Passive At-Home Health Monitoring Systems for Older Adult Care

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Abstract

In this position paper we discuss some of the limitations that can arise with the adoption and usability of home health monitoring systems designed for older adults. This work first reflects on our research done previously which discussed how the discourse around older adult care which constrains system design continues to ignore collaborative care efforts. We then discuss how our current research, which is centred around designing a platform of sensing technologies for monitoring mobility-related behaviours of people with Parkinson's at home, aims to account for collaborative care efforts.

CCS Concepts

• **Human-centered computing → Accessibility systems and tools**; • **Social and professional topics → Seniors**; • **Applied computing →** *Health care information systems.*

Keywords

at home, passive monitoring, older adults, health, care, Parkinson's

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1 Introduction and Background

The World Health Organization defines active aging as "continuing opportunities for health, participation, and security" [36]. There are many opportunities for technological advancements to assist people with living 'actively' for longer, including 'older adults.' The growing number of digital health and assistive computing interventions has allowed older adults to self-manage their health and remain involved members of society (e.g., [33, 39]). Key et al. [20] have suggested that technologies once designed for more contained care networks for 'older adults' in institutional settings should be carefully interwoven into the domestic sphere.

Smart home technologies and other more passive health monitoring at home systems are one way to bridge caregiving and healthcare in the home for older adults. When framed within a medical model, aging focuses on deficiency or tragedy [37, 40]. As Vines et al. [45] highlight, this type of focus within HCI manifests as developing technologies for older adults that focus on risk prevention. Often these risk-averse technologies aim to keep an older adult safe through remote monitoring. As Lazar et al. [24] found when examining a teleoperated wellbeing companion designed for older adults, the "paternalist design" caused users not to engage with the technology. In their study, participants felt that interactions were asymmetrical since the teleoperator would ask personal questions but not reciprocally answer. Although the participants were the intended user audience, the design led to them stating that the technology was more suited for the "older or more sick." There is then a limitation in the framing around how home health monitoring are developed which trickles down into faulty implementation.

The faults in implementation of home health monitoring systems also arises from a lack of consideration for collaborative care efforts that occur in households in which one person is receiving care support. Specifically looking at Parkinson's and HCI research there has been the increasing acknowledgement of caregiver/patient collaboration (e.g. [22, 30, 34]). Nunes and Fitzpatrick [34] highlight the complementary perspectives of people with Parkinson's and their carers in understanding the progressive impact of the disease - the people with Parkinson's 'inside' perspective of the felt impact on their body and the carer's 'outside' perspective of the observed consequences on the people with Parkinson's behaviour. They argue that a deep knowledge is acquired through the collaborative adaptation of behaviour developed to cope with the evolving condition. Similar arguments are seen in the work of Mishra et al.

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[30] who offer a more focused look at collaborative self-tracking in support of coping and care in the context of Parkinson's. The work highlights the collaborative work of consensus building over ambiguous symptoms and the implications for every day care support negotiated between carer and people with Parkinson's. Acknowledging that the complementarity of perspectives can contribute to a singular narrative of disease progression. While such work points to the potential value that carer perspectives can bring, the concerns of the work were primarily with the ways that such combined perspectives shaped the collaborative achievement of coping and care - something not well explored by current medical measures and progression tools that share health information with clinicians.

Some smart home technologies promise to improve older adults' safety through monitoring capabilities. Often these systems are designed to allow for equally shared power over care management [23]. Whole home technology systems achieve power equivalency between live-in/out informal and formal carers through health information sharing [35]. However, as Storer and Branham [26] suggested, most at-home solutions only imitate institutional care. Moreover, HCI researchers have shown that smart home technologies can create shifts in power dynamics, leading to power imbalances [14, 32] and coercive behaviours [28]. However, understanding how the more extensive societal frame and discourse on care affects home health technologies and their users had yet to receive thorough investigation.

Butler, who coined the term 'ageism', describes it as "systematic stereotyping and discrimination against people simply because they are old" [7]. Because ageism is systemic, it can be internalised by members of a society [27], and implicitly incorporated into a design [45]. In looking at technology adoption, McDonough [27] found that embodied ageism influences the "digital divide" by encouraging older adults to be pessimistic about their abilities and underestimate the usefulness of technological devices. Furthermore, older adults might be hesitant to adopt or likely to abandon certain technologies as a form of resistance against or denial of moving towards a state of dependency [8]. Although adopting technology is often seen as a choice, expanding digital health can mean less agency over how one's care is managed [31]. Thus, for those who do adopt technology, there is limited understanding of why or how they are convinced to adopt technologies which are perhaps embodying ageist influences.

Our research on passive at-home health monitoring systems for older adult care has been exploring the different contextual layers associated with these systems. We first looked at the societal context that frames how such systems are designed, marketed, and then 'sold' to older adults as tool for health. We then looked more closely at the home context and how embracing collaborative care understanding can help the medical context. In the future we aim to explore the context of a system itself looking more at the flow of health data and the stakeholders directly impacted by the system.

2 The Societal Context that Frames Passive Sensing of Older Adults at Home

To understand the effects of the larger societal frame, we examined the discourse used during the onboarding of a home health monitoring system (HHMS) for older adults developed by a research group. We consider onboarding to include participant facing outreach (similar to marketing) materials for the system, explanations from research technicians about the system, and the initial use of the system. The system we examined was developed by a research group that was not apart of the University of Bristol. The system and its promotional materials were developed and designed without any input from us, who were asked to assess it based on overlapping interest in smart home systems and older adult care. Since this was an independent assessment separate from the research group's project, we were asked to be discreet with our description. The system records data from multiple sensors, mainly motion sensors, a sensor equipped mug, and a wearable device on the care recipient. This data is then analysed by the system's AI algorithm for patterns in, for instance, movement, fluid intake, and heart rate. Users interact with the system and analysed data insights through an application/website, a voice assistant, and the wearable. Besides minor differences in the types of sensors offered, the presentation of the system showed that its functionality was comparable to already commercially available devices. The system's overall purpose is to help with at-home older adult care management.

In our paper (published CHI '23 [10]) we explored how key terms often used to promote at-home health care systems (independence, peace of mind, and safety) are expressed and distorted by our participants' discourse during the onboarding process. In this research we examined the onboarding of one HHMS that was currently not commercially available and therefore was not known by the participants. However, the discourse used by this system was comparable to other consumer care systems and revealed potential issues in the way these systems are currently designed and promoted, and provided implications that such systems could potentially institutionalize homes.

Although it had been suggested that telecare systems can shift care network dynamics and responsibilities [32], our findings showed how quickly this shift can occur during the initial onboarding process. To show this shift we used critical discourse analysis to examine interview data [17]. By focusing on transitivity [15, 18] with our interview data, we could examine participants' behaviors before they received the system, as they were situated within the HHMS's narrative, and finally how their behaviors changed. Our findings showed that the onboarding of the HHMS did not align well with the ideologies of the participants, creating situations in which the system did the opposite of what participants felt it promised to do and shifted power dynamics.

While the system we studied (and systems like it) claim to be beneficial for all members of a care recipient's care network, the discourse in the onboarding process and participant facing outreach materials misled our participants. We observed established collaborative care networks being replaced by a new hierarchy of care that formed around the system. Those monitored had the least control, then informal and formal carers, and finally, the technologists had the most control. Aligning our findings with those of Storer and Branham which discussed how, in an attempt to distance themselves from institutional settings, accessibility and care technologies have unintentionally mimicked and adopted institutional frameworks [26] by removing power from people in care and their carers. Others have shown the importance and influence of established collaborative care networks [8, 31, 33, 39] which we observed can be disrupted early in the system adoption. Thus, our research stresses the importance of designing for collaborative care networks while also revealing novel insights into how the system's onboarding and participant facing outreach materials contributed to creating at-home institutionalization, even before the adoption and appropriation of the technology.

Our research has found that onboarding and outreach material/marketing sets expectations and should allow for transparency. This focus on balancing equity and accommodation of practices of collaboration in care is in line with the increasing body of work on "interdependence" [3, 4, 11, 38, 44]: developing technologies to support mutual reciprocity. Supporting interdependence during marketing can support decisions around adoption, use and appropriation in collaborative informal care interactions, building on recent HCI care scholarship [1, 5, 19, 39, 43]. Since the home health monitoring system affects the entire home ecosystem, not just a specific location, we found that informal carers (delineated as secondary and tertiary users by Soubutts et al. [39]) need to be more equally engaged prior to use and adoption during onboarding and within the marketing of these devices. Based on our analysis, we found that both informal carers and care recipients will not interact with the devices in the same ways, so they need to have negotiable agency over adoption and use decisions during the set-up and onboarding.

3 Embracing Collaborative Care in Passive Sensing of Aging in Place

To better ensure an at-home system for monitoring older adult health would be more conducive to collaborative care, we began work on building such a system. Our current research is part of a larger interdisciplinary research program in the UK that aims to develop a platform of sensing technologies for monitoring mobility-related behaviours of people with Parkinson's[1] at home over a long period of time, with a focus on the platform's utility to improve clinical trials of disease modifying therapies (DMTs) in Parkinson's. In our first study, we analysed how to acknowledge and include caregivers and other household members within such a platform. The research team and study participants are based across two places in the North and South of England.

In examining the role informal caregivers, we observed that they acted almost as a form of highly advanced situated 'sensor' in the home, in helping people living with Parkinson's understand and monitor their progression. Researchers have pointed out that symptoms-tracking in Parkinson's is often a collaborative effort between the person with Parkinson's and their informal carer [30, 34, 42]. Mishra et al. [30] extensively investigated the role of self-tracking technology in coping with Parkinson's. They illustrated the dynamic temporal aspects of self-tracking and how tracking helped participants to gather both explicit short term, periodic data to report to their neurologist and to cope with denial/acceptance of long-term progression [30]. They pointed out that carers also have a critical role in observing and tracking symptoms, or serving as someone to compare one's symptoms against. However, they acknowledge that further research on the different (and changing) roles of carers over time is necessary to take place to inform the design of collaborative tracking tools for Parkinson's.

Nunes and Fitzpatrick [33, 34] unpacked the dimensions of self-care for a person with Parkinson's at home while discussing the role of carers, suggesting that any collaborative care technology should support organising practical tasks, negotiating and compromising, as well as allow dynamic changes in self-care. In [33], they highlight that despite being used collaboratively since symptoms tracking tools[2] for Parkinson's are not designed for that purpose users often find them lacking. While these tracking tools allow for some forms of data sharing [13], they generally focus on one adult as the source of input. In [34] they further clarified the roles that they found caregivers to play as collaborators in care, focusing on the positive ways caregivers get involved by encouraging exercise, reminding them about medication, assisting with tasks, providing emotional support, co-adapting their lifestyle, and adapting their collaborative care activity to match progression.

While carers are considered important in the context of progressive conditions like Parkinson's, as discussed in the previous section, digital health technologies designed for long-term monitoring in the home are not acknowledging well the complex roles of the household in noticing and tracking symptoms. Moreover, while some research has explored the perspectives of people with Parkinson's on the sharing and use of their personal data accumulated through self-tracking (e.g. [21]), there is a lack of focus on data-sharing attitudes within the household and specifically for the complex context of co-tracking symptoms collaboratively where household dynamics will impact tracking and how (and if) the carer/care recipient's data should be merged.

This study specifically builds on the arguments in [34] and [30] but with more explicit consideration for tracking in the context of clinical trials which would rely on long-term implementation of a monitoring system. We examine the role informal caregivers play in helping a person with Parkinson's understand and monitor their progression as well as consider how to include caregivers in the design of a digital diary that supports collaborative reporting of symptoms. We highlight how informal carers and other household members help people with Parkinson's make sense of their symptoms and how they observe and monitor their Parkinson's progression, taking the role of Carer-as-Sensor. Based on the findings, we discuss considerations for the design of technologies to support the collaborative recording of qualitative household reporting for clinical treatment trials for Parkinson's.

In our findings, instead of focusing on how Parkinson's singly affects the person with the diagnosis, we instead look at the role caregivers play in coping and understanding symptoms. We aim to highlight the different roles of the carers in noticing, monitoring and co-managing symptoms; also addressing the role of technology where relevant as it is intertwined with the reality of tracking symptoms at home. Through our findings, we seek to explore the ways the household co-manages symptoms, how symptoms are calibrated with others, how symptoms are observed, and finally how symptoms are hidden.

3.0.1 Co-Managing Parkinson's and the Roles of Carers: Informal caregivers and family members affect how people with Parkinson's

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[1] Parkinson's more greatly affects those over the age of 65, however this research has included those with young-onset to gain a wider perspective.

[2] See for instance, Parkinson's Disease Manager, Parky for Parkinson's, PD&Me.

manage their symptoms through collaborative efforts and assisting with task completion. The following sections unpack the collaborative dimensions of managing symptoms, focusing on the different levels of assistance provided by carers, their changing role over time, and how these might contribute to or hinder the needs of people with Parkinson's.

3.0.2 Making Sense of Symptoms through Comparison with Others: Beyond everyday actions and collaborative activities that make up the mundane [33] aspects of co-managing Parkinson's, participants would also use caregivers as a means of validating that symptoms were related to Parkinson's (and not another co-morbidity like age).

3.0.3 The Roles of Carers in Monitoring Symptoms: Sometimes the person with Parkinson's can be unaware of symptoms, and so their informal caregivers and family members are necessary to track symptoms [30].

3.0.4 Hiding Symptoms from Others: While Mishra et al. [30] described 'escape-avoidance' coping as cause for people to potentially track their symptoms more positively, we found that people would not only not report symptoms but would also actively avoid others to hide them. Although there were not many instances, this would have a significant impact on the ability of a carer to provide quality observations of symptoms.

Caregivers positively impacted how those living with Parkinson's dealt with Parkinson's by promoting healthy habits and helping them monitor their symptoms. Our participants relied on others to help with completing tasks and understanding their symptoms through comparison to others, using their Carer-as-Sensor. While our participants mostly viewed their relationships with others positively, this could lead to negative impacts on oneself. Participants could prioritize household needs over their health with not taking medication or risking a chance of falling, or even avoiding being around others to prevent their Parkinson's being on display to reduce caregiver burden.

When considering collaborative care environments in HCI and CSCW, the focus tends to be on maximizing care benefits, supporting communication, improving physical and mental health, and helping interpersonal relationships (e.g. [8, 34, 39]). However, in the context of clinical trials hoping to develop new medical therapies or medications, instruments that promote behaviour change can bias or invalidate the data. Guidelines for developing Patient Reported Outcome (PRO) instruments are thus useful for ensuring the measures are accurate and beneficial, and importantly standardized and limited in their impacts on behaviour. However, no guidelines currently exist for Observer Reported Outcomes (ObsRO) [29].

However, our Findings show how caregivers play a key role in noticing and understanding Parkinson's symptoms. The inclusion of ObsRO measures in conjunction with PRO measures can be valuable as this will provide data assessors with both an outside and inside perspective on the effects medications or therapies are having on the person with Parkinson's.

4 Future Work

Besides not being well designed to consider collaborative household care, ensuring privacy and security of home monitoring systems for health is properly understood and designed for also needs further attention. Already researchers have found that users of such technologies are known to overlook privacy concerns related to 'dataveillance' if they believe that the data is essential to themselves or trusted others such as family members or clinicians [12, 25]. Researchers have also found that users desire unobtrusive devices [6, 12] and allow for relatives to observe each other in a "friendly" manner [16]. While these preferences are seen across users, older adult users are more likely to adopt monitoring technologies to benefit or appease others than to gain agency over their own health care [6, 12]. They often cannot gain agency because the data is presented without enough context, or it is not considered relevant or useful [12].

The lack of understanding of systems is further complicated with the greater application of AI into home monitoring systems for medical purposes. Designing around data governance from a patient perspective has been one way to include patients in the development of Medical AI particularly if the data is to be used in clinical trials. Kulkarni et al. [21] found that patients with Parkinson's were concerned about how pharmaceutical companies would monetise off their data in the case of clinical trials. Participants also worried that after consenting this could place them in a powerless position if a corporate takeover occurred and ownership of the data changed hands. They found that cultivated trust through time, effort, transparency, and assurance was needed for participants to want their data to be included in the development of Medical AI. As Tahaei et al. [41] found in their systematic review of Human-Centred, Ethical, and Responsible AI research, to gain trust and acceptability of the target groups from which one is taking data, efforts need to go beyond simple explanations, and development should include target users. However, inclusion of patients along with clinicians can be difficult as industry leaves little time for extensive user testing often forcing a choice between the two [46]. But by including both patients and clinicians in co-design, Ayobi et al. [2] found that this helped data scientists to better anticipate the potential harms an ML model could cause to relevant stakeholders. Thus, further exploration into how to guide the design of Medical AI to include more easily patients as well as clinicians is needed.

We believe that for end users to fully understand a monitoring system and how it has been designed with their privacy in mind they should be more involved in the development process of the AI back-end of such a system. In the next phase of our Parkinson's focussed research we plan to conduct co-design workshops to translate the user requirements of stakeholders (people with lived experience of Parkinson's, clinicians, pharmaceutical representatives, and engineers) into concrete specifications for the design of the data fusion to produce clinical outcomes. We believe that by including various stakeholders in the Data Life Science Cycle will help to ensure that we are able to build a sensing system that is ethical and captures the highest quality of data that ensures end user trust in AI outputs.

5 First Author's Background

While my most recent work as a Research Associate at the University of Bristol has focused on at-home monitoring, my masters and PhD work explored community inclusion of people living with dementia. My PhD thesis took a design approach to explore the complex social concept of interdependence and how it could shape technologies to support people living with dementia – and specifically looked at supporting social interactions in community spaces. To situate my design work, I aimed to identify the structures around social programs for people living with dementia that occurred in community settings. To understand interdependence in the context of social programs I needed to expand the existing interdependence framework to incorporate contextual or organizational interdependencies [9]. I then conducted a long-term community-based participatory design study with members of the dementia community in Bristol, UK. This process allowed me to identify the value of this methodology in discovering opportunities for designing in positive interdependencies. Furthermore, this research helped me to inform and filter the design space around developing technologies which could help support positive interdependencies. Through a filtered design space I developed a set of design requirements which I then used to develop and test a prototype with members of the dementia community. This test demonstrated the efficacy of our design requirements by facilitating participants to interdependently move around a community space. Finally, my thesis aimed to highlight the current limitations of our understanding of interdependency as a concept and the further research needed.

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