Respecting care home residents' right to privacy: what is the evidence of good practice?

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Abstract

Purpose – *The purpose of this paper is to review and discuss evidence of good practice in respecting care home residents' right to privacy. The right to privacy is a fundamental human right as enshrined in international and domestic law and standards. In the context of increasing interest in using a human rights approach to social care in care homes for older people, this literature review summarises research evidence on what respecting the human right to privacy of care home residents entails in practice.*

Design/methodology/approach – *This literature review followed a rigorous systematic approach to the scoping review, inspired by the Joanna Biggs Institute's guidelines for conducting systematic reviews. A total of 12 articles were included in the review.*

Findings – *The research took a multidimensional understanding of privacy in their studies. The dimensions can be categorised as physical, inter-relational or related to personal data. The review highlights three good practice points. First, it is good privacy practice in care homes to make available single-occupancy bedrooms to residents since this offers the opportunity to personalising this physical space with furniture and other belongings, adding a sense of ownership over the space. Second, residents appreciate being able to choose when and how they spend their time in their own bedrooms. Third, it is good practice to respect residents' private physical space and private choices, for example by knocking on doors before entering or agreeing with the resident when it is permissible to enter. The review also found that in some studies privacy considerations were relevant to communal living areas within care homes, including the use of surveillance cameras and the sharing of personal data.*

Originality/value – *This literature review adds to the body of academic literature on human rights and social care in practice. It also highlights areas for future research relating to the right to privacy in care homes.*

Keywords *Older people, Human rights, Care homes, Good practice, Right to privacy*

Paper type *General review*

Background

The right to privacy is a fundamental human right, contained in Article 12 of the Universal Declaration of Human Rights and Article 8 of the European Convention on Human Rights 1950. This states that "Everyone has the right to respect for his private and family life, his home and his correspondence".

Academic and non-academic authors have recognised the importance of maintaining the human right to privacy of care home residents as part of a dignified and autonomous life (see Cahill, 2018; Care Quality Commission (CQC), 2017; Bayer *et al.*, 2005). A wider debate on a human rights approach to social care in residential care homes is gaining momentum and with it the right to privacy of care home residents (e.g. Cahill, 2018; CQC, 2017).

This review of research aims to report evidence of good practice when care home residents' privacy is respected. Thus, it systematically focusses on reporting evidence of practice in care homes which enables residents to have a sense of privacy. Whereas some research on the right to privacy and relevant practice has taken place in acute hospital settings (e.g. Baillie, 2009; Leino-Kilpi *et al.*, 2001), less addresses the context of care homes and social care.

Privacy as a concept is notoriously hard to define, as noted widely in the literature (Tugendhat, 2017, p. 132; Westin, 1967; Bauer, 1994). Rather, it is considered multidimensional, with no one universal definition. As a human right, it is an essential aspect of human dignity. The state must respect, protect and implement the right to privacy and courts of law have applied the right to privacy in a large variety of different cases (Tugendhat, 2017). Scott and her colleagues argue that the concept is relevant to all areas of human activity within society (Scott *et al.*, 2003a, b). However, everyone's privacy needs are personal to them and therefore it is contended that they cannot be generically defined (Scott *et al.*, 2003a; Burden, 1998).

The protection of privacy is core to ethical nursing practice (Nursing and Midwifery Council (NMC), of Ethics, 2008; International Council of Nurses, 2012) and some research has explored what the concept means for hospital settings (Leino-Kilpi *et al.*, 2003; Schopp *et al.*, 2003). To define good nursing practice, authors have attempted to define privacy for their purposes. Woogara (2005), for example, in an article on patients' right to privacy in hospitals used this definition:

> Privacy is broadly distinguishable as two forms: privacy of the person and information privacy, Information privacy implies that strangers should not obtain knowledge of patients' data without permission. Privacy of the person denotes a sense of identity, worth (dignity), autonomy and personal space that each adult human being has: a sense of boundary between "I", "me", "mine" and other people and the world (Woogara, 2005, p. 274).

This current review is not based on one definition. Rather definitions of privacy were extracted from the articles that were included in this study. The review shows that in care homes the concept of privacy is also multidimensional. Whereas there are factors that seem to make it easier for care home staff to respect residents' privacy, such as the availability of single-occupancy rooms, the evidence suggests that residents' ability to make choices, to be autonomous and communicate effectively with staff are pivotal in respecting their right to privacy.

Method

This review followed a systematic approach inspired by the Joanna Biggs Institute's (JBI) manual for conducting systematic reviews (JBI, 2018). However, due to the limitations further outlined below, this review is essentially a scoping review based on a systematic approach.

According to the JBI, systematic reviews aim to provide a comprehensive, unbiased synthesis of many relevant studies in a single document using rigorous and transparent methods. The attempt is to uncover "all" of the evidence relevant to a question (JBI, 2018). JBI's approach was considered most relevant for the purposes of this review, as it is particularly suitable for the research question and the nature of the body of literature, which is mostly qualitative rather than quantitative. Other methods, such as the Campbell systematic review process (Campbell Collaboration, 2017) were considered but not found suitable either because of the methodologies or the kind of evidence necessary to conduct such reviews.

The possibility for bias and errors should be kept as limited as possible to ensure the quality in systematic reviews, according to the JBI. As such, a step-by-step process should be followed. The steps are:

1. formulating a review question;
2. defining inclusion and exclusion criteria;
3. locating studies through searching;
4. selecting studies for inclusion;
5. assessing the quality of studies;
6. extracting data;
7. analysing and synthesising the relevant studies; and
8. presenting and interpreting the results.

Search strategy

RQ1. What is the evidence of good practice for respecting care home residents' right to privacy?

The research question was developed in January 2018 by the authors and noted down in a research protocol, together with the search strategy, the inclusion/exclusion criteria and the data extraction tool.

A systematic literature search took place in January and February 2018. Five databases (CINHAL, Web of Science, ASSIA, PubMED and Jstor) and three journals (*Journal of Elder Abuse and Neglect*, *Ageing and Society* and *The Journal of Adult Protection*) were searched online using a combination of four keywords and their variants. The keywords were: "right to privacy", "privacy", "private life", "private space"; "care homes", "residential care", "nursing home", "long term care"; "older people", "elderly", "aged"; and "best practice", "good practice", "protection", "respect", "dignity", "quality of life". The articles that were identified were furthermore scanned for additional articles. In this initial step, 149 articles were identified, of which 15 were duplicates. The remaining records were screened against the inclusion and exclusion criteria set out below. The authors reviewed potential articles in February 2018. The inclusion and exclusion criteria were as following:

Inclusion criteria

1. privacy or one of the variables included in the title, abstract or the keywords;
2. peer reviewed articles written in the English language and published between January 2000 and January 2018;
3. research context of nursing/care homes or other long-term care facilities for older people providing social care;
4. included evidence related to good practice regarding residents' privacy within the care setting; and
5. qualitative, quantitative, mixed method papers and literature reviews were included.

Exclusion criteria

1. Studies not written in English.
2. Research setting of health/acute/short-term care e.g. hospitals or respite services and privacy in health/nursing care.
3. Research focussing on groups other than older people; such as children, young people or pregnant women/mothers of new-born babies.
4. Aimed at identifying bad but not good practice or offering "only" a theoretical discussion of privacy.

In total, 21 full-text articles were assessed for eligibility of which nine were excluded based on the inclusion/exclusion criteria, using the PRISMA Flowchart (PRISMA, 2009) as recommended by the JBI (JBI, 2018). The remaining 12 articles were tested against the JBI's critical appraisal tool for qualitative research, systematic reviews and text and opinion (Joanna Briggs Institute, 2017a, b, c). The articles that were included provided evidence for good practice either through original research or through rigorous methods used for reviewing literature. The main reason for exclusion was that the articles did not provide any evidence or expert opinion for good practice when respecting privacy in care homes or long-term care settings.

Data extraction and analysis

Data were extracted from each of the 12 articles retrieved according to a predefined template (Table I). The template recorded basic information about the study, such as title, research aim, context and method, as well as the definition of privacy used in each study, the main findings, and reporting of evidence for good practice. A thematic synthesis of the data was used to obtain the results of the review.

Table I Overview of articles and data extraction template

Title of study	*Publication*	*Author/Year of publication/study location*	*Study participants*	*Method*	*Definition of privacy in study context*	*Study aim and relevant findings*	*Good practice identified in text*
Sexual consent capacity: ethical issues and challenges in long-term care	*Clinical Gerontologist*	Jennifer Hillman/ 2016/USA	Care home resident, male, aged 75 years ($n=1$)	Qualitative case study	Author considers privacy in the context of expression of sexuality in care home residents. She suggests that privacy is a multi-dimensional right. Privacy is a physical space in order to engage in sexual activity and intimacy/Privacy as relational space between two or more people, in which they choose to engage in sexual activity. She also argues that this needs to be balanced with a consideration for potential harm to the resident and others' rights	Aim of the study was to find out whether sexual consent capacity assessment can support expression of sexuality in care homes Findings: Sexual consent capacity assessment can help to respect care home residents' expression of sexuality but also protect them from harm and the rights of others	Assessment of sexual consent capacity requires a careful evaluation of a resident's knowledge, reasoning and voluntariness that includes an awareness of ethical issues, family dynamics, environmental constraints, legal rights, staff attitudes and overarching stigma. The use of an interdisciplinary committee or team can provide essential information regarding underlying medical, social, familial, financial and religious issues that may contribute to an understanding of the resident's sexual behaviour
Autonomy, privacy and informed consent 3: elderly care perspective	*British Journal of Nursing*	Scott, P.A. *et al.*, 2003b/Scotland as part of a European study including Finland, Germany	Care home residents and nurses (n=261; residents n=101; nurses n=160)	Quantitative study (structured interviews for residents, self-completion questionnaire for staff)	No single universal definition, privacy is a multidimensional concept	Explored the ethical issues in maintaining privacy in long term care settings. In total 11, privacy items were explored. The authors found consistent agreement between staff and residents. The results indicate that nurses seem to be sensitive to protecting residents' privacy during nursing care activities	Authors argue that the positive responses in the study regarding privacy stem from good facilities, public engagement and education around the right to privacy
Surveillance technologies in care homes: Seven principles for their use	Working with older people	Fisk, 2015/UK		Theoretical paper with practice implications based on pre-existing evidence about care home residents' opinions on the use of surveillance cameras in the care home environment	No definition for privacy is forwarded. Author speaks of privacy in the light of autonomy, data protection, choice and consent to the transmission, sharing, erasure, processing and storage of video or image footage. The author recognises that the risk for privacy to be compromised is greatest when personal tasks are undertaken e.g. in the bath-and bedroom. He also recognises the need to balance autonomy and the duty of care	The author explores principles around the use of assistive technology, particularly telecare systems such as monitoring technologies including cameras, "hidden mirrors" (technology to view pallor, pulse and breathing rate) and audio recording devices in care homes in order to minimise negative impact on the right to privacy	Author forwards following principles for the use of assistive technology: Overt surveillance (i.e. visible cameras) inside care homes and transparency around it in the communication with residents, staff, contractors and relatives Due regard to residents' consent for cameras in private bedrooms and careful consideration of how the footage is processed and kept Safeguards in place regarding who can access information gathered through surveillance technology. Data, images or video footage should be treated as if they belonged to the residents Careful judgement on how technology can support a conflict between autonomy and duty of care

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Table I

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	Ageing & Society,	Harnett and Jonson, 2017/ Sweden	Residents, relatives, staff and managers of 5 care homes (*n*=45 participants, 14 focus group interviews and 7 individual interviews)	Qualitative, observation and interviews, using Erving Goffman's frame analysis (Goffman, 1974)	Authors understand privacy as an essential part of a home-like atmosphere in a care home. Privacy means personal physical space as opposed to communal, public space, personal preference and choice as opposed to control through care home staff and managers. The authors refer to "private meal frames" as mealtime situations, in which residents have a control over what they eat, where they eat it and when they eat	The study has three findings: (a) an institutional frame for care home mealtimes was dominant (b) there were substantial difficulties in introducing private frames (c) successful creation of private or home like mealtimes illustrates an overlooked skill in care work. Creating a non-institutional mealtime depended on staff interaction with residents Study suggests that private framing of mealtimes is to be preferred over institutional framing. Private meal scripts are personal, residents have control over what they eat, when and where they eat. Private meal scripts challenge paternalistic and institutional scripts	Staff initiated discussion among residents using self-disclosing comments, personal anecdotes and the introduction of topics of common interest Such discussion involved staff acting outside institutional meal scripts and to some extent outside their expected work roles. The effect was the creation of what was both personal and private, which was clearly appreciated by residents and staff alike
The factors influencing the sense of home in nursing homes: a systematic review from the perspective of residents	*Journal of Aging Research*	Rijnaard *et al.*, 2016/ The Netherlands	Systematic review		The authors understood privacy as an essential contributor to a feeling of being at home. The authors suggest that privacy is a multidimensional concept that includes the physical space, a psychological space involving choice and control and an interactional space between residents and co-residents as well as staff	The review identified 15 "major" and "micro" factors under three themes influencing the sense of home of nursing home residents. The three themes are attitudes and social interaction, the built environment and the outdoor environment. The preservation of a sense of privacy is an essential part within various identified factors and include a private space	The authors identified following good practice: Physical private space: Having private spaces, with private sanitary facilities (toilets but not necessarily showers/bath tubs), ideally with various rooms including a separate bedroom or recess for sleeping, Residents are free to decorate and make the room familiar and personal with own furniture, memorabilia, pictures and paintings Psychological/interactional private space: Residents can withdraw from communal areas into their private space, in which they can spend time as they wish. Within this space, they can keep old habits such as performing household chores, being able to do things oneself, being able to care for oneself, Residents can invite and host guests in their private rooms, conversations in isolation from others are possible. Rooms can be locked. Agreement on the use of keys appears to be important in the relationship and respect of privacy between staff and resident. Although nursing staff have keys, the locked door symbolizes privacy. The staff are welcome when the residents need assistance Residents receive help mostly from a caregiver instead of technological solutions

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Maintaining dignity for residents of care homes: a qualitative study of the views of care home staff, community nurses, residents and their families	*Geriatric Nursing*	Hall *et al.*, 2014/ England	Care home managers, care assistants, care home nurses, community nurses, residents and their families (*n*=121, managers *n*=33 ,care staff *n*=47, residents *n*=16, relatives *n*=15 and community nurses *n*=10)	Qualitative, interviews	For the authors privacy is an aspect of respecting dignity. The author defined the concept as seclusion from the presence or view from others. The authors argue that privacy is related to choice, control and respect. They suggest that it is a multidimensional concept, including personal physical space, private data	69 out of 121 participants considered privacy to be an essential aspect of maintaining dignity in a care home setting. Perceptions of dignity must be balanced with considerations of risk, particularly for people with dementia	Respecting residents personal space, like knocking before entering a room, closing curtains and doors when providing personal care. Residents bodies are shielded from view of others. Having a private room respecting of information which means not discussing personal information or reading letters in front of others. Seeking permission to enter a room
The implementation of new generation care surveillance technologies	*Gerotechnology*	Van der Weegen, Lukkien and Cornelisse, 2016/ The Netherlands	Institutional psychogeriatric care and care for people with disabilities (ages unreported) (*n*=3 sites)	Focus groups (questionnaires) and interviews inside the 3 research sites	Authors do not define privacy in the article	Smarter algorithms in ambient intelligent surveillance technology can decrease the level of false alarms during the night, which leads to enhanced privacy, autonomy and comfort in residents and reduction in workload for night staff	Personalised surveillance technology with training, coaching and deployment of super users, individuals who can maintain the systems. Small scale pilots to map context specific needs and barriers prior to organisation wide implementation
The design of caring environments and the quality of life of older people	*Ageing & Society*	Barnes, 2002/UK	Literature review		Privacy in the physical environment: visual, acoustic and olfactory (Keen, 1989) need to be separate from others personal space, which is defensible to others and becomes claimed territory with control over it	Authors argue that privacy in care homes can help to increase or maintain the quality of life in care homes. Evidence from the reviewed literature suggests that personal, defensible space is a major factor for life satisfaction. The determinants of enhanced or maintained quality of life may broadly be summed up as those factors which permit residents to control and organise their life in care	Personal, private space and spaces for interaction. Personalise rooms. Decide on ventilation/temperature levels
Architectural factors influencing the sense of home in nursing homes: An operationalization for practice	*Frontiers of Architectural Research*	Eijkelenboom *et al.*, 2017/ The Netherlands/ International	Literature analysis		Authors define privacy in terms of "private space" opposed to public space i.e. a private room as opposed to a shared room. In this private space, a resident can be on his/her own, talk in private, and create a personalised environment, with personal belongings and furniture	The study aimed to examine the architectural factors that contribute to a sense of home and how these can be implemented in design guidelines for practice. The built environment can contribute to a sense of home in nursing homes, of which privacy is an essential part. The article provides evidence-based design guidelines for a care home environment	Authors identified following good practice: Residents have a private space, at least bedroom but ideally also sanitary facilities and space to host guests. Residents can control their privacy by withdrawing from public spaces and by locking the doors In their private space, residents have control. They can perform chores, talk in private or be on their own. The private space is personalised, with personal belongings and furniture and residents have control over these belongings Rules between resident and staff govern the private space e.g. the doors are not opened without prior notification e.g. through knocking

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Older people's experience of their free will in nursing homes	*Nursing Ethics*	Tuominen *et al.*, 2016/Finland	Care home residents (*n*=15)	Qualitative, interviews	The authors considered privacy in the light of "free will". The authors define free will as a feeling of being able to make choices freely and voluntarily among a range of possibilities according to personal values. In practice, free will means freedom from obstacles to carry out one's desires and a right to determine one's interest, values and life free of interference (Tuominen *et al.*, 2016, p. 23)	The study's purpose was to consider how older care home residents define free will and what factors promote or are barriers to expressing such free will in a care home environment. Older people experience own free will as an action consistent with their own mind. Major promoter of free will were good physical conditions and health, which impacted the ability to demand rights, when nurses were professionally skilled and respected them and their needs are understood	Authors identified following good practice examples: Having a private, single occupancy room. Residents can choose to Spend time in their own room or shared parlour
What evidence is there about specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions? A literature review	*Palliative Medicine*	Rigby *et al.*, 2010/ UK based study, international papers in English language	Narrative review based on 29 papers		Authors speak of privacy in context of a private physical space, i.e. single bed rooms and spaces for grieving family members and in context of social interaction, i.e. being without the interference of others without choice, being alone	The environmental space for older people nearing the end of life or dying should support the individual's specific needs for social interaction and privacy, be homely, allow space for spirituality and support the caring activities of staff, families and residents	The authors do not directly comment on evidence for good practice in meeting the needs for privacy. But, in their discussion they mention good practice in terms of physical space and social interaction. As such, a mixture of single or multiple occupant rooms should be available, and individuals should be able to choose according to personal preference. Garden spaces should be accessible without requiring assistance by staff. Individuals should be given the choice to worship in their rooms, alone or with others
An exploratory study of Chinese older people's perceptions of privacy in residential care homes	*Journal of Advanced Nursing*	Pau Le Low *et al.*, 2007/China	Care home residents (*n*=20)	Qualitative interviews	According to the authors, privacy is a fundamental principle of humanity. They understand privacy as multidimensional with four aspects, as forwarded by Leino-Kilpi *et al.* (2001): physical privacy, psychological privacy, social privacy and informational privacy	Socio-cultural influences determine older people's perceptions of care in residential care homes. Participants shared their understanding of the meaning of privacy. One said that privacy is about concealing things from others, keeping secrets. Generally, the article suggests that residents consider privacy to be related to individual needs as opposed to the collective unity of the care home community. Many of the studies participants did not perceive privacy according to their interpretation of the concept relevant in a care home. Chinese values of maintaining balance and harmony shaped their perceptions of privacy and infringements of privacy. Chinese people valued psychological and social privacy more over physical and informational privacy. Development of culturally appropriate care is essential for respecting privacy	Authors argue for following good practice points: Increased sensitivity towards older people's interpretations of privacy by eliciting privacy preferences Availability of lockable cupboards to secure personal belongings, locking doors and closing curtains during bathing and toileting Covering up body parts during intimate care, care staff enter bathrooms with permission Being able to choose to spend time in isolation from others and when to talk to others. Being able to choose when to spend time alone with families by leaving the premises or retreating to personal bedrooms Family issues and household matters are not discussed in front of other residents

Limitations

This review had several limitations, which means that it does not qualify as a "systematic review" under the JBI's definition. For example, this review is part of a doctoral study with a single reviewer rather than multiple reviewers as necessary for a JBI review. The JBI software for conducting systematic review was not used and some of the steps involved in the process, particularly the double processing through a second reviewer, were not followed.

A further limitation to this review is that it does not represent all the literature available on this topic. For example, only peer-reviewed academic articles were considered. This means that potentially valuable literature, such as books and book chapters or contributions published by non-academic sources, do not directly inform this review (such items include, e.g. Cahill, 2018; Chadwick and Gallagher, 2016; Care Quality Commission, 2014).

The search terms used for this review presented another limitation. Only contributions with the word "privacy" and "care homes" or one of the variables in the title, abstract or keywords were included for initial review. It is possible that some authors have provided good privacy practice illustrations in articles which focus on topics other than privacy such as quality of life, respect or dignity in care homes.

As such, it is possible that this review has missed evidence of such examples because these authors did not mention privacy and/or care homes in the title, abstract or keywords of their contribution. However, due to constraints on time and resources, this review had to be limited to academic articles focussing on evidence for good privacy practice in social care within care homes for older people based on the keywords.

Results

Conceptualising privacy

The concept of privacy, as mentioned above, does not have one fixed definition. Thus it was not surprising to find a variety of approaches to the concept within the 12 articles. Essentially, many suggested that privacy of care home residents amounts to having control and choice over one's personal and exclusive space, including the body, personal belongings, bed and bathrooms, personal data, food, as well as time and relationships.

Some authors aimed to locate privacy within a wider philosophical idea, specifically the concepts of humanity (Pau Le Low *et al.*, 2007), dignity (Hall *et al.*, 2014), free will (Tuominen *et al.*, 2016) or homeliness (Rijnaard *et al.*, 2016). Here, authors considered privacy as an aspect of each of these concepts but without offering any deeper theoretical discussions of the relationship.

Few proposed a limited definition for privacy, such as "seclusion from view" (Hall *et al.*, 2014) or "personal defensible space" (Barnes, 2002). In one contribution, the authors argued that the concept is culturally sensitive and that everyone has his or her own understanding of it (Pau Le Low *et al.*, 2007).

Most commonly however, authors showed an extensive and multidimensional understanding of privacy. There was frequent reference to the "private physical environment or space" and "the private social/psychological/interactional space", which were considered as interrelated (Hillman, 2016; Pau Le Low *et al.*, 2007; Rijnaard *et al.*, 2016; Hall *et al.*, 2014; Eijkelenboom *et al.*, 2017). These private spaces were virtually always conceived of as opposite to public, communal spaces within care homes. Few mentioned "data privacy" as another dimension (Hall *et al.*, 2014; Pau Le Low *et al.*, 2007). Most papers discussed these dimensions in the light of the concepts of "choice", "control", "autonomy", "personal preference", "ownership" and "respect" (Fisk, 2015; Hillman, 2016; Pau Le Low *et al.*, 2007; Rijnaard *et al.*, 2016; Hall *et al.*, 2014; Eijkelenboom *et al.*, 2017; Van der Weegen *et al.*, 2016; Barnes, 2002; Tuominen *et al.*, 2016).

Some authors recognised that, in a residential care setting, at times the right to privacy must be balanced with other considerations, notably risk of possible harm to the resident in question and/or other residents (Hillman, 2016; Hall *et al.*, 2014).

The evidence of good practice from the articles can largely be organised under four themes: the ownership of private spaces, respecting private choices, protecting private data, and approaches to balancing the right to privacy and risks of harm. These are discussed in turn.

Theme 1: ownership of private physical spaces

The majority of researchers discussed the significance of private physical space in relation to care home residents' right to privacy (Hillman, 2016; Harnett and Jonson, 2017; Pau Le Low *et al.*, 2007; Rijnaard *et al.*, 2016; Hall *et al.*, 2014; Eijkelenboom *et al.*, 2017; Barnes, 2002; Tuominen *et al.*, 2016; Rigby *et al.*, 2010). The availability of private, single-occupancy bedrooms was frequently argued to be pre-conditional for ensuring privacy in any institutional care setting (Tuominen *et al.*, 2016; Rigby *et al.*, 2010; Eijkelenboom *et al.*, 2017; Barnes, 2002; Rijnaard *et al.*, 2016). Care home residents generally expressed a desire to have their own toilets for their own personal use and a separate exclusive room in addition to their bedroom. This would be for entertaining family and guests (Rijnaard *et al.*, 2016). Exceptions to this were end of life care settings, in which some residents in one study preferred to share their bedroom with others (Rigby *et al.*, 2010).

Residents appreciated the opportunity to personalise their own rooms with pieces of furniture, pictures and other items, which added to a sense of personalisation and thus privacy (Hall *et al.*, 2014). Lockable doors and/or lockers for personal items as well as being able to control ventilation and heating added to a sense of control over the private space. During personal care assistance, blinds or curtains on windows provided enabled the shielding of residents from the sight of others, which again added to a sense of privacy being respected.

One study (Pau Le Low *et al.*, 2007) was based in a Chinese care home, in which multiple occupant rooms are common. Residents reported that having available a locker to safely store personal items was valuable in terms of privacy considerations.

Theme 2: respecting private choices and personal preferences and leaving residents in control

The inter-relational, social or psychological dimension of privacy was often explained as residents being able to make choices, express personal preferences and staying "in control". Several good practice examples were highlighted, which were directly linked to the first dimension, namely, private physical spaces. Several authors also discussed good privacy practice within communal living areas of the care home. These will now be outlined in turn.

Private choices in private places. According to many authors, simply occupying a private physical space does not amount to good privacy practice in care homes. Residents must also be able to make choices regarding the use of these private spaces on several levels and have these choices respected.

First, residents reported that being able to choose when to withdraw from communal living spaces in the care home and spend time in their private rooms adds to a sense of control. Second, residents appreciated the opportunity to choose how they spend their time within their own private spaces. One study mentioned the value of residents being able to engage in household chores and caring for themselves (Rijnaard *et al.*, 2016). Residents also appreciated being able to invite others into their rooms and to engage in conversations. Another study mentioned the importance of being able to pray and worship in one's own room (Rigby *et al.*, 2010).

Several authors highlighted the need to protect the private physical space. There were numerous references to the importance of knocking on a resident's door before entering, providing residents with a key to their bedroom door and agreeing on rules about when a staff member or visitor can unlock a resident's door.

Private choices in public places. Some studies mentioned good practice in respecting private choices in communal spaces, such as gardens, living or meeting rooms. One study used the concept of privacy in relation to mealtimes and reported a shift in social roles between staff and

residents when the latter were provided with a choice over what, when and where to eat at evening coffee time (Harnett and Jonson, 2017). While the element of privacy is hard to determine, the researchers thought that change in social roles meant that staff engaged differently with residents, sharing personal anecdotes and common interests, which both residents and staff appreciated.

Another study (Rigby *et al.*, 2010) reported how family members of care home residents who were dying liked to be able to withdraw into a "private" space within otherwise communal living areas, in which they could feel on their own for a while. Accessible outside spaces, which residents could enter without asking for support, were another good practice example, as reported by residents within this study although the element of privacy is not explicit.

Theme 3: keeping personal information private

A few studies discussed the handling of personal information, for example relating to a resident's family or health, from a privacy perspective (Fisk, 2015; Pau Le Low *et al.*, 2007; Hall *et al.*, 2014). In one study, residents expressed a wish not to have family matters discussed in front of other residents (Pau Le Low *et al.*, 2007). In another, residents said that "personal information" should not be discussed or letters read out in front of others (Hall *et al.*, 2014).

Theme 4: balancing the right to privacy with risk of harm

Care home residents are often frail, in need of support and/or have cognitive impairment (Fisk, 2015; Hillman, 2016). Some studies highlighted the risk of harm to care home residents if the level of respect for their physical privacy and private choices was maintained to the same extent as those of residents without substantial impairment (Hillman, 2016; Fisk, 2015).

One study (Hillman, 2016) considered capacity to consent to sexual activity in a care home for residents with dementia. Whereas maintaining sexual relationships is an important part of a person's private life, in the case of people with dementia, lacking the ability to consent to such activity, the risk of possible harm either to themselves or others needed to be balanced. The author considered privacy in terms of physical privacy to be intimate and in terms of relationships, in which individuals choose to become intimate. The study reported that staff could use a sexual consent capacity assessment tool, which helped both the care home staff and the resident to decide whether the desired sexual activity was risk-free for the individuals wanting to engage in intimacy.

Another study (Van der Weegen, 2016) focussed on the availability of technological solutions to increase the privacy of care home residents and at the same time reduce staff workload. Such technology, which entailed surveillance cameras, was particularly said to be useful when staff members were trained how to maintain the hard and software and when everyone involved received detailed information about its uses and the way it worked.

Fisk (2015) forwarded specific principles for the use of monitoring technology, which includes cameras but also other devices such as health monitoring tools. He argued that such technology can be helpful in care homes settings but that ethical issues around its use need consideration. Fisk recommended that it would be good practice for surveillance cameras and other devices that capture images or footage of residents and others in the environment to be visible and that there should be transparency and consent as far as possible.

Discussion

This review has highlighted the many aspects of the right to privacy relating to care home settings, be it in theory or in practice. Despite the elusiveness of the concept, many of the authors proposed a similar idea in defining privacy – and good privacy practice – within a care home.

Three main good practice points emerged from the review. First, it is good practice to offer private rooms to residents, which can be personalised with furniture and other belongings, enabling individuals to make their own choices over decoration. Second, residents appreciate being able to choose when and how they spend their time within these private physical spaces without

being disturbed. Third, it is good practice to respect residents' private physical space and private choices by knocking on doors or agreeing with the occupant when it is permissible to enter. The review further highlighted that there are privacy considerations in communal living areas within the care homes, particularly relating to mealtimes. In terms of the use of cameras in care homes, consent and transparency around the use of such technology need attention to help balance the inherent risk of such devices in reducing residents' privacy.

Besides these good practice points, this review highlights the significance of skilled staff who elucidate and understand the needs of individual residents and who are willing to respect them. Privacy, as this review shows, is a person-centric concept, which in its very core is about individuals' lives in a community. Staff willingness to get to know the residents as individuals and engage with them seem to be a cornerstone for good privacy practice in care homes.

This review has also highlighted the need to balance the right to privacy with other considerations, particularly the duty of care and rights of other residents. This becomes especially relevant when a resident or residents have cognitive impairments and their decision making or insight is impaired.

Conclusion

This review shows that researchers conceptualise the right to privacy as a multidimensional concept in a care home, which demands certain environmental and inter-relational pre-conditions. The review also highlights the many aspects of the right to privacy that need to be considered in the light of duty of care and other rights. These aspects include the handling of personal data, the use of surveillance technology, sexual relationships in the care home, and so forth.

While this review provides a broad summary of good practice for respecting care home residents' right to privacy, it also highlights the need for further research and investigation of good practice. A range of systematic reviews could be useful, especially if they include all the relevant literature. In the light of a growing population of people with dementia, guidance on good privacy practice for people with dementia could be particularly timely and useful.

The literature search for this review also made apparent a lack of evidence-focussed contributions on the human right to privacy in care homes. In most of the articles included in this review, "evidence for good privacy practice" had to be extracted from a much broader focus on other related issues, such as sexuality, end of life or autonomy in care homes. No quantitative studies or targeted qualitative studies focussing on evidence for good privacy practice could be found. Some of the authors included in this review made the point that different people have different privacy needs. More in-depth research is needed to identify privacy needs of people living in care homes, including their wishes around the use of personal data and surveillance.

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Further reading

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