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PRIVACY IN AGED CARE

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ABSTRACT

The extension of privacy laws to cover private sector providers and the proposal of a National Health Privacy Code highlight the importance of examining privacy issues in aged care policy and practice. Although privacy in health and aged care may also include physical, psychological and social dimensions, it is informational privacy that is the focus of these recent changes. In this paper a range of privacy practices in aged care are examined, drawing on theoretical, policy, practice and research literature. It is argued that aged care policy makers and providers need to move beyond the setting of privacy principles and management strategies, and also examine specific day-to-day privacy practices as they occur in different aged care settings. While privacy is often a valued commodity, the construction of an issue as private can sometimes be seen to limit the expression of diverse identities and to reinforce social inequality.

INTRODUCTION

The management of privacy issues in aged care occurs at both public and private levels. Publicly aged care organisations are accredited according to their commitment to maximising clients' privacy and dignity. Personal information is managed in line with relevant legislation, including the Privacy Act 1988 and the Privacy Amendment (Private Sector) Act 2000. Much is said by policy makers and managers about the importance of privacy. Yet, at a more intimate and private level, aged care workers manage privacy issues everyday in their relationships with older consumers. They enter consumers' homes and rooms, negotiate access to their personal space and, at times, touch the private places of their bodies. The last of these is important because it reminds us of the role of the body in understanding privacy and the ease with which the body can be taken for granted in gerontology [1].

This paper looks at these different dimensions of privacy in aged care, focusing on physical, psychological, social and informational privacy practices. Implications for the recognition of diverse identities in aged care are also considered. The paper makes use of theoretical, policy, practice and research literature in developing arguments. Privacy

research has involved quantitative surveys [2,3] and qualitative studies, the latter including participant [4] and non-participant observation [5] and in-depth interviewing [6-8]. The paper begins with a discussion of the conceptualisation of privacy, before considering implications for policy, practice and research.

CONCEPTUALISING PRIVACY

Despite its longings, a claim to privacy is not a claim to complete withdrawal from the public world; rather it is a claim to, among other things, a partial and controlled withdrawal. According to Solove [9, p.1087] 'Privacy involves one's relationship to society; in a world without others, claiming that one has privacy does not make much sense.' In western societies, the private is defined in relation to the public. For Bailey [10, pp.15-16]

The two terms construct each other and discursively shift from side to side. But ... it is the contrast between them, the need to distinguish one from the other, the necessity of making the distinction in any particular social and political situation, that endures.

The relationship between the public and the private has changed over time. Throughout much of western history, it was the public that was most clearly defined, with the private acting as a residual concept [10]. However, the period of late modernity is particularly characterised by the rise of privacy as a social good [10]. In the face of globalisation, the expansion of information technology and the threat of various big brothers, privacy offers a moral haven: a retreat to the individual and all that the individual values. Yet despite the ascendancy of the private, issues continue to be constructed both publicly and privately. This is no truer than in aged care, which, like care generally, is 'at the forefront of public-private relations' [11, p. 261]. In the mobilisation of governments and communities in aged care delivery, body care - that most private of activities [1] - becomes a public act.

There is considerable debate over the conceptualisation of privacy, both of its core or essential meaning and of its dimensions. For Hollander [12] one meaning shares its Latin origins with terms such as deprive and privation and refers to the stripping away or loss of something. Like the army private, it represents an individual who is not official or otherwise distinguished. A second meaning is closer to the concept of personal and relates to property, the body and secrecy [12]. Links with property and ownership are reflected in the way we talk about other dimensions of privacy: for example, ownership of one's body and information about oneself. The sense of privacy as property or territory is also reflected in the idea that we carry around with us (and control access to) a privacy zone or bubble [9] and in the way we place personal items to mark out this zone.

In aged care privacy is considered an indicator of quality of life [13]. Kane [13] links privacy to dignity and draws on Westin's [14] definition of privacy as solitude, intimacy, anonymity and reserve. In a grounded theory study of older people's experiences in hospital, Jacelon [15] conceptualised privacy as the interface between self-dignity and inter-personal dignity. Privacy is also commonly conceptualised in relation to the body,

such as in the delivery of personal care, and in relation to space, such as in the management of personal territory. Researchers usually examine privacy in residential and hospital settings and see it as an important quality in relationships between older consumers and health and aged care providers [16]. The restriction of consumers' privacy is often seen to be indicative of institutionalisation [17] and infantilisation [7,18].

Privacy is constructed through cultural norms and traditions and thus is sensitive to cultural differences [2]. The extent to which the concept of privacy exists in non-western cultures is much debated. For example, while some Chinese scholars claim that there is no concept of privacy in traditional culture, according to Chan [19], three of Westin's [14] dimensions of privacy – solitude, intimacy and reserve – are highly valued in Chinese culture. For Chinese people in Hong Kong, western influences have contributed to unique privacy patterns, although the importance of being open and honest in spousal and filial relationships is maintained. According to Hafez [20] in most Islamic countries there is an acceptance of the distinction between the public and the private, with an emphasis on protecting the private realm of the person and the family. How non-Anglo migrants and their descendants, including older people, manage and adapt their privacy practices to Australian norms needs to be examined. Understandably these people may have different expectations of the way aged care is delivered and further research is needed to develop culturally appropriate services [21].

In considering privacy in health care, Leino-Kilpi et al. [16] outline four dimensions that are also relevant to aged care:

- physical privacy: the extent to which one's body is physically accessible, as reflected in concerns about personal space and the marking out of territory;
- psychological privacy: the control of cognitive and affective processes, the ability to form values, and maintenance of a personal identity;
- social privacy: the management of social contacts, including control over the participants, frequency, length and content of the interaction;
- informational privacy: the control over personal information collection and distribution.

Inevitably these dimensions overlap. Solove [9] argues that we should resist the temptation to overly categorise privacy and that 'we should act as cartographers, mapping out the terrain of privacy by examining specific problematic situations' [9, p.1087]. Thus, privacy involves social practices that need to be understood within specific contexts.

PHYSICAL PRIVACY

Physical privacy in aged care centres on the construction - physically and socially - of the home and the room. In community settings, the home is commonly considered a private space, although some rooms, such as bedrooms, bathrooms and toilets, are more private than others. In hospitals, older patients are aware that while bed curtains afford visual privacy they do not prevent overhearing private conversations [15]. In aged care policy and practice physical privacy is most often considered in relation to residential care. In

this context, the traditional 'Home' is a public setting, where frailty is exposed and personal power publicly diminished [22]. Here the room becomes the home and the private space, primarily because of the dominance of the bed, but also because prized and intimate objects mark the individuality of the occupant [4]. In a study of 686 randomly selected nursing home residents, de Veer and Kerkstra [3] identified that those who said there was insufficient opportunity to be alone were less likely to feel at home, felt that nurses were less resident-centred and felt disturbed more by other residents. Importantly private rooms provide a space for engaging in private behaviour, such as sexual behaviour [23]. Unwanted intrusions can literally be shut out - with varied success [4] - of the person's life. However, residential homes might also benefit from semi-public spaces, like a small lounge, to facilitate intimacy between residents and visitors and prevent intrusion into the more private space of the resident's room [24]. In constructing private spaces, physical privacy practices facilitate psychological and social privacy. This is evident in Australian policy, which has increasingly valued residents having their own room and bathroom [25]. The implementation of this policy and its impact on the maintenance of psychological and social privacy needs to be researched.

Such policy is based upon western assumptions about space and relationships. People from non-western backgrounds may have different expectations regarding the provision of private rooms and bathrooms. For example, in a Hong Kong qualitative study, 10 Chinese elders placed in a residential home raised none of the usual concerns about communal living, such as sharing bathrooms [26]. In contrast, a similar study of older South Asian people in a British community hospital highlighted the value placed on single rooms and single sex bathrooms [27]. A different sense of modesty in South Asian cultures meant that for these interviewees privacy was compromised when using services constructed mainly for white British people. As noted earlier, there is a need for Australian research examining the privacy preferences and practices of older people from culturally and linguistically diverse backgrounds, as well as those of older indigenous people.

PSYCHOLOGICAL PRIVACY

Psychological privacy is rarely constructed as such in Australian policy, although it can be seen to relate to other commitments. For example, the residential care standards set out in the Quality of Care Principles 1997 prioritise independence and identity expression through participation in community life inside and outside the facility. Additionally, 'individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered' (Standard 2.8). Nevertheless, in residential settings, studies indicate that residents' experience of privacy is most positive not so much when staff comply with privacy rules [5], but when residents are involved in meaningful interdependent relationships with staff [5-7]. For Applegate and Morse [5] privacy, as expressed in client-worker relationships, is about respect for the older person's individuality.

As noted, the construction of the home as a private retreat is important not just when considering physical privacy but also in terms of an individual's identity, agency and self esteem: as represented in the term homemaking. Understandably, the possibility of

transfer from one's own home to a residential home can be perceived as a threat to identity and personal power [22]. Similarly, home burglary involves a disruption of identity and ontological security, not just property invasion [28]. To facilitate psychological privacy, policy makers, providers and researchers need to examine how older people maintain a sense of identity and home and how this might be threatened.

SOCIAL PRIVACY

The Quality of Care Principles 1997 highlight the importance of older consumers engaging in social activities and maintaining friendships, noting that they have the right to control their own lifestyle so long as this does not infringe the rights of others. Social privacy in aged care relies on such principles, as well as on formal and informal codes of practice in individual organisations. Knocking on doors before entering or telephoning in advance are minimal ways providers can enable older people to have some control over who they have contact with. Yet in the delivery of community care services older people probably have little say in who provides the service, especially when there is high demand. Additionally older people may have little control over the number of professionals requesting from them detailed and personal information. In their study, Roe et al. identified that when receiving help at home the constant stream of visitors can seem like an invasion of privacy [8]. In communal environments older consumers also have little influence over who they have contact with and inevitably not all interaction is likely to be pleasant. While older people's right to control access to their networks may be respected in aged care policy, further research is needed to examine the extent to which this occurs in practice.

As suggested in the Quality of Care Principles, to maximise social privacy it is important that older people be provided the opportunity to form and maintain meaningful relationships. The failure of residential homes to provide private spaces for sexual expression and intimacy is well documented [6, 29-31]. Similarly, rarely are non-care needs - like sexual needs - considered in community-based assessments [32]. Social privacy also extends to the quality of relationships with service providers, which can also be intimate. While a survey of 76 hospital patients suggested that they are indifferent to invasions of their personal space because they are psychologically prepared for this in hospital [33], qualitative research by Roe et al. [8] highlighted that in older people's own homes they display discomfort in being naked in front of carers when bathing and dressing. Karner [34] in a study of 39 home care workers, found that assigning fictitious kin relationships to aged care workers may help older people integrate a stranger into the home and accommodate intimate contacts. Essentially intimacy and social privacy emerge from the development of trust and respect in personal encounters with staff [35]. The extent to which Australian aged care policy facilitates this in practice needs careful attention.

INFORMATIONAL PRIVACY

The current emphasis on informational privacy reflects a cross-government concern that the expansion of information systems potentially exposes personal information to

unwarranted public scrutiny. Recent initiatives, spearheaded by the Federal and State Privacy Commissioners, seek to consolidate and extend informational privacy legislation across the public and private sectors and to improve consumer access to personal information.

While the Privacy Act 1988 has long applied to public sector organisations under the Commonwealth Government's jurisdiction, its application in aged care has been highlighted more recently. The *Aged Care Assessment Program Operational Guidelines* [36] emphasise that aged care assessment teams are obliged to implement the Privacy Principles set out in the Act. The Privacy Amendment (Private Sector) Act 2000 extended the Privacy Principles to private sector organisations, including private health and aged care services. As with state legislation (such as the NSW Privacy and Personal Information Protection Act 1998), providers are required to develop management plans outlining how their organisation meets objectives generated by the privacy principles. Additionally, the Aged Care Act 1997 requires that approved residential and community care providers comply with the standards set out in the Quality of Care Principles 1997. These include respect for clients' rights to privacy, dignity and confidentiality. Under the community care standards, clients should be informed of the provider's privacy and confidentiality procedures and should have access to their personal information. Given claims that residential accreditation procedures do not appear to have impacted on service quality [37], research is needed into the effects of aged care standards and accreditation processes on privacy practices in the delivery of aged care.

Considering the level of older people's participation in the health care system, current developments in the management of personal health information are of particular interest. In response to concerns over the proliferation of privacy legislation, the management of health information and the development of electronic health records the National Health Privacy Code aims to provide a single set of rules that can be implemented in each Commonwealth and State jurisdiction [38]. It is intended that the Code will relate not just to information imparted between patient and health provider but also to the exchange of health information between agencies, including research bodies and insurance companies [38]. Despite these developments, Bomba and Hallit [39] critique the enforcement of the health privacy reforms by a complaints system, arguing that more rigorous privacy auditing should take place.

FROM PRINCIPLES TO PRACTICES

Although the language and emphasis is different, the framing of privacy principles in law and policy reflects the treatment of privacy and confidentiality in professional codes of ethics. Like such codes [40], statutory principles need to be seen in the context of other (possibly competing) principles. For example, the National Health Privacy Working Group [38] makes clear that privacy is balanced with the need to gather information to benefit health systems planning. However, unlike professional ethical principles, the statutory principles are more explicit regarding which principle should take priority. For example, the Privacy Act 1988 requires that record-keepers not disclose personal information unless certain conditions are met, including if 'disclosure is necessary to

prevent or lessen a serious and imminent threat to the life or health of the individual concerned or of another person' (Principle 11, 1c). In this instance a principle of safety takes priority over the privacy principle.

Like codes of ethics, there may be a disconnection between statements about what ought or must be done and what actually is done in the daily contacts between consumers and providers. As Solove [9] suggests, it seems important that aged care policy makers, providers and researchers focus not just on principles and strategies, but also on privacy practices as they occur on a daily basis within specific contexts. This would entail an examination of the different and possibly conflicting ways in which managers, workers, carers and consumers view a matter or practice as private and the extent to which it is discussed or enacted openly. These individuals can be seen as ethical agents [41] each making decisions to respect or breach privacy conventions depending on the situation at hand. An example of in-depth research examining privacy practices is Jacelon's [15] grounded theory study of five older hospital patients. In one situation a male doctor sat next to a female patient while she was on the toilet because she felt this was the only place she could have a private conversation with him. In this circumstance the need for a private conversation was deemed to have priority over the privacy of toileting, although Jacelon concludes that the dignity of the patient was reduced overall.

That different people involved in aged care may each see and enact privacy differently raises an important question: could privacy codes and practices be forced onto consumers? Might they be coerced or co-opted into treating a matter as private because of pressure from others? In the following discussion, the tensions between privacy practices, identity expression and justice for marginalised identity groups is considered.

PRIVACY, IDENTITY AND JUSTICE

While it is hard to imagine being against privacy, feminist scholars [42] have argued that the failure of liberal capitalist systems to guard against gender inequality is particularly evident in the construction of the private. For example, a husband's right to 'chastise' his wife was in the past seen as a private matter so long as no permanent injury was sustained [43]. According to MacKinnon [44] the experience of women seeking equal rights has been a story of leaving the private to seek citizenship, justice and equality from the public realm. Older people, particularly older women, may also be restricted to a private world where non-paid work, such as home-based care-giving, is constructed as female, private and informal [45]. Even when justice is promoted through a respect for privacy, equality is not always achieved. For example, a commitment to privacy has long been used to promote freedom of sexual expression leading to the reform of laws that criminalized homosexuality [46]. However, reforms achieved through privacy rights represent only a grudging acceptance of sexual diversity and fail to acknowledge that gay and lesbian identities extend beyond private sexual behaviour [46].

It is in relation to the public recognition of diverse identities that privacy practices need to be particularly scrutinised. According to Harrison [47] some of her gerontology students claimed that a concern for privacy would stop them from openly acknowledging

clients' sexualities. This would mean that older gays and lesbians become invisible in aged care. They are relegated to a private world. These concerns are also evident in non-age specific research on homosexuals' experiences in accessing health care [48]. Yet, disclosure of sexual identity is essential in facilitating rapport, honesty and understanding when communicating with health care providers [49]. It is essential that a commitment to privacy be not used to hide from talking about topics seen as sensitive. Forming trusting relationships, drawing on flexible assessment tools and encouraging older people to talk about the meaningful dimensions of their life provides a context in which diversity in identity is expressed [50]. Further research is needed into how privacy practices limit or enable older people to be open about their identity(ies), including their sexual identity, when in contact with aged care providers.

CONCLUSION

Qualitative research assists in exploring the complexity and context of privacy practices as they occur in aged care settings. Further in-depth analysis of practitioners' management of ethical dilemmas involving privacy would be valuable. One strategy could involve critical path analysis: identifying privacy decisions made, highlighting options available at these critical points and considering alternative paths and likely consequences [51]. Quantitative research using standardised instruments and probability samples is also needed to test the ideas emerging from qualitative studies and to survey privacy practices and preferences. One instrument that could be used and developed further is de Veer and Kerkstra's [3] perceived and preferred privacy instrument, which has achieved moderate to high levels of internal consistency. Importantly such instruments provide measures of the experience of care rather than its outcomes [22]. It is also essential that privacy researchers sample widely: reflecting the cultural, sexual, gender, socio-economic and geographic distribution of the older Australian population.

As a concept, privacy is notoriously difficult to pin down, although it is generally talked about positively. However, a concern for privacy *above all else* may limit the expression of diverse identities. This is not to argue that privacy should be imbued with negative traits. Rights to privacy are usually constructed in the context of other rights, including rights to safety and identity expression. Nevertheless, it is important to recognise that privacy is not a benign concept and is usually constructed - albeit implicitly - within political contexts. It is also essential that aged care policy makers and providers be involved not just in setting privacy principles and management strategies, but also in examining the realities of privacy practices as they occur in different aged care settings.

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