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## Cameras on beds: The ethics of surveillance in nursing home rooms

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### ABSTRACT

Surveillance cameras are increasingly being deployed in nursing homes and assisted living facilities, with insufficient attention to what is ethically fraught about this way of assuaging concerns about abuse and other personnel challenges. With seven state laws now regulating camera monitoring and more on the way, it is urgent for us to consider the ethical implications of how we use technology to keep older adults safe. Drawing on findings from the first facility survey on this topic, we address three ethical issues: the risk that in-room cameras pose to residents' privacy and dignity, the risk of undermining care workers' sense of being fiduciaries for residents, and the probable extension of camera use by facilities to monitor staff and residents. We argue that with an aging population, intensifying strain on the care workforce, and ease of access to Web-connected cameras, this is a critical moment to address these ethical challenges.

### KEYWORDS

Aging; decision making; confidentiality; nursing; privacy; law


From nanny and child cams to pet cams, the use of Web-enabled video cameras for care purposes is becoming normalized (Stark and Levy 2018). With growing ease of access and affordability, families with loved ones in nursing homes<sup>1</sup> or assisted living commonly turn to monitoring cameras to protect elders in residential care, hoping that this surveillance will help protect their loved ones from harm. Seven states have now passed laws to regulate the practice, some have regulatory guidelines, and others have bills in progress. This phenomenon presents complex issues for law, ethics, and public health.

In this essay, we present new data from a survey of nursing homes and assisted living facilities about family-provided cameras in resident rooms, and we address three critical ethical issues they raise. First, how do in-room cameras affect the privacy and dignity of the residents? Second, how might being under surveillance shift care workers' sense of being fiduciaries for the residents? Third, how might the likely expansion of camera use from the discretionary (families bring them in voluntarily) to the routine institutional scrutiny of staff and residents intensify these

ethical challenges? Drawing on findings from the first survey of its kind on this topic, this essay addresses these ethical issues as part of the larger question: How can we use technology to keep nursing home residents safe without disrespecting and even potentially dehumanizing both the residents and the care staff?

### An underappreciated public health issue

Elder abuse is a pervasive public health problem that is expected to increase as the number of people with Alzheimer's disease and related dementias (AD/RD) rises with population aging (Burnes et al. 2015; Hall, Karch, and Crosby 2016). This problem has attracted fewer resources for interventions than have child abuse and intimate partner violence, leading gerontologists and geriatricians to call it an "underappreciated" public health problem (Institute of Medicine [IOM] and National Research Council [NRC] 2014). The consequences of elder abuse are serious, including premature mortality, dementia, functional decline, depression, stress, and malnutrition (Dong 2015). It is estimated that 10% of older adults

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<sup>1</sup>The U.S. government defines nursing home in the following way: "Nursing home is a term that includes both skilled nursing facilities and nursing facilities. Nursing homes primarily engage in providing residents skilled nursing care and related services for residents who require medical or nursing care and rehabilitation services for the rehabilitation of injured, disabled, or sick individuals" (Medicare.gov Nursing Home Compare Glossary: <https://www.medicare.gov/NursingHomeCompare/Resources/Glossary.html>). The philosophy of the assisted living facility centers on enabling residents to age in place in a home-like environment and is often operationally defined as "one that provides or arranges at least the following: 24-hour staff, housekeeping, at least two meals a day; and help with at least two activities of daily living (ADLs)" (Hawes, Phillips, and Rose 2000, 2).

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in the United States experience neglect, financial exploitation, or physical, sexual, or psychological abuse (IOM and NRC 2014; Lachs and Pillemer 2015). Abuse is thought to be dramatically underreported, particularly among those with cognitive impairment (IOM and NRC 2014). We have no reliable prevalence estimates of abuse or neglect in nursing homes, where residents may face threats from other residents in addition to staff (Gibb and Mosqueda 2004; Lachs and Pillemer 2015). Half (50.4%) of U.S. nursing home residents have AD/RD (Harris-Kojetin, Sengupta, and Park-Lee 2016). The families of these residents are most likely to seek camera surveillance because their relatives cannot report how they are being treated, and they are concerned about elder abuse and related problems.

Family members place cameras in their loved ones' rooms, overtly and covertly, because they fear or suspect that abuse, neglect, or theft is occurring, most often at the hands of staff (LeadingAge 2016; Levy, Kilgour, and Berridge 2019). This use of cameras by family members has become so prevalent that seven states (Louisiana, Illinois, New Mexico, Oklahoma, Texas, Utah, and Washington) now have passed laws that explicitly permit private individuals to use camera devices in residents' rooms in nursing homes and/or assisted living communities provided that certain procedures are followed, and at least a dozen others have had bills proposed (Levy, Kilgour, and Berridge 2019). In the context of this policy movement, there is surprisingly limited academic research on the prevalence, efficacy, or residual effects of cameras in resident rooms and on stakeholders' views of them. Resources such as the Justice in Aging Law Center, which does not provide legal advice to individuals, report fielding regular calls for advice. This absence of research has left family members to turn to Internet searches to seek guidance on the ethical, legal, and technical problems involved. Some reach out to ombudsmen (E. Carlson, personal communication, March 18, 2016). The National Center on Elder Abuse in collaboration with the National Consumer Voice for Quality Long-Term Care offers a fact sheet (2018) and a webinar (2017) that begin to outline the complexity of camera use, but actual guidance remains limited. It is becoming increasingly evident that this issue demands thoughtful discourse on multiple levels to inform a pragmatic approach that directly benefits residents and their loved ones.

Absent prevalence data, we began with a survey of nursing home facilities to gather data on their use of and policies about in-room cameras as a first step

toward understanding the scope of this issue. Through open-ended questions, we were able to capture rich responses from 273 respondents on perceived risks and benefits of in-room camera use that express ethical standpoints. We present the findings from the survey and offer three directions for academic engagement with this issue: ethical analyses of underarticulated challenges, empirical research on stakeholder preferences and models to improve relational care in nursing homes, and sociolegal analyses to understand how vulnerabilities are addressed through state laws.

## Methods

The first author conducted an eight-question, anonymous online survey through the Center for Gerontology and Healthcare Research at Brown University to learn about nursing home and assisted living policies and current use of cameras in resident rooms. The survey included six closed-ended questions and two open-ended prompts: "Please take this opportunity to comment about concerns you might have about the use of cameras in resident rooms" and "Please take this opportunity to comment about advantages you might see in the use of cameras in resident rooms."

## Recruitment

The survey was distributed electronically to members of the American Health Care Association and National Center for Assisted Living in 2016. The American Health Care Association (AHCA) is a non-profit federation of affiliate state health organizations that is the largest organization representing long-term care in the United States, and includes nonprofit and for-profit nursing facility and assisted living providers. The National Center for Assisted Living (NCAL) is the assisted living arm of this organization. The link to the survey was shared with the National Center for Assisted Living newsletter subscribers with 8,353 recipients on the distribution list in assisted living facilities and in the AHCA national newsletter that has 13,633 recipients on the distribution list. AHCA reports that newsletter recipients serve primarily in leadership roles of facility administrator and executive director.

## Response

In total, 273 participants responded from 39 states and Washington, DC. We cannot calculate a response

rate because the survey was widely distributed and anonymous, and we were unable to track the number of newsletters opened. As a result, we draw upon these survey data primarily to understand the range of ethical concerns raised by facility leaders, rather than to establish conclusive findings about the representativeness of such views among facilities. The Results section first reviews responses to closed-ended questions and then summarizes responses to open-ended prompts.

## Results

Of the 273 that responded, 55% of the respondents represent nursing homes, 23% represent assisted living providers, and 22% represent a combination of both. Staff members from facilities of all sizes responded in roughly equal numbers. Thirty percent of respondents report that their nursing home and/or assisted living community allows family members to install cameras in resident rooms. Regardless of their camera policy, 18.7% report knowledge of at least one camera in use. Of these, most reported being aware of between one and three cameras in resident rooms in the facility.

A far greater proportion of assisted living facilities than nursing homes reported current use of cameras by family members, and 11% of respondents reported that their facility has been the one to initiate the use of a camera in a resident's room. Less than half of the 103 facilities that either allow cameras and/or have a camera in use require notification of a camera's presence, such as a sign alerting staff and visitors, suggesting that the use of a camera may not be known by or made salient to people entering a room. When families use covert surveillance, roommates and visitors, in addition to facilities and staff members, are likely unaware that their interactions are not private. In fact, some survey respondents cited the problem of obtaining consent from a roommate when a camera is covertly used.

## Advantages and disadvantages

Three-quarters of the respondents wrote in at least one disadvantage ( $n = 204$ ), and more than half noted at least one potential advantage ( $n = 154$ ). Respondents noted many more concerns over the practice than potential advantages, with a total of 323 statements of disadvantages and 200 comments about advantages.

**Potential disadvantages.** The majority of respondents (172) wrote that the privacy of residents would

be inappropriately invaded, and many extended that concern to roommates,<sup>2</sup> staff, and visitors. This issue was often paired with concern over the dignity of residents and explanations of the intimate nature of care provided on the bed. For example, one respondent from a mid-sized nursing home posed the rhetorical question, "Is this really what the resident would want to have recorded about themselves?" They went on to explain, "Many of the residents have dementia, so how do we ascertain if this is what they would want or not want? Does the family have the right to insist? The resident's dignity may be violated by their own family." This problem was echoed by others in mid-sized combination facilities: "Invasion of a resident's privacy, even with a diagnosis of dementia, or whether you think they won't know or can't understand. As a resident advocate I think that is a huge dignity issue." Some noted that it would invade physical as well as emotional privacy for residents and staff. Respondents noted that such invasion of privacy undermines a home-like experience, and others likened it to processes of institutionalization. As an administrator of a large combination facility wrote, "Installation of a camera recording the most private spaces is the very definition of institutionalization."

The potential negative effects of this use of cameras on staff were identified by 32 respondents in terms of its potential to demoralize, offend, stress, add undue pressure, intimidate, and show lack of confidence in staff. Participants worried that this form of surveillance could impede care relationships. As one respondent from a large nursing home explained, "I feel it would really negatively affect the relationship building that we try very hard to promote with person-centered care." Others wrote that it would contribute to a culture of mistrust. For example, a respondent from a large combination facility wrote: "There are no advantages that outweigh the concerns and the kind of culture you create by doing this." Others raised the possibility that cameras could have both positive and negative implications, like a participant from a mid-sized combination facility who wrote, "This would make staff, and perhaps residents very self-conscious, leading to potential mistakes that could lead to injuries due to this intrusive watchful eye. The converse is also a possibility—that staff and residents would feel more responsible, accountable

<sup>2</sup>A minority of nursing home rooms are single-occupancy. A survey of a single state found that 39% were private rooms (Shippee, Henning-Smith, Kane, and Lewis 2015), and another study established that 29% of residents live in single-occupancy rooms (Kane et al. 2004). Approximately three-quarters of assisted living facility units are single-occupancy (Hawes et al. 2003).

and supported by the watchful eye of the camera.” Respondents also noted the potential for a misleading or selectively edited feed to fuel improper litigation as well as data insecurity, susceptibility to hacking, and public posting as a form of abuse.

**Potential advantages.** The most commonly raised potential advantage was the use of cameras as a tool to deter abuse or determine truth in abuse or theft allegations (111 respondents). While some noted the dual uses of determining truth in abuse or theft investigations and motivating staff to provide quality care, others wrote that cameras should only be used to aid investigations. For example, a participant from a large combination facility specified that “The only possible advantage would be to be a tool in an investigation.” A respondent from a mid-sized assisted living facility wrote that “As an administrator who has done multiple investigations into alleged theft or abuse cases, which typically had been unfounded, a camera could provide some much needed verification in cases of allegations.”

The use of cameras by facilities for quality improvement and to correct staff behaviors was a commonly cited potential advantage. Fifty-two participants wrote that cameras could be used routinely to improve quality care by keeping staff “on their toes” and vigilant about providing good care because they are aware they are or may be under surveillance. As one respondent from a mid-sized nursing home explained, “Having staff know they’re being watched may cause them to be more mindful about the importance of kindness, patience, and proper caregiving.” Another from a small assisted living facility wrote, “I do believe the care staff would cross their T’s and dot their I’s, no short cuts.” A respondent from a large combination facility explained that “Staffing is a challenge in a lot of buildings so we certainly don’t want to seem like we are looking for reasons to fire anyone, but I think a camera being present would hold staff to a high level of accountability and reduce risk of abuse.” Less frequently noted were the potential peace of mind gained by family members and the possibility of explaining resident behaviors or showing good care to families.

Finally, 24 respondents cited the use of cameras by facilities for a range of care purposes, including the detection, documentation, or explanation of falls and the monitoring of residents in real time as a form of care. A small nursing home participant noted: “We have found the cameras to be of value when a patient is anxious or has history of rolling out of bed. The person monitoring the camera has time to alert a

CNA [certified nursing assistant] before an issue/accident happens. We use the cameras for those patients who have a risk of falling out of bed, pulling out feeding tubes, tracheostomies, etc.” Similar uses for care provision were noted by a participant from a large nursing home, who wrote, “It also can provide better checks on residents who are on 15 min checks, elopement risks [resident leaves facility without staff knowledge], etc.” Others described detection of behaviors that would not otherwise be known. For example, a participant from a small assisted living facility explained that with cameras “we were able to monitor clients sneaking foods and sleep habits.” Another small nursing home participant cited the tension between privacy concerns and the appeal of this practice from the facility management side: “We would actually prefer to have cameras installed by the facility to record resident and staff behavior but due to privacy concerns, have not.”

Unexpectedly, many of the potential advantages that participants offered were related to use by facilities, not by family and not for abuse detection/deterrence or use in formal investigations. This finding indicates that we should anticipate an expansion of camera use from family-initiated to facility-initiated for purposes like real-time resident monitoring for care provision and surveillance of staff for quality control.

## Discussion and directions for future academic engagement

These findings underscore the need for attention to the complex, normative dimensions of the growing practice of camera use, which has received strikingly little attention from researchers (Social Care Institute for Excellence 2015).

**Violation of privacy and dignity.** Concerns over threats to privacy and to dignity were the most frequent responses to the question of cameras in resident rooms. Nursing homes are a complex space for regulating privacy, because they are simultaneously public and private spaces (Levy, Kilgour, and Berridge 2019). Nursing homes are places of employment for care staff; the work practices in which staff engage are highly regulated, and institutions face liability risks for maltreatment that occurs there. At the same time, numerous intimate activities occur in nursing home rooms, including medical care, bathing, and using the toilet. Recall the comment noted in the preceding section: “Invasion of a resident’s privacy, even with a diagnosis of dementia, or whether you think they



won't know or can't understand. As a resident advocate I think that is a huge dignity issue." Some participants raised the difficulty of obtaining consent from residents with dementia, but more often, participants cited threats to dignity when privacy is invaded by cameras.

The problem of consent with dementia is well described in the gerontology literature and by Mulvenna et al. (2017) and Levy and colleagues (2019) with respect to nursing home cameras. We live in an era in which bioethics too readily collapses respect for persons into respect for autonomy, which leaves out what we owe people who lack autonomy. But respect for autonomy itself is a derivative obligation rooted in the more fundamental obligation to respect persons as persons. As expressed by participants, this obligation includes respecting the dignity of persons even (and perhaps especially) if they lack autonomy and/or awareness of how they are being treated. In fact, we are obligated to treat deceased bodies with respect for the dignity of the person who has passed away. We certainly owe people with advanced dementia respect for their dignity regardless of whether or not they are aware of how they are being treated. In addition to this non-utilitarian duty to respect persons as persons, there are also utilitarian arguments that if people see elders being treated disrespectfully, they will not trust residential care facilities in the future when they may need to receive such care.

**Reduction of fiduciary responsibility.** The second ethical issue is focused on the relationship between staff and residents. Residents spend more time with nursing assistants than any category of worker, and these workers conduct the most intimate care. Each day, nursing assistants provide a median of 2.4 hours of hands-on care per resident (PHI 2016). Surveillance of workers can send a message that they are not trusted to provide for the patient's best interests, which could erode their own sense of being fiduciaries for the residents they take care of. The point here is not to say that workers in these contexts necessarily have the right not to be surveilled. There is debate about the degree to which workers ought to have legal rights to privacy at work, particularly in environments in which safety is at risk, and we leave that avenue open to future consideration. Rather, it is to say that respect for persons is based on respecting relationships of care and that surveillance practices risk denigrating these relationships. In the worst-case scenario, practices that dehumanize workers will also dehumanize patients.

We are also not arguing that surveillance is more dehumanizing than is abuse. Rather, like many of our survey respondents, we are concerned with undermining that which enables rich, caring relationships. When we instrumentalize relationships, which camera surveillance arguably contributes to, staff members may be treated as if they are individually insignificant and interchangeable performers of functional duties of care. This perpetuates a means–ends instrumental idea of what care relationships in nursing homes are. It raises the question: What are the consequences of treating people as if they have no capacity—or are not trusted—to have a professional ethical bond to a resident? This potential for instrumentalizing relationships is most pronounced in the surveillance of workers by facilities, to which we now turn.

**Facility-initiated surveillance of staff and residents.** The third ethical challenge pertains to the very likely expansion of scope and purpose of surveillance monitoring from family-initiated to facility-initiated. Facilities may use cameras in resident rooms as a way to regulate staff in general, rather than just to detect abuse, and for real-time resident monitoring as a form of care provision. This potential ongoing use of cameras for purposes other than detection or deterrence of abuse raises especially pressing questions in the context of widespread understaffing related to both care and job quality in residential facilities.

Expanding surveillance of staff and replacing human care with monitoring arise in the ethically troubled context in which structural factors undermine empathic care in nursing homes. Direct care staff members do very challenging work for an average hourly wage in the U.S. of \$11.87 and \$19,000 annually (PHI 2016). Injury and turnover rates are remarkably high (American Health Care Association 2012; Castle and Engberg 2005; PHI 2016) and contribute to understaffing, which makes the work more challenging for those remaining staff members to pick up the slack (Wiener 2003). The use of cameras is ultimately one response to a breakdown in social structural supports for positive caregiver–resident relationships that exacerbate the institutional problem of abuse. As we discuss later in the article, compared to surveillance, the direction of resources into these gaps is arguably far more likely to humanize care.

In addition to monitoring staff, facility-initiated camera use is likely to expand to become a source of care provision, according to survey participants who wrote that facilities monitor residents for the purpose of supplementing or augmenting the care residents receive, particularly in the form of risk reduction. The

ethical issues raised by facility-initiated cameras are not actively debated in the United States (Niemeijer et al. 2010), but there is a nascent body of research on the use of cameras by facilities for purposes other than the detection or deterrence of abuse or neglect. Researchers have raised concern about the potential restriction of resident activity due to surveillance for risk reduction, and the possibility that staff remote monitoring of resident rooms through cameras will contribute to the problem of isolation and loneliness in residential facilities (Niemeijer et al. 2011). For example, Woolrych and colleagues and Robinovitch and colleagues have explored the potential use described by our participants for fall detection and comprehension by staff, as well as challenges of informed consent and privacy with this use (Robinovitch et al. 2013; Woolrych et al. 2013; 2015). Upon studying how facilities use cameras to understand how falls occurred, the researchers also note negative potential implications for staff and residents related to the disciplinary potential and parallels with processes of institutionalization (Mortenson, Sixsmith, and Woolrych 2015; Woolrych et al. 2015). The review of videos to understand the cause of falls prompted staff members to consider limiting residents' activities in order to reduce risk, such as when falling that occurs during physical play or exercise activities is analyzed. The authors caution facilities against obviating risk at the expense of resident freedom and well-being (Woolrych et al. 2015).

**Practical steps to address ethical concerns.** We suggest three next steps: empirical research, legal analyses, and health services research to substantially build the relational aspects of care in nursing homes.

First, there is virtually no academic research on the efficacy or residual effects of cameras in resident rooms as a tool to prevent or detect abuse, and the lack of research on views of residents is striking (Niemeijer et al. 2010). This gap is also present in research on facility-driven camera use for nursing home resident care. In an ethnographic study of resident experiences with surveillance technologies with people with dementia or intellectual disabilities, residents resisted the use of cameras with reports of negative feelings about being watched (Niemeijer et al. 2015). More engaged research like this is needed to learn whether real-world practices reflect stakeholder perspectives. In our view, this represents a promising area for enhanced interdisciplinary collaboration, combining empirical social science research with ethical analysis (Dunn et al. 2012).

Second, legal analysis is needed. Despite the absence of research on the effects or desirability of

monitoring cameras in nursing home rooms to detect or deter abuse, U.S. state policymakers are making decisions about how to regulate their use for this purpose. Three of the seven state laws were passed in the last three years. In 2016, Utah became the second to apply these rules to assisted living communities. These laws are being passed without the benefit of data about camera use, so it is particularly important for us to understand the range of approaches state policymakers are taking to address this issue. Given the complexity of the interests at stake, how are states balancing these factors in their policies? Are they doing so in a way that optimally protects nursing home residents? Important questions include: How are residents', family members', nursing home facilities', and care workers' privacy and other interests prioritized and protected through these laws and guidelines? Are the potential negative consequences that were identified through this survey addressed, and how?

Third, research is needed to address the economic and cultural barriers that prevent implementing better models of relational care in nursing homes. What does a better culture for relational care look like? The movement that some participants cited hopefully is nursing home "culture change." Core elements of the growing culture change movement include empowerment of staff, resident-directed care and activities, decentralized decision making, and design of homelike living environments (Koren 2010; Miller et al. 2014, 2018). One survey participant suggested implementing culture change practices as an approach more appropriate than surveillance for supporting care and safeguarding residents. The person wrote that "management of the facility should be engaged enough to see and be in tune to their staff and the staff should know the residents well enough to know what their residents needs are going to be. And they should implement the Eden Alternative program [a specific culture change program] to help do so." Consistent staff assignment to enable connected relationships with residents is one among many nursing home culture change practices (Koren 2010). Other person-centered practices aim to deinstitutionalize the nursing home experience by creating a more homelike environment where resident privacy is valued (Miller et al. 2014). Survey respondents raise important points about the potential for conflict between surveillance in resident rooms and best practices like person-centered care and culture change efforts, which are proving to be effective methods for improving care processes and outcomes (Miller et al. 2014).

## Limitations

Without a response rate, we cannot generalize these findings to facilities nationally. It is possible that respondents who had direct experience with or strong feelings about the use of cameras were more likely to complete the survey, which may skew our findings. Further, we cannot confirm that more than one respondent did not report on the same facility; however, this would not be a limitation regarding our findings from the open-ended questions, as our goal is to understand a full range of perspectives on potential advantages and disadvantages.

## Conclusion

The significant legal, ethical, and social implications of surveilling nursing home and assisted living residents and caregivers suggest that we need to engage more seriously with the ethical dimensions of this practice and conduct empirical research on stakeholders' perspectives and outcomes. The need for this level of engagement is pressing at a time of renewed attention by policymakers and an uptick in proposed bills across the country. The ethical position that has driven the practice is that family members should feel secure in the safety of their relatives. The actual security of residents is clearly the most immediate and primary aim that should be privileged in analysis, and we argue that this issue is best addressed when the full range of countervailing ethical issues is also examined. Though residents and staff are the two parties who are placed under camera surveillance, neither is likely to be a decision maker when the question of camera use arises. Policymakers, facilities, and family members thus have great responsibility for understanding how camera use might affect the vulnerability and quality of life of residents with dementia. To do this, we need research that addresses the ways that surveillance might affect residents' privacy and dignity and might promote an overly technocratic, less relational culture of care. We suggest that the ethical concerns identified here be addressed with targeted multidisciplinary research if we are to address this significant public health problem, particularly as population aging continues its rapid growth.

## Author contributions

Berridge developed and conducted the survey and conducted the first round of analysis of the data. Levy and Halpern provided further analysis and Berridge, Levy, and Halpern drafted the article.

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## Conflicts of interest

None.

## Ethical approval

This study was exempted from review by Brown University's Human Research Protection Program.

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