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Policy Commentary

Monitoring the monitors:

Medicaid integration of passive remote monitoring technology

Clara Berridge, PhD, MSW

Assistant Professor

School of Social Work

University of Washington

clarawb@uw.edu

Abstract

Implementation of passive remote monitoring is advancing faster than our knowledge base about appropriate and ethical use. For all the media and research attention these technologies are getting, there has been very little discussion about how they are positioned to be integrated into health plans, yet their integration is key to how they will be incorporated into social work practice. As coverage of passive remote monitoring technologies expands in Medicaid home and community-based services (HCBS), new policies that support informed decision-making, consenting processes, and regulations for ethical, appropriate use are urgently needed. Research translation often trails policy, but the rapid development and implementation of technologies that passively collect and transmit new information about older adults call for a more responsive approach. In this commentary, I describe passive remote monitoring technologies, their implementation in Medicaid HCBS, and ethical issues. I conclude with specific suggestions for policy and practice to start addressing these issues.

Keywords: Public policy/social welfare policy; Home and community-based services; Long-Term Care; Long-term services and supports; Technology; Medicaid; Ethics

Introduction

To reduce reliance on in-person assistance, states have begun paying for location tracking, sensors, and Web-cameras through Medicaid waiver programs, making Medicaid the first third-party payer to cover this category of technologies (Berridge, 2018). These passive remote monitoring devices collect and transmit information about an older adult that caregivers can monitor remotely. The idea is that if their location, activities, or movements can be tracked, analyzed, and interpreted, then the risks they face can be managed efficiently. But crucial financial, social, and ethical cost-benefit questions remain, such as those concerning privacy, autonomy, and informed consent and the potential, with reduced human contact, for isolation. Therein lies a dilemma. Although potential cost savings are strongly appealing to stakeholders, the ethical issues require protective policies that state Medicaid programs currently lack.

Discussion of third party reimbursement is overdue because it has significant implications for how public payers and managed care organizations will provide services to a growing older adult population and to adults with disabilities. There is a lot at stake in how we are incorporating passive remote monitoring technologies into elder care, yet the ways that these technologies may change the quality of life of older adults has been given little systematic attention (Brownsell, Bradley, Blackburn, Cardinaux, & Hawley, 2011). Research has identified significant ethical challenges, but we stop short of offering solutions that can be implemented. In this commentary, I describe passive remote monitoring technologies, their implementation in Medicaid HCBS, and ethical issues. I also suggest policy and practice changes to start addressing these issues.

Passive remote monitoring technologies

Unlike personal emergency response systems (PERS) that require the user to actively push a button, passive monitoring systems collect and transmit data about the type and frequency of activity in a home without the individual having to take any action or be aware that it is happening. Location

tracking is a common passive remote monitoring tool, and sensor-based monitoring indicates changes in behavior or movement for interpretation as a possible problem. For example, lack of movement may indicate a fall, or departures from someone's typical wake-up time may indicate a health problem. Web-cameras, ubiquitous as pet and "nanny cams," are another form of elder care monitoring that can be used passively or without awareness by those who are on view.

The risks associated with passive remote monitoring will be familiar to most social workers. The particular family conflict that alerted me to this issue epitomizes power dynamics and tensions between care and control that social workers recognize. In 2014, I met Ingrid, who was in her 90s and lived in an independent living apartment with the support of regular home aides. Ingrid's daughter described to me how she convinced her mother to agree to use a sensor system that detects movement through her apartment, bathroom, and bedroom doors as well as refrigerator use. Ingrid had been reluctant, telling her daughter, "I don't think I'd like that." Her daughter reported that other family members were "totally against it" because they felt it invaded her privacy. But Ingrid's daughter explained to her mom, "I'm thinking nursing home, or staying in the apartment," and ultimately, she proudly emphasized, "I won." After she won adoption of the sensors and realized she could track when the home aides were coming, going, and opening the refrigerator, she decided to take it a step further by installing a 360 degree Web-camera with audio so she could watch everything occurring in her mother's tiny apartment. While at work, she watched her mother through her phone. Ingrid didn't want sensors, but she ended up with a camera on top of the sensors. These conflicts and divergent priorities in resource restricted contexts will be increasingly mediated by social workers. I draw attention to the fact that these needed conversations are not mandated in current Medicaid policy and how that presents a problem for social workers.

Medicaid implementation and policy

In the U.S., a key barrier to widespread use of these technologies has been the lack of reimbursement by third party payers. But now, state Medicaid programs are expanding their coverage of technologies to monitor recipients of HCBS. The goal is to make up for gaps in human care while retaining safety and enhancing independence. This expansion of passive remote monitoring is taking place both in the developmental disability waivers and aging waivers, though it has been a more contentious issue within disability services where some provider agencies have covertly replaced nighttime aides in residential facilities with cameras in bedrooms. The use of an off-site aide who monitors live camera feeds of a 24-hour care facility is problematic in relation to safety, privacy, and dignity. Fortunately, requests for these technologies in aging waivers are more often intended to supplement rather than replace human support, but concerns remain about the potential to contribute to isolation and override beneficiaries' concerns. This emerging policy trend in Medicaid waiver programs for older adults covers devices to track beneficiaries' locations, activity monitoring sensor systems, and Web-cameras (Berridge, 2018).

A significant policy problem is that most states do not have specific service categories that allow them to track when they are paying for a given technology, and therefore State Medicaid agencies and the Centers for Medicare and Medicaid Services (CMS) are unable to recognize which beneficiaries are using a given technology (Berridge, 2018). The ways that location tracking, sensors, and cameras are categorized in administrative tracking systems in practice are confusing and nontransparent. Depending on the state, these technologies are variously placed under services categories called PERS, Specialized Medical Equipment and Supplies, Communication, Assistive Technology, Environmental Modifications, and Goods and Services (Berridge, 2018). The use of generic categories makes it impossible to discern where location tracking, movement sensors, or cameras are captured. Importantly, given the rapid transition to managed LTSS, some states have a clause that permits managed care organizations (MCO) great discretion, regarding use of sensors or cameras. This is reflected in the "Cost Effective Alternative

Services" and "In Lieu of" clauses that further obscure what's actually being paid for when MCOs manage state LTSS programs (Medicaid Managed LTSS). The implications of not tracking use for both regulation and building best practices are obvious.

Most state waiver managers and MCO representatives acknowledge potential issues such as difficulty achieving informed consent and the loss of autonomy, but many report that their offices have never discussed potential ethical issues related to these three categories of monitoring (Berridge, 2018). Some managers report difficulty balancing conflicting interests when the state gets requests from family for technologies like location tracking that may trigger anxiety for the older adult. States generally lack special consenting processes for these technologies, including Web-cameras. These stakeholders want guidance on what type of information beneficiaries want generated, with whom they want it shared, and an understanding of how to support ethical decision-making for beneficiaries with cognitive impairment (Berridge, 2018). These are all areas where social work researchers can contribute.

Could we have a serious conversation about ethics?

Gerontologists have cautioned about the use of location tracking outside of the home, activity sensors inside the home, and Web-cameras at a time when we still don't have answers to important questions: *For whom? Under what conditions? Who decides and how are people with memory loss involved in those decisions? What are the costs and benefits?* Like the policy arena, ethical issues of passive remote monitoring have been treated relatively superficially in the research literature (Ienca et al., 2017; Meiland et al., 2017; Sánchez et al., 2017; Novitzky et al., 2015; Bowes, 2012; Hoffman, 2013). Social workers and families are thus without a map to guide their decisions.

The ethical issues are significant. Passive remote monitoring may risk frequency of human interaction; threaten dignity or infantilize; threaten personhood; cause feelings of shame, humiliation, low self-esteem; lead to or increase confusion; negatively impact relationships and power relations; restrict rather than enhance freedom; override instead of promote autonomy; and cause feelings of

being controlled by the system (Alzheimer Europe, 2010). In practice, sensor systems can disrupt both behavioral and decisional autonomy, causing older adults to be hyper vigilant about their behavior to avoid triggering an alert to a caregiver. For example, someone may rush in the bathroom to avoid automatically triggering an alert to a caregiver after a designated time elapses. Paternalistic decision making processes can be used to bypass informed consent or to pressure older adults to agree to subject themselves to monitoring (Berridge, 2017a; 2017b).

It is important not to paint "age technologies" with a broad brush. Technologies have diverse implications and ethical aspects and should be examined in their specificity. For example, an assistive technology such as a self-driving wheelchair has different ethical aspects than a telepresence robot that allows a caregiver to "beam in" and maneuver around an older adult's home. And those ethical implications further differ from those of AI companion robots. Indeed, it is likely that new ethical codes will be required to manage AI-mediated services. Each of these examples collects new information, but the ways in which they mediate care and relationships may differ dramatically.

Recommendations and implications for social work

Social workers need to be aware of the complex issues at play that are not yet the subject of MSW or employee training programs. Social work principles include promoting self-determination and acknowledging one's right to risk (Dotolo, Petros & Berridge, 2018). The first practical way to avoid coercive practices around adoption decisions is for social workers to not dismiss rejection of these technologies as technological incompetence, noncompliance, or "initial" (vs. real) resistance (Loe, 2010; Neven, 2014), but rather, to understand that peoples' responses to interventions offered them are meaningful and should be taken seriously. Social workers in partnership with researchers need to learn how to engage older adults to ensure they have opportunities to understand the function of a technology and express their preferences. We must help families navigate competing preferences, consider risks and benefits, and make decisions that uphold the values the older adult cares about.

Second, evidence is needed to identify the factors associated with positive outcomes that can inform appropriate, ethical use. This requires data. Best practices should be developed for tracking state Medicaid programs' use of passive remote monitoring so that these potential data can inform practice. At a minimum, new waiver service categories are needed so beneficiary outcomes can be assessed. A few states have created technology-specific administrative service categories and can serve as models. Massachusetts, for example, has a category called "Home Based Wandering Response Systems" and Washington has a PERS+GPS modifier under the larger category, "PERS." Pennsylvania specifies a "Telecare" category for sensors (Berridge, 2018). Our ability to collect new information about beneficiaries should be regulated, and that requires that states and CMS be empowered with basic information about when technologies they are paying for are in use.

Third, clauses like the "Cost Effective Alternative Services" and "In Lieu of" clause that some Medicaid Managed LTSS programs have can obscure what states are paying MCOs for in managed LTSS. These clauses should be reconsidered to enable public oversight. Finally, consenting procedures need to be put in place to help Medicaid beneficiaries engage in decision making. This should be coupled with training about technological tools and ethical issues for support coordinators to help ensure that these procedures are meaningful.

Both researchers and practitioners must be aware of the issues discussed here given the important policy and practice questions raised by the diffusion of passive remote monitoring technologies. Medicaid trends heighten this urgency. Both the expenditure growth in HCBS (Eiken, 2017) and rapid transition of states to Medicaid Managed LTSS (NASUAD, 2017) are likely to spur greater use of passive remote monitoring technologies. Medicare reimbursement appears on the horizon. Without more applied research and advocacy by social workers, our ability to develop informed policy and practices that enable least restrictive housing without reductions in quality, well-being, or access to non-technological supports may be eclipsed by economic concerns.

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