff

Staff recognised that it was hard for residents to settle in as the facility was not their own space. They noted that it took weeks or months for a resident to settle but also observed that some residents never do reconcile with the notion that this facility is now their home. A staff member described the preferred process at the facility where she worked, of easing a potential resident into the adjustment to moving prior to the permanent move, with short visits and engagement with residential activities.

> *There is a few steps that often people need to go through, not just the application part, but a personal journey until they realise this is actually a good place. I think it's quite normal. So, we've recognised that early on. [....] When they do come, what we do say is, "Why don't you come to a Wednesday informal happy hour kind of a thing, or to one of our activities, which is a social interaction with the other people living here?". If that goes well then, "Why don't you stay respite for a weekend, or a day or week?". If they got that pathway, a little social interaction, possibly a respite weekend or a week, then a lot of those answers, a lot of those fears and a lot of those assumptions are being dispelled.* (S3F)

The transition often appeared harder if there had not been prior planning before a crisis has expedited the move.

> *I suppose the trouble is how that comes about that the person goes to residential care. Is it a crisis? Have they just come from hospital? Everybody is bawling about devastated that they're going into care. And, "Oh my god, and then dad's on his own and what are we going to do about him because mum's now in a care home? How are we going to pay for it? We don't know any of the staff?" That can overrun a lot of the whole settling process and maintaining those connections.* (S1F)

Staff recognised people's reluctance in moving into a facility and identified that they had a key role in the adjustment process.

> *It takes at least three weeks for people to settle in; some people never do, they never settle in. No one comes here willingly, or hardly ever, so you're always on the back foot, but with support, care and just genuine love [people adjust] Communication is really huge.* (S22F)

It was apparent to staff that the move to care was only one of many major adjustments the resident was grappling with.

> *I mean, it's huge for some people coming into a place, and moving out of their home, and they have a period of grieving really, because their homes been sold, and that's a big thing; this is selling up a person's home.* (S15F)

Staff considered that the resident's sense of autonomy and control in the decision to move impacted on the time it took to adjust and their attitude towards the change.

> *Some transition in easily 'cos their choice – others are pushed in by family but are still independent – it's a huge transition for them.* (S14F)

Grief and loss played a major role in residents' experiences in transitioning to the care environment.

> *The tearfulness! The men. They can get very tearful, "My wife, my wife, my wife, when's she coming home?" To me that is sad. Men. I notice it with men mainly. They're the ones who seem to miss their wives, whether it's because the wives have always done so much for them in their lives. Some of the ladies we've got here with their husbands still alive; they seem to adjust a little bit better. Don't ask me why, but they seem to adjust better - yeah. Some of them, it is a very big adjustment, especially if they've still got a husband or a wife outside. So, we try to make it that it's not a big adjustment and they don't feel that they are really missing out on anything. It is very sad to see it when they do get separated like that.* (S11F)

Several staff spoke of their efforts to make residents feel at home, noting that each person's situation differed. For those who believed they were only coming for respite care, the idea that this move was permanent was difficult, whereas others experienced relief with the transition.

> *Sometimes they think they're just coming here for a holiday, and it's working with them to get them through that, and then we have people that come in and say, "I should have done this years ago".* (S15F)

Across the interviews with staff there was a common thread of staff expressing a commitment to making the facility a home for residents.

> *This is their home, 'They don't live in our facility, we work in their home'. That's our motto, and so we try and make everything as much like a home rather than an institution.* (S15F)

Staff commonly spoke of their role in becoming part of residents' social lives. However, they were also aware of funding constraints which meant that staffing levels did not readily allow for this level of staff availability.

> *Well I think if you take the view that it takes a community to raise a child that also applies in aged care. Certainly, the way the facilities are funded at present they don't have the time or means to provide an entire support network. There's a lot of connections, and especially family connections that are a lot closer that really deserve to be supported and respected that people really, really need.* (SF1)

Residents

For residents, the transition was linked to four areas – separation from networks; grief, loss of control; and perceptions of benefits of living in a facility. One resident was very clear that she had experienced significant grief from the transition to care. She identified that she would have valued being able to talk about the grief process.

> *The sense of loss through grief is huge. It would be great if there was someone we could talk to about many things. Grief and loss of giving up homes and your belongings is huge,* and people don't talk about *it. This needs to change. Agency people could visit which could be helpful.* (R25F)

Grief was closely related to the sense of loss of control and separation from networks. The resident below described the multiple losses of independence and socialising.

> *[I] don't like the thought-management control my life – told what to do like school, at home can do my own meals – here got what is given, I miss cooking a lot. My daughter put me in here – I'd rather be at home. Everything gets done for you here.*

Q: *For you, what are the benefits of living here?*

A: *I don't know. Don't ask me. My daughter*

> *put me here. You lose your friendships and people coming to see you and people coming for dinner. (R24M)*

The resident below also identified that the facility was not a place she ass ociated with home.

> *They do tell you that this is your home, it's not a prison but it does feel like it. Very much so.* (R16F)

Diminished social networks was a significant issue for many residents.

> *Friends I had outside, I miss them, whereas they might pop in at home; they won't do it here and I find that I have lost a lot of friends.* (R23F)

Others also spoke of the loss of control.

> *[I] can't go out, you can't go away, and you can't have people in and that. No benefits really. You have to do what you're told, that's all.* (R3M)

A female resident had lived in a boarding school as a child and believed that this experience of communal living as a young person had helped in her adjustment to the RACF setting. For her it was a similar context.

> *It's not unfamiliar to me because I was raised really... I say raised, but I attended four years in a Presbyterian boarding school, so I am familiar with the life.* (R20F)

The converse was the experience for several residents felt there were benefits for them being in care. They expressed relief at moving into the RACF and viewed the transition pragmatically with a give and take attitude. The following resident explained he had a history of suicide ideation and felt the care setting meant he had support to get through those periods in his life.

> *I wouldn't be alive if I was still at home. I would have committed suicide. It hasn't given me the nurturing I would like, but it's certainly giving me the sustenance that I need.* (R8M)

For some it was an informed decision to move into care and they expressed relief from the pressures of managing everything on their own and the safety they had from not living alone

> *Everything is done for you. You don't have to worry about anything at all. You don't have to pay the power or the phone, you don't have to do any shopping, don't have to do any washing; everything is completely done for you here.* (R9M)

> *I don't have to wash the dishes. I don't have to make my bed, but apart from those things, I feel safe. I've never really thought about it; I'm happy. I can't think of anything wrong.* (R23F)

Family

A resident finding a special friend soon after moving in appeared to make the transition easier for adult children who were worried about their parent's transition. Family members spoke about the friendship adding meaning to their parent's life. The following example illustrates this point. A daughter saw the mutual benefit of a friendship between her dad and another resident. From her perspective the mutual caring of their new relationship added meaning to both their lives and renewed and encouraged their engagement in living.

> *[The staff have] actually said to us that [Name] and dad have been very good for each other. [Name] was particularly depressed when she went in there; since she's met dad, she's really getting on with life now. And for dad, he was quite a recluse; he just wanted to stay in his room and do nothing. Now he's going out on bus trips, because [Name]'s wanting to go, but doesn't want to go on her own, so because he cares for her, he's required to go.* (F7F)

As with both staff and resident interviews the diminishing social networks resulting from transitioning to living in a RACF environment created a significant sense of loss and grief. Adult children experienced the grief of being an onlooker to their parents, separated through the move to care. The following situation, her mother's cognitive decline was more than the father could manage, but that did not spare either the grief.

> *[The daughter explained] she [mother] said "it's like a divorce". They were her [mother's] words. [For the father still at home] I don't think it's as easy as he thought it would be. I think he's quite lonely. I think it's quite lonely for him, even though mum drove him crazy. (F9F)*

A daughter described her father's surprise that he did not find the level of connection in the move to the facility that he had expected.

> *I think he had the idea when he went into the care environment that it would provide a level of social connection. I think that's what he was looking forward to. But my impression was that he found most of the people quite annoying and didn't really want to spend a lot of time interacting with them socially. I don't think he found it very easy to make those friendships in the facility and I think he avoided some of the social programmes because he found some of the people hard to get on with.* (F5F)

However, a son observed how much happier his mother was in the move to care.

> *Some really old friends have stayed in touch; and this another kind of weird thing. People that she was at school with 70 years ago still pop around or ring her up; so those really old friends have lasted the distance, which is interesting. It was a new lease on life. That's a cliché expression, but it really was for her and the last two years have sort of been that really.* (F11M)

Section summary

Staff, residents, and family members highlighted that the transition to care commonly, but not always, resulted in a period of significant grief and adjustment for residents and family members. The major transition experiences occurred because the move typically meant dislocation from many aspects of the resident's previous life; it was much more than moving to a new house. Although staff acknowledged the grief process there did not appear to be any formal processes or professional staff to assist residents and families with this shift. There is a significant opportunity for social workers and counsellors who work with older adults to be much more engaged with residents and families through the transition process.

LONELINESS AND THE MANAGEMENT OF RELATIONSHIPS

All participants—residents, staff, and family members—noted that the initial transition to RAC (a period of up to six months or more) was not uncommonly a very painful process, eliciting grief and loneliness. Participants identified numerous reasons for the loneliness. Often the location of the RAC facility meant people were no longer situated within their community. Partners in decades-long relationships were separated. The move to RAC separated residents from previously enjoyable connections, such as neighbours. Those relationships, though ostensibly superficial were often long-term and had provided daily social engagement that was now lost. The built environment of RAC inhibited social connections (see section on physical space). The expression of intimacy and sexuality arise in a context.

The context of residential aged care can easily be one that alienates people from themselves as they were, and as they are now, and this alienation makes it harder rather than easier for moments of intimacy and sexual expression to arise. The majority of facilities did not signal to staff, residents, and family members that intimacy and sexual expression were desirable or even permissible. In the interviews, residents, when asked about sexual expression, queried whether such activity would be allowed; they expressed anxiety about overstepping an invisible behavioural line. The contrast is striking compared to other communal living contexts. Living in a university hostel for example creates a neighbourhood in which intimacy and sexual expression very readily arise but the neighbourhood of RAC can dampen these possibilities and can, counter-intuitively, increase isolation despite propinquity.

Staff

Participants noted that there were both external and internal factors in the move to a RACF that had the potential to exacerbate loneliness. Staff gave examples of the grief of separation when one partner needed a higher level of care than the other and was moved to a different part of the facility:

> *Well, we have a married couple and the husband is down the bottom [of the facility], and the wife visits almost every day. He hates it [the separation]. He has behavioural problems now. When she leaves he starts misbehaving. And, he worries.* (S18F)

In the above quote the notion of misbehaving (a word commonly used to describe children's misdemeanours) perhaps minimises that the resident's behaviour might be a grief response.

Participants noted that residents did not always have ongoing relationships with their families on entering residential care, which resulted in disconnection and loneliness:

> *Yeah, unfortunately non-Māori, which we see a lot here, come in and the relationship with whānau slowly goes on a decline. Whereas Māori that whānau relationship never ends.* (S9F)

Participant one also spoke of the loss of intimate family connection in the transition to RACF:

> *There's a lot of connections, and especially family connections that are closer that really deserve to be supported and respected that people really, really need. I think that's the greatest loss of coming to residential care, is that potential loss of intimacy.* (S1F)

Staff participants commonly spoke of their role in sustaining important connections in residents' lives. Respondent three described how she enabled a resident's cat to live in the RACF, because this was an important relationship:

> *I said, "Why couldn't the cat be here?" Because I could see how important that cat is for that person. Anyway, we put a cat door in the ranch slider, and the cat moved in. There was a bit of hiccups here and there, but now the cat is walking around and living in the room, and moving about for the last year or so, and she's happy; because she's got her cat that she connects with.* (S3F)

A nurse manager spoke of the fiscal problems that impact on the ethos of creating real community in residential care facilities:

> *Well I think if you take the view that it takes a community to raise a child, that also applies in aged care. Certainly, the way the facilities are funded at present they don't have the time or means to provide an entire support network.* (S1F)

Participants detailed the ways they created opportunities for family networks to be sustained:

> *We have an open-door policy; people can come anytime. We encourage family to stay for meals; we encourage family to celebrate things like birthdays.* (S14F)

Staff participants typically spoke of seeing themselves as part of the network of residents' lives; that care was much more that attention to physical care:

> *Q:* *To what extent do you think that fostering connections. Including supporting intimate relationships is the role of residential home care staff?*
>
> *A:* *Well I think it is part of our role given that they have come into care and intimacy is part of the care. You are having the whole person come in so you should be catering to all their needs, not just showering, getting dressed, the intimacy and the touch thing is part of who they are as well, so we should be facilitating and fostering that.* (S5F)

These every-day, long term relationships between staff and residents at times posed challenges for staff in terms of the maintenance of professional boundaries, and staff at times experienced vulnerability:

> *We've got a very charismatic male caregiver who everybody loves, and a lot of the female residents would fall in love with him, and [put him in] the position that he felt quite vulnerable at times being alone with those people, because at one stage, two of the female residents were having quite florid fantasies which sort of became real to them.* (S7F)

Staff commonly spoke of families at times contributing to residents' loneliness by disrupting the formation of new relationships:

> *Some people are really good about parents forming relationships and other people can't stand the thought of it.* (S5F)

A staff member told of the distress for staff when a couple in a newly formed relationship were separated by staff at the demand of family members:

> *They were both fully for each other, and then the families told us to stop it. We did it. We stopped it. Then he passed away about a week later after we stopped it, then she passed away two days after him. It was just stupid. We didn't know what to do, as the workers, because we knew that we were kind of taking away their reason for living.* (S17F)

The above quote is a stark illustration of how the residential context can exacerbate loneliness. It also highlights the problems that EPoA can create, when the family member who holds the EPoA can in New Zealand over-rule what health professionals believe is in an older person's best interests.

Participant one spoke of how an institutional mindset obstructs opportunities for meaningful relationships, particularly if they involve sexual intimacy:

> *I think if it's a friendship, or if it's a family member then it's fine, we're very embracing, but if there's any kind of hint that it could be some sort of other relationship, I think we then become, and by we I'm using the 'royal we' not myself; I think institutions that I've worked in, and I've been doing this for 25 years, become very closed to any other sorts of relationships outside family. Even when we've had husband and wives in together; I think there's been obstacles put in their way.* (S1F)

Participant seven also described the part that staff, and the limitations of the built environment played in undermining the development of intimacy; keeping residents apart from those they might wish to be close to:

> *If a relationship develops between residents within the rest home, of a non-platonic nature, or if one's come in and the spouse is outside, or it's a partner is outside; I still think we're quite obstructive, because we don't have the places for them to go. Their rooms are small, and I've just found that my colleagues' attitudes around relationships is that there's a cut-off age, and that's usually probably 65, and then after 65, whether it be handholding, kissing, or anything; just should stop, and that it's, it just doesn't happen.* (S7F)

The above quote illustrates the interplay of both attitudes and architectural limitations that create conditions that invite loneliness.

Residents

Some participants identified that their social world shrank significantly; typically, people beyond the person's closest social circle initially visited intermittently but over the course of a few months visited less or not at all. One respondent (R4M), who became widowed after the move to RAC, described the losses involved in the transition to RAC:

> *You're allowed to put your own things on the wall, which is important. There's not much space for anymore. I used to have a library of books, but I had to get rid of those when we went into [facility]. We had the equivalent of a three-bedroom house and a garage and so on, but that had to all disappear. So, I have none of my books. I do have colleagues that still come, but there's only a few of them. You soon drop out of circulation.* (R4M)

For the above resident, loss of the inanimate and loneliness for the animate each appeared to accentuate the other. In his description it seems possible he was lonely not only for people, but also for the company of his books, which reflected to him who he was. The sense of requiring permission permeated residents' interviews and added to residents' perceptions that their world was reduced and beyond their control.

> *Friends I had outside, I miss them, whereas they might pop in at home; they won't do it here and I find that I have lost a lot of friends, because I think - I don't know because when I was out and had friends in these sorts of places, I would think twice before - you wouldn't pop in on them; you'd make an arrangement somehow. It's all just so different. Whereas friends down the street, going past would perhaps pop in and say, "G'day,". So, you don't have that, because if people want to come in or if you want to see them, you have to arrange.* (R23)

Although staff participants emphasised their readiness to accommodate family and friends, and their wish to create a home-like environment, residents typically described RAC as an ersatz home, with one of the markers of the deficiency being the feeling of dislocation from a previous life. The following respondent had not found kindred spirits in the facility:

> *I feel somewhat incomplete when you have an interest in anything in particular. You can't get the full enjoyment out of some situations because of that. There's a certain sense of limitation on most things that you do. That would come down to the social attitudes of the majority of the people that live here.* (R9M)

However, some participants preferred the move to RAC, as it meant they were more socially engaged:

> *There are differences between being in my own home in being here. I was on the verge of being lonely, because there was very little contact. I was in [Town], and by the beach, a holiday place. There's no reason for people to call in on a dear old woman. I had no sort of, background of friends up there.* (R5F)

Loneliness for some was due to the death of most of the significant people in their life, partners and long-term friends:

> *We shifted from [City 1] to [City 2] where two of my best friends were. They died and that was the end of that relationship. They were lovely friends. They were at my 70th birthday, and I'm now 78. All at my birthday party signed that walking stick. So, in a way I carry them with me. One lives here in [City 2] and one is in [Town]. That's all the male friends I've got. So, it's a bit lonely at times for real friends.* (R8M)

Loneliness at times resulted from family interference, with disruption of a new relationship. A widower described how he did not explore a new relationship further due to his family's wishes:

> *So as far as family goes I am sure they would be resentful [about a new relationship], in fact there was one girl I did know, I was fond of her. There was 20 years between us, but the family were very anti that. I do feel slightly resentful over it. It probably wouldn't have worked out anyway but were fairly close friends for a while.* (R14M)

A participant described how the daughter of her new male friend had disrupted the relationship:

> *I have got a rather nice relationship at the moment with one of the boys [residents]. Unfortunately, the daughter is against her father having a relationship, he is lovely, he really is. I told her she [daughter] has spoilt her dad's enjoyment. We had something going for us which was good. It is shame she won't see the nice side of me and I told her there is one. She has hurt me.* (R14F)

Participants had widely varying perceptions and accounts of the role of staff in ameliorating loneliness. Some participants have not received the level of care they wanted, even if they recognised they were unable to live independently:

> *It hasn't given me the nurturing I would like, but it's certainly giving me the sustenance that I need.* (R8M)

Respondent five provided an account of her observations of the task-orientated care that exacerbated residents' isolation:

> *Staff, I'm talking about; I don't think they're that tuned to seeing the residents as whole personalities even. Here they call them 'cares,' the chores that they have to do. They're so busy running around their cares, doing their cares, that I don't actually think they see you as a real person.* (R5F)

The above resident was acutely aware of the task orientated focus as she has moved from a facility that had adopted the Eden Alternative principles of holistic care. Conversely, some participants appeared to consider that the staff were now part of their circle of significant people, and greatly valued those staff who took the time to know them as people; to share something of themselves and to get to know the residents as individuals:

> *The staff here are out of this world. [Name] is just beautiful, she really is. [Name], [Name] and all the head staff are beautiful. The Filipino girls are lovely too. They are. You can have a lot of laughs with them, and we do. We have dances. We have all sorts of things in here.* (R7F)

Staff interactions and engagement with residents appeared to be influential in either deepening or easing residents' loneliness.

Family

For some residents, the transition meant separation from a long-term spouse who remained in the family home. Family member nine described her mother's intense grief going into RAC; that the separation from her husband felt like a divorce:

> *Yeah, I think so. The girls [staff] here are just lovely. When mum gels with someone she really does gel with them. Like, she tells us how the lovely the staff here are. They're friendly; that's the relationship they have. She trusts them; especially now. [....] She loves them. She values their friendship I think, and just the way they care for her. (F2F daughter)*

A daughter spoke of the dislocation and grief for her father, who in quick succession experienced the death of his wife and then a move to care:

> *Dad lost mum. She passed away, so it was quite traumatic for him, because he went from living in his own home with mum, because dad has Alzheimer's, so caring for him to her getting really sick, passing away, and then having to move his old world into a rest home, so it was pretty traumatic. The first six months were really rough, but he's settled in really nicely now, it just took a long time.* (F7F)

The above relative described how a big part of her father settling was that he formed a new relationship. The daughter was relieved that the woman's family were also supportive of the relationship:

> *I'd be gutted if [Name]'s family said no, and they took her away, because dad would just lose the plot. That would be like losing his wife all over again. To lose another person he's fallen in love with, to have them taken away from him, it would be just tragic. I reckon he would lose the plot completely.* (F7F)

The above is another example of where the EPoA held by relatives of a person living with dementia can be used in ways that exacerbate loneliness.

A community-dwelling partner spoke of the isolation he saw for many residents:

> *I've seen these unfortunate ones there. It's like their family put them there, and then they forget all about them; out of sight out of mind. That sort of thing, and I've seen that in about four different rest homes.* (F3M)

...staff, residents, and family members bring their own lifelong attitudes and experiences about gender and sexual diversity with them to the residential care environment.

The above family member had re-partnered with another resident after his wife had died in the same facility.

A widow spoke of the grief of being physically apart from her resident husband as he lay dying, as she could not fit on the bed beside him. Due to her own health problems she could not sit for the hours it took him to die:

> *If it had been possible and I could have crawled onto the bed and lay beside him, so that my legs weren't hurting, I could have stayed there right till the end, and I would have.* (F1F)

The same family member also spoke of seeing other residents' family members disrupt any expressions of intimacy and sexuality:

> *There was one lady there who her husband and died some time ago. She obviously needed a sexual relationship because she used to chase all the men. Some of their families actually took them to another rest home because they didn't want [their] dad cavorting with this other woman who wasn't his wife. But, I mean, we're still people. Even if the mind is not all there we still have feelings. As long as the other resident was okay with it, I don't see why the family couldn't be okay with it as well.* (F1F)

A daughter described that the move to the facility had been a mixed blessing for her widowed mother; that she has been reinvigorated with all the company, and also now had more connections with people who then died:

> *It was a new lease on life. Certainly, as far as fostering connections goes, they've got quite a significant social programme at this place. Every week they've got a calendar of all the events that are happening, and so there are happy hours, for instance, on a Friday afternoon. There's morning tea every morning, as well as there's a dining room where they go and have their meals, so those are very social things; as well as the events that they have. I noticed this with my mother, is that she found that she gets to know people, but then they die as they tend to do at a certain age; and in a place like that, you're surrounded by very elderly and often very unwell people. People are going to pass on. That's something which mum has mentioned a few times as being a bit sort of depressing really.* (F11F)

The above respondent raised the significant reality for people living in residential care; even with excellent communal opportunity, part of living amongst this age group means that death of new friends and partners will commonly be in the mix of this living context.

A manager noted how discreet a gay resident felt he had to be with his language when referring to his male partner in front of staff.

The loneliness may occur because there are assumptions that certain relationships are not permissible. A sister described the isolation for her gay brother who was living in a Catholic care home and had not come out:

A: I don't know how you could in a place like that [have an intimate relationship]. His being gay would maybe be a problem for him; it's not a problem for me. Maybe the home, I don't know what their attitude would be. I don't know whether they know he's gay or not. Maybe they don't. He's had a wife. He's got children, so he doesn't present as a gay man.

Q: You've never asked him whether he's let staff know that?

A: No, I haven't, no. I'll bring it up if I can sometime actually, at the right moment. (12F)

The above quote illustrates one of the many problems when a discussion about sexuality and identity is not of the admission process. The sister was waiting for the right moment to raise what she thought was likely to be a difficult topic, rather than staff normalising the centrality of this information. This respondent uses the refrain repeated by residents and family members; "in a place like that;" an ersatz home in most instances.

Section summary

The data indicated that some of the loneliness of older age is a fundamental challenge for this age group of older people, with the ill-health and death of friends and intimate partners being a common part of lived experience. Residents, staff, and family members all noted the major transition involved in the move to residential care. Residents and family members spoke of the loneliness for the treasured possessions that people associated with their identity, such as the loss of a library as part of the downsizing to move into care. The data also highlight that residents need overt information about how 'at home' they can be in the care facility. Residents held back from intimate relationships because they imagined that there were unwritten rules that would become apparent it they crossed on invisible line. Residents often used the word, "allowed" in pondering about the possibility of intimacy in a residential home, as if permission would be required, rather than taking for granted that intimacy and sexual expression would be ordinary facets of life. The power of an activated EPoA also made it legally possible for family members to disrupt the burgeoning of expressions of sexuality and new relationships. Given the legal authority held by the person with the EPoA, staff were sometimes aggrieved by family members' decisions and yet had no power to intervene in steps taken by families that staff perceived exacerbated loss and loneliness.

Findings Cluster 4: Diversity

RELIGION

While survey respondents and interview participants made distinctions between religion and ethnicity, they were frequently considered together by participants as indicators of diversity, and often difference. As we reported in the quantitative section, 'No religion' was the largest category of religious affiliation (n=138, 36.5%), followed by Christian (n=121, 32.1%) and 'I belong to a religious organisation but I am not active' (n=64, 16.9%). Three-quarters of European and Māori survey respondents reported 'No religion', but 60 percent of Asian respondents identified some religion (most often Christianity but also Other). It is difficult (and perhaps not especially important), then, to identify whether attitudes towards intimacy and sexuality were shaped more by religious, or ethnic affiliations, or some combination of the two. As we saw in Table 3 earlier, there were significant differences (p<.05 in every indicator) in openness to expressions of sexuality between survey respondents who identified 'No religion' (which was combined with 'religious and not active') and those who identified as Christian; 'No religion/inactive' respondents uniformly show a greater openness to difference and diversity than did identified Christians. What is not clear is whether expressed opinions are genuinely held beliefs, or beliefs that respondents felt they 'should' have. Again, the distinction may be moot. If staff do not have access to ongoing education and training, and must instead rely on their personal values when making decisions, however, these distinctions become important.

Staff

Staff with strongly held religious beliefs (or who felt they must express strongly held religious beliefs) must navigate distinctions among their workplace, professional association, and personal values and ethics. In every case participants told us that it was their professional values that would prevail.

> *I think we would have to put our own spirituality and beliefs aside. I can't just go, "Ooh yuck", because it is a natural thing. If something does occur and maybe they've forgotten this is not the time and place.* (S4F)

Public expressions of sexuality and same-sex intimacy were the greatest challenges for religious staff. One manager made a clear distinction between staff attitudes and staff behaviour towards residents.

> *I could never change their belief, but I could influence them and say, "Is this unacceptable? What makes it unacceptable?" I normally go about it with risk assessment; hazard towards patients; towards resident and towards the staff as well. I say to them, "If it does not pose any risk at all or any harm; then who are we to say that this is incorrect, or this is not right?"* (S12F)

Other managers and supervisors echoed these thoughts.

> *Q: So, even if there were differences in religious views or beliefs, people could put those aside to look at what is bringing wellbeing to that person? I don't want to put words in your mouth.*
>
> *A: No, that's exactly it; that is it. As long as that person's wellbeing is being looked after and thought about, that's all that matters to be honest.* (S20F)

Some managers saw the complexities presented by staff diversity as teaching opportunities to educate staff about all kinds of diversity:

> *I do see [diversity] as a difficulty… Yes, we are quite diverse here. Whilst we are quite diverse, we have a very large percentage of overseas nurses which I think helps, but then we do have a lot of New Zealanders and some of our overseas staff where the culture does limit conversation and so on, but the more management of a facility like this does embrace things like the [Silver] Rainbow seal, and just in our conversation, and inviting people like yourselves in, all we can do is get them on the bus and just then to come along with us. It's up to us to help them make that mind-shift and embrace the fact that it's progress, and it is out there and it's real.* (S16F)

One staff participant identified very clearly as Christian, although she felt her Christianity required her not to judge other people.

> *Q: How do you reconcile your personal values with your professional values, if your personal values are quite different from your professional values?*

A: *Well at the end of the day I have to remember, if I'm looking at it, my personal values, I don't get to judge people, because Jesus is the judge of everybody, not me. My job is to love people, and I love them as they are, because that's how he loved them. I'm watching his example.*

Q: *So, your faith is a strong source; your Christian faith is a source of your values?*

A: *Absolutely.*

Q: *And yet in the workplace you have to kind of balance that?*

A: *Yeah.* (S13F)

That she did not judge came through quite clearly as she related an event that had happened at her facility:

Q: *Some facilities have policies that allow for the use of escorts and sex workers. What do you think?*

A: *When I started here, and in my early years of caregiving [...] I did the cleaning for a year or so, and they needed me for nightshift. And the reason they needed me for nightshift was because one of the staff members had been removed very swiftly, after it was discovered that she had been leaving the facility to do blow jobs for a gentleman in the [facility] at a certain price.*

Q: *He would actually pay her?*

A: *Yeah. There was sexual contact. The only reason she was found out, was because she tried to put the price up, and he rang the manager. He rang the village manager and complained about the price going up. If she hadn't been so greedy she could have got away with it for a long time.* (S13F)

It appears that what was offensive to this quite Christian interviewee was not so much that another staff person was providing sexual services to residents, but that she was greedy; and it was greed that caught her out.

Additionally, some staff also work in facilities that are owned by religious organisations, and in those instances managers and supervisors also felt that they had to navigate the space between their professional values and ethics and those values and ethics they felt would be expected by the religious organisation. This navigation resulted in some creative compromises, but in each case staff who were interviewed said that their professional values always were the most important factor in decision-making.

Q: *What about sex workers, and the opportunity for residents to have a sex worker come in?*

A: *I don't know what [Facility's] policy is on that. Because it's a Christian facility, a [Denominational] facility; I don't know how open they would be to that. I've worked in facilities in the past where the managers have had no problem, and it's a process that I've had to work through, and I've come to a place where I have no problem with it.* (S7F)

I think it is religious values because we're under the [Religious denomination]; but then again it's the values, but because we're bound by the [Religious denomination]; but if you see that, well actually it's into our day-to-day life. [...] I've been here twelve years; I've developed, embraced three things for me, to ground me into the ground, that to remind myself, that hey, first things first. For example: Treat everyone the way you wanted to be treated. When I grow old, treat me the way you wanted to be treated; count your blessings; and be a blessing. I'm counting my blessings [...] A few years ago, we had a [...] resident [who] was a lesbian, she had a partner. Even nurses became like, oh this is strange. What was the term? It's about when it comes to religion? They didn't have [anything to] say. When it comes to religion they didn't know what to say. (S10M)

Residents

There can be little doubt that residents are acutely aware of both the attitudes of staff and other residents about intimacy and expressions of sexuality by residents.

Q: *Given the varying degrees of acquaintances, friendships and even the more intimate relationships that are part of most people's adult lives, how easy has it been, or how difficult is it, to continue with these relationships here?*

A: *Difficult.*

Q: *Do you want to expand on that for me?*

A: *I tend to be a bit shy. Most of the people around here are Christians and most of them I believe are devout Christians. That makes it quite difficult.* (R12M)

But perceived disapproval extended beyond just sexuality to other perceived vices:

Q: *What about if there was a resident who wanted to pay for sexual services, like have an escort or a sex worker come in; how do you think staff would look at that?*

A: *Not really sure about that, in so far as anything that seems to be breaking the rules would be frowned upon. While that's not a rule, that would seem to be... because a lot of these people are very religious.*

Q: *The staff?*

A: *The staff, because they come from South East Asia and places like that. They have what some would call Christian attitudes, which are very deeply embedded. They would very quickly take a stance on what you were doing.*

Q: *So, you guess it would be kind of uncomfortable for them?*

A: *Like, my bottle of whiskey that's sitting there; it's been frowned upon by three or four people. A wee bit of discretion is the better part of valour.* (R9M)

Perceived disapproval inspired mischievous thoughts:

A: *They're very religious girls, these girls [care staff]; they went to church.*

Q: *Do you think that has an impact?*

A: *Of course it does. I'm sure it does. As I said, I would like to ask one of them, "How do you cope for a whole 12 months without having sex? What's it like when you go home? Your husband is at home waiting, and do you ever talk about it?" I would love to know that. But, I never ask them. I don't think they would tell me. They would probably slap my face. Well, no they wouldn't do that, they couldn't do that.* (R8M)

However, perceived disapproval did not only come from staff who were Christians. One resident who clearly identified as Christian not only expressed her disapproval of sex work, but also experienced disapproval from non-religious staff.

Q: *There are some care homes that actually let residents pay for sexual services. So, if someone wanted an escort or a sex worker, I guess a prostitute to put it boldly, and they let them do that, do you think that is a good or a bad thing?*

A: *Well, I wouldn't like it no. As a Christian I wouldn't like it. I don't think if that was able to happen here that I would like to stay here.*

Q: *What about the staff here? If you say that they have a very Christian philosophy...*

A: *The owners do, yes.*

Q: *Might you imagine that they probably wouldn't be... I don't want to put words in your mouth.*

A: *One of the staff here I have said to her about being a Christian, and she said, "You just frighten everybody, that's what Christians do". She's got no belief at all. But, I just keep telling her that I'm going to pray for her anyway. She just smiles and takes no notice of me at all. The staff, probably two or three of them maybe. But, I don't know about the others. I know that [Name]'s not; definitely not. They all allow you to do your thing. They know that I'm a Christian and they know that I've got my Bibles here. They have been told that they are not to interfere if I am having my prayer time.* (R13F)

Family

One family member felt the different religious backgrounds between facility staff and their family member were a potential source of values clashes around sexuality.

> *I know most of the [staff] that work where dad is are Filipino or something similar to that; they don't necessarily have the perfect grasp of English. So, if they have an insight as to why he would want to do that [have an intimate relationship], and most of those particular staff, people tend to have a religion. Dad has no religion. I think education around why he would want to [have an intimate relationship] and the fact that just because it's not their belief, doesn't mean it can't be something he wants to do, and that they have to respect that.* (F7F)

That same family member felt that facilities should put their values up front for potential residents and family members to see before they make the decision to live there.

> *When you go and view rest homes to book yourself in, maybe that's the sort of thing that they should say: "Well, we're a very open-minded rest home here; we have no problems with race, religion, sexuality", and let the people know that that's okay. "In our particular rest home we're quite conservative, we believe that religion's quite important or we believe that same-sex marriages a very important factor, or same-sex relationships or whatever you want to call it, so therefore if you are a gay couple, it's probably not the best place for you."* (F7F)

Section summary

It is clear that religiosity is important in the lives of many people who participated in this study: staff, residents, and family members. Whether it is a strongly held 'traditional' belief in an established faith system, or an equally strong held non-belief, religion and the systems of values and ethics it represents is important. Religion has become co-mingled with ethnicity in this study; we do not perceive this as a problem since it is not the beliefs themselves that are an issue, but the way expressions of religiosity (or non-religiosity) create an environment of respect, inclusion, tolerance, or negative judgment in the RACF. For our purposes, religion is a cultural construction, regardless of how deeply held, and must be managed in the same ways as other cultural constructions such as culture, ethnicity, generation, and so forth.

We are also mindful, however, that religions set out values frameworks, and where those religious (or personal) values align or do not align with professional values is the nexus of interest for all helping professions. In all cases, when staff make decisions they must be made in favour of the profession of the decision-maker, and aligned with workplace values and facility policies. We are not convinced that staff can "put aside" their deeply held personal beliefs, however. Managers and supervisors will want to provide education and training opportunities to policies which allow staff respectfully to reflect on how they can navigate any dissonance or space between their religious (or non-religious) values and workplace expectations. This is equally true for facilities that are owned or operated by religious organisations who employ staff who are not members of that religious group.

At least one family member has suggested that facilities make a transparent statement about what kinds of relationships, values, and behaviours will be welcome at the facility before an individual becomes a resident. Religion was raised by interview participants mostly around issues of legal behaviours and relationships which remain difficult or contentious for some religions, such as sex work, private masturbation, or same-sex couples, we encourage facilities to consider making such statements available as part of routine orientation to the facility. This will allow potential residents, their partners, spouses, and families, to make fully informed decisions about whether the facility is the right fit for them. Gentle education about religious (or non-religious) tolerance for residents can also be provided as part of their induction to the facility. This would leave no doubt in the minds of residents about what kinds of behaviours and relationships will be supported by staff, and provide a welcoming environment for staff and residents. We note that this kind of orientation is already in place a number of facilities.

Finally, we refer again to the specific section on tangata whenua in this report. It may be difficult to separate the expectations of cultural tikanga from missionary religion, in both Māori and Pasifika communities, and we are not entirely sure the distinction is necessary. The sacredness of tinana, the mana of the individual, and the tapu of the relationship between individual, āwhai, whānau, hapu, and iwi are essential aspects of Māori wairua, particularly in kaumātua and kuia. Each whānau will have expectations of how these are managed, and we encourage respectful conversation about how intimate relationships will be managed with whānau, kaumātua, and staff early in the move into care.

GENDER AND SEXUAL DIVERSITY

It is clear from both quantitative and qualitative data that staff, residents, and family members bring their own lifelong attitudes and experiences about gender and sexual diversity with them to the residential care environment. Whether it is working, living, or caring, attitudes towards gender and sexual diversity in all groups ranged from strong support, to 'live and let live', to 'don't ask don't tell', to 'keep them away from me'. It is notable that there was a lot of ascription of attitudes to other groups—that is, some residents thought that staff would not approve, some staff thought that same-sex couples would not be welcome by residents, and there was some virtue signalling to be consistent with perceived religious beliefs. There is a large amount of qualitative data on same-sex couples and gender and sexual diversity, which is not surprising since we asked about this issue directly in our interviews.

In the staff survey, slightly over half of respondents (n=245, 56.6%) agreed with the statement that same-sex couples have the right to be sexually intimate with one another, while 188 (43.4%) were neutral, or disagreed with the statement. Of the 281 respondents who agreed with the statement that intimate relationships are a lifelong human right, 200 (71.2%) agreed that same-sex couples have the right to be sexually intimate with one another; positivity about sexuality in one area appears to flow into other areas. Some staff also drew heavily on their own beliefs in this area ("I believe in God but I think [having gay residents] would be alright"). The differences in attitudes towards the survey question on same-sex sexual intimacy by religion was significant: the mean score of respondents with No religion (m=3.95, SD=1.13, n=202) was significantly higher (indicating greater acceptance) than either Christian (m=3.50, SD=1.29, n=121) or Other religion (m=3.5, SD=1.31, n=55; p<.05).

A number of residents felt that management and staff in the facility set the tone, and even while they as residents might personally be supportive of same-sex couples, for instance, they were confident that such couples would present a challenge to staff. Many resident participants were aware that they reflected the values of their generation, and that social attitudes had changed significant in the last few decades. Staff, for their part, articulated their ambiguity about how welcome same-sex attracted and trans persons would be in their facilities. Many referred to personal networks to demonstrate their openness to gender and sexual diversity. While some staff were strongly supportive of including gender and sexually diverse residents, others were much less so, and felt that working with such residents would present a difficult challenge for them. Family member participants struggled with the issue: again, while some were supportive, some felt that sexual and gender diverse residents would present a challenge to staff. Some were openly hostile to the idea of gay or lesbian residents in the same facility with their family member.

Staff

The values conflict that was apparent in the survey data was echoed in interviews with staff. There was an assumption by some participants that religious faith was somehow in conflict with respecting the rights of same-sex couples ("Even though…"). A female staff person whose relatives were the managers of the facility, seemed to struggle to be careful with her language to say,

> *Even though I believe in God, I also think if two… same-sex marriage or people were to come in, that we should respect their wishes as well in that area. We don't have any as such come in, but if they did come in, I would hope… And I also know that my [relatives]… because we have friends ourselves that have had both, and I believe that they have treated and respected my friends appropriately, and not, "Yuck, you're not the kind of person that we'd… And you're going to hell and we're not". So, I'm very grateful that I've been brought up, where my [relatives] might not like what they do, but they keep that to themselves.* (S4F) [Pauses in original interview]

A resident opposite-sex couple who were interviewed together emphasised how important management was in setting the tone and standards for a facility:

> *We haven't noticed any [same-sex relationships] but certainly I would say that [Staff Name] who is such an incredible person, she would make us all feel comfortable even if something had happened. Let's say if two men came in holding hands out of the blue to exercises, she would say, "Welcome guys come in and join us!" and we would all be part of the story. We are all part of each other's story. (R25 M-F Couple)*

A male facility manager reflected on how staff attitudes had changed over the years.

> *A few years ago, we had a resident [who] was a lesbian, she had a partner. Even nurses became like, "Oh this is strange" […] This was the senior nurses; the older nurses. Again, that nurse now is 74 or something like that, [they are] are older, now old-school nurses.* (S10M)

There was an assumption by some resident participants that new settler staff would probably have difficulty with same-sex couples because of religious or cultural norms:

Q: *Your sense is though, without really knowing, that if there was a gay person or couple, that that would be supported by staff members?*

A: *Possibly. I don't know whether that would challenge some of them. Given they're a very high proportion of people from the Philippines, I don't know how the Filipino would deal with it, because it's a strongly Catholic country […] You don't know if you face them with the sort of realities that are out there.* (R4M)

A manager noted how discreet a gay resident felt he had to be with his language when referring to his male partner in front of staff.

> *Then I had a patient as well; he had cancer, who had a partner for 30 years; but he said to the staff that, "Oh by the way, my friend is coming to visit me," and it saddened me.*

Q: *And his friend was male?*

A: *Yeah, male, but actually it was his partner, but he calls him friend, because it felt I guess… not felt but he had that self-protection I guess, you know; guarding, like in oh, I don't know; kind of like that. But I said, "No, it shouldn't be this way". So, moving forward as we go on; how can we combat that through education?* (S10M)

One male resident provides an example of the way staff have communicated their values and expectations about sexuality to residents.

Q: *Do you think same-sex relationships would be supported here?*

A: *Same-sex?*

Q: *Yeah, like two men or two women?*

A: *No. They'd get really upset about that.*

Q: *Who would have a problem with that?*

A: *Staff, I think.*

Q: *What makes you think that?*

A: *The way they talk and the way they act.* (R3M)

One staff person was definitive about her support for lesbian and gay people:

> *I've got a [senior staff person], she sits opposite me... She's gay; I don't have an issue at all. We've had a gay man in here, and he used to get visitors and then he'd put a sign on the door; 'acupuncture; having acupuncture; don't disturb.' We knew what was going on, but hey at the end of the day that was his room, that was his choice and that was his right.* (S23F)

Another female staff person, although apparently personally supportive of gender and sexually diverse residents, expressed a wait-and-see attitude about how sexual diversity is managed in RACF.

> *As far as sexuality in rest homes, it's going to be interesting. I do hope one day that I am somewhere when there is a lesbian or a gay person, or a transgender person so I can just sit back and observe just what goes on. No, I haven't found it challenging at all; it's just another bit. I mean, they're so complex; it's just another small part of who a person is, and yeah, you just make it happen; I just hope we do. I would really hope that the residents out there, if they've got those needs and wants; would feel comfortable. I suspect not [...].* (SF7)

She was nevertheless clear that understanding the sexuality of residents in her facility was important to understand and be available to the resident.

> *But I do know that the last time I was here I never skipped over the sexuality part of the admission, and hopefully having that discussion with them. Let them know that they would be safe enough to come and talk to me, but yeah, I suppose at the end of the day you never really know.* (S7F)

Although the above participant was clear that she included sexuality and relationships in her assessments, other senior staff claim that no resident has disclosed a non-heterosexual identity to them. Still others say they actively avoid asking about relationships on admission. This don't-ask-don't-tell policy appears to prevail, and supports silence around the issue. That silence means that both residents and staff are largely left on their own to work out how to manage same-sex intimacy and relationships in the residential setting. Silence also communicates that the issue is unspeakable. One female manager claimed

A: *I mean, quite frankly I wouldn't know the sexual orientation of my residents; nothing's been brought out to me.*

Q: *Nothing's in the open that would suggest that?*

A: *No, but I should imagine absolutely. I mean, it's so socially acceptable now, this will be happening in the future.*

Q: *If you had two males or two females that were married, and came in here, how do you think the staff would handle that?*

A: *It would be interesting. I don't know, it would be interesting to see; I think it would be a really interesting thing to actually look at. I mean, that's a personal thing; I suppose where some staff would be totally accepting, and others would be horrified. (S14F)*

Another female staff person also avoided the question not only about sexuality but resident relationships more generally:

> *I don't usually ask [residents] about intimate relationships; I guess it depends on what you mean by that, but usually know if they're married or not. I usually have to ask the uncomfortable question when I'm interviewing them about their family background and everything like that, and I would have to say, "Are you married?". Ask what their husband's name is, like if he's deceased or not.*

Q: *Yeah, so it mainly stays on that sort of more married/unmarried?*

A: *Yes. I don't really have any cause to say, "What's your sexual preference?" That sort of thing hasn't really presented itself.*

Q: *Or boyfriends or girlfriends; would you ask those sorts of questions?*

A: *No, I haven't been asking those questions* (S24F)

It is a puzzling to imagine how psychosocial or person-centred care could be managed in such an environment. Not asking such questions contributes to the silence about not only gender and sexually diverse residents, but also sexuality and intimacy more generally. Perhaps an answer lies in the response of a male resident, who said that it was not only staff for whom same-sex sexuality and intimacy were problematic, but also for some residents:

> *Q: How easy or hard do you think it would be for a couple who were same-sex?*
>
> *A: You'd be ostracised.*
>
> *Q: Would that be from the staff or the residents?*
>
> *A: Residents. Very, very conservative.* (R9M)

Transgender residents

Regardless of how residents, staff and family members felt about gender and sexual diversity it is clear that there are already residents who are members of gender and sexually diverse communities, including trans persons. They have received a wide variety of welcomes from staff:

> *We've had a lady come and stay here who was transgender; she was lovely. That was the first and only one that I've known in 18 years I've been here.* (S14F)

One female staff person related a story she'd heard in quite a roundabout way:

> *I've got a girlfriend who lectures at [Name] University, and she's got a person there who has transitioned from male to female, and has a female partner. She talks to me a lot about it, and one of her colleagues wanted to do some research into transgender people who come into aged care, because apparently she visited an aged care facility in Auckland, and it was a dementia unit, and this person had been living as a woman for the last 15 years of their life; had come into the dementia unit, and the family said, "We want him dressed back in men's clothes." And [they] only provided male clothes, because they didn't want the rest of the family to have to cope [...], and so this person wanted to do study around this. What happens if we have a pre-operative transsexual who's had it half done; what are we going to do if somebody comes in and wants to be called they, it, the, rather than he or she?* (S7F)

Although this participant appeared to use quite crude language, she continued,

> *Because we're not coping with it very well in the outside world. [It is] even harder in aged care, and I don't think there's any policies and procedures around it; I don't think there's any education around it.* (S7F)

Residents

A female resident was quite indignant about the way same-sex couples might be treated by both staff and other residents:

> *And stop looking it as a numbers game; how many people can they get through the doors, and actually what's going to work for the environment[...] I have no problem if I was in a rest home and there was a gay couple in there; it wouldn't bother me in the slightest. But this lady in particular that's in there with dad and she is only 67 years old. So, potentially she could be one of those people, and she's struggling with an out-of-marriage friendship between a man and a woman. What's she going to be like if a gay couple was to enter the rest home?* (F7F)

Another female resident was adamantly supportive, and was not shy about challenging residents she perceived as intolerant:

> *A: I do know we have some gay people here who are lesbians, and we have gay men that actually work here. They're lovely. We've got no qualms about it. That's up to them. I just say what your ethnicity is, is yours. What you do with your life if your business; no-one else's business.*
>
> *Q: Do you think other residents would be as tolerant and accepting?*
>
> *A: There were a few when I first came in here that would not talk about it at all. I just said, "That's ridiculous. It doesn't matter what a person is. It's what's inside". I said, "How they treat you, and how you treat them." If you're going to treat them different, because they've done nothing different to you, why are you doing it?" I said, "You've got to stop and think, what if that happened to my family." I said, "They don't try to do it; it's something that happens to their life and that's it." I couldn't give a damn what anyone is.* (R8F)

Several other residents spoke about what they thought were negative attitudes of other residents. One female resident was personally supportive, but was quite concerned about the response a gay couple might receive from other residents:

Q: *What about other residents; do you think other residents would be fine with that?*

A: *Not all of them, no. I can see a lot of gossip; perhaps even nastiness.*

Q: *So, it might be quite challenging for a gay couple?*

A: *It could be, yes. That's just from my experience from other people. Yes, I would say there would be a few here perhaps that would be a bit nasty about it.* (R23F)

Another resident was aware that his hetero-stereotypes were quite dated, and acknowledged that old attitudes made accommodating to the possibility of a same-sex couple difficult for him. Nevertheless, he thought that others of his generation would share those attitudes, and make life in residential care more difficult for "homosexuals" and same-sex couples. Both residents and staff might share these negative attitudes:

Q: *It could be pretty tough if there were [gay residents]?*

A: *Yes, if they were openly gay; I think that would be difficult for them.*

Q: *Because of the views of other people?*

A: *Other people. Well, there's a lot of older people, and over all our lifetimes we might still hang onto the views we had 50, 60 years ago. But history has moved on for them, and if you just listen to the radio and television it's quite open now.* (R10M)

Other residents were less reflective in their negative views:

> *Ummm... I don't know because I don't accept it personally but on the other hand I can understand it. It's just an 'off' thing I don't agree with. I wouldn't accept it myself.* (R14M)

A: *Only once; only once [...] A man who came in was very ill and his [male] partner came in most days, and a lot of his friends and that.*

> *As long as gay people stay away from me I don't care what people do; that's other people's lives. I don't know [...] The family has got to be happy about it as well, and every family is different. It might not be a drama for some families. My sister and I would be quite horrified if that happened to mum.* (F8F)

On the other hand, some family members had relatives who were in residential care who they knew to be gay, were unclear whether this information was available to staff:

Q: *I am aware that your brother-in-law identifies as gay. How has that been in that sort of care setting?*

A: *Well, what I have observed, nothing whatsoever. I'm not aware of how many staff know he is gay. He's not mentioned any lack of empathy because he's gay, from any of the staff. But he's only been there a few months [...]*

Q: *So, you don't think he would have felt that he couldn't say that he was?*

A: *If he was asked, I can't say what he would say, but the impression would be that if somebody wanted to know then he would let them know that yes he was gay. Of course, with the other guy, [Name], his brother is there. As you know [Name] was gay. He visits regularly. I have never seen anything from staff. So, I don't know in some ways.* (F4F)

Other family members, children of parents who were in residential care, were aware that their parents were a different generation, and had different values and attitudes about gender and sexual diversity than they did. They had a warning and some advice for residential care facilities, whilst drawing large conclusions about gay elders:

> *We're a lot more open to it now in my age group, but I've got only, like, 15 years until I'm 65. So, in 15 years' time are rest homes going to be equipped for the possibility that a gay couple's going to want to come and live in a rest home? I don't believe they are at this stage [...]When you go and view rest homes to book yourself in maybe that's the sort of thing that they should say, "Well, we're a very open-minded rest home here; we have no problems with race, religion, sexuality," and let the people know that that's okay. "In our particular rest home, we're quite conservative, we believe that religion's quite important", or "We believe that same-sex marriage is a very important factor", or [...] "If you are a gay couple, it's*

...staff education and training is essential, and staff education to sex work and the facility policy on access to sex workers is no exception.

> *probably not the best place for you".* (F7F)

Section summary

There are strongly held views on many sides about gender and sexually diverse residents. Residents will bring their previously formed ideas and values with them when they enter a facility. It is equally clear that gender and sexually diverse persons, including trans persons, are not theoretical notions, but are already residents, and if staff do not know about them then it may be because they have not asked. Staff, and also resident, education about gender and sexual diversity is urgently needed. Of staff survey respondents, only 56.6 percent agreed with the statement that same-sex couples have the right to be sexually intimate with one another. As we saw from the interview data, staff appear to set the tone for the facility, and residents will take their lead from staff. It is also clear that there are residents who are perfectly willing to take other residents to task for negative or judgmental views. As marriage equality is the law of the land, and trans persons become more common, facilities must be prepared for same-sex couples and trans persons: it really is *a numbers game*. As one family member said, "When you go and view rest homes to book yourself in maybe that's the sort of thing that they should say we welcome you here, or this is probably not the best place for you". It was disappointing to learn that in some facilities asking residents about important people in residents' lives was considered intrusive or too difficult. This means that residents are not provided an opportunity to disclose who they are, or who their important relationships are; or are effectively required to make an announcement if they wish to be seen and understood other than in cis-heteronormative ways. Silence forces residents in effect to hide in plain sight. Maintaining silence about relationships, sexuality, and identity is not respectful: asking questions of every resident with a genuine openness to whatever the replies are, creating opportunities for disclosure (or not), and respecting the answers is respectful. Not to ask these questions or create opportunities for residents to disclose is simply to reinforce dominant cis-heteronormative assumptions.

Staff also will face unexpected ethical and practice dilemmas in this area: if a resident with dementia identifies as a trans person, and family members insist on treating their family member as if they still identified as their sex assigned at birth, possibly using their 'dead name', then that family are effectively denying decades of their family member's struggles to exist. This is not simply a question of sexual behaviour, or even intimacy, but goes to the very essence of the way an individual understands themselves. Facility intake staff, managers, and other staff cannot remain ignorant of such fundamental struggles by failing to ask about gender, sexuality, and intimacy at admissions, or effectively erasing the hard-won identities of their residents by acceding only to family wishes in matters of appearance and presentation. Yet these are not simple issues, and they require that facility staff be prepared to engage knowledgably and sensitively.

SEX WORK

One of the drivers behind this project was the question of resident access to paid sex workers. In workshops and presentations throughout the country over the four years preceding the launch of this project, facility staff quietly spoke with research staff about how their facility did (or did not) provide access to paid sex workers. In almost all cases, where access was possible, it was the resident himself who paid. However, no facility we are aware of puts it "on their list of offerings", as one resident (R4M) phrased it. Sex work has been decriminalised in New Zealand since the passage of the Prostitution Reform Act 2003 (Bellamy, 2012), and although underage sex work and unsafe sexual practices are banned, brothel operators are now regulated by the Ministry of Justice, and the PRA enforced by the Ministry of Health and the Labour Inspectorate. Regulation has not removed social stigma, however, and respondents and participants disclosed a variety of responses to the question of sex work in RACF.

The question of access to sex workers was included in the staff survey and in interviews with staff, residents, and their family members. It is not surprising then that there is substantial project data on this topic. Staff survey responses to the question "My workplace should allow access to sex workers for residents who want this service, provided the resident is the one paying" were about equally divided: 131 (30.2%) agreed, 157 (36.3%) disagreed, and 145 (33.5%) were neutral. While a small majority disagreed, then, nearly two-thirds of staff respondents did not disagree. This range of responses and reactions is also reflected in interviews. Some interview participants were unreservedly supportive, and some were very opposed. Others held more nuanced views. Whilst some did not personally like the idea of resident access to sex workers, they could see how sex work might be a service that residents might use. Interestingly, a number of residents felt that staff opposition would be a key factor in whether or not access to sex work would be possible in their facility, regardless of the residents' own opinions. Some participants acknowledged that responses to the idea of sex work (like gender and sexual diversity) was possibly a generational issue, with younger staff and family more likely to be open to the idea. Family member participants were generally more opposed than staff and residents, and this may be because the idea of their family member engaging with a sex worker was simply unimaginable (F2F, F4F, F5F). Some staff participants expressed concern about the health risks to their residents (S2Group), and some family participants were concerned about financial and safety risks to residents (F8F, F10F). Many staff participants were not aware of any facility policy on access to sex work (S2Group, S12F), although two (S19M, S24F) understood such access as a "right" (and one said that the resident was "entitled", S12F), and would therefore make arrangements. One staff respondent said that she and some of her colleagues had "actually visited a massage parlour to actually see kind of how a room could be made nice" (S7F).

We were also told about sex work that was going on within facilities (S13F, S22F).

In the end, most participants constructed access to sex work as a matter of privacy (S15F), and that residents who wished access to sex workers should be able to do so, provided the resident paid for themselves.

Staff

Some staff participants were unreservedly supportive of the idea of engaging sex workers for clients.

> *Yes, I would totally support that. If I thought there was need for that or a resident asked I would assist them to do that.* (S5F)

> *I think that's a great idea. I think it's an awesome idea. I wonder, we've had quite a few ACC clients who were younger and more functional, or probably more physically capable as much as anything. Yeah, I think they really miss out, I think they miss out big time again in that way.* (S1F)

> *I'm coming from a younger [perspective], and at the same time as well as - what is important in life, your own values. Like, my own values; for me it's like I'm living on the day as it is my last. For this particular resident, if tomorrow he died or she died, I know that she had a good day, even having a massage, or sex with another sex worker; isn't that amazing that we have been part of that, that I advocated and facilitated that. She died happily.* (S10M)

> *What happened was that every weekend he brings a younger sex worker. They would go to his room.*

Q: *And you know that that person was a sex worker?*

> *Mmm. [Nods] He tells us. He says, "I'm not going to do it during the weekdays. I'm going to do that on the weekend because there's less people. Perhaps you don't think I'm allowed to do that." I said to him, "Why not? You are entitled to that. We just need to make sure that we will not be disrupting other residents, other people". [...] But to be honest, we don't have a specific policy in regards to that.* (S12F)

> *If there was a need for it; yes, we probably would be able to do that. I know—not here, but outside of here—someone has worked in a facility like that where they had that service for people [...I]t's their home, and it's what they do in their room behind closed doors is up to them really.* (S15F)

> *We haven't done it here, but if someone wants us to do that, if a resident brings it up, I'm sure it's their right. [Staff would assist them.] Totally education, though, because some people, they might think that kind of thing you're not allowed to do that. But, through education, through training they would get to understand their needs as well.* (S19M)

> *It's okay. I don't have a problem with that either. They have their needs as much as we do; young or old. Who are we to say no?* (S20F)

Regardless of personal feelings, or facility policy (or the lack of it), a number of participants acknowledged that sex work was going on in facilities where they worked.

> *We did have one in this other facility I was working in, and we actually paid for him... it was a male; he paid, but we arranged for him to have a female visitor...* (S22)

Policies and education about sex work for all staff, residents, and family members are important to staff. To deny the reality of resident sexuality, or imagining that sex and sex working do not occur, leaves residents vulnerable to financial and other kinds of exploitation. Unless professional boundaries are explicit in relation to sexual expression with residents, unqualified, unregulated, and even unethical staff may not be aware of problematic power relations in providing sexual services to residents.

Ignoring or dismissing the possibility that sex occurs in RACF may also have affected staff responses in the case of a resident who was also a small businesswoman:

> *We even had in that same home, in the village, an elderly lady that was selling services from her home. We thought was quite funny. I'm not sure how we found out. I didn't want to ask, but that was quite funny. (S22F)*

Not all staff or facilities were supportive, however.

> *I don't know what [Facility's] policy is on that. Because it's a Christian facility, a [Denomination] facility; I don't know how open they would be to that. I've worked in facilities in the past where the managers have had no problem, and it's a process that I've had to work through, and I've come to a place where I have no problem with it. I know I've said here off the cuff in the nurses' station, "Maybe we should get a hooker in", or, "Maybe we should let them get their leg over". And there's been laughing, but nothing's ever been followed through. So I wouldn't know what [Facility's] official policy is. I would suspect it would be a no, but that's just mean.* (S7F)

Some staff participants were reluctant to support engaging with sex workers because of risks they associated with sex work, rather than sex work itself.

> *Well, I don't know. I really don't. We'd have to work a plan out for that. It would be the care leads and the manager, and the family, and the doctor probably, and everybody. Yeah, because you never know, he might expire.* (S8F)

> *Mine's a bit no [to sex work], because that's inviting them to have infections. I mean, sexual infections [...] We don't know if they're really clean; how can you prove it? I mean, if I am a sex worker; how can I prove it to my client that I am clean?* (S2Group)

> *I don't think [the owner-managers] would let call girls come to the place. Only because in the past a lot of call girls are associated with drugs and associated with gambling, and that could be quite dangerous in a place like ours, if they worked around. [...] It would be quite a big step for [the owner-managers] if they did let someone in. I think it would put everyone else in danger. But, if you're talking about if [a resident] really wanted to go outside, if they were escorted and everything, then that maybe something they would talk about.* (S4F)

This same staff person's personal reluctance to endorse sex work came from a moral perspective of protecting the sex worker.

> *I haven't actually asked them if they would consider that. Although, I know that in the past, prior, just knowing work girls in the past, that's quite a hard one. I know they're doing their work. But then just with the values that [the owner-managers] have, that that could be quite damaging work to the girl in the end, in her mind.* (S4F)

Some participants recognised that their reluctance to endorse sex workers for residents was because of their own feelings, but were prepared to acknowledge that sex workers could be acceptable to residents.

> *Personally, I don't feel that comfortable with it myself, but it's their right, and so we are here to make sure that they are supported, happy, and they have their rights.* (S24F)

Q: *And so for you [...] when you encounter a situation that is a dilemma about a resident wanting to have some kind of relationship or engage with a sex worker [...] do you speak with the families?*

A: *Yes [...] If it involves finance. [...]*

Q: *What if it didn't involve money?*

A: *No, I don't have to.*

Q: *So, if there's no money involved, or the resident can pay themselves...*

A: *Yes, yes, yes.* (S10M)

And some participants had simply never thought about it.

> *I've never really thought about it. I can't just imagine it actually. I'm trying to picture it with someone here. I don't know. Undecided on that one.* (S18F)

Residents

Resident responses were divided among clear support of sex work (or stipulated out-calls only), and some clear objections. A surprising number of residents equivocated and simply noted that it was staff who would most likely disapprove of such activity, and either did not have, or were reluctant to share, their own opinions about sex workers. Nevertheless, a few residents acknowledged that the practice was already going on, and that they had taken advantage of it.

> *Yeah, they can't stop you. I can't afford to pay for one. Bugger it! (R6F)*

> *Actually, they do that. They have a Māori lady come in. I get the paper; it's in the paper. I might give her a ring to come and see me. I gave her a ring and she comes to see me. It wasn't easy of course. What can you do around here? But, she talked to me a bit. I gave her $80.00. Too much.*

Q: *Did the staff know that you were doing that?*

A: *I think so. I didn't care really.*

Q: *You just organised that on your own?*

A: *Yeah... Yeah. She was a Māori lady... She was more fun than anything else. I was laughing all the time.* (R3M)

The question to residents about sex workers at times evoked both their interest in expressions of sexuality and also their lack of experience. The following quote reflects both curiosity and a major knowledge deficit, and the question appeared to put an idea in the mind of one female resident:

> *Okay. I wouldn't care about that. [...] I don't know whether the staff would know. I don't think they're involved enough with the residents to know. You could easily bring a sex worker in here. I wouldn't dream of having a sex worker visit me. I would have a stripper come to a party, and it's given me a good idea. I would dial up a stripper, but it wouldn't enter my consciousness to have a sex worker. And what I'm saying is not because I'm 83, but because I was born pre-anyone even thinking of sex working.*

> *Anyone born after 1970, might think of a sex worker. Our generation, or say pre-1950, we would never have thought of it. [...] I like these toy boy fellas, you know, that's a much better idea, I wish I knew some around [City].* (R5F)

Bringing a sex worker into the facility was too much for one male resident: far better to make it an out-call.

> *No, I wouldn't advise anybody thinking that way, to call in a prostitute. I can understand the feeling, but I think they'd be better to go outside.* (R10M)

Several residents either completely opposed the idea of sex workers, or thought the very idea of sex workers in an RACF was simply unimaginable.

> *Well, I wouldn't like it no. As a Christian I wouldn't like it. I don't think if that was able to happen here that I would like to stay here.* (R13F)

A: *Oooh no, a definite no. I think we have one man here who could be interested in having a prostitute.*

Q: *Do you feel that this would not be acceptable by the staff?*

A: *No.* (R18F)

Q: *What about if hypothetically there was a resident who wanted to pay for sexual services?*

A: *Goodness, we wouldn't even know, would we?*

Q: *I know I'm asking some questions you may not have considered before.*

A: *Imagine that - imagine that? [...] we'd all be up in arms if they had someone come in from outside; they would definitely be up in arms.* (R22F)

Q: *What about if a resident wanted to pay someone for sexual services, like get an escort to come into their room. You're looking very shocked. Or a sex worker come in. What do you think?*

A: *Geez. No, I don't.*

Q: *Do you think staff would be okay with that?*

A: *I don't know, you'd have to ask the staff. I'd be flabbergasted. I wouldn't want to know.* (R24M)

> *I don't think that would go down very well at all. It would have to be a sneaky arrangement.*

Q: *"A sneaky arrangement"?*

A: *Yes, definitely, but it could happen.*

Q: *But your sense is that staff would not really be [supportive]?*

A: *No, I don't think they would approve at all.* (R23F)

It is difficult to know whether the participant below (R8M) is speaking rhetorically or hypothetically, or whether he actually does use sex workers. In any case his comments reflect what he thinks the views of staff will be about sex workers: that the entire topic is off-limits to discussion since he believes staff would understand the entire topic as "disgusting".

Q: *If a resident wanted to pay for services, say from a sex worker or an escort, how do you think staff would view that?*

A: *Disgusting.*

Q: *Really?*

A: *Absolutely. Why do you need that?*

Q: *So, you don't think staff would understand the need that someone might have for that?*

A: *No, I don't think so. It's not a topic that they're even brought up; for example, [if they asked] "How do you cope with your sexuality?" and I might be honest with them, but it's never been asked.*

Q: *So, the whole subject of sexuality is taboo?*

A: *Absolutely taboo, yes.*

Q: *Would family or staff have any say in [your relationships]?*

A: *It just wouldn't happen. I mean, my family don't know that I go and pay for sexual whatever you call it – activity. They don't know that. I'd never tell them. The same with the staff here; I would never tell them.* (R8M)

Some residents felt that engaging a sex worker would offend the religious or cultural sensibilities of staff. Their comments also highlighted the extent to which some residents have come to view their RACF as more of a workplace than their own home.

> *If I suggested that to some of the nurses, I think they would be actually be quite offended by it. Remember again, these are not native New Zealanders, these are people from, as I say, predominantly from the Philippines. The lady that you brought you, [Name], she's from the Philippines; her husband is in the Philippines. He's also a nurse. She wears a ring. I think they might find it a bit distasteful, yeah, but I don't know. They don't put it on their list of offerings.* (R4M)

> *Not really sure about that, in so far as anything that seems to be breaking the rules would be frowned upon. While that's not a rule, that would seem to be... because a lot of these people are very religious [...] They come from South East Asia and places like that. They have what some would call Christian attitudes, which are very deeply embedded. They would very quickly take a stance on what you were doing.* (R9M)

The latter comment (by R9M) suggests that some residents imagined there were policies or rules related to sexual expression where in fact there may not have been any; in the event, the resident was unsure. His assumption was that his life would be governed by staff attitudes. On the other hand, some residents thought that engaging a sex worker was none of the business of staff or anyone else.

> *I really don't think it's got anything to do with the staff, personally myself. That's a private thing. Who's to know? I mean, as long as it is done discreetly, who the heck is going to know? [...] I'm quite sure that [staff name] would be quite happy with it, providing they're saying, "As long as you keep it to yourself. Do it discreetly. You don't have to throw it in everyone's face".* (R7F)
>
> *Well, that's their business, it doesn't involve me. I'm not interested, put it that way. I always like to try and live by the motto 'live and let live', as long as you don't interfere with me.* (R19F)

Family

While a few family members had a supportive or live-and-let-live attitude provided residents were protected from physical or financial harm, most family members were opposed to the idea of sex workers for residents. This is not surprising, since for some it will be the first time they had considered the possibility of a parent being sexual. Family members—particularly daughters, in our study—assumed responsibilities that perhaps were not theirs to assume. Sex work did not fit in with their notion of a genteel care facility.

> *I wouldn't like that. No. I guess here, this is our first time dealing with a rest home, and because [Facility] is so little and it is like a home. It's just so lovely here. I couldn't imagine that happening here.* (F2F)
>
> *I've never thought about it. I don't want to think about it. If that's what they want, then so be it.* (F9F)
>
> *Everyone for their own choice, but myself, personally I couldn't do that, no.* (F3)

> *Q:* *There are some care homes in New Zealand that allow residents to access to escorts and sex workers.*
>
> *A:* *Wow! [...] That creeps me out a little bit more. I didn't know that one. It does creep me out. I don't know. I have no respect for that industry or those people. I guess they would use protection and stuff like that, but I certainly would never allow my mother, no matter what state she was in mentally. My sister and I would never allow her to access those kinds of services [...].* (F8F)

That this daughter would assume that she had the right to intercede with her mother's decisions regardless of her cognitive ability highlights again the importance both of having facility policy, and of educating family members to policy.

> *They can come to the actual room? Well, they'd have to be vetted very well as in STDs and safe sex and all that sort of thing. I'm not sure about that one. I don't think that will ever happen because there's a lot of...I just can't see something like that happening in a rest home. (F10F)*
>
> *I can't imagine that happening in the age group that people are in care. I can't see that that would happen [...] If someone wanted it to happen, I think that would be something that the people who run that facility, I don't think they would approve of that. That's my own personal view. I think that would be so remote. I can't imagine that happening. [...] I can't imagine it being "Hip-hip-hooray and here is having sex every day with a prostitute" [...] I find that a very strange question to be perfectly honest.* (F4F)

However, some family members were perfectly happy for residents to have access to sex workers—provided they paid personally.

> *I've heard about this happening in not rest homes but retirement villages where they're living independent lives, or they get taken out of the retirement village to a place where they can. When you say access, does that mean they come and see them, or they go to see...?*
>
> *Q:* *Either way.*
>
> *A:* *Either way? Oh, why not?*
>
> *Q:* *We're of course talking about residents paying for it on their own, because it's not part of the facility's services.*
>
> *A:* *Oh, God no, no, they'd have to pay. Good on them, as long as it's in a safe environment, that's all I would say, and people know where they are. Yeah, good on them.* (F10F)

> *I have no problem with that at all actually, so long as the resident is being protected sexually and financially. Because in my dad's case, dad's got no concept of money, so she could say, "I'll just get it out of your wallet," and take everything.* (F7F)

> *Q: It also sounds like if someone was seeing a sex worker, you would have a 'live and let live' attitude.*
>
> *A1: Oh, of course I would.*
>
> *A2: Oh yeah, let them.*
>
> *A1: I would not condemn it. No way.*
>
> *A2: No, let them go for it.*
>
> *A1: If they're happy, let them be happy. Let them do what they want to do.*
>
> *A2: Exactly.*
>
> *A1: At their age, they're allowed to do whatever they want to do.* (F3, M-F Couple)

And some family members would find the idea of sex work and the conversation about sex quite difficult. Interestingly, one family member would have appreciated a conversation—or at least some introduction to the notion of sexuality—at the time their family member was oriented to the facility, which would have made later discussions easier.

> *It's really hard to kind of decide what I would... I find it just so difficult to imagine him ever, ever kind of going there really. It's quite difficult to think, what if he had asked me that?' I guess, I would have been confronted by it to be honest. I guess I would have tried to talk to one of the staff about it, but that would have been an awkward conversation to have. I guess it's the kind of thing that you sort of imagine maybe that might be part of the material that they give you at the outset; so that's kind of covered in some ways. So, that approach is not just something you have to make cold from like, "Guess what?!"* (F5F)

Section summary

Access to sex workers is happening in RACF in New Zealand, if not in all facilities, at least in a number of them around the country, in urban, suburban, and rural areas. While staff in some facilities appear to be prepared to respond to resident requests for sex workers, a number of staff are not, and are looking to policies and management to provide guidance. We heard at least one case (S13F) when staff themselves were offering sex for sale. Facilities may not yet be ready to put access to sex workers on their "list of offerings", but it is essential that facilities have policies in place to address access to sex workers, and to educate staff and residents to those policies. At a minimum, all residents and key family members (including holders of EPoAs) should be made aware of existing facility policies at least at the time of admission so that residents are fully aware of their options, even if they choose not to use them. The reactions of many participants indicated that the topic of sex work was beyond their imagination in the context of RACF. Preparatory education for all may pre-empt a crisis when the unimaginable occurs.

We do not take a view on whether access to sex workers is a right of residents, but we do support the observation of many participants that residents have a right to privacy, and as long as residents are competent to make financial decisions elsewhere in their lives, they have a right to spend their own money on sex workers without the need for the facility to notify the family or EPoA, or to seek their permission. Our data indicate that both staff and family members often have a hazy understanding of EPoA as this relates to residents' sexual expression, and therefore this is a particular area that warrants clear policy and education. To include third parties unnecessarily on decisions about sex workers is at best institutional risk management, and at worst simply gossip.

We have advocated throughout this report that staff education and training is essential, and staff education to sex work and the facility policy on access to sex workers is no exception. A facility should be prepared to arrange sex work services in the same ways as it arranges other contracted personal services (such as hairdressers, or manicurists). In our view if a facility enables access to sex workers for residents of care facilities, then it would be best for that facility to develop a relationship with a regular group of providers and work with the New Zealand Prostitutes Collective to train this regular group on how to work safely and appropriately with older persons. Ensuring that everyone is informed, knowledgeable, trained, and safe will reduce the likelihood of incidents becoming public.

We want to underscore the perhaps unexpected but critically important ethical and practice dilemmas that staff will face particularly with transgender residents.

Again, regular, respectful, and informed education that invites staff to consider their own values and experiences is essential.

Discussion

WHAT COUNTS AS CONSENT IN RESIDENTIAL CARE?

One of the aims of this research was to use the insights gained from staff, residents and family members working in an RACF environment to inform the ethics of sexuality. Consent clearly plays an important role in the ethics of sex, but what counts as consent in residential care is understood very broadly. The most important theoretical insight gained from our participants is that a complete ethics of sexuality is not simply about decision-making – it is also about pleasure, wellbeing, community, and relationships. Consent matters, but it is not the only value that matters.

It is clear that staff, family, and residents are familiar with the language of consent and the fundamental moral importance of consent in the context of sexual intimacy. The views of these three groups thus mirror the dominant position in the literature on the ethics of sex, and the language used in public discourse on the ethics of sex. While there remains some anxiety about the capacity to consent, the attitude amongst staff in particular was that so long as the participants are consenting, there is nothing morally concerning about their behaviour.

Staff did however express a significant level of confusion and disagreement about consent; both about what consent involves and the application of a consent standard to intimate activity taking place in the context of residential care. This confusion was particularly evident in situations involving residents with diminished cognitive capacity. It was common for staff to look to the behaviour of a resident when determining whether consent was present. This was true even in cases where the resident has diminished cognitive capacity, and may not be legally competent to give consent to sexual intimacy. In these cases, staff seemed to be focussing on assent (willingness or agreement) rather than consent (agreement given by someone who is cognitively capable), although they did not use this language. However our survey data indicated that staff sometimes struggled with interpreting behaviour. When we asked staff whether it was easy to tell whether a person with dementia consents by looking at their behaviour, 203 (46.9%) disagreed; only 90 (20.8%) agreed, and 140 (32.3) were neutral. Treating behaviour as a candidate for a consent indicator is one of the ways in which attitudes to consent differ in residential care – outside of this context, behaviour would not generally be considered sufficient evidence of consent, and this is particularly true in circumstances involving a person who was not fully cognitively competent at the time.

While staff were comfortable with the language of consent, and aware of its moral and legal importance, they were also sensitive to the fact that they were operating in a particular context. Consent is both a moral and a legal notion, and while these are connected, they are not the same thing. It may for example be the case that someone is legally not considered capable of giving consent, even though they are in fact capable of giving the kind of consent that matters morally.

Staff in residential care are in the unusual position of being able, and sometimes being obligated, to mediate and manage the moral decisions that other adults are making about the sexual and intimate lives. They also have general legal, professional, and moral obligations to look after the residents – including promoting resident wellbeing, and maximizing autonomy. Staff are therefore frequently dealing with conflicting obligations. For example, a professional judgment that an intimate relationship is in a resident's interests may conflict with a legal obligation to prevent those who are not capable of consenting from engaging in intimacy.

While there are differences in the way that consent is treated in the context of residential care in comparison to other contexts, it does not follow that this difference in treatment is a mistake. The confusion residents, staff, and family members expressed about the application of moral norms around consent in the context of residential care may be understood as reflecting the fact that while these norms are clear in theory, applying them in practise – particularly in the context of a web of relationships of dependence – involves balancing a number of competing obligations and values. Consent matters, but it is not the only value that matters.

What kinds of ethical decisions are being made about expressions of intimacy and sexuality in residential care?

Our data show that staff are generally making decisions which at the very least take into account the wants and desires of the residents, both in cases involving residents who are fully competent and cases involving those who are not. It was also common for family members to feel that they should have a say in the decisions being made by and for the resident; this was the case even when the resident was cognitively competent. We also found that staff were likely to over-consult or over-notify family members, often to the resentment of residents. Residents themselves frequently described their decision-making as being limited or otherwise affected by the attitudes and values of others. The perceived attitudes of staff, assumptions about how other residents would react, and beliefs about how family members would feel all had an impact on the extent to which residents felt able to exercise choices about their sexual and intimate lives.

Ethical decisions about expressions of intimacy in residential care are therefore being made in a context where the ability to make private, autonomous decisions is significantly diminished. Our interviews with residents and staff revealed that while sexual intimacy was considered a right, and sometimes a need, residents in themselves often felt unable to exercise their rights in this domain without experiencing judgment, disapproval, or interference.

Staff tended to rationalize decisions not to interfere with expressions of intimacy on the grounds that if the participants appeared to be happy with the situation, they were therefore consenting. It was common for staff members to express the view that their own values and personal beliefs should play no role when they were involved in a resident's decision-making, however whether it was the case that in practise staff usually leave their own values at the door was less clear. In the absence of education to facility policy, and consent, intimacy, and sexuality more generally, staff inevitably rely on their own personal, (non-)religious and cultural values. Residents were often under the impression that staff would not approve of expression of intimacy, and modified their behaviour accordingly.

Staff were also generally aware of the fact that it was common for family members to want to be involved in the decision-making process, and many staff members felt a duty to keep the family informed. Family members commonly expressed the view that because they had greater knowledge of the resident they were better placed to make decisions about sexual intimacy than staff were. This assertion is based on a premise that may not be fully supportable, or supportable in all cases, that is, that the family members are entirely familiar with the intimacy expectations and sexuality of the resident in care. This may be an area for further research. Nevertheless, for family members, the resident's previous attitudes, behaviours, and desires were often thought to be particularly important in determining what kinds of decisions should be made for and about them in the present. Family members tended to rationalize their decisions, and their involvement in these kinds of decisions, on the basis of the assumption that what the resident would have wanted, were they capable of making their own decisions, was an important moral consideration. While family members are often the best-placed to make decisions on behalf of residents in other domains, such as health or finances, decisions about sexual intimacy are clearly more difficult. For example, it is unlikely that most residents would want their adult children making decisions about sex and intimacy on their behalf.

> *Our recommendations are evidence-led, drawn from the experiences of these three groups from facilities of all sizes, and are applicable across the sector.*

Residents themselves did not tend to experience their decisions around sexual intimacy as decisions with an ethical component, but were rather focused on the practical and relational realities. As we discuss in the section on loneliness and relationship management, residents were well aware of the impact an intimate relationship would have on the wider community of the residential care facility, and this often factored into their decision-making.

What are the implications for understanding the ethics of sexuality and consent?

Our research has important implications for policy and practise in the context of residential care, which we set out in the recommendations section, but it also has important theoretical implications. Both the theoretical literature on consent and public discourses around consent take place under the assumption that those involved are generally capable of making decisions on their own behalf (are cognitively competent), are autonomous, and have an expectation of both physical and emotional privacy. Most adults expect that they will, for the most part, be able to act on their decisions around sexual intimacy without the involvement or surveillance of others.

The conditions under which those in residential care are making their decisions are clearly quite different from those described above. Decisions made in the context of residential care take place in a communal living environment (which is for some a home, for some a hospital, and for others a workplace), in a context of relationships of care and dependence (between staff, residents and family), and are decisions that are sometimes made by, or on behalf of, those with diminished cognitive capacity.

The kinds of decisions made under these circumstances, and how these decisions are made, provide useful insights for a general ethic of sexuality and consent. After all, none of us are fully autonomous ideal agents making our individual decisions in splendid social isolation. An ethic of sexuality and consent which begins with this

capacity, it is likely the case that legally speaking, the residents were not able to give consent to sexual activity. It may even be the case that morally speaking, the residents were not able to give consent to sexual activity. In practice when making decisions staff took other features of the situation into account, and used ‘consensual’ as a synonym for morally permissible.

It does not follow that staff were making a mistake in doing this, however – on the contrary, the insights gained from staff in particular show that a complete ethics of sexuality is not simply about decision-making – it is also about pleasure, wellbeing, community, and relationships. One way to take these other values into account is to fold them in to the notion of consent. Because staff were so used to using the language of consent (likely due to the fact that it dominates the public discourse and is a legally recognised—and mandated—notion) they often attempted to frame these considerations as having to do with consent. However, this runs the risk of stretching the notion of consent to breaking point. Consent, both morally and legally, is about the decisions made by a cognitively competent person. There is no need to try and fold every other morally relevant consideration into this one concept. Rather, a complete ethics of sexuality should recognise that traditional notions of consent are not the only thing that matters.

Broadening our understanding of what matters morally in this way helps us to understand that a complete ethics of sexuality is not simply about decision-making. It is also about pleasure, wellbeing, community and relationships. Staff recognized this despite expressing confusion about the notion of consent, but the confusion they expressed may well be explained by the fact that these other important values don’t fit neatly into a consent framework. What this implies is that creating an environment where residents both have and feel the freedom and autonomy to engage in intimate and sexual relationship requires more than a simple checklist of consent criteria. It requires open, informed, healthy, non-judgmental engagement with the resident about what they desire, feel, think, and hope for. The alternative – rigidly applying legalistic notions of consent, or moral notions of consent that have been developed against background assumptions of cognitive competence – risks dooming anyone whose cognitive competence may be in question to a life devoid of intimate touch.

CLUSTER 1: DECISION-MAKING

It is clear from both the qualitative and quantitative data that decision-making was a source of confusion and struggle for staff, residents, and family members alike. Specific sites of confusion and disagreement included when and whether a resident was capable of making a decision, the role of staff in decision making, and in particular the role of family.

Staff were generally comfortable with residents engaging in sexual intimacy in private, although there was confusion about the extent to which staff had a role in facilitating sexual intimacy rather than merely allowing it. While it was frequently acknowledged that residents had both a right to engage in sexual intimacy, and a right to make their own decisions about sexual intimacy, it was also clear that staff in particular struggled when it came to evaluating when and to what extent residents should be considered capable of making their own decisions. This was particularly the case when it came to residents with diminished cognitive capacity – staff found themselves having to make decisions about the extent to which they should be involved in the resident's decision-making process. The result of this was that staff frequently engaged in risk-averse decision-making: they consulted with family members and EPoA holders when it was not necessary to do so, or they intervened in situations where it was not necessary to do so to protect residents.

Policies and procedures with regards to residents' decision-making around sexual intimacy were frequently absent, or not well understood. Staff were aware that a resident whose ability to make decisions may be compromised (due to dementia, for example) may not be capable of consenting. But what was not clear to staff was what this meant for them – how they were to make judgments about a particular resident's capacity to consent, and whether and when the resident's diminished capacity meant that staff had an obligation to either intervene in that resident's decisions, or make decisions on behalf of the resident. This is one area in particular where clear, specific policies and guidance would be useful, although not enough. Specific education,

Confusion around EPoAs was one instance of a broader problem – general tension and confusion about the role of the family. Some family members expected to be involved in all aspects of decision-making, and experienced considerable stress and resentment when they felt the staff were not including them. Some residents also experienced their own resentment about the extent to which they felt family were interfering and taking over. Staff were frequently put in the position of having to manage their own relationship with family members, and mediate the relationship between family members and residents. Specific education about EPoAs would help mitigate some of these issues. However perhaps more important that guidelines is simply the recognition that relationships can be complicated, and that it would be useful for relationships and relationship management to be recognised as a priority for discussion in the transition to care.

CLUSTER 2: MANAGEMENT, POLICY, AND EDUCATION

The data from this study reinforced how much managers set the tone for a facility and its staff and residents. Managers provide the context for conversations, education, and the ethos of a facility. If a manager is open to dialogue about intimacy and sexuality, then they send a signal to staff to be open, transparent, and to seek guidance when required. If on the other hand a manager suppresses or avoids such conversations, where intimacy and sexuality are unspeakable, then staff are left to make decisions on their own, to rely on their own values, and will be reluctant to seek guidance. This latter approach increases risk to the facility or agency. Such facilities are less likely to have useful policies in place, less likely to provide staff education or training, and create an atmosphere of anxiety. This appears to be a particular risk for smaller facilities, where there is likely that the owner and the manager are the same person. It is essential that managers, as the most experienced of the staff, and also as the legal and moral authority within a facility, be prepared to talk openly and frankly about sexuality and intimacy with staff, to support staff, to provide for regular education, and to create an environment where staff can seek out support and guidance when necessary.

Policies and procedures are essential in all aged care facilities. Although staff we interviewed were aware of the importance of policies, we found that staff in very few facilities were aware of facility policies regarding sexuality and intimacy. Policies should address issues of consent, privacy, respect for the identities of transgender residents (which we will address further below), the availability of sexuopharmaceuticals, and access to sex workers. The policy framework of a facility should also include what to do in the event of the declining capacity of the resident to give consent to a relationship or sexual encounter. Model policies exist (Cook et al., 2018; Dessel & Ramirez, 1995/2013), and we encourage facility managers and boards to consider these for local use.

We encourage respectful conversations with whānau, kaumātua, and kaimahi about how intimate relationships will be managed early in the move into care

There appears to be little if any education to support staff effectively to implement policies about intimacy and sexuality, or resident misdemeanours. Policies allow staff to be consistent in their responses to residents (and each other) instead of relying on individual staff values and beliefs. Further, expecting staff to know the words of a policy is necessary but insufficient. Staff will have more confidence to respond to residents if they understand the legal and ethical issues and frameworks that underpin a policy. No policy can anticipate every possible situation, and helping staff to understand the principles as well as the policy will help them interpret the policy in novel or unanticipated situations.

We found no residents who were aware of specific policies pertaining to their rights to intimacy and sexuality, and this is concerning. The absence of a policy or discussion about sexuality convey to residents that there is something unspeakable about sexuality, which can only negatively affect both relationships and care for the resident. Indeed, resident participants frequently spoke to us about their expectation of staff disapproval should they consider an intimate or sexual relationship, or seeking a sex worker (even though some participants were already doing both). Sexuality and relationships are a part of being human, and the literature is rich with evidence that sexuality and relationships enrich the quality of life of residents. Residents must have an opportunity to discuss their sexual needs—both medical and psychosocial— with appropriately trained staff. Explicit discussions of a policy on intimacy and sexuality would alert residents to their rights, and also inform prospective residents and their families of issues they might not otherwise consider until a critical event occurred.

We found that staff and residents at times witnessed and had to respond to unwanted sexual behaviours. From the descriptions they provided to us, it appeared that staff decisions were guided by their own moral compass rather than having reference to policies and ongoing education. Managers described ways they role-modelled to staff and residents how to manage behaviours. In general, these responses consisted of desexualising or infantilising older adults. This approach in turn led to staff minimising behaviours of residents who were cognitively competent: inappropriate behaviours were not named as harassment or assault. This view implies that older adults are no longer fully sexual beings, so therefore any sexual expression, including inappropriate boundary-crossing (groping, touching, masturbation during care) did not carry the same moral weight as they would if enacted by a younger person. Managers must lead the response to provide policies and educate staff to interventions for unwanted sexualised behaviours, and to residents to explain what kinds of behaviours and interactions are and are not acceptable.

If there is a single finding from this study that requires immediate and universal attention at all facilities, it is the importance of regular education about intimacy and sexuality. Larger facilities were more likely to provide education, but two-thirds of staff at facilities of all sizes expressed a desire for more education. Half of staff at smaller facilities said they had never received education on resident intimacy and sexuality; this may be because the education had never been provided, or was simply unmemorable. The need and demand seem quite clear to staff and to us, and in our view the sector must heed and respond by providing education specifically related to intimacy and sexuality. For staff, such training should include at a minimum an examination of personal values and beliefs (such as religious beliefs or non-beliefs), working with diversity, sexuality, and ageing, how to manage resident misdemeanours, responding to residents about intimacy and sexuality, consent, and ethical dilemmas, and, of course, training to facility policy. Education should begin at the time of the staff interview by communicating facility or agency values, continue through induction, and be updated regularly for all staff. We underscore that all staff should be involved in education and training about sexuality and intimacy, not only clinical or care staff: administrators, kitchen and support staff, cleaning, building maintenance and groundskeeper staff all potentially have contact and interactions with residents. Contractors and locum staff should also at least be provided with policies during their orientations. The way staff education is structured is important: education should be engaging, encouraging, respectful and empowering. We also acknowledge that senior staff, managers and supervisors are taking advantage of informal ‘teaching moments’ to address issues in the moment and to upskill staff on key skills and attitudes in working with residents.

RACF may also wish to consider developing educational opportunities for residents (and their families) about intimacy and sexuality in older persons. While not all residents will take advantage of the opportunity, it would appear that at least some residents are interested. Changing bodies mean changing physiology, different emotional reactions, and different ways of creating and living intimacy in order to live fulling lives.

CLUSTER 3: PHYSICAL AND EMOTIONAL SPACE

Through the process of undertaking this research it became evident to us that consideration of intimacy and sexuality in the RAC context can only be fully comprehended through scrutiny of contextual influences. We identified four components that shaped the (im)possibility of residents experiencing intimacy and sexual expression related to the physical and emotional context of RAC. Firstly, the extent to which residents, staff and family members perceived that residents were entitled to real rather than tokenistic privacy had a major impact on residents’ sense of being at home and therefore able to act in ways that they would in the privacy of their own home.

Secondly, residents' felt experience of being at home, or not, was influenced by the built environment and furnishings, which typically signalled to residents that the place they occupied was something of a liminal space; neither entirely their own home nor completely a work environment. Thirdly, the transition to care commonly had a profound effect on residents' sense of self and(dis)connection from significant people, places and lifetime artefacts (due to space restrictions for the latter), and involved a process of grieving. As such, the move to residential care cannot be readily equated with earlier life experiences of moving place of residence and relocation related to employment. Often the move was associated with a life crisis, such as the death of a partner, or a marked health deterioration. These related aspects impacted deeply on residents' sense of place and homeliness. Fourthly, 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. Even had they not they lived in residential care, many were living on without their closest life companions who had died. Though most made new friends and some developed intimate and sexual relationships, residents knew these were ephemeral connections. Residents, staff, and family members described new relationships that budded briefly before death or major disablement caused another experience of separation.

In terms of privacy, residents' accounts reflected the culture of the facility. Commonly, residents had mentally relinquished their sense of entitlement to prior levels of privacy, and perceived this loss was one that came with the move to RAC, an ersatz home. Staff accounts illustrated that although they knew it was their responsibility to uphold privacy, the routinisation of care meant lapses in practice. For example, fundamental privacy practices that occur normally prior to entering a person's home, particularly knocking on a door and waiting to be invited in, were commonly foregone when entering residents' rooms. In the staff interviews, it appeared that staff were somewhat inured to the limitations of the built environment and worked within the constraints rather than critiquing how fit-for-purpose the environment was. Although aware of couples who had been separated due to different care level needs, staff appeared to accept the inevitability of this practice, and did not express critique of the obstacles to sustained intimacy and co-habitation for partners. Managers described problems of under-resourcing that further facilitated routinised care practices.

Interviews with residents highlighted that the shift to residential care is a move to communal living; something that was typically entirely unfamiliar. This intimate neighbourhood may not reflect individual residents' preferences, giving rise to feelings of displacement and a loss of control. Residents wanted the homeliness of RAC to be expressed through relational interactions between staff and residents rather than being merely recipients of merely functional care.

Although staff commonly expressed that they wanted the facility to be experienced as a home, staff and some residents expressed ambivalence about residents having sex; that sexual intimacy did not fit their picture of homeliness. Of note, residents assumed a more regulated climate than might be the case within the facilities in which they lived. They were reluctant to ask questions about their rights due to a desire to fit in. Also, a number of residents had clearly internalised ageist views that sexual desire later in life was something of a grubby secret. This ageism led to a reluctance to ask questions about their sexual rights, and also led to some residents gossiping about others and expressing scorn about and overt signs of intimacy and sexual expression. Those who newly re-partnered within RAC were aware that their relationship was on-show and attracted at times considerable attention.

Although residents, staff and family members acknowledged the grief process for residents in the transition process there did not appear to be any formal interventions, education or designated professional staff to assist residents and families with this shift. The data set indicated that some of the loneliness of older age is a fundamental challenge for older people, with their own disrupted health, and the ill-health and death of friends and intimate partners being a common part of lived experience. There is a significant opportunity for registered nurses, social workers and counsellors who work with older adults to be much more engaged with residents and families through the transition process.

CLUSTER 4: DIVERSITY

Diversity is a theme that emerged in every aspect of this study. Diversity is a generic word that comprehends a wide variety of differences. Everyone is different of course, but in this context diversity refers especially to differences that are marginalised, hidden, ignored, or otherwise devalued. We include, of course, diversity in residents, family, and staff. There are four areas that we believe are critical to consider: tangata whenua, religion, gender and sexual diversity, and sex work. In every area, staff education, and in some cases resident and family education, is urgently needed in facilities of all sizes.

Consent for Māori in the aged residential care context embraces another layer of complexity. In-depth understanding of te ao Māori both of kaimahi and kaumātua and their whānau is required in each facility to ensure that tapu and noa of te ao Māori are not breached. This would have an impact far wider impact than the mana of the kuia or koroua in care. This study finds that the lenses through which these groups view the world are strongly based in te ao Māori. However, there is not a unitary understanding of te ao Māori: where people have grown up, who has been involved in their life learning, and what their journey through life has been, all mean that within this world kaimahi and kaumātua will have a rich diversity of perspectives. It is important to engage meaningfully with Māori, particularly in respect of intimacy and sexuality.

Further research specifically in the area of Māori working and living in residential care will be useful, particularly given the anticipated increased life expectancy of Māori, and the ever-increasing diversity of Māori. Understanding how whānau and RACF manage cognitive decline in kaumātua will be an

important area of further research and planning.

Religiosity (and non-religiosity) is important in the lives of many people—staff, residents, and family—who participated in this study. While the impact of religious
beliefs on residents m
owners/managers or
beliefs or religious va
considered acceptabl

an impact. In this study it was not possible to separate the different effects of religion and ethnicity on knowledge, attitudes and behaviours about consent, intimacy, and sexuality. It is not the beliefs themselves that are an issue, but the way expressions of religiosity (or non-religiosity)
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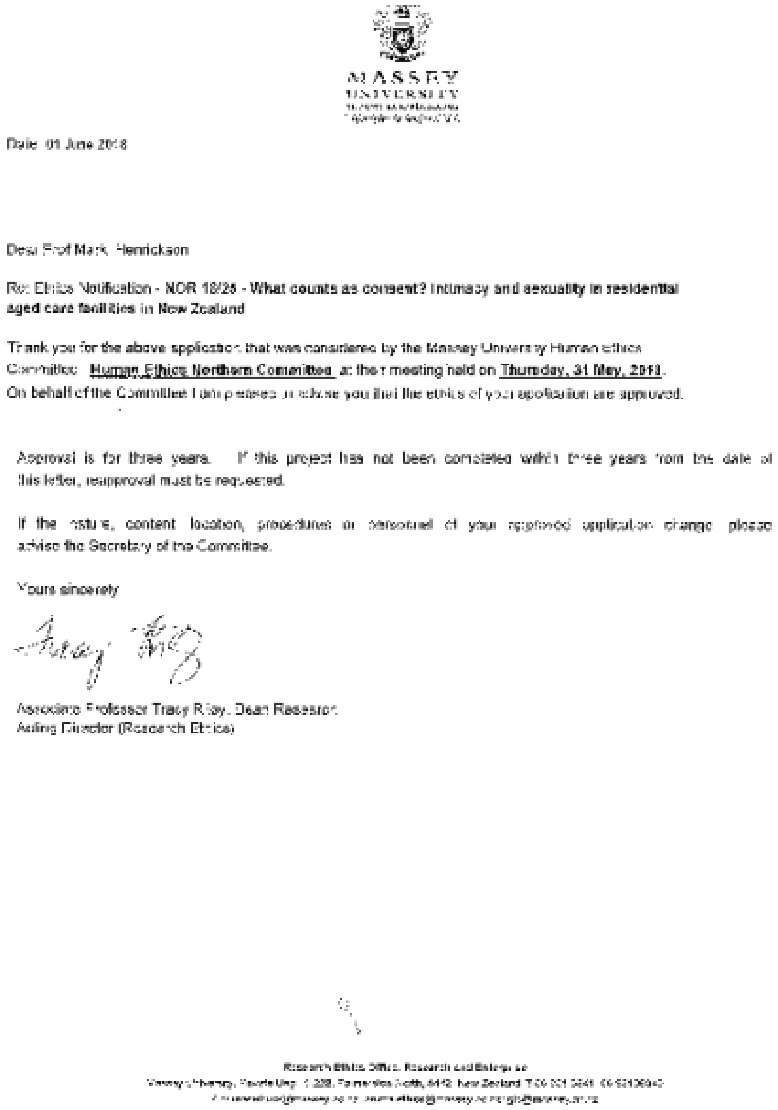


MASSEY UNIVERSITY

Date: 01 June 2018

Dear Prof Mark Henrickson

Re: Ethics Notification - NOR 18/26 - What counts as consent? Intimacy and sexuality in residential aged care facilities in New Zealand

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Northern Committee** at their meeting held on **Thursday, 31 May, 2018**.

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

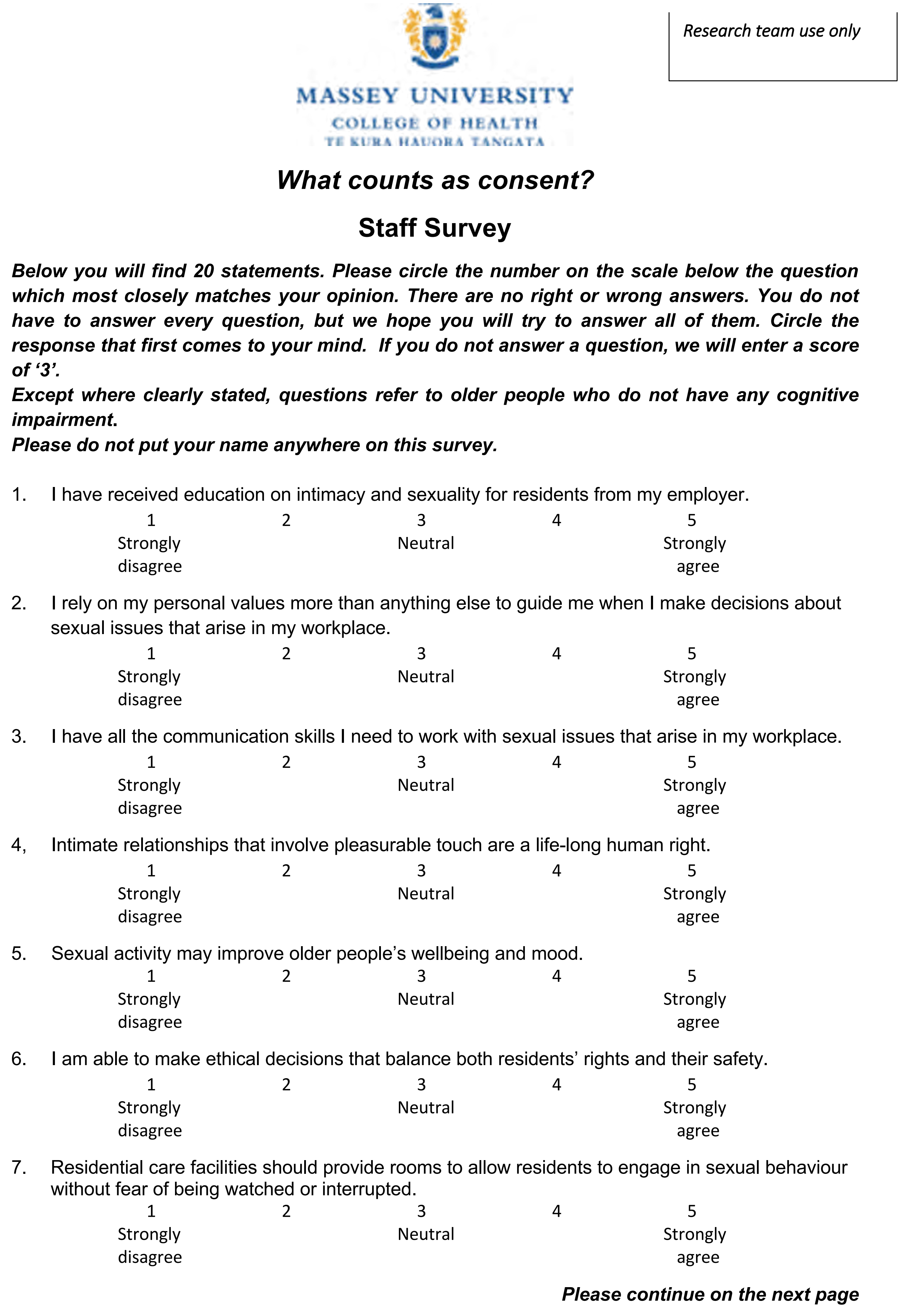
Yours sincerely

Tracy Riley

Associate Professor Tracy Riley, Dean Research
Acting Director (Research Ethics)

Research Ethics Office, Research and Enterprise
[illegible]
[illegible]

ethical frameworks. Religion as a cultural press cannot be ignored in designing education and training for staff. Religious beliefs and practices are often so important to individuals that they are not aware of the influence of these beliefs on their values and practices, and that there are other kinds of (non-)beliefs and practices that are equally valuable to other people. Staff can be supported to become aware of how their own beliefs affect the care they provide, and always to work



Research team use only

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

What counts as consent?

Staff Survey

Below you will find 20 statements. Please circle the number on the scale below the question which most closely matches your opinion. There are no right or wrong answers. You do not have to answer every question, but we hope you will try to answer all of them. Circle the response that first comes to your mind. If you do not answer a question, we will enter a score of '3'.

Except where clearly stated, questions refer to older people who do not have any cognitive impairment.

Please do not put your name anywhere on this survey.

1. I have received education on intimacy and sexuality for residents from my employer.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

2. I rely on my personal values more than anything else to guide me when I make decisions about sexual issues that arise in my workplace.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

3. I have all the communication skills I need to work with sexual issues that arise in my workplace.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

4, Intimate relationships that involve pleasurable touch are a life-long human right.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

5. Sexual activity may improve older people's wellbeing and mood.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

6. I am able to make ethical decisions that balance both residents' rights and their safety.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

7. Residential care facilities should provide rooms to allow residents to engage in sexual behaviour without fear of being watched or interrupted.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

Please continue on the next page

8. I am interested in further professional education about intimacy and sexuality in residential aged care.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

9. Staff should prevent a relationship between residents if family members object to the relationship.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

10. Staff should allow residents who are mildly affected by dementia to engage in sexual activity.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

11. I know enough about the law and about ethics to deal with sexual issues in aged care.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

12. A resident of an aged care facility should be able to have a casual sexual relationship with another resident who consents.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

13. People over 65 have little interest in sexual activity.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

14. I can tell whether a person with a dementia consents to sexual activity with another person just by looking at their behaviour.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

15. Two male (or two female) residents have the right to be sexually intimate with one another.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

16. My workplace should allow access to sex workers for residents who want this service, provided the resident is the one paying.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

17. People living with dementias can never reliably consent to sexual intimacy with another person.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

Please continue on the next page

18. My main responsibility is to ensure that the 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.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

19. Residents should be able to use a facility's internet in private to meet their legal sexual interests.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

20. Consent to sexual activity and agreeing to sexual activity are the same thing.

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

In these last two questions, please circle ONE letter next to the answer that most closely fits with what you would do in the situation.

21. Imagine you are entering a TV room and you see that while residents are watching TV. Two of the residents expose sexual parts of their bodies to other residents. What would you do?

a) Cover them with a blanket
b) Ask them to leave the room
c) Report the incident to your manager
d) Ask other residents to leave the room
e) Just ignore the situation

22. Carol is a resident with dementia and can no longer make her own decisions about her personal care. Carol has been married to David, her second husband, for 20 years. One day when David is visiting you find them having sex. Carol appears to be enjoying it. Her daughter from her first marriage has Power of Attorney. What would you do?

a) Tell David to stop
b) Leave them to it, but check up on Carol later
c) Leave them alone but report the incident to your manager
d) Let Carol's daughter know
e) Do nothing – there is not a problem with this situation

Is there anything else that you would like to tell us about sexuality and ageing from your work experiences?

Please continue on the next page

And finally, we'd like to ask a few questions about you. Put a tick on the line that best describes you. (These questions are optional, but your answers will be very helpful to us. Remember that no one will know who you are, and your responses will never be disclosed at an individual level.) Do not put your name anywhere on this survey.

What is your age group?
____Under 20 years
____ 20-30 years
____ 31-40 years
____ 41-50 years
____ 51-60 years
____ Over 60 years

How many years have you worked in your current work (even if you have changed employer)?
_____ Less than 1 year
_____ 1 to less than 2 years
_____ 2 to less than 5 years
_____ 5 to less than 10 years
_____ 10 years or more

What is the highest academic qualification you have completed?
_____ Less than high school
_____ High school
_____ 2-year diploma
_____ Bachelor's degree (three *or* four year)
_____ Postgraduate diploma
_____ Master's degree or higher

What is your primary role at your workplace?
____ Manager
____ Nurse
____ Social worker
____ Health care assistant, community support worker, or similar
____ Something else (please tell us what your role is): ______________________________

How do you describe your ethnicity? _________________________________

What is your country of origin?
____ New Zealand
____ Other

Is English your first language?
____ Yes
____ No

How do you identify your religion? *(In this question, 'practicing' means you attend a religious event, such as a service or ritual, at least once a month over the last year.)*
_____ I have no religious affiliation
_____ I belong to a religious organisation but I am not active
_____ I am a practicing Christian
_____ I am a practicing Muslim
_____ I am a practicing Buddhist
_____ I am a practicing Hindu
_____ I am active in some other religion or faith community

Thank you for your participation! Please put your completed survey in the secure box that has been provided for you. If you are interested in participating in an interview to explore some of these issues further, please contact a member of the research team at (09) 212 7023

Research team use only

Appendix 3: Tables

Table 1: Target sampling strategy

Region	Large	Medium	Small	Total (%)
Northland	0	2	1	3 (8.6%)
Auckland	1	2	5	8(22.8%)
Waikato	0	1	0	1 (2.8%)
Bay of Plenty/ East **Coast**	0	1	2	3 (8.6%)
Taranaki	0	1	1	2 (5.7%)
Wellington	1	1	3	5(14.3%)
Marlborough/Tasman	1	1	0	2 (5.7%)
West Coast	0	1	1	2 (5.7%)
Canterbury	1	2	2	5(14.3%)
Otago/Southland	1	2	1	4(11.5%)
Total	**5**	**14**	**16**	**35(100%)**

Table 2: Regional Distribution of Interviews

Region	N (%)
Northland	7 (11.5)
Auckland	15* (24.6)
Waikato	3 (4.9)
BOP	6 (9.8)
Wellington	3 (4.9)
Marlborough/Tasman	7 (11.5)
Westport	2 (3.3)
Canterbury	18 (29.5)
Total	**61 (100)**

*includes four groups

Table 3: Distribution of Socio-demographic Characteristics of respondents (N=433)

Size		
Small	161	37.2
Medium	158	36.5
Large	45	10.4
Unknown	69	15.9
Age group		
Under 20 years	8	2.1
20-30 years	75	19.4
31-40 years	72	18.5
41-50 years	89	23.0
51-60 years	97	25.1
Over 60 years	46	11.9
Work Experience		
Less than 1 year	61	15.8
Less than 2 years	51	13.2
Two to less than 5 years	84	21.7
Five to less than 10 years	77	19.8
Ten years or more	114	29.5
Qualification		
Less than high school	27	7.2
High school	138	36.6
Diploma	43	11.4
Bachelor	118	31.3
Postgraduate diploma	37	9.8
Master's Degree	14	3.7
Role		
Manager Group	35	9.0
Nurse	66	17.0
Health care Assistant	217	55.9
Other roles	70	18.1
Ethnicity		
Asian	84	27.1
European	151	48.7
Māori	29	9.4
Pacific	15	4.8
African	7	2.3
Others	24	7.7
Country of origin		
NZ	209	54.0
Others	178	46.0
English your first language		
Yes	239	61.6
No	149	38.4
Religion		
No Religion	138	36.5
I am not active	64	16.9
Christian	121	32.1
Buddhist	5	1.3
Hindu	19	5.0
Muslim	7	1.9
Other religion	24	6.3

*Not all participants responded to all questions

Table 4: Roles by ethnicity

Role	Asian n (%)	European n (%)	Māori n (%)	Pacific n (%)	Other n (%)	Total n (%)
Manager	3 (8.8%)	25 (73.5%)	0 (0)	0 (0)	6 (17.6%)	34 (11.0%)
Nurse	34 (60.7%)	11 (19.6%)	5 (8.9%)	0 (0)	6 (10.7%)	56 (18.2%)
HCA	42 (26.3%)	69 (43.1%)	18 (11.3%)	12 (7.5%)	19 (11.9%)	160 (51.9%)
Other role	5 (8.6%)	44 (75.9%)	6 (10.3%)	3 (5.2)	0 (0)	58 (18.8%)
Total	84 (27.3%)	149 (48.4%)	29 (9.4%)	15 (4.9%)	31 (10.1%)	308 (100%)*

*Not all participants responded to all questions

Table 5: Ethnicity by roles

Role	Asian n (%)	European n (%)	Māori n (%)	Pacific n (%)	Other n (%)	Total n (%)
Manager	3 (3.6%)	25 (16.8%)	0 (0)	0 (0)	6 (19.4%)	34 (11.0%)
Nurse	34 (40.5%)	11 (7.4%)	5 (17.2%)	0 (0)	6 (19.4%)	56 (18.2%)
HCA	42 (50.0%)	69 (46.3%)	18 (62.1%)	12 (80.0%)	19 (61.3%)	160 (51.9%)
Other role	5 (6.0%)	44 (29.5%)	6 (20.7%)	3 (20.0%)	0 (0)	58 (18.8%)
Total	84 (100%)	149 (100%)	29 (100%)	15 (100%)	31 (100%)	308 (100%)*

*Not all participants responded to all questions.

Table 6: Religion and ethnicity

	Ethnicity					
Religion	**Asian** **n (%)**	**European** **n (%)**	**Māori** **n (%)**	**Pacific** **n (%)**	**Others** **n (%)**	**Total** **n (%)**
No Religion	10 (6.2)	115 (71.4)	22 (13.7)	3 (1.9)	11 (6.8)	161 (100)
Christian	50 (51.5)	25 (25.8)	4 (4.1)	7 (7.2)	11 (11.3)	97 (100)
All others	24 (53.3)	7 (15.6)	1 (2.2)	5 (11.1)	8 (17.8)	45 (100)
Total	84 (100)	147(100)	27 (100)	15 (100)	30 (100)	303 (100)

*Not all participants responded to all questions.

Table 7: Ethnicity and religion

	Religion			
Ethnicity	**No Religion** **n (%)**	**Christian** **n (%)**	**All others** **n (%)**	**Total** **n (%)**
Asian	10 (11.9)	50 (59.5)	24 (28.6)	84 (100)
European	115 (78.2)	25 (17.0)	7 (4.8)	147 (100)
Māori	22 (81.5)	4 (14.8)	1 (3.7)	27 (100)
Pacific	3 (20.0)	7 (46.7)	5 (33.3)	15 (100)
Others	11 (35.5)	11 (35.5)	8 (29.0)	30 (100)
Total	161 (100)	97 (100)	45 (100)	303 (100)

*Not all participants responded to all questions.

Table 8: Frequency of KAB survey responses (N=433)

Items	Disagree	Neutral	Agree	Mean	SD
Knowledge					
I have received education on intimacy and sexuality for residents	111(25.6)	122(28.2)	200(46.2)	3.29	1.39
Sexual activity may improve older people's wellbeing and mood	43(9.9)	151(34.8)	239(55.2)	3.70	1.07
I am able to make ethical decisions that balance both human rights and their safety	21(4.9)	98(22.6)	314(72.5)	4.03	0.95
I am interested in further professional education about intimacy and sexuality in RAC	30(6.9)	114(26.3)	289(66.8)	4.02	1.02
I know enough about the law and ethics to deal with sexual issues in aged care	129(29.8)	179(41.3)	125(28.9)	2.97	1.10
It is easy to tell whether a person with dementia consents by looking at their behaviour	203(46.9)	140(32.3)	90(20.8)	2.51	1.23
Consent to sexual activity and agreeing to sexual activity are the same	152(35.1)	156(36.0)	125(28.9)	2.82	1.20
Attitude					
Intimate relationship that involve pleasurable touch are a lifelong human right	33(7.6)	119(27.5)	281(64.9)	3.98	1.14
I rely on my personal values more than anything else	96(22.2)	146(33.5)	191(44.3)	3.35	1.26
Staff should allow residents who are mildly affected by dementia to engage in sexual activity	127(29.3)	199(46.0)	107(24.7)	2.84	1.11
A resident should be able to have a casual sexual relationship with another resident who consents	81(18.7)	145(33.5)	207(47.8)	3.38	1.19
People over 65 have little interest in sexual activity	65(15.2)	118(27.3)	250(57.5)	2.26	1.23
Same-sex couples have the right to be sexually intimate with one another	58(13.4)	130(30.0)	245(56.6)	3.72	1.24
My workplace should provide access to sex workers	157(36.3)	145(33.5)	131(30.2)	2.84	1.37
People with dementias can never reliably consent to sexual	115(26.6)	173(40.0)	145(33.4)	2.87	1.14
Main responsibility is to ensure people in my care are well and happy even if this means allowing them to engage in sexual behaviours that the family may not approve	106(24.5)	166(38.3)	161(37.2)	3.15	1.22
RACF should meet needs of residents who want to use shared internet in private	133(30.7)	152(35.1)	148(34.2)	2.99	1.26
Behaviour					
I have all the communication skills I need to work with sexual issues that may arise in my workplace	64(14.7)	161(37.2)	208(48.1)	3.46	1.09
Staff should prevent a relationship between residents if family members object to the relationship	131(30.3)	184(42.5)	118(27.2)	3.03	1.21
Facilities should provide rooms to allow sexual activity for residents	73(16.9)	144(33.3)	216(49.8)	3.49	1.23

Table 9: Differences in cKNOW, cATT, cBEH and demographic characteristics (N=433)

Socio-demographic characteristics	Frequency	cKNOW (SD) (Range 7-35)	cATT (SD) (Range 10-50)	cBEH (SD) (Range 9-15)
Age group (years)				
<30	83	23.15(3.07)	31.78(6.19)	9.38(1.65)*
31-40	72	24.19(3.52)	31.59(6.92)	10.30(2.17)
41-50	89	23.49(3.77	32.15(7.88)	9.78(2.44)
51-60	97	22.93(3.75)	33.22(6.70)	10.26(2.53)
>60	46	23.80(4.38)	32.28(7.21)	10.65(2.53)
Work Experience (years)				
< 1	61	22.59(3.30)	31.11(6.04)*	9.80(2.08)
1<2 years	51	22.84(2.33)	31.19(7.35)	9.54(2.33)
2<5 years	84	24.04(3.44)	31.15(7.09)	9.96(2.32)
5<10	77	23.80(3.73)	32.27(6.79)	10.15(2.10)
≥10	114	23.56(3.66)	34.11(7.09)	10.37(2.34)
Role				
Manager	35	24.48(4.21)	37.97(6.72)*	11.71(2.32)
Nurse	66	24.30(3.16)	33.15(6.59)	10.01(2.17)
HCA	217	23.29(3.49)	30.63(6.71)	9.82(2.17)
Other roles	70	22.62(4.19)	33.51(6.52)	9.81(2.32)
Ethnicity				
Asian	84	23.86(3.47)	29.83(6.92)*	9.55(1.88)
European	151	23.69(3.50)	35.45(5.94)	10.45(2.15)
Māori	29	23.00(3.99)	31.93(6.04)	9.51(2.30)
Pacific	15	24.26(5.14)	28.60(6.31)	10.80(2.53)
Others	31	23.29(3.07)	31.58(7.69)	10.22(2.72)
Country of origin				
NZ	209	23.32(3.84)	33.73(6.67)*	10.15(2.31)
All other	178	23.58(3.46)	30.62(6.94)	9.82(2.18)
English as first language				
Yes	239	23.32(3.72)	33.88(6.7)*	10.17(2.34)
No	149	23.59(3.57)	29.58(6.51)	9.72(2.08)
Religion				
No Religion	202	23.18(3.86)	33.87(6.45)*	10.13(2.32)
Christian	121	23.84(3.31)	30.65(7.37)	9.96(2.13)
Other religions	55	23.79(3.79)	29.98(6.79)	9.87(2.37)

*p <0.05

Table 10: Relationship between cATT and cBEH

	Frequency n	cATT Logistic linear regression Score 10-30 VS 31-50 Odd ratio(95% CI)	cBEH Logistic linear regression scores 3-9 vs 10-15 Odd ratio(95% CI)
Work Experience (years)			
<1	61	Reference	-
1<2	51	0.73(0.27-1.93)	-
2<5	84	1.58(0.042-2.63)	-
5<10	77	0.86(0.33-2.21)	-
≥10	114	0.50(0.20-1.23)	-
Occupation			
Manager Group	35	Reference	-
Nurse	66	0.39(011-1.40)	-
HCA	217	0.21(0.06-0.69)*	-
Other roles	70	0.27(0.07-1.01)	-
Qualification			
High school	165	-	Reference
Diploma	43	-	1.19(0.55-2.51)
Bachelor	118	-	1.33(0.63-2.00)
Postgraduate diploma	51	-	1.53(0.72-3.24)
Ethnicity			
Asian	84	Reference	-
European	151	3.49(1.56-7.83)*	-
Māori	29	1.55(0.54-4.36))	-
Pacific	15	0.93(0.29-3.75)	-
Others	31	1.61(0.62-4.20)	-
Religion			
No Religion	202	Reference	-
Christian	121	0.31(0.15-0.64)*	1.00(0.56-1.78)
Other religion	55	0.35(0.01-0.82)*	1.04(0.53-2.04)
Negative attitude	-	-	Reference
Positive attitude	-	-	4.87(3.00-7.91)*
Low knowledge	-	Reference	Reference
High knowledge	-	4.16(2.24-7.71)*	2.33(1.40-3.86)*

**p* <0.05

Table 11: Size of the facility and received education and training

	I have received education (N=364)		
Size	Disagree N (%)	Agree N (%)	Total
Small	88 (54.7)	73 (45.3)	161
Medium	93 (58.9)	65 (41.1)	158
Large	14 (31.1)	31 (68.9)	45

p=.004

Table 12: Size of the facility and interest in further education and training

	I am interested in further education (N=364)			
Size	Disagree N (%)	Neutral N (%)	Agree N (%)	Total
Small	11 (6.8)	44(27.3)	106(65.8)	161
Medium	12 (7.6)	41(25.9)	105(66.5)	158
Large	1 (2.2)	12(26.7)	32 (71.1)	45

p=0.77

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