

SCHOOL OF SOCIAL WORK

UNIVERSITY *of* WASHINGTON

Remote Monitoring Technology to Support Caregiving: Dyadic Perspectives and Ethical Considerations

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September 15, 2017

Elder Friendly Futures



Research Funding

This work was supported by grants from:

The Greenwall Foundation

The Arnold P. Gold Foundation

Agency for Health Research and Quality, National
Research Service Award [T32 HS-000011]



The larger questions

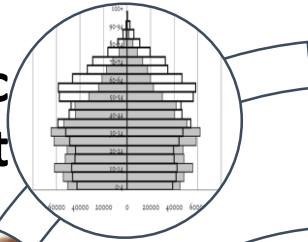
- How do we understand privacy in today's context where digitized selves, trackability, big data and predictive analytics proliferate?
- How do we ask questions about new socio-technical practices that appear to challenge existing expectations and meanings of privacy?
- What purpose does privacy serve and how do we develop policies and practices to protect it?
- How do we weigh values at play in new ways of monitoring health and safety? (dignity, autonomy, freedom, relationships)

Overview

- Insights from research in multiple disciplines
- Findings from two caregiving dyad studies (prospective and post-implementation of technology) in independent living
- Ethical issues that arise in practice
- Differences between caregiver and older adult perspectives
- The importance of comprehension in consenting to use



Demographic Shift



Increase in Chronic Conditions



Reduction in Workforce and Family Caregivers



Promotion of HCBS

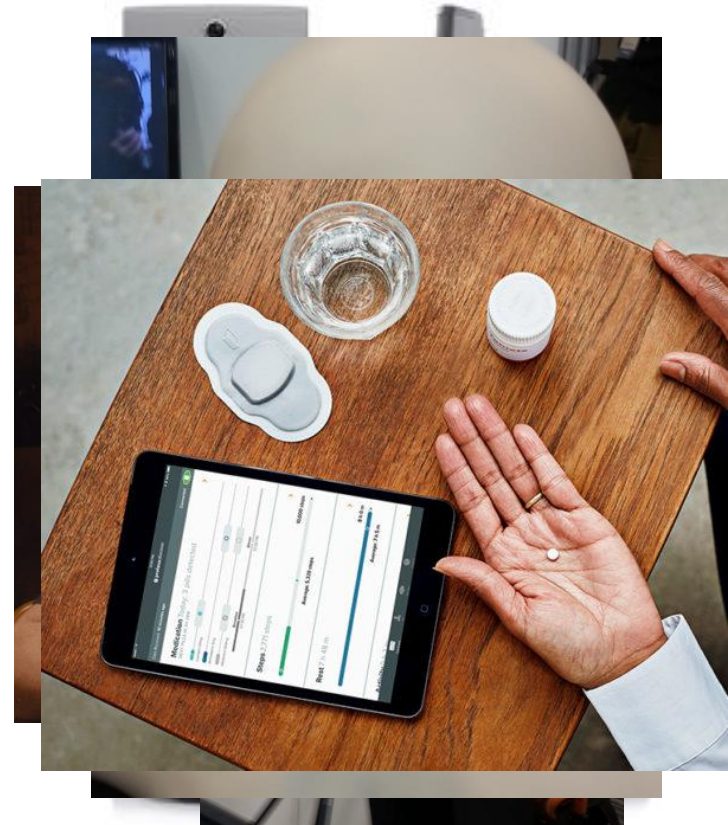


There is no such *thing* as technology

Pols, J. (2016). Good relations with technology: Empirical ethics and aesthetics in care. *Nursing Philosophy*

Gerontechnology

- smarthomes
- internet of things
- assistive technology
- wearables
- telehealth
- mhealth
- remote patient monitoring
- cognitive/behavioral coaches
- personal robots
- AI/machine learning for robotics
- ingestibles



Technology is a social practice

Basic Tenets of Science & Technology Studies (STS):

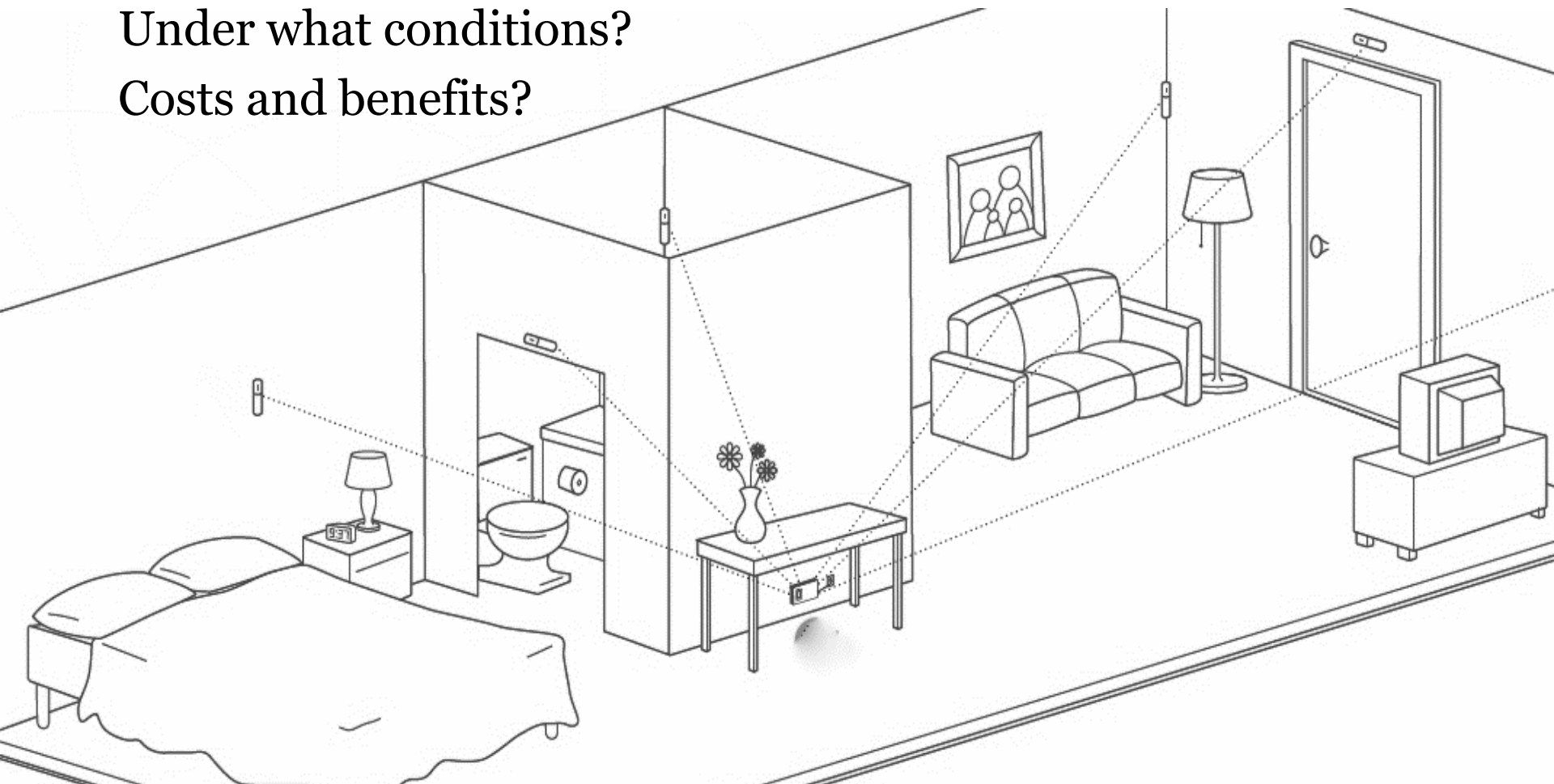
- **Technology embodies and reinforces values**
 - What values are emphasized?
 - risk management, independence, safety, privacy?
- **Technology is *profoundly* human** (Neven, 2014; Lehoux, 2008)

The Active—Passive Shift

For whom?

Under what conditions?

Costs and benefits?



Sensors: Transmission of New Information

- Time up in the a.m.
- If in bathroom for > 60 mins
- Use of refrigerator
- Apartment door motion
- # of nighttime bathroom visits
- General activity index



Nonadoption & Discontinuation

2% (23) residents adopted; 20% discontinued

- **Don't want people in their business/Intrusive/Privacy invasion**
- Caused behavior alteration
- “It's for the frail elderly” / identity conflict
- Imprecise / false alerts
- Family doesn't want to be bothered
- Residents don't want to worry children /caused children more worry
- Irritation and confusion with memory loss

Limitations to How We Treat Privacy

- Hurdle to be overcome rather than a value
- Tradeoff: Autonomy/Safety vs. Privacy
 - **Privacy's role in protecting autonomy?** (Gomez, Mantovani, & De Hert, 2013)
- Disconnect between privacy theory and applied research (Townsend, Knoefel, & Goubran, 2011; Mittelstadt et al., 2014)

What does privacy mean to you?

Older adults

- To do as I please
- To not be told what to do or how
- Do something in private - without people knowing things about you
- Being alone
- Not feeling watched

Adult children

- Feeling unrestricted regarding how you lead your life
- Not having others know your business
- Being in personal space alone
- Not being monitored
- It's individual and personal

Behavioral Autonomy

There is another case where she begged me to withdraw... whenever she went in the bathroom the ticking clock started: *Ok, 1 min. 2 min, if I don't come out in 60 minutes then my children will get the call, then they will come out!*

-Social worker

Mom started avoiding sleeping in her recliner because she was afraid it would show inactivity and trigger an alert

-Adult daughter

Behavioral autonomy

Lilly: “I wouldn’t feel good because I’d be afraid to do anything because I know the camera’s watching.”

Clara: “When you say afraid to do anything, can you give me an example?”

Lilly: “Uh, suppose I’m not supposed to cheat and I go (laughs) in the refrigerator and get something.”

Boundary Intrusion Occurs in These Moments

1) Behavior disruption (behavioral autonomy)

2) Adoption decision (decisional autonomy)

- “revisiting” decisions not to adopt
- moralizing
- ultimatums / bypassing residents to engage family

2) Caregivers know things about residents that residents don't know they know

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We Revisit

When residents say *would you recommend this to your mother*, I say yeah, but it all depends on whether my mother really wants to take care of herself. If she doesn't value herself and she's willing to fall and break her hip, then be more invalid than she is, then it's her call. So sometimes that motivates people. I say it's all up to you. How much you value yourself, how much you want to take care of yourself?

-Social Worker Supervisor

Ultimatums

“My mom said *‘I don’t think I’d like that.’* Then I explained: *‘I’m thinking nursing home or staying in your apartment.’* I won.”

-Adult daughter

Perceived ability to persuade

Adult children thought they could persuade their parents to adopt technologies that the children found useful.

This was expressed in diverse ways, from talking about the importance of “how I frame it” to “I could get her to do anything I wanted.”

Adult children expected initial resistance and eventual acceptance: “Mom would resist but I could get her to come around.”

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2) Caregivers know things about residents that residents don't know they know

- to prevent residents from connecting feelings of privacy invasion to the monitoring system
- because not all residents understood what data were collected and shared

Negotiating Boundaries on Behalf of Residents: Preventing Feedback

It depends on who the person is. If they're happy with the system I'll remind them they have it. If they're not...if they ask, 'Why are you calling anyway?' or 'Why would you think I wasn't sleeping well?' – then I'll tell them.

-Social worker

I observed a woman in the bathroom 8 times a night. I called her into my office and she came to my office and I said, 'You look pale. Have you slept well?'

-Social worker

No, my son doesn't look at that [online]. I don't want him to look at that. I don't want them to know all my business.

...I don't know, he may go online, I don't know if he can see it. Can they go online? I'm not telling them. Let them find out themselves. I don't know because no one has ever said, 'How come you went out that early?'

-Kathryn, sensor user

Shared understandings of boundaries?

The case of intimacy

“In my mind - it didn't occur - but if I had company or a friends coming over, particularly a male friend, it might bother me although they don't know there is anybody here. Do you know, do you know what I'm saying? They don't know, there could be 10 people here, there could be an orgy in the living room [laughs]. But still. It still bothers me that I'm being monitored.”

-Former sensor user, 85

“But here that would be, but that is a really big hypothetical, it would be such an outlier, but I'm not sure it would be worth saying that privacy can be an issue. I think.”

-Social Work Supervisor

Romantic relationships

“She may love someone and um, they may think, uh, she’s crazy because she loves someone at her age. It could be another woman and uh, they don’t like that.”

-Mother, Jude, 88

“There is some level of privacy that's taken away, and depending on the person, it could affect how they lead their lives or how they feel like they can lead their lives. Your life is open and exposed in a way that it wasn't.”

High likelihood of different perspectives

Mother, Jude on sensors:

“I think her children are really being good, they want to take care of her. And she [Theresa] wants them to mind their own business. I think the whole thing is terrible. She has no privacy. How many times she goes to the bathroom, when she gets up. Oh, and when she has people come in. Hm. I think that’s terrible (laughs). She’d feel like, uh, it’s the gestapo checking on her.”

Daughter, Lyn on sensors:

“My mom is very adaptable and cooperative. Yeah. She wouldn’t mind any of it. If she knew that it would be helpful to take care of, um, her and also to keep the family at ease, she would cooperate.”

Shared understandings of boundaries?

“I don't think she would feel like her privacy was going just by me monitoring her on a camera. Only if there is sound would it affect her privacy. Because then you'd know every single little thing, every phone call you hear. A camera, I think she'd feel safer. I don't think she would mind if it was just in regular rooms, not near the bathroom. I don't think she would mind. I actually thought of doing that. So I could keep an eye on - - like something happens to her, I can see. I could see if she's okay. I'm still thinking about it. We just put the little cameras in our house.”

- Daughter Melissa

“I think that my mother is entitled to a certain amount of privacy, and I think that getting back to the whole question of self-worth, to me, the more and more one feels one's privacy is being invaded, the more and more degraded some can feel. I think you can cross the line between monitoring and caring for and putting someone under a microscope, and when all is said and done, I personally would find this invasive...I mean, there is a fine line between caring for your parents and wanting to look out after them and reducing your self-worth.”

-Son, Dan on sensors

Creative & unintended use of sensors

- Someone to talk to
- Unmet need: accessible subsidized housing in home region
– isolation and loneliness
- Keeping falls private / keeping EMS away

Control over fall response

“If I call the super he will not pick me up. He will call the hospital. The ambulance would come but I don't like to go to the hospital because there's nothing wrong with me and if it's not serious they make you wait for a long time for hours. I could just move across the floor so the sensors would not know that there is no movement. That's what I think. I just scooted scooted scooted just sitting on the floor. So that's why the system doesn't know.”

-Sue, sensor user

In Summary: Examining Assumptions

The optimal technology is “unobtrusive” such that older adults don’t have to interact with it.

Individuals are not passive tech users or passive recipients of care.

Rejection or ‘misuse’ of technology by older adults can be dismissed as noncompliance, tech incompetence, or ‘initial’ (vs. real) resistance.

By examining creative use and resistance, older adults’ priorities become visible (Loe, 2015; Neven, 2014; Berridge, 2017).

Ideas challenged by researchers and industry

Older adults are a user group

One size does not fit all. Personalized, tailored, adaptable tech is critical for a diverse population with diverse, changing needs (Greenhalgh, 2015; Mynatt et al., 2015; Wherton et al., 2015; Dinesen, et al., 2016; IBM, 2016).

Plug and play and predictable impact

The impact of a particular technology is not fully predictable and cannot be imposed on top of practices, but rather, developed in context of social relations (Pols, 2016; Greenhalgh, 2015).

<https://vimeo.com/128873380>

Thank you

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