

Independence for Whom? A Critical Discourse Analysis of Onboarding a Home Health Monitoring System for Older Adult Care

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Home health monitoring systems (HHMS) are presented as a cost-effective solution that will assist with collaborative care of older adults. However, instead of care recipients feeling like collaborators, such systems often disempower them. In this paper, we examine the dissemination, onboarding, and initial use of an HHMS to see how the discourse used by developers and participants affects users’ collaborative care efforts. We found that the textual information provided often contrasted with how our participants managed their care. Instead of providing participants with ‘independence,’ ‘safety,’ and ‘peace of mind,’ care recipients were placed in a more dependent, less proactive role, and care providers were pressured to take on more responsibilities. We position HHMS, as they are currently marketed and onboarded, as normalizing pseudo-institutionalization. As an alternative we advocate that the discourse and design of such systems should reflect and re-enforce the varied roles care recipients take in managing their care.

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

Additional Key Words and Phrases: critical discourse analysis, onboarding, older adults, accessibility

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1 INTRODUCTION

The World Health Organization defines active aging as “continuing opportunities for health, participation, and security” [75]. 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 [2, 16, 73]. Key et al. [54] 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.

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 [58]. Whole home technology systems achieve power equivalency between live-in/out informal and formal carers through health information sharing [74]. However, as Storer and Branham [63] 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

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imbalances [38, 70] and coercive behaviors [67]. However, understanding how the more extensive societal frame and discourse on care affects home health technologies and their users has yet to receive thorough investigation.

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. We examine the discourse used during entry interviews, observations of research technician explanations, and retrospective interviews using critical discourse analysis. Examining an HHMS onboarding process allowed us to see how participants' discourse changed from before they received the system, after being introduced to the system, and finally through their initial reactions once they used the system. The system we examined records data from multiple sensors, such as motion sensors throughout the home and a wearable device on the care recipient, and interacts with the users through a digital dashboard, a voice interface, and the wearable. The system's overall purpose is to help with at-home older adult care management.

This paper explores 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. We examine the onboarding of one HHMS that is currently not commercially available and therefore was not known by the participants. The discourse used by this system is comparable to other consumer care systems, revealing potential issues in the way these systems are currently designed and promoted, and providing implications that such systems can potentially institutionalize homes. Our research also provides an example of how HCI researchers can use critical discourse analysis to examine not just literature [63] or advertising [4] but the whole onboarding process. Finally, we also build upon Storer and Branham's [63] work by encouraging researchers and designers to critically examine societal influences by laying bare potential consequences if a device is incompatible with the complex social dynamics of care.

2 BACKGROUND AND RELATED WORK

2.1 Medical Model and Ageist Frameworks

When framed within a medical model, aging focuses on deficiency or tragedy [82, 90, 91]. As Vines et al. [99] 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. Storer and Branham [63] have suggested that medical model-based designs can lead to a power imbalance between the carer and care receiver. As Lazar et al. [59] 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." Thus, designing technology based on the medical model can perpetuate ageist stereotypes, which suggest that successful aging means not displaying "frailty and decline" [82]. Since focusing on the positive is advantageous [20], positive language is more prominent in marketing and onboarding, however within HCI little attention has been paid to the consideration of how promotional materials and onboarding potentially serve to disguise design limitations, improperly set expectations, and impact overall user experience.

Butler, who coined the term 'ageism', describes it as "systematic stereotyping and discrimination against people simply because they are old" [23]. Because ageism is systemic, it can be internalised by members of a society [66], and implicitly incorporated into a design [99, 101]. In looking at technology adoption, McDonough [66] 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. In their study of self-management of health in a Continuing Care Retirement Community, Caldeira et al. [24] found that older adults resisted certain health monitoring activities because they were a reminder of their aging. Additionally, Pena et al.'s [10] interviews with older adults suggest that resistance to adopting technology is a form of protest. The older adults in their study viewed technology as a tool to keep them from engaging with society. Although adopting technology is often seen as a choice, expanding digital health can mean less agency over how one's care is managed [69]. 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. Butler, who coined the term 'ageism', describes it as "systematic stereotyping and discrimination against people simply because they are old" [23]. Because ageism is systemic, it can be internalised by members of a society [66], and implicitly incorporated into a design [99, 101]. In looking at technology adoption, McDonough [66] 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. In their study of self-management of health in a Continuing Care Retirement Community, Caldeira et al. [24] found that older adults resisted certain health monitoring activities because they were a reminder of their aging. Additionally, Pena et al.'s [10] interviews with older adults suggest that resistance to adopting technology is a form of protest. The older adults in their study viewed technology as a tool to keep them from engaging with society. Although adopting technology is often seen as a choice, expanding digital health can mean less agency over how one's care is managed [69]. 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.

2.2 Marketing Technology to Older Adults

While the effects of the entire onboarding process have received little attention, researchers have examined how discourse in marketing and news articles affects older adults' pre-perceptions and expectations of technology. Fuchigami et al. [37] found that news articles reiterated medical model and ageist narratives by positioning the consumption of assistive technology (AT) as the way to maintain independence for low-vision older adults. In contrast, they also found that a few news articles discussed how ATs could hinder an older adult's independence and safety since stigmas associated with the AT could make them a target for crime (such as theft) or cause them to avoid using them so that they will not look "old" [36]. This suggests that narratives about a device before adoption or use can shape how older adults and other users/stakeholders perceive it and interact with it; how this interaction is shaped is less documented.

While news articles seem to want to encourage older adults to purchase assistive technologies, overall, advertisements reinforce technology as being for the young [78]. Persaud, Grauerholz, and Anthony [78] investigated representation in video advertisements for assistive technology and discovered that they "perpetuate harmful cultural scripts" and often do not even depict older adults interacting with the technology when featured in an advertisement. Furthermore, Xi, Zhang, and Ayalon [104] found that comparing older versions of technologies to newer upgraded versions in advertisements helped sustain negative self-stereotypes older adults held about themselves and increased feelings of technophobia. Their research further suggests that the discourse and imagery for framing and marketing technologies can potentially be off-putting for older adults. Vermeer, Higgs, and Charlesworth [97], in investigating advertising for surveillance technology for older adults living with dementia, found that often higher external systems, like media

representation, directed the discourse. Beyond discourse being shaped by the dominating medical model and ageist frameworks, governmental agency agendas to promote 'aging-in-place' as a means of cost saving also came into play [71, 79, 97]. This meant that the discourse surrounding surveillance technologies, while promoting safety for older adults living with dementia, did not address older adults. By leaving older adults out of the marketing narrative, technologies often do not reflect the complexity of care networks, leading to acceptance and adoption issues [88, 89]. This suggests understanding these pre-perceptions and expectations is still needed.

2.3 Home Monitoring for Care

Although before 2019 people's acceptance and willingness to be monitored had been documented by the HCI community [19, 32, 46, 55, 61], since the COVID-19 pandemic, home-monitoring systems have emerged as a potential affordable at-home care technology. Often participants will 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 [32, 61]. Researchers have also found that users desire unobtrusive devices [19, 32] and allow for relatives to observe each other in a "friendly" manner [46]. 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 [19, 32]. They often cannot gain agency because the data is presented without enough context, or it is not considered relevant or useful [32].

Current commercial technologies designed to assist with at-home care monitoring available at the time of writing seem to have responded to the results of these findings. For instance, in 2021, Amazon introduced the Alexa Together service to US markets as part of its Care Hub [6]. This service would allow live-out family members to unobtrusively support and monitor their older adult relations through that loved one's Alexa device. Additionally, the service would also allow the user to call emergency services. The service's overall purpose is to help coordinate care and not monitor specific aspects of a users' health. In the UK, more health-oriented products like Lilli Technology also allow unobtrusive monitoring with discreetly placed sensors that track a user's behavior [60]. The behavior data is then collated into a web or app dashboard accessible by care practitioners, the user, and the user's designated friends and family. The goal of such health-oriented devices is then to provide more proactive, preventive monitoring services. Since preventative care can create savings for the UK's National Health Service (NHS) and city council provided services like occupational therapy, a local UK city government began piloting the use of Lilli with residents who are already receiving some form of social care [62].

In theory, these systems seem to follow a medical model of care by ensuring things like 'independence', 'peace of mind', and 'safety' by allowing care providers and receivers to share secure access to health monitoring data equally. These systems acknowledge the complexity of care [46, 85] by allowing various stakeholders to share in monitoring and management. While HCI researchers have examined how technologies, including smart home and voice assistant technologies, for coordinating care [11, 26, 38, 43, 65, 85] can affect care relationship dynamics, few have looked at how these relationships are affected by the discourse around these specific technologies and during the onboarding of such technologies [33]. This includes the rapid expansion of voice assistants as accessible interfaces, and their increasing use as part of care ecosystems that permeate care relationships and the wider household [56, 89]. In this paper, we will examine how the medical model and ageist terms are manifested during the initial use of a home health monitoring system.

3 METHODOLOGY

To examine the ramifications of onboarding discourse, we used critical discourse analysis [21, 34] to understand how the onboarding of a health monitoring smart home system that included a voice-activated assistant is perceived by older adult households. The system we examined was developed by a research group unaffiliated with the authors. The system and its promotional materials were developed and designed without any input from the authors, 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 analyzed by the system’s AI algorithm for patterns in, for instance, movement, fluid intake, and heart rate. Users interact with the system and analyzed 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, such as Lilli and Alexa Together (see figure 1).

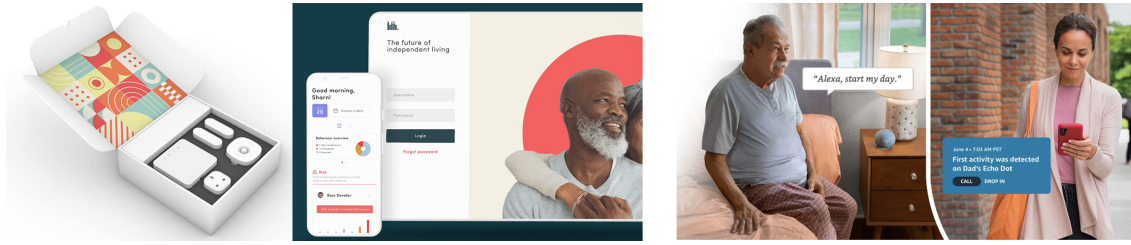


Fig. 1. Systems such as Lilli [60] place sensors like motion sensors around the home with an associated application that produces data insights and interactions by a carer or family member, while products like Alexa Together [6] rely on a centrally located or multiple voice assistants to allow with family members to assist care recipients, but do not analyze data to establish patterns. The system we analyzed was comparable in that it monitored patterns, allowed for voice interaction, and allowed carers to assist from afar. Amazon and all related images are Trademarks of Amazon.com, Inc. or its affiliates.

During our study, onboarding involved an initial meeting with a technician who would follow a script to discuss user needs and choose sensors, then with the kit participants received a system overview and a how-to guide about the voice assistant, and finally, users could email or phone the group for additional technical assistant. Initially, textual data, such as the HHMS research group’s website content, system overview, and how-to guide about the voice assistant, were examined to understand the ideology behind the design as influenced by medical and ageist framing. We then compared the discourse around the HHMS studied to systems with similar target users, e.g., Amazon and Lilli, to determine key terms used to describe home health monitoring systems that incorporated informal carers as part of the care management network.

Additionally, eight participants (five households) were recruited for three interviews and an observation session to investigate their expectations, experiences of engaging with the research group’s technicians, and perceptions after the initial use of the system in their homes. Four participants were also asked by the research group to participate in a feedback session which the first author also observed.

4 RECRUITMENT

Five households were recruited with at least one older adult aged 65+ living with a chronic health condition (see Table 1, all names are pseudonymized, all identified as white). Up to three additional adult (18+) members of the household

could also be involved in the study (the maximum number that the researchers could financially reimburse for their time) and included people such as the person's spouse/informal carer and one participant's live-out adult daughter who provided care remotely.

Our study was advertised to prospective participants through mailouts via a local city council in the UK and through an online recruitment website. Interested participants contacted the authors via email or telephone as provided in the study information materials mailed out or advertised on the website. Once potential participants had the chance to discuss the study with the authors, they were provided with online informed consent documentation (participant information sheet and consent form) to read through and complete before data collection started. This research received institutional ethics (IRB) approval from our university. All participants were reimbursed £10 in shopping vouchers for each interview they completed (up to one hour), and the household was further compensated through an offer that they could keep the system at the end of the study.

Pseudonym	Age	Interviews Present At	Gender	Role
Alice	82	Entry (E); Onboarding (O); Initial Use (IU); Technician Follow Up (F)	Female	Care Recipient with formal carers (not interviewed)
Ben	76	Entry (E); Onboarding (O); Initial Use (IU); Technician Follow Up (F)	Male	Care Recipient
Beth	NA	Entry (E); Onboarding (O); Initial Use (IU)	Female	Informal Carer/Spouse of Ben
Carl	69	Entry (E); Onboarding (O); Initial Use (IU); Technician Follow Up (F)	Male	Care Recipient
Carol	61	Entry (E); Onboarding (O); Initial Use (IU); Technician Follow Up (F)	Female	Informal Carer/ Spouse of Carl
Diane	66	Entry (E); Onboarding (O); Initial Use (IU);	Female	Care Recipient
Daniel	NA	Entry (E)	Male	Informal Carer/ Spouse of Diane
Dana	NA	NA	Female	(Once a week) Informal Carer/ Daughter of Diane
Elizabeth	96	Entry (E); Onboarding (O); Initial Use (IU);	Female	Care Recipient with no formal or informal carers

Table 1. List of pseudonyms for participants.

5 INTERVIEW PROCEDURE AND DATA COLLECTION

Three semi-structured interviews, observation of the onboarding meeting with a HHMS research group technician, and the observation of a follow-up feedback session with the HHMS research group were conducted. Semi-structured interviews allowed for in-depth conversations between the first or second author and each participant over the telephone or via videoconferencing (Zoom or MSTeams). Participants were sometimes interviewed individually or together, depending on the participants' preference at the time of the interview. Interviews lasted up to 1 hour, with the shortest being 26 minutes, totaling 15 hours 43 minutes. Interviews were recorded and transcribed verbatim after each interview took place.

Observations of the pre-installation onboarding interviews allowed us to determine the households' expectations about the device and how they hoped it would help with their care (E)¹. After this interview, the participants had an onboarding session with a HHMS research group technician. Immediately after the onboarding session, participants were interviewed by the first or second author to gauge if their expectations had changed or if they had any additional thoughts about the devices or explanation (O)². Within three weeks, participants received their system in the mail and installed it on their own. Once the system was set up and participants had used it for at least a week, an "out-of-box" post-install interview was conducted by the first or second author. The post-install interview provided us with insights into whether participants felt their expectations were being met and if they understood the use and purpose of the devices (IU)³.

Observation of the participants' initial onboarding interview and, sometimes, a follow-up conversation with a research group technician were observed and audio-recorded (F). These onboarding conversations were transcribed verbatim. Further, the language used in the HHMS research group's participant facing outreach materials (their website (W) and information pamphlet (IP) on the HHMS) was analyzed to uncover the dialectic between written promotion and how the participants interpreted the system's functions.

6 DATA ANALYSIS

Data analysis was influenced by the critical discourse and interpretive framework designed by Burnett et al. [21]. The 'critical' approach was chosen as it would allow the authors to examine the intersubjectivity [83] that is woven between the overarching medical model and ageist framing and how this dominant discourse influences the dialogue created between the HHMS research group and system users. Discourse analysis was chosen to show if the language used during onboarding influenced or changed the participants' language in any way.

The interview text served to examine how the ideology surrounding the HHMS was interpreted and influenced system perception and the subordinate discourse [64]. After careful reading of the interview data, and as part of the critical discourse analysis, the first author decided to focus on coding for transitivity [45, 50] since according to Halliday [45] transitivity "enables human beings to build a mental picture of reality, to make sense of their experience of what goes on around them and inside them" (p101). Coding for transitivity involved identifying verbs and the point of view used by participants and categorizing them into one of the six processes outlined by Halliday (Material, Verbal, Mental, Relational, Behavioral, Existential) [45]. Focusing on transitivity with the interview texts allowed the authors to translate codes into understanding how participants constructed their environment and relationships before and after the health system was introduced into their homes.

After an initial analysis of the language used on the HHMS website and through other text materials, we concluded that the discourse used throughout the website and materials indicated that it was being promoted more towards informal carers and older adults since devices for formal carers center on cost and timesaving [17, 25, 31]. We then compared the phrases and language used by similar systems [6, 60] to determine the prominent terms/themes used. First, we looked at frequency of words and then thematically grouped those with less frequency. 'Independence' on all the sites analyzed was prominent on each home page, and it was prominent in our qualitative data corpus, so it was pre-selected as a deductive theme. On the websites, fall prevention came up frequently (as other researchers have noted e.g., [97]), but the website also repeatedly mentioned using the system for preventative care. Since many of care

¹What devices do you own? Do you share any technology in your home? Do you currently use any technology to help manage your health and wellbeing?

²What are your impressions of the system? Do you think all your questions were answered?

³How confident do you feel using the system? How did you find the system set-up? Do the devices give you peace of mind?

systems advertised were collecting large amounts of health data, privacy and data protection were terms that were also prominent on the websites. We concluded that these collectively dealt with the higher-level issue of ‘Safety,’ our second theme. Discourse also included repeated mentions of aspects of supporting/monitoring from a distance and life getting in the way of care responsibilities, so we concluded the onboarding also focused on the mental toll that informal caregiving can take [42, 43], with the offer of ‘Peace of Mind,’ our third theme. Thus, our findings are framed around these three prominent terms from the care lexicon: independence, safety, and peace of mind.

7 FINDINGS

In each subsection, we first discuss how the terms of ‘independence,’ ‘safety’ and ‘peace of mind’ have been used to influence the dominant discourse created through the system design and participant facing outreach materials of the HHMS. We provide an in-depth examination of the effects of the dominant discourse on the subordinate discourse used by a participant. With this we demonstrate how each term took on a new meaning for the participants after the system was introduced to them. Finally, we compared the experiences of our participants to summarize the effects of initial onboarding and use on older adult participants.

7.1 Independence

7.1.1 The Role of Technology Within Established Views of the Independence/Dependence Binary. The UK care narrative focuses on the positive-negative continuum of independence versus dependence. The economic cost of care is one way this binary is demonstrated. Older adults must be strategic about spending their money to stay independent. *"We haven't got loads of money to splash about. On the reverse side, is that we can't get anything off the state. We have to virtually pay for everything"* (Ben, E). Older adults unable to access limited public care services are left with two main options: spend their savings until they are dependent on the government or depend on unpaid, informal carers [79]. Technology, in current discourse, is hailed as a cost-effective solution that can stall governments from being overwhelmed with dependents [25, 31, 62] and reduce the amount of effort required by informal carers [18, 30, 59].

Unsurprisingly, the term ‘independence’ was found in multiple places on the HHMS research group’s website and similar commercially available HHMS websites too: *"Combines everything you need to empower older people to keep their independence at home"* (W p1). As Haak et al. [44] found for older adults, living at home is closely linked to feeling independent. However, by associating ‘independence’ with ‘keep’ and ‘home,’ the website discourse enforces the idea that dependency is the same as loss of agency. While the connection between ‘independence’ and ‘home’ is often positively thought of as ‘aging in place’ with technology helping this be achieved [24, 59, 89], by framing technology as a tool for agency, it becomes a necessity [10]. Our study participants acknowledged how technology helps them manage their care needs. However, our participants only viewed technologies that assisted their mobility, such as electric wheelchairs or stairlifts, as necessary for their independence. As Alice summed it up, other technologies exist as something *"that's beside [her] all the time"* (E).

7.1.2 Ben and his wife/informal carer Beth. In our study, we saw that participants considered non-mobility related technology as tools to give them ownership over their own care and wellbeing. However, we found that there was a distinction between individual and collective ownership with our participants. For all our participants, care technology was discussed in terms of individual ownership, while care management was discussed as a collective activity in which those collaborating had equal ownership. Ben acknowledged, *"I have sleep apnea. So, I have a C-PAP machine"* (E),

referring to his condition and device using the individual first person, "I". Yet, when discussing the C-PAP machine's set-up and use, Ben and Beth speak in the collective first person, 'we'.

Ben: The [machine] I've got now will transmit the data direct to the hospital. But we haven't managed to do it yet. For some reason or other –

Beth: We've tried, but it doesn't seem to be working. (E)

The collective approach to care management meant that after being introduced to the system, Ben did not focus on how it could help him be more independent from Beth. After using the system, Ben and Beth experienced some loss of independence over their care management since they had to continuously rely on the HHMS research group to use the system. While the research group wanted to provide information that was appropriate for individuals who were not 'tech-savvy': "*no need to be tech-savvy to install the system*" (W p3) their explanations were sometimes seen as lacking detail, aligning with current societal views of older adults not being tech-savvy [10].

Ben and Beth found that having to rely on the research technicians was contradictory to the collective approach they normally took when issues arose around care management. Ben complained that the instructions provided were not comprehensive enough and thus required dependence during set-up:

"I think the instruction leaflet, now I'm reasonably compos mentis, and I can read. And if there's anything I don't understand medically I'd put over to [Beth] and she can read and she can interpret what we have to do [...] But, I felt it fell short on a lot of information that it could have given me, quite simply, because if I'd have that information I wouldn't have needed [the research technician] but I did." (IU)

Ben usually takes on the role of the expert in technical matters, while he sees Beth as the medical expert since she is a retired nurse. Thus, the limited instructions disempowered Ben and took away the part of his care management that he was normally responsible for. Given Ben's background as an engineer, he felt that the instructions assumed it was unimportant for the users to understand how the devices functioned. The decision to exclude such explanations felt paternalistic to Ben in assuming that users only needed to know the basics.

Besides excluding certain explanations, some design decisions also limited users' control causing them to have to reach out to the HHMS research group. Ben had difficulties getting his watch to connect with the charger but felt dismissed by the company when he reported that he could not charge the watch. Instead of considering that the watch was faulty, technicians kept repeating how to charge the watch. Ben, insulted that the technicians were not validating his complaint, states his credentials in frustration to prove his knowledge of technology:

"Either I've got a faulty watch that won't charge for some reason or... Alright, I might be a pensioner, but I am also an engineer. An electrical engineer at that. I should be able to just get those two contacts together. I'll give it another go, but if I can't charge that watch [he whistles, low to high] back it goes." (F)

Thus, the assumptions of users' abilities with technology caused once unnecessary and non-existent dependencies to emerge for our participants and gave the tech company a more important role in their care management.

Besides forming a power dynamic between the users and the research group, the system also caused the care recipients to become more dependent on their carers. While the discourse used in the text and onboarding information provided to participants was ambiguous at times, the assumption that the carer is more in charge of the system was clear to our participants. Ben even stated, "*the instructions are written as [if] for a carer.[...] So, it has to be a carer that is going to be doing everything*" (IU). This need for greater dependency on carers further eroded the more collective

approach our participants took towards their care management. Thus, he and Beth expressed confusion over how the system would allow someone receiving care to be more independent.

Ben: I think somebody with Alzheimer's wouldn't make head or tail of [accessing and comprehending the dashboard] anyway.

Beth: But I also think even somebody – and I'm just trying to think – elderly people that are fairly compos mentis, would have difficulty doing something like that. (IU)

In their opinion, without the technical ability to log in and set up the dashboard, a user would have to be dependent on someone else to give them access to their data. Meaning the system forced care recipients to rely more heavily on those supporting them, disempowering them from living independently.

7.2 Safety

7.2.1 Trust and Balance Between Care Recipients, Providers, and Technologies are Key for Preventive Care. The website described HHMS 'safety' features as being "ready for [care] emergencies" (W p1) and able "to prevent unsolicited access [to user data]" (W p3). To prove credibility and authority, the HHMS research group assured potential users of their system's data safety by citing that they met specific ISO and GDPR standards. The discourse used in the HHMS website attempted to mitigate distrust by reassuring potential users of the system's security. However, the 'criteria' being met were not fully explained beyond listing the standards. In other smart home literature, it has been shown that authoritative jargon can intimidate users from seeking clarification of jargon, even if the intent is to prove trustworthiness and security [22].

During the onboarding sessions, we observed that no participants questioned how the HHMS research group would use or store their data. When asked, Carol referenced the UK's NHS and justified the need to share data with health providers: "I think with the health service, I suppose it's beneficial for us for ongoing support, isn't it?" (E). This aligns with the current narrative told to health care providers that they should trust AI systems to accurately track and proactively capture changes in patient behaviors [6, 58, 60, 106]. Proactivity is stressed in care management discourse since it mitigates risks and gives patients a sense of security or safety in maintaining good health [51]. In line with Lupton's research [61], we also found our participants construed that not sharing one's data was viewed as not being proactive with one's care.

However, the discourse on HHMS' website was ambiguous about whether it is the carer or the care recipient who is supposed to be proactive about using the system for care management. In the introduction on the homepage, the care recipient was actively encouraged to "better manage their own [care] needs" (W p1). However, the discourse elsewhere on the website made it unclear who the active user was, or placed the care recipient in a passive role. For example, by not saying who will be enabled to take "proactive measures to prevent emergencies" (W p1). Yet, other discourse suggests that protective care actions are the role, and indeed the responsibility, of the carer: "[the system] keeps an eye on your loved one [...] to keep you aware" (W p1), with the word 'keep' suggesting control or having custody over something [68]. Therefore, the system's outreach material suggested that there is an imbalance between carer and care receiver regarding care management.

7.2.2 Elizabeth. While some imbalance was seen through the shared care practices our participants used before they acquired the system, the care recipients had relatively active roles in maintaining and monitoring their health safety. At the time the study began, Elizabeth was asked by her doctor to monitor her blood pressure, and since she lives alone with no formal carers she "got a machine to do it and it's easy" (E). Then during her onboarding, she further stated that she is careful with her diet since it helps her maintain her health. "I do have a varied diet and I'm quite sensible. I used to

be a nurse, you see, so I know what I'm doing"(O). Overall, Elizabeth actively took on tasks or adopted technology to manage her health and care.

Thus, one major issue with the system was a lack of focus on the use and user experience of the care recipients. The design of the system, and indeed the participant facing outreach material and the onboarding process, assumed that live-out informal carers had to be shouldering most of the care responsibilities [85], *"We can't all be with our loved ones 'round the clock"* (W p1). Therefore, although the dashboard/app was discussed during onboarding with the care recipients, its necessity was not stressed. Elizabeth, after being told about the dashboard had concerns: *"I just have to be careful I don't look at [screens] too much because it affects my eyes"* (IU). Elizabeth's health meant she might have to limit how often and even if she could access the dashboard.

Yet, without access to the dashboard, despite the claim on the HHMS' website (*"you can ask for [...] health information, and more by voice"* (W p3), participants, like Elizabeth, had no way of taking proactive measures to monitor any health changes. Care recipients were not encouraged or asked to take proactive actions to ensure they could access the data on the system. Instead, the onboarding made assumptions that if steps were missed by the care recipient, someone else, such as an informal carer, would take care of it. Although when Elizabeth was able to get a friend to help her log in, neither was able to glean anything useful from the data: *"[My friend] said she thought that some of the room [sensors] were monitoring the temperature of the room. But I couldn't see that. The only thing I saw was the number of steps per day"* (IU). Without knowing how to read the dashboard, the data being collected could not be used to take proactive measures.

Additionally, the dilemma with creating a holistic health smart home system is that users often already have other devices they have appropriated into their care management practices. As a result, at times, our participants either ignored or abandoned the system since they did not trust that it helped them remain safe. According to the HHMS's website, using the system would support independence by making it so *"no pendants [are] required"* (W p3), playing into the trope that safety pendants are seen as a sign of one's dependency [24]. However, some of our households, like Elizabeth's, reported that this did not align with their lived experience of using pendants in comparison to their lived experience of using the system. The limitation of having only one stationary voice assistant meant that being separated by only a room rendered the device inaccessible. *"I've used [my pendant] three times since, in, I don't know how many years, must be 10 years [...] but] If I fall down the stairs and I'm in the hall, I doubt if [the voice assistant] can hear me around the corner if I called out to [it]"*(IU). Beyond the physical proximity limitation, the system could not recognize a user if they were not wearing the wearable or were outside of the voice assistant's range.

Elizabeth further showed misunderstanding of who was monitoring her and had access to her data. She had planned to be away from her home for a while and wanted to save on electricity by unplugging the system but she was concerned: *"would that panic the people who are monitoring?"*(IU) Elizabeth believed her data was being monitored by the company since she received an email that said: *"[your] monitor is offline, so please put it right"*(IU) after she had briefly unplugged the system to get it to reset. The uncertainty around how her data was being used then highlighted the lack of focus given towards making sure users understood the system's safety and privacy features during onboarding.

7.3 Peace of Mind

7.3.1 Care Technologies Can Reduce Stress Associated with Managing Care. Worry associated with care can affect both giver and receiver, thus many of the features highlighted by the research group to give *"peace of mind for all"* (W p1) have the potential to benefit the entire care network. Major concerns for care management for both carers and care recipients are maintaining hydration [15, 35] and getting enough nutrition [72]. Regarding nutrition, the system states

that certain sensors can monitor appliances in the kitchen *"such as fridges or microwaves"* (IP p6), which would allow a user with access to the dashboard to review nutrition related data of the care recipient, such as eating enough or eating at the proper times.

For hydration, users were provided with a sensor-equipped mug that allowed the system to remind the care recipient to drink liquids and it also had functionality to *"encourage or congratulate [their] hydration habits"* (W p3). While congratulating is meant as positive reinforcement, it has been shown that such tactics often do not help with habit formation [92].

Overall, tracking a loved one, particularly those with risk of fall or dementia, has been shown to relieve worry in carers [16, 24, 80] and care recipients [89]. For example, a care recipient with diabetes needs to be aware of their blood sugar levels, but so might a carer if they oversee preparing their meals. The AI used in the system supports tracking health metrics and creating alerts for changes in health metrics, but also allows configuration of alarms, alerts and reminders *"to keep life running smoothly"* (W p3). Since the system could warn of changes that would take away some uncertainty, decreasing anxiety [40]. While the phrase 'running smoothly' further implies that users will also have the control to maintain a stress-free lifestyle.

7.3.2 Carl and his wife/informal carer Carol. Until they were introduced to the system, many of the care recipients did not seem to have major concerns about the ramifications of improper nutrition or hydration. Carol, however, had been monitoring Carl's weight "because that's one of the things, obviously with dementia, that can change" (E). To achieve this Carol would oversee "writ[ing] down in [his] diary" his daily weight. Moreover, when Carol and Carl were introduced to the mug, they saw it as something that would help Carl manage his hydration habits.

Carl: If it's a nice big mug, I'll be using it.

Carol: It's going to be useful as well because obviously as maybe his memory changes it will be useful to monitor how much he is still drinking – so if I need to remind [him] more to drink. (O)

Still, before getting the system, our participants' conversation around peace of mind tended to focus on the carers and not on care recipients. Peace was sustained through care recipients adopting safety-related technologies (like pendants). Another care management concern that our carer participants raised was the desire to be aware of the care recipient's current health status.

Despite the system's attempts at providing peace of mind for carers, the informal carers we spoke with mentioned flaws and missing functions that would prevent them from being worry-free. While some participants, like Beth (Ben's wife) had medical training as a nurse allowing her to be more critical of the system's monitoring limitations, this did not always help. Even with some medical training, Carol found that even with some medical training, understanding how to use the system to take appropriate preventative measures was unclear. Carol had little issue with inputting the amount of sleep and steps for Carl into the system, but the pair were quick to admit that they had randomly chosen the step goals.

Carl: What is a reasonable amount of steps? Because like we just sort of plucked a figure out of the air and I seem to be achieving my goal.

Carol: I mean I put in 2,000, I don't know if that's kind of – (IU)

Not having any guidance on what was considered healthy behavior meant that even if the system was accurately tracking a care recipient's movement, amount of sleep, or hydration, those without medical training could not use this information or adapt the goals in a way that would assist them with care efforts. Carl found the watch kept causing

him concern since the information it displayed did not match what Carol said was on the dashboard: “*Because [the watch] keeps saying LO [...] And on the dashboard of course it’s saying my temperature is normal*” (IU). Even though Carl liked what the watch could potentially let him do as a care recipient, he learned to distrust the information the system gave. Not having proper guidance or knowledge about how to understand one’s personal health data increased stress and worry since neither carer nor care recipient was well enough informed to determine disinformation.

Mental distress for the care recipients tended to be a reaction to having their agency taken away. Carl would switch to using the second-person to express mental distress. Carl used ‘you’ to appeal for a more interactive explanation of how to use the system in the ‘right way’: “*If you had something like that that you could access, so you could see or have somebody else interacting with it then you would know whether you’re interacting wrongly*” (IU). Carl then used ‘you’ as more of a collective need to suggest that not just him but others would benefit from such explanations. However, Carl’s used “I” when discussing the neglect and almost abandonment he seemed to be feeling from his interactions with the voice assistant: “*I’ve tried to acknowledge it or get it to say hello to me when I get up in the morning, but it won’t. Until it’s pill time or something*” (IU). Carl seemed to dwell on the lack of verbal behaviors, expressing this type of transitivity behavior more than the other participants after receiving the system. Dementia can cause a lack of confidence [81, 95] and Carl’s insistence that he is a “*technophobe*” could be causing him to see himself as faulty and not the voice assistant. Thus, the voice assistant not responding could be causing psychological harm as it may be perpetuating a negative internal narrative. For the care recipients, the system not functioning as they expected caused distress that could occasionally cause tension in the household, but for some of our participants, it caused self-doubt.

7.4 Initial Onboarding and Use Affect How Independence, Safety and Peace of Mind are Expressed

Prior to using the system, we found that our participants had established collective care relationships and ways in which they used technology to maintain a sense of independence, remain safe, and have peace of mind within these relationships. However, in our study we found that these established relationships, instead of being added by the system, were eroded.

For instance, initial onboarding and use resulted in a new dependence on the HHMS developer. Before using the system, our participants talked about many objects within their homes with a sense of collective ownership. However, for Carol and Carl, they felt that “*it’s theirs*” (Carl, IU). Although technological assistive devices would have a single owner, the care recipient, their use, especially for care management, was done collectively. However, since they had to rely on the research technicians to use the device, neither felt ownership over the system. The paternalistic stance was also seen in how device issues were handled, like in the case of Ben’s issue with his watch, furthering the distance between the household and control/ownership of the device.

Participants without the technical confidence or ability then would become more dependent on their carer to assist them. Elizabeth, for example, needed her friend to log in and set up the dashboard and this was also the case for Carl and Carol, since Carl is living with dementia. Before using the system, Carol discussed the ways she and Carl work together to help him maintain his independence:

“I tend to sort of wake up around about the same time [as Carl], but I don’t always get up purely because if I come down and interrupt his routine then he gets disorientated, and while he’s still got that independence, I just let him do [his morning routine alone]” (E).

The pair hoped that the system would be another tool that could help Carl function independently and have more agency over his own care. However, Carl found that, “*The only way I can get [my data] is to wait until [Carol] is around*

so that she can have a look at the – [dashboard]" (IU). Without equal access to his data, Carl is unable to reflect on his health needs independently. Instead, Carol can individually reflect on Carl's health and then as gatekeeper, can choose to share or hide Carl's data from him.

For participants like Elizabeth and Alice, the system reduced the tools accessible to them that could assist them with preventative care measures. When asked about the dashboard in the Initial Use interview, Alice said she was unaware of its existence. She could only state that *"I didn't have that"* (IU) and that *"I didn't know that"* (IU) in relation to accessing and reviewing her health data. In her use of the system, she could not see value in using the devices to help her set health goals, nor how this would be possible. Although Alice needed her carers *"[they] do everything for her"* (E), she still made care decisions, such as choosing to move *"here to be near [her daughter]"* (E) and making the decision to have her daughter do *"[her] private washing"* (E) rather than the formal carers. Not being able to effectively use the system hindered Alice from gaining agency in using preventative safety benefits.

Another issue that hindered care recipients' use was difficulty setting up the device. Lack of clarification either during the onboarding or with the HHMS manual meant that some participants spent hours figuring out how certain devices, such as the smart plug, worked. Diane spent multiple hours trying to resolve issues with the HHMS voice assistant. Diane's daughter, Dana, who would informally provide her care on Fridays, spent a couple of her visits solely trying to get the system to work. *"We have an arrangement where [my daughter] she will come up for two hours on a Friday. But the last two Fridays, she's been dealing with... that"* (IU). Dana had to put off completing the tasks she would normally do for her mother, which potentially meant she would have more work to do later. Instead of being able to focus on routine care management and wellbeing activities, the system distracted care recipients from focusing on their health needs and created more work for carers, throwing off the established balance our participants had created for their care management.

Additionally, there were expectations for the holistic use of the system that did not live up to the reality of the user experience and lead to distrust in the system's abilities. Alice noted that she would hear the system talking to her, giving her a reminder or something but not be able to make out what was said: *"[The voice assistant] speaks to me in the morning first of all, but I can't hear that because I'm not – I'm in the bedroom, and she's in the lounge"* (IU). Thus, encouraging users to solely rely on the system's voice assistant as a way of reaching help potentially puts a user's health and safety at risk. For someone like Alice, who has speech difficulties and can have difficulties communicating with a voice assistant even if they are in the same room, this risk would increase.

Finally, we found that introduction the system into our participant households led to mental distress for both carers and care recipients. Beth found the system to be unhelpful since it could not monitor or even capture physiological issues that she needed data on to provide Ben with care:

Beth: "Well you take last night. I'd got up to go to the loo, I came back and [Ben] does have problems with hand tremors and everything else, but it was worse than normal and he wasn't 100 percent with it [...] and I know before now, if he hasn't taken [his painkillers] this is what will happen [...] but of course [the tremors] not being picked up at all in the middle of the night, with anything. And you're talking about diabetes; that was one thing that I suddenly thought, hang on, is there a problem with his blood sugars?" (IU)

Beth's experience caring for Ben taught her how to handle Ben's tremors, but even she expressed a moment of self-doubt. Although the hand tremors meant he needed to take his painkiller in the past, it could have been related to his diabetes. For Beth to have more confidence, she would need a home health system that either captured more physical health

metrics or explicitly catered to her and Ben's health needs, for instance by monitoring his blood glucose levels. In some ways, having medical training as a nurse allowed Beth to be more critical of the system's monitoring limitations.

However, mental distress was also manifested through engagement with the system in ways that could degrade social networks and the self-image of care recipients. Diane said that her frustration with trying to get the system to work created significant conflict between her and Daniel. *"When it was both of us together [trying to get the system to work], I thought we were going to have a divorce! (laughs) We've been married 34 years, but I thought we are going to have a divorce"* (IU). The mental stress of getting the voice assistant to respond to her made Diane want to send the system back to the HHMS research group on multiple occasions. However, Daniel disagreed and insisted on keeping the system since he and their daughter had put in so much time to get it set up, even though it was a source of ongoing tension. *"I told [the research technician] I just want to send the whole thing back. But [Daniel] said, 'don't do that because we have invested so much time' [...] so I'm not going to send it back... at the moment"* (IU).

Through our findings we saw how the dominant discourse shaped the system design and promotional materials and then how this affected the discourse used by individual households in a relatively short period of time. Then by comparing households we were able to see that not only is discourse affected, but care dynamics overall can be affected and influenced by what participants perceived a system should be providing.

8 DISCUSSION

We examined the initial onboarding and use of a HHMS to discover how key terms (independence, peace of mind, and safety) associated with care and care management were expressed in the description of the HHMS and by the study participants. Although it's been suggested that telecare systems can shift care network dynamics and responsibilities [70], our findings show how quickly this shift can occur during the initial onboarding process. Critical discourse analysis in HCI is relatively underutilized [39, 63, 100], and rarely has been used to examine interview data [49]. However, by focusing on transitivity [45, 50] 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.

We discuss how our study reflects current trends towards normalizing at-home institutionalization. We then suggest how shifting the focus of marketing and onboarding home health monitoring systems to reflect the fluidity of collaborative care can prevent system abandonment, avoid creating people's homes into pseudo-institutions [63], and avoid intensifying power imbalances in care.

8.1 Technology Leading Towards At-Home Institutionalization

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 research group had the most control. Aligning with the findings 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 [63] by removing power from people in care and their carers. Others have shown the importance and influence of established collaborative care networks [24, 48, 69, 88] 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.

The system's onboarding and participant facing outreach materials were entrenched with discourse around the trope that care recipients depend on others. Care recipients felt discouraged to set up the system themselves since it was addressed to the carer and that their ability to use technology was being questioned. For instance, before acquiring the system, our participants actively participated in their care management with technology such as wearing pendants to alert emergency contacts or regulating sleep with C-PAP machines. As Mort et al. [70] warn, the use and adoption of a monitoring system like the one studied *"shift[s] agency away from the older person, where decisions can be taken based on sensor/movement data about which the client may not be aware."* Our findings showed that care recipients unable to access certain system features were forced out of an active role and into a passive one during onboarding, before they even received the system.

In the onboarding and outreach materials/marketing of these systems, limitations are not clearly indicated. For instance, the reality of having only one voice interface device in one place in the home means that it is only accessible when in the same room, a limitation that was not expected by Elizabeth and Alice. Furthermore, not informing people about the need for a separate device (tablet/phone/computer) for specific features makes it more likely that care recipients find themselves in a passive role with limited control. By limiting the control of those being monitored, the system subversively takes away the independence it promises [67, 70] and moves towards pseudo-institutionalism [63]. Additionally, home health monitoring systems are only operational within the home, which promotes a *"staying-at-home"* mentality [3], which can potentially further isolate the care recipient. This mentality contrasts with the positive 'aging in place' or *"aging-at-home"* [3] discourse as it can cause carers and care recipients to believe recipients are only safe at home. Exacerbating vulnerability can potentially increase the likelihood of abuse [67], and we extend these findings by showing that onboarding and outreach materials separately recreated an institution-like influence on the view that people are safer confined.

From the carer's perspective, they are fulfilling their moralistic duty [63] by asserting and enacting measures that they deem appropriate for safety and care [7]. However, we found that the design of the onboarding and outreach materials can lead to imbalanced paternalistic practices. For people with memory impairments, like Carl, a carer's blind faith in the system could lead to detrimental impacts on the care recipient's mental wellbeing. Worse still, it could allow bad actors to take advantage of this imbalance, especially if they trust their carer to handle their needs [77]. Even with the best intentions, the advice given in the user manual, for instance, could easily encourage a carer to harm their loved one or patient unintentionally [57]. As Ben and Beth found, pets easily set off sensors, which could cause a carer to assume their loved one or patient is wandering and to consider restricting movement, such as adding locks to doors. Thus, our findings point out that beyond the design of the system potentially aiding abusers [67], the language used in onboarding and marketing materials could even encourage those with good intentions to follow potentially harmful advice.

Despite these issues with home health monitoring, economic pressures, as well as potential economic benefits, encourage the self-care industry [12, 59, 70]. Economic pressures due to lack of resources for carers [79] make it easy for research groups and companies to convince healthcare providers to trust AI systems to track and capture changes in patient behaviors accurately [60, 62, 86]. This faith in the benefits of AI systems even led to the UK's NHS boosting funding to its AI in Health and Care Award funding by £36 million [86]. Trusting systems over patients leads care away from the patient-centered model [53] which promotes creating a dialogue between carer and patient towards relying on evidence-based medicine [41] which prioritizes clinicians and gives onus and control to the carer.

As they are currently designed, onboarded and marketed, home health monitoring systems can convince care recipients that the technology will help them as much as it will help their carers to achieve "*peace of mind for all*" (W p1). Our research has shown that this starts to unravel during onboarding, where unequal access and unequal control starts the process of normalizing pseudo-institutionalization. Thus, stressing that beyond understanding how ageism and medical models affect only system design, attention within HCI is necessary to recognize how this influences the promotion or encouragement to adopt and use a system that can potentially be harmful. Normalization with technologies such as the one studied and those widely available then enables further development of the culture around pseudo-institutional technologies for care.

8.2 Shifting the Onboarding and Marketing to Reflect Equitable Collaborative Care

While accommodating collaboration and equity into the actual system design is unparalleled, our research has found that onboarding and outreach material/marketing can also set expectations and 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" [9, 13, 29, 87, 98]: 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, 14, 52, 88, 96]. 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. [88]) 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.

Onboarding and marketing can promote collaborative and equitable use and decision-making by clearly stating information about data accessibility. Our main users could not know who or how often their data was accessed, nor could they turn off the sensor tracking to pause data tracking. Such limitations potentially put users at risk for abuse or privacy invasions. Transparency through signposting who has made control setting changes, added notifications/alerts, and accessed the data could protect users from potential gaslighting or other forms of abuse [67]. Enabling and disabling features for privacy should be more nuanced and give the person being monitored the ability to override any changes. In this way, transparency could then be used to trigger discussion around care. If a carer thinks a feature is useful, but the care recipient thinks it invades their privacy, they will have to negotiate what is best for the wellbeing of the care recipient. Transparency of roles is also important for equal interdependent use of a HHMS. Although passive sensor-based systems are more likely to take away the care recipient's agency [70], design decisions that purposefully bring them into care management decisions are crucial. Giving more agency to care recipients is better since clinicians do not necessarily want continuous access to patient data as it puts more liability and responsibility on them [47]. However, as many of our participants noted, accessing a separate app or dashboard was sometimes not possible due to access/ability, memory or dexterity issues; taking away agency. By not being able to configure the set-up themselves, users felt like they were being given orders to obey, in line with Hwang et al. [48] findings on ICT for aging. Therefore, beyond supporting collaborative use in the onboarding and marketing, incorporating more multimodal ways of interacting with the data or controls during set-up is critical. For instance, if voice commands do not allow for entire access to system control and data, then potentially an incorporated screen is necessary for viewing data [84] or changing settings. Additionally, devices should be able to connect to a printer either manually or via Bluetooth so that participants without access to the app/dashboard have a way of viewing, sharing, and curating their data on paper [24].

Before getting the system, our participants universally expressed vigilance around their health and hoped the system would provide them with more insights. However, none of our participants mentioned how the data helped them reflect on their health. One remedy for this could be, instead of reminding users to drink water, asking them if their lips or mouth feel dry or if they feel muscle fatigue [103]. Such questions would cause the user to reflect on their body while informing them about common symptoms of dehydration. Mindful reflection on chronic health conditions through technology has helped reduce stress for those living with multiple sclerosis [8] and has allowed collaborative reflection of symptoms between informal carers and those living with bipolar disorder [47]. While, ethically and practically, home health systems are unable to provide clinical advice without a clinician, they can encourage users to self-reflect on how they are physically feeling and note any symptoms they have. Additionally, to assist with understanding health data, during onboarding such systems could provide average baselines for people of similar age, gender, and weight with a disclaimer that certain health conditions might affect or change these. Also, the system or technicians can provide interactive tutorials that help users interpret and engage with their data [33, 84]. These tutorials could scaffold users into actively involving their clinician since users will be better informed and thus empowered to discuss their care management [16]. By informing care recipients in this way, a HHMS could help sustain collaborative care by motivating care receivers to take more responsibility and control of their care management; allowing care providers to take a more supportive role [73].

Although the human-centred approach to the functional design of home health monitoring systems is paramount, how such systems are onboarded and marketed also affects how users perceive the device, set expectations, and try to use the system initially. If they perceive that the device aligns with how they manage their care, they will be interested in adopting it. However, they may gain contempt and distrust in such systems if that perception is not met, or worse suffer distress or relationship tensions with new power imbalances introduced into the household. It is advantageous for onboarding and marketing to match the system’s functionality to support human-centred collaborative shared care.

8.3 Lessons Learned Through Applying Critical Discourse Analysis to HCI

We chose to apply critical discourse analysis (CDA) to our data since it would allow us to examine how higher societal discourse influences the narratives used in not only onboarding and promotional materials, but also the discourse used by our participants. With this methodology, referenced material connected to empirical data are woven into findings to demonstrate their grounding within established societal structures. Thus, it is more common to see CDA appear within HCI literature in relation to policy [5, 27], advertisement [4], textbooks or teaching materials [100], or applied to literature review [63]. Within HCI, we rarely find it applied to interview data. This is further complicated by the fact that CDA can encompass a variety of discourse analysis methodologies [102]. For instance, Outila and Kiuru [76] used Foucauldian discourse analysis to examine interview data related to older adults’ inclusion or exclusion of a picturephone into their daily life. While Foucauldian is a type of CDA, it applies Foucault’s ideas systematically to an empirical study. Since CDA can be applied using different approaches, it gives researchers flexibility in focus. This approach has been relatively underutilized in HCI, but it does show promise through its ability to connect societal discourse with empirical data.

Based on our findings, we believe that those working in instances in which it is necessary for interviewing to be conducted in pairs or groups may find CDA useful. In our case, we know that often in care situations a power dynamic between carer and care recipient can form, which can change how care is enacted [74, 93, 105]. This often makes interviewing the pair together a challenge for researchers as it can be difficult to separate participant voices [28]. However, by looking at transitivity we found that power dynamics become more transparent since we could more

easily highlight when there was a more equally shared point of view or an individual stance. For instance, in Section 7.3.2 in the Findings, through an exchange between Carol and Carl we can see that Carl is focused on first-person material possession and first-person behavioral, while Carol shifts the conversation back to focus on second-person behavioral and then first-person behavioral:

Carl: If it's a nice big mug, I'll be using it.

Carol: It's going to be useful as well because obviously as maybe his memory changes it will be useful to monitor how much he is still drinking – so if I need to remind [him] more to drink. (O)

Carl is focused on potentially owning the mug that comes with the system and using it himself, while Carol is focused on how Carl's behaviors are changing (his memory changes) and how her behavior needs to adapt (by monitoring and reminding). Even if Carl is to agree with Carol, there is still evidence that his focus and goals were originally different. Furthermore, Carol may have ultimately said more in this example, but both participants demonstrated two types of transitivity suggesting that even with participants who have memory or speaking difficulties a lot can be understood from even short responses. However, looking for transitivity is only one approach to CDA. While we found CDA to be useful, without more published applications of CDA in HCI it is too soon to see the implications of further application of this method.

8.4 Limitations

Designers of HHMS's often assume that live-out informal carers handle the care responsibilities of an older adult who lives alone. However, except in the case of Alice, who had formal live-out carers, and Elizabeth, who had no carers, most of our participants lived with a spouse. Thus, most of the participants were not necessarily the target audience for the HHMS we studied. Moreover, typically a UX researcher from the HHMS research group would meet with the users every two weeks to work out any issues– this was not the case for our study since only an initial onboarding (and in some cases, one additional follow-up meeting) occurred. More meetings might have meant that various issues could have been resolved more seamlessly if regular meetings with a HHMS UX researcher had occurred throughout the study.

Additionally, the lack of cultural diversity among our participants means that all of the challenges involved in marketing and onboarding could not be captured. For instance, if our participants come from historically minority cultural backgrounds, given the history of medical abuse often inflicted on these populations [94], we suspect trust might have been more impactful during onboarding. More research is needed to understand how societal care discourse intertwined with racial, colonial and feminist discourse affects care providers' and care recipients' use of home health monitoring technology.

9 CONCLUSION

Home health monitoring systems generally promise care recipients and providers independence and peace of mind by allowing users to monitor the health and wellbeing of older adults receiving care. We examined the onboarding process and participant facing outreach materials of a home health monitoring system through the lens of critical discourse analysis. Our findings revealed that the existing interpersonal relationships of older adults and their carers sometimes worked in opposition to the design of the outreach materials and onboarding and, indeed, the system. Instead of giving the person receiving care more independence, peace of mind, and a sense of safety, systems such as the one studied force them to become more dependent on others to share or explain data. Additionally, the functionality of the device

and their lived experiences with it did not allow carers to gain peace of mind, in contrast to the onboarding and outreach materials' discourse. This paper builds on (dis)institutionalizing at-home HCI care research, expanding it to show that such systems, even in their onboarding and marketing, reflect institutional discourse by limiting control of those being monitored, limiting their access to data, and increasing their dependency on carers. We propose that beyond design changes, the onboarding and marketing need to reflect the interdependent relationships between those receiving and giving care.

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