Forum

Towards Responsible Implementation of Monitoring Technologies in Institutional Care

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Abstract

Increasing awareness of errors and harms in institutional care settings, combined with rapid advancements in artificial intelligence, have resulted in a widespread push for implementing monitoring technologies in institutional settings. There has been limited critical reflection in gerontology regarding the ethical, social, and policy implications of using these technologies. We critically review current scholarship regarding use of monitoring technology in institutional care, and identify key gaps in knowledge and important avenues for future research and development.

Keywords: Health, Ethics, Public policy, Artificial intelligence, Health equity

Amid growing awareness of errors and harms in institutional care settings (e.g., hospitals, assisted living, long-term residential care), monitoring technologies are increasingly advocated for improving the safety and quality of care (Laplante, Kassab, Laplante, & Voas, 2018; Nosta, 2018; Senate of Canada, 2017; Zeidenberg, 2018; Zwijsen, Depla, Niemeijer, Francke, & Hertogh, 2012). Population aging, and in particular the assumption that it will make the "burden" of caring unsustainable for future generations and health systems, is a frequently cited justification in media and policy for investment in research and development of such technologies (Nosta, 2018; Senate of Canada, 2017; Zeidenberg, 2018). The discourse around the use of monitoring technologies has been dominated by enthusiasm about their "transformative potential" to improve health care quality, safety, and effectiveness of care (Laplante et al., 2018; Maron & Jones, 2018; Senate of Canada, 2017). Systematic implementation of such technologies across institutional settings promises to reduce future costs of chronic disease management (e.g., replace professionals, reduce unnecessary treatment) and thus

address anticipated deficits in human resources due to population aging (Laplante et al., 2018; Senate of Canada, 2017). Further, monitoring technologies are advocated to improve diagnostic accuracy and risk prediction, thereby enabling earlier diagnosis and improving access to treatment for older adults (Laplante et al., 2018). Yet, there have also been concerns regarding "irresponsible innovation," including that "failed" technologies may further threaten the sustainability of the health care system (Greenhalgh, Fahy, & Shaw, 2017; Kerr, Hill, & Till, 2018).

Given the potential impact of such technologies on older adults, providers, and systems, there is a pressing need to reflect on the values that underpin interest in implementing monitoring technologies, and how these values can be (re)aligned with the public good. Our purpose here is to contribute to broader efforts across critical gerontology and science and technology studies (Berridge, Halpern, & Levy, 2019; Kerr et al., 2018; Peine & Neven, 2018; Van Oort, 2019) to question dominant assumptions underpinning existing literature on monitoring technologies, and reflect on the influence of these assumptions on research, policy, and

implementation. We begin by describing common types of monitoring technologies used in institutional settings, focusing on the types of data they collect. We then critically review what is currently known about their ethical, social, and policy implications, including guidance regarding their implementation in institutional settings. In our review, we also include research from noninstitutional settings to highlight the kinds of research that may be needed in institutional settings. We conclude by highlighting important avenues for research to inform future efforts to responsibly develop and implement monitoring technologies.

Examples of Monitoring Technologies and the Data They Collect

Monitoring technologies used in institutional care settings include smartphones, wearables, and sensors embedded in everyday institutional objects (e.g., mattress, bed) that can continuously and passively collect, transmit, and process data regarding the movements, activities, and physiological outcomes of older adults. One type of data collected by such technologies is visual or image-based, generally using vision sensors (optical and infrared) embedded in cameras that wirelessly record and transmit video feeds of an environment in real-time (e.g., room, hallway) to another location. With advances in computer vision and other analytics, visual data can now be interpreted in real-time by intelligent monitoring systems that can independently take actions when an anomaly is detected (e.g., triggering an alarm to notify providers) (Coahran et al., 2018; Khan, Ye, Taati, & Mihailidis, 2018).

Monitoring technologies are also used to collect data about individuals' real-time location (i.e. their movements across space and time). This type of data is collected using different types of location sensors and technologies, including GPS, RFID, and Wi-Fi (Niemeijer, Depla, Frederiks, & Hertogh, 2015). To enable location tracking in real-time requires that a tag or chip be attached to the individual being tracked (e.g., in a wristband, clothing) and that it continuously sends out location data to the server. Finally, monitoring technologies are also used to collect "behavioral" data, which includes older adults' daily and nocturnal activities and physiological parameters (Khan et al., 2018). As with location data, to collect these data typically requires that sensors be embedded in something that is worn by, or is in contact with, the individual who is being monitored (e.g., wristband, clothing, mattress).

There is growing interest in collecting such data in institutional settings both continuously and passively using "intelligent" systems made up of multiple interconnected devices and artificial intelligence (Stark, Tietz, Gattinger, Hantikainen, & Ott, 2017). A key assumption underpinning this interest is that technological monitoring is less intrusive than traditional methods (e.g., direct observation) and that it can enable "just-in-time" intervention with more accurate and reliable collection and processing

of data (Laplante et al., 2018; Potter et al., 2017). Such technologies are referred to as "passive" because they collect and transmit data without the individuals who are being monitored having to take any action to enable collection of data or to request assistance when an adverse event is detected. One example of this type of technology involves the use of sensors that are embedded in the clinical environment (e.g., mattress, bed, ceiling) and that automatically capture motion and visual data of patients and generate alerts regarding bed exits and falls (Potter et al., 2017). While wearable monitoring technologies may engender more awareness of monitoring, current research suggests that older adults (and family members) do not fully understand how such technologies function, what data they collect and for what purpose, nor how they can impact their future care (Hall, Wilson, Stanmore, & Todd, 2017; Niemeijer et al., 2015).

Ethical and Policy Implications Identified in the Literature

Discussions of ethical implications of monitoring technologies, including guidance regarding their adoption, have largely been framed within the paradigm of the principlist approach to bioethics (Ienca, Wangmo, Jotterand, Kressig, & Elger, 2018; Khan et al., 2018; Robillard, Wu, Feng, & Tam, 2019; Yang & Kels, 2016). This paradigm emphasizes consideration of risk and benefits to individuals, with the primary goal of achieving a balance between respecting their autonomy to make informed choices and ensuring their physical safety. The dominance of this paradigm has consequently narrowed ethical reflection to utilitarian balancing of benefits and risks largely related to a perceived tradeoff between autonomy and safety (Ienca et al., 2018; Yang & Kels, 2016). For example, while explicit acknowledgment of ethical values or considerations is largely absent in empirical research on monitoring technologies, when present, it is often confined to protecting human subjects in the immediate research encounter (Ienca et al., 2018). Moreover, the requirement for such protection is perceived to be an impediment to the research and innovation progress (e.g., creating a "major bottleneck") (Khan et al., 2018, p. 830). Even when ethical reflection is extended to consider potential risks beyond the immediate clinical/research encounter, such as in the context of implementation of these technologies, individual privacy and autonomy continue to be emphasized as the main ethical issues (Hall et al., 2017; Niemeijer et al., 2015; Nilsen, Dugstad, Eide, Gullslett, & Eide, 2016; Zwijsen et al., 2012). The value of using technological monitoring to increase physical safety in institutional settings is taken for granted within ethical analyses, thus reaffirming biomedical and managerial priorities of control and risk management (Ienca et al., 2018). For example, the fact that monitoring may intrude on individuals' privacy is considered to be manageable through traditional safeguards to personal health information (e.g.,

informed consent, encryption, secure storage). This is despite recent critiques in data ethics literature that traditional criteria for human subjects protections are insufficient to protect privacy in the context of large volumes of data since they do not consider "*what is done* with the data after it is obtained" (Metcalf & Crawford, 2016, p. 7, original emphasis).

While support of autonomy is an important value for guiding ethical reflection on monitoring technologies, it is questionable whether older adults in institutional settings are in a position to refuse consent. For example, monitoring technologies are frequently targeted at persons living with dementia, but because of their cognitive impairment, they most often are perceived as lacking capacity to make decisions regarding their use of technologies. The commonly reported refusal of monitoring technologies by persons living with dementia is assumed to be "resistiveness" or "noncompliance" and is attributed to their cognitive impairment or to inadequate technological design, rather than to a valid expression of choice (Ganyo, Dunn, & Hope, 2011; Nordgren, 2018). Moreover, it is also considered to be ethically justifiable for family carers and providers to influence, or coerce, persons living with dementia in order to overcome their refusal if it is determined that the monitoring technology is beneficial to them, or is "essential for survival, health and hygiene" (Nordgren, 2018). Similarly, research with providers and family carers suggests that they may be more enthusiastic about monitoring technologies than older adults, and may even override or dismiss care recipient preferences (Berridge & Wetle, 2019; Yang & Kels, 2016). Given that a key justification for the use of monitoring technology is to replace or reduce the need for direct supervision by family carers or providers, it is not unreasonable to imagine than the bar for interference under conditions of austerity may be set particularly low. Moreover, while monitoring technologies are currently implemented on an individual basis, if these were to become standard to "usual care," or if continuous data collection was to become seen as necessary to organizational quality improvement, it is unclear whether obtaining informed consent will continue to be regarded as necessary (Martinez-Martin, 2019). There is already a precedent for this with the implementation of closed circuit video monitoring as a "fall prevention strategy" (Sand-Jecklin, Johnson, & Tylka, 2016).

There also appears to be little recognition across ethical analyses of the ethical risks posed by monitoring technologies for providers working in care institutions, and for care relationships. The limited available literature has primarily considered how such monitoring may intrude on providers' privacy based on the legal recognition that providers, like other types of employees, have a "reasonable expectation to privacy" in the workplace. In Canada and the United States, workplace monitoring is legally permitted to ensure safety, avoiding liability, and guarding against theft and property damage (Determann

& Sprague, 2011; Phillips, 2014). However, legal limits on workforce monitoring vary across jurisdictions; only some jurisdictions require that employees are notified of monitoring and/or that organizations demonstrate that there is a legitimate need for monitoring that has a benefit that is proportionate to the intrusion on privacy. For the most part, both family carers and institutional organizations perceive the risk to providers' privacy posed by monitoring as justifiable based on providers' professional duty of care; a frequent justification to the incursion on providers' privacy is that monitoring may support efforts to prevent elder abuse (or accusations thereof) (Berridge et al., 2019; Hall et al., 2017). The "nothing to hide" argument is thus used to compel providers to embrace monitoring technologies, suggesting that their desire for privacy is synonymous with their desire to engage in illicit or undesirable activities. Yet, the promotion of monitoring technologies as a "solution" to the problem of abuse presumes that individual providers are wholly responsible, which this ignores structural factors (Grigorovich, Kontos, & Kontos, 2019) that recent research has linked to violence in long-term care homes. There is also no research that supports the assumption that the use of monitoring technologies is effective for detecting or deterring abuse or neglect within institutional care settings (Berridge et al., 2019; Hayward, 2017). Moreover, with few exceptions (Berridge et al., 2019), there has been limited acknowledgment that monitoring may also pose risks beyond privacy to providers, and that it may negatively affect the quality of care or care relationships. Scholarship on workforce monitoring outside of care settings suggests that they may reinforce historic labor inequalities, prompt anxiety and fear, and added emotional labor (Van Oort, 2019).

Feminist, critical race studies, and other critical scholars in science and technology studies have proposed ethical alternatives to the emphasis on informed consent and mitigation of individual risks in regards to monitoring technologies (Benjamin, 2016, 2019; Breslin, Shareck, & Fuller, 2019; Kerr et al., 2018). Drawing on ethical values of relationality, intersectionality, and social justice, these scholars argue for the need to consider collective harms and institutional responsibility by identifying and preventing structural inequities that may be produced (or reinforced) by the use of technologies. For example, Benjamin (2016) argues for the need to structurally support the right to "informed refusal" beyond simply assuring individuals that they "can 'opt out' at any time since the latter places the onus on "already vulnerable individuals to question those in authority" (p. 5). Similarly, other scholars have suggested the need to develop participatory and "downstream" consent processes that support the education of vulnerable individuals regarding the types of information that is collected and could be inferred using monitoring technologies (Breslin et al., 2019). Finally, additional ethical protections have been proposed to enhance transparency and accountability in health care in regards to artificial intelligence more

generally, including audits of algorithmic decision making (Benjamin, 2019). Despite these promising alternatives, to date, there has been little uptake of these ethical values and considerations in scholarship on monitoring technologies, particularly concerning their implementation in institutional care settings.

While there has been less attention to policy than there has been to ethics in literature on monitoring technologies, there is growing recognition that current regulatory frameworks will be insufficient to guide systematic implementation of such technologies across care settings. For example, it has been suggested that the routine use of artificial intelligence in health care more broadly will require the development of new forms of legal and nonlegal interventions to prevent new liability risks (e.g., misdiagnosis, privacy breach), as well as structural inequities (Hoffman, 2019; Martinez-Martin, 2019; Yang & Kels, 2016). This is important because current antidiscrimination laws in the United States and Canada do not sufficiently protect individuals from discrimination by employers and others based on predictions of their future health problems (other than based on genetic information) (Hoffman, 2019). Hoffman (2019) has thus suggested that developing legal and professional safeguards similar to those used to regulate genetic testing and counseling could be useful, yet no such legislation or regulations have been developed. On a smaller scale, there has been some policy development at the jurisdictional level regarding the use of monitoring technologies in long-term care homes in the United States and Canada (Levy, Kilgour, & Berridge, 2018; National Assembly of Quebec, 2017). For example, several jurisdictions in Canada and in the United States have recently developed regulations to allow residents (and their family members) to install monitoring technologies in private rooms to capture any instances of abuse or neglect (e.g., Illinois General Assembly, 2019; National Assembly of Quebec, 2017). There has also been some development of case law in this area regarding the use of data collected by such technologies for evidence in criminal cases (Levy et al., 2018).

For the most part, policy analyses of the implications of systematically integrating monitoring technologies in the United States and Canada have been limited to existing regulations around informational privacy and data ownership (Martinez-Martin, 2019; Senate of Canada, 2017). For example, both the United States and Canada have federal laws that protect the privacy and security of personal health information: the Health Insurance Portability and Accountability Act (United States Department of Health and Human Services, 1966), Personal Information Protection and Electronic Documents Act (Government of Canada, 2000), and the Privacy Act (Government of Canada, 1985). Both countries also have jurisdictional laws in this regard (e.g., California State Legislature, 2016; Goverment of Ontario, 2004). Generally, these regulations emphasize the responsibilities of "covered entities" or "custodians" (e.g., institutions) to ensure informed consent to collect and use

personal health information and set boundaries regarding how this information is used and shared. However, such laws are generally concerned with identity theft, they operate on a complaint-only basis, and allow personal data to be used by institutions in secondary and tertiary ways without the knowledge or permission of the individual (e.g., for quality improvement). This is in contrast to the European Union, which has stricter and more proactive privacy regulations (European Union Commission, 2018); these regulations enable individuals to not only consent to the collection and use of their data, but also allows them the right to opt out and even have their data erased.

Despite the gaps identified in existing scholarship, the available research does importantly emphasize that decision making regarding monitoring technologies should be based on their relative benefits and risks. Thus, a review of the empirical research on their impact on older adults, providers, and health systems is critical to determine whether there is sufficient evidence to inform implementation.

Impact of Monitoring Technologies on Older Adults, Providers, and Health Systems

Much of the research on monitoring technologies has focused on demonstrating that these can accurately measure and store data in a simulated environment, and that with the use of machine learning and other artificial intelligence techniques, they can support precise detection of trends and patterns in the data. Little research has explored the impact of monitoring technologies on individuals and health systems in real-life settings, and thus it is challenging to determine whether they do in fact have added benefit for quality of care or health and safety. The limited available evidence comes from small scale (e.g., short term, one unit) and atheoretical evaluations; key gaps also remain with respect to the perceptions and experiences of care providers, older adults, and family members.

The most commonly cited health benefit of implementing monitoring technologies for older adults in institutional settings is the prevention of falls and other adverse events (e.g., pressure ulcers, exacerbation of chronic illness) through early detection. However, evidence of this is both limited and inconsistent. For example, a randomized control trial (RCT) (Sahota et al., 2014) found that a monitoring technology did not reduce falls or the time it took for nurses to respond to the fall of an older patient in an acute care setting. However, an observational study (Potter et al., 2017) in acute care concluded that a reported reduction in the rate of falls was the direct result of the implementation of a monitoring technology and greater provider awareness of fall risk.

Monitoring technologies are also assumed to enable greater freedom of movement and to decrease the safeguards that restrict older adults in institutional settings (e.g., bed straps, locked doors). However, here too the evidence is contradictory. Niemeijer and colleagues (2014) found that

while some individuals did experience greater freedom of movement, not all benefitted from this; some individuals became upset when getting lost in unfamiliar areas or at the withdrawal of care as a result of being permitted to walk unaccompanied by a provider. Even when monitoring technologies are implemented for the explicit purpose of enabling more freedom/reducing the use of restraints (Niemeijer et al., 2014; Zwijsen et al., 2012), providers tend to use these to supplement physical and environmental restraints (e.g., locking doors at night), rather than as an alternative. One study even found that in hospital settings, the use of a smart bed to alert providers to risk of falls led to increased restraint of patients who moved too much in bed and "falsely" triggered the alarm (Timmons, Vezyridis, & Sahota, 2019).

There is more evidence that monitoring technologies may have benefits for some older adults living with chronic disease in noninstitutional settings, including lower risk of death, readmission, reduction of symptoms of depression, and improvements in blood pressure control (Dinesen et al., 2016; Liu, Stroulia, Nikolaidis, Miguel-Cruz, & Rios Rincon, 2016; Queiros, Dias, Silva, & Rocha, 2017). The use of monitoring technologies may also enhance the freedom of movement of persons living with dementia who are permitted to go outdoors unsupervised (Bowes, Dawson, & Greasley-Adams, 2012). There is however little evidence that monitoring technologies can improve clinical outcomes, health-related quality of life, or fall prevention (Liu et al., 2016; Noah et al., 2018). Moreover, reviews of monitoring studies in noninstitutional settings consistently emphasize that there is an urgent need for research to more conclusively support claims of benefits, and to bolster providers' confidence in the clinical validity of monitoring technologies in particular (Dinesen et al., 2016; Queiros et al., 2017).

Another claim that is inconsistently supported by evidence is that monitoring technologies in institutional settings decrease the workload of providers; existing research suggests that they do not, and there is evidence they in fact can increase it. The introduction of new technologies requires that care providers learn how to use them and assume new data management responsibilities (Coahran et al., 2018; Fisher & Monahan, 2008). Providers report that monitoring technologies disrupt their usual workflow and practices (e.g., structured care routines, infection control) and that responding to triggered alarms interferes with other (parallel) activities (Coahran et al., 2018; Potter et al., 2017; Timmons et al., 2019). High rates of "false alarms" also lead to desensitization and inspire lack of trust in these technologies, both of which decrease providers' response time and their continued engagement in traditional monitoring (e.g., nightly rounds) (Coahran et al., 2018; Niemeijer et al., 2014; Potter et al., 2017; Stark et al., 2017; Timmons et al., 2019). Finally, technical malfunctioning and regular maintenance of the technologies create additional work for providers who have to not only care for

patients, but also for the technologies to ensure that they operate smoothly (e.g., resetting the system, retrieving devices that are moved, recharging (Fisher & Monahan, 2008; Niemeijer et al., 2014; Potter et al., 2017; Stark et al., 2017; Timmons et al., 2019).

Finally, the most commonly cited health system level benefit of monitoring technologies is that their use will contain or reduce the cost of care (e.g., cost-effectiveness). A common target for cost reduction in institutional settings is thus automation and decision support, with the intention of reducing or replacing the labor of providers with technologies (e.g., replacing the need for bedside observation). Yet here too the evidence is inconclusive as very few studies have been conducted on the costs of monitoring technologies, and full economic evaluations are particularly rare (Bowes et al., 2012; Krick et al., 2019). For example, Niemeijer and colleagues (2014) found that implementing monitoring technologies led to cutbacks in the number of nighttime providers. However Stark and colleagues (2017) found that the use of such technology did not reduce the level of care provided or its associated cost. In fact, they found that the level of care increased significantly in both the intervention group and in the control group.

In contrast, there is some evidence that the use of monitoring technologies in noninstitutional settings may reduce system level costs through improvements in self-management for chronic disease (Dinesen et al., 2016; Liu et al., 2016; Queiros et al., 2017). However, clear evidence in this regard is still limited. An RCT of a multimodal monitoring intervention provided to older adults living at home with chronic disease and comorbid depression was found to result in fewer emergency room visits, but did not result in fewer days in the hospital at 12 months after baseline (Gellis, Kenaley, & Have, 2014). Similarly, while one RCT found that remote monitoring at home was associated with lower rates of hospitalizations for older adults with chronic obstructive pulmonary disease (Pedone, Chiurco, Scarlata, & Incalzi, 2013), another RCT did not (Antoniades et al., 2012). Finally, a recent scoping review of economic evaluations alongside RCTs of monitoring for chronic disease management in home settings found that monitoring resulted in increased average costs per individual in six of the nine studies included in the review (Kidholm & Kristensen, 2018). The authors suggest that the added costs may be the result of the program costs associated with the implementation of monitoring technologies, as well as the lack of reduction in other types of costs (e.g., hospital admissions or use of primary care).

Discussion and Implications

Our review of the current scholarship on monitoring technologies suggests there is limited and inconsistent empirical evidence regarding promised improvements. Further, evidence that monitoring technologies may introduce new types of risks, such as disruption of care, increased workload

related to data management, and technology maintenance, may undermine otherwise good intentions with the use of these technologies. Our analysis calls into question the "transformative potential" of monitoring technologies and yields important recommendations for their future development and implementation.

There is a need to develop a more robust and interdisciplinary evidence base for monitoring technologies prior to their systematic implementation in institutional settings. This work must engage older adults, families, and care providers to understand what they consider to be key risks and benefits, and to develop social and institutional mechanisms that could be used to mitigate these risks and to build trust. It will be necessary to broaden ethical and policy reflection and development to more fully account for power and context of the intended use and added value of monitoring technologies. To this end, based on our review, critical approaches to science and technology studies seem to be a fruitful starting place for understanding and planning for how implementation of monitoring technologies might contribute to exploitation and structural violence such as involuntary compliance and discrimination.

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Conflict of Interest

None reported.

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