Senior Care for Aging in Place: Balancing Assistance and Independence

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ABSTRACT

Increasing demands for senior care raise the challenge of how to support independence in older adults while assisting their health management. Most seniors would like to age in place, but concerns about safety lead many to move to a place that can provide basic care support, such as a Continuing Care Retirement Community (CCRC). CCRCs provide different care levels for seniors, from independent living to nursing home. In this paper we examine how independent residents of a CCRC manage their health through a series of self-care and collaborative care activities. We interviewed 18 independent residents and five staff members of a CCRC. We have found that their care involves both external monitoring and self-care, and self-tracking is an integral part of self-care. These different forms of care are interconnected and complimentary. However, negative connotations associated with aging limit their effectiveness. Examining how these care practices function could inform the design of technology for a broader population of seniors aging in place.

Author Keywords

older adults, elderly, aging in place, self-care, collaborative care, CCRC, self-tracking

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

INTRODUCTION

The world population is aging. The percentage of older adults (most often defined as 65 or older [54]) is increasing, and is projected to represent 21.4% of the population of the U.S. by 2050 [38]. Gradual functional decline may limit seniors' ability to conduct household tasks (e.g. carrying groceries). These limitations often lead to moving in with relatives or into a care institution to obtain assistance from others [20]. However, an estimated 90% of older adults wish to remain

in their own residence for as long as possible [24]. Furthermore, leaving their home can limit seniors' autonomy, and providing more assistance than necessary increases risks of disenfranchisement and socio-cognitive limitations [37].

Understanding older adults' care practices is essential for *aging in place* technology design. Aging in place research seeks to empower older adults to remain independent in their own residences for longer. Successful aging in place frequently necessitates that older adults perform self-care activities for health management. To do so, many also engage in self-tracking by regularly measuring a health indicator (e.g. blood pressure). A recent survey has estimated that over 70% of older U.S. adults self-track to manage their health [27]. However, self-tracking technologies are overwhelmingly designed for younger populations [21]. Because older adults' self-tracking practices differ from other age groups' [27, 10], it is important to understand their particular needs in order to design technology that supports senior self-care.

The population targeted by aging in place research is very similar to the seniors who live independently in Continuing Care Retirement Communities (CCRCs). CCRCs are residential communities for seniors that "offer a tiered approach to the aging process, accommodating residents' changing needs" [1]. CCRCs offer different levels of care to residents, ranging from independent living through full nursing care. Independent residents receive minimal support from these institutions, but have relocated to the CCRC in preparation for a future when they might require more help [30].

Approaching aging in place as a design opportunity raises a critical research question: how do independent older adults perceive and manage their self-care and the assistance they require from others? To answer this question, we conducted a qualitative study with independent seniors at a CCRC in the U.S. Studying the care practices of independent CCRC residents informs aging in place research by characterizing the virtues and challenges of sociotechnical systems designed to support senior independence. We interviewed 18 residents and 5 staff members. We have found that senior care involves self-care and several forms of collaborative care including the retirement community and healthcare providers. These practices are interconnected, but tensions arise from seniors' desire for independence. We argue that technology should leverage external monitoring and self-care in senior care, and

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CSCW'17, February 25–March 01, 2017, Portland, OR, USA.
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ACM ISBN 978-1-4503-4335-0/17/03 ...\$15.00.
DOI: <http://dx.doi.org/10.1145/2998181.2998206>

should be carefully designed to prevent aging stigma, and to better appeal to this population.

BACKGROUND

The independence of older adults is highly affected by their health. Thus, supporting independence requires health management strategies, as well as tools that facilitate daily activities, such as chores and self-care tasks. Research in aging in place and in self-tracking has investigated how technology can be applied to these purposes.

Older adult care

Older adults start requiring assistance when they experience a “functional status decline,” a state of difficulty in accomplishing activities of daily living [59]. Functional decline has been linked with emotional health, cognitive impairment, falls, lack of physical activity, and chronic illness [59]. In addition to functional decline, older adult care is complicated by other health management needs, such as attending to a chronic illness. Two thirds of older adults in the U.S. have 2 or more chronic conditions [26]. The most common are high blood pressure (61%), high cholesterol (48%), heart disease (34%), arthritis (31%), and diabetes (28%). These conditions do not directly cause significant functional decline until they are in advanced stages. However, they do increase the risk of dangerous medical incidents such as diabetic coma or heart attack. Thus, in order to foster independence and prevent decline, it is important to address these influencing factors and support the management of these conditions.

Older adults often engage in self-care activities to manage chronic conditions. Self-care encompasses daily actions taken to mitigate the negative effects of an illness on quality of life, including managing treatments, symptoms and psychological aspects [4, 16]. Older adults face unique challenges for self-care due to the higher likelihood of having multiple chronic conditions [16]. Research in senior self-care has focused either on clinical tasks (e.g. taking pills) or on psychological aspects, but the two are inextricable in daily living [16]. In order to better understand and support self-care, it is important to focus on everyday tasks and experiences, investigate existing collaborative relationships with clinicians and caregivers, and to expand the impact of self-care research on medicine and on self-care technology [45].

The health management of older adults can also involve informal caregivers, such as family members, who are often elderly as well and may have other responsibilities such as children and a professional life [56]. It is important to consider the perspective of these caregivers when designing technology for senior care, in order for these systems to facilitate the work of these stakeholders [12]. For older adults who have experienced minimal or no functional decline, the assistance provided by caregivers may consist of simple tasks such as helping with treatment compliance or seeking medical help when necessary. Care technologies might act as substitutes for caregivers in certain activities, facilitate the interaction between caregivers and older adults, or assist with self-care.

Some seniors may move to a retirement community such as a CCRC. CCRCs provide multiple levels of care to their

residents, including independent living, assisted living and skilled nursing. Seniors are able to choose to move to independent living while they are still independent, and live in the same community until end-of-life. Older adults move to CCRCs because they anticipate future care needs, want to reduce chore workload, and avoid burdening family members in the future [30, 39]. These institutions have care practices that assist independent residents, and extend their autonomy for as long as possible without compromising their safety. Their lifetime care agreements incentivize CCRCs to provide appropriate and cost-effective care to residents. As a result, their residents require less hospital care and transition later into nursing home care [52].

Aging in place

Aging in place research seeks to augment self-care in older adults to enable them to retain their independence for longer, and delay the need to live with a caregiver or move into an assisted living institution. Living in a long term care institution is estimated to be 12-60% more costly than living at home [36]. In addition, 90% of older adults in the U.S. wish to age in place [24]. Older adults expect that smart home technologies could benefit them by offering features such as emergency help, prevention and detection of falls, and tracking health indicators (e.g. blood pressure, glucose) [22]. Directions in aging in place research also include recognizing and addressing crises, supporting daily routines, and helping relatives to achieve peace of mind [43].

Different monitoring systems have been proposed, including a community daily check-in system that leverages peer support [3] and digital family portraits, used to promote awareness of the daily activities of an older adult to remote family members [51]. Wearable alarm systems that provide a means to call for help in emergencies are available commercially [60], but have shown mixed results, including limited use [42, 35]. Systems that monitor behavioral (e.g. motion, use of the shower) and physiological (e.g. heart beat, temperature) cues can be used to detect changes in health and activity of older adults, improve their quality of life, and reduce hospitalizations [28]. While older adults have been found to accept being monitored, they want to have control over how their data is collected and displayed to others [63]. While these systems have the potential to be coercive, it is important to understand their use, misuse, and non-use in practice in order to assess their effectiveness, and to create improved designs [42]. Most aging in place systems have only been tested for a short time, or with a limited group of participants [47]. There is a need for more research on technology implemented in real-world settings with independent older adults.

Self-care through self-tracking technology

Using technology to support aging in place requires investigating how to better assist senior self-care. Recently, self-tracking has been studied as self-care technique. Self-tracking refers to repeatedly measuring and recording data about oneself, and reflecting on the data collected. Although the majority of older U.S. adults self-track, adoption of self-tracking technology among senior citizens is extremely low. While seniors are interested in using technology for health

management [21, 46], this population is commonly excluded from the design process of such technologies, and as a consequence their unique needs are seldom supported [21].

Self-tracking practices

Although older U.S. adults use self-tracking for health management more often than younger age groups, they seldom use self-tracking technology. According to a 2013 survey [27], 71% of older adults track fitness-related variables (weight, diet, or exercise), and 52% track other health indicators or symptoms. In comparison with other age groups, older adults are significantly more likely to self-track, more likely to use paper or medical devices (e.g. glucometer), and much less likely to use computer programs (2%) and mobile tools (1%). They also use self-tracking to monitor health indicators, such as blood pressure, in order to identify abnormalities. Behavior change and self-knowledge are more common goals amongst the general population [10].

Self-tracking has been investigated as a self-care tool for chronic illness management [15, 25, 45, 60], but questions remain about how these tools can be used by older adults. Different life contexts as well as having multiple chronic conditions can significantly affect the needs of this population [16]. Prior work that addressed the use of self-tracking by older adults has investigated activity trackers, such as pedometers, and lifelogging cameras (e.g. [18, 34, 41]). Medical devices such as blood pressure cuffs can cause anxiety in older adults who do not fully understand how to manage the disease [57]. Grönvall and Verdezoto [31] have suggested that, while self-tracking is empowering and creates a higher understanding of a disease, older adults may not be able to remain tracking as they require more assistance. Better supporting this population's self-tracking practices requires understanding how they currently engage in self-tracking, and examining the reasons that limit technology adoption for this purpose.

Supporting doctor-patient communication between older adults and caregivers is a promising application of self-tracking, since senior care involves both self-care and receiving care from others, including professional caregivers as well as family and friends. Nonetheless, while 58% of older adults who track share data with a health provider [27], communication may be hindered by incompatible expectations between patients and health providers regarding patient-generated data [11, 15].

While previous work has investigated specific aspects in older adult care and self-care and proposed technologies for aging in place, not enough is known about sociotechnical systems for senior care. In this paper we investigate care and self-care in a setting that has implemented such systems and examine their effectiveness and impact on independent seniors.

METHODS

To investigate the care and self-care practices of older adults, we conducted a qualitative study in the independent living unit of a CCRC in the U.S. Our interviews and observations allowed us to understand how these practices function and are perceived by seniors.

	Age	Gender	Tracks	Physical disability	Tech use
P1	95	male	glucose	moderate	low
P2	87	male	steps	none	high
P3	82	female	glucose	none	moderate
P4	77	male	glucose	none	low
P5	74	female	BP	moderate	high
P6	75	female	BP	none	low
P7	89	female	BP	moderate	low
P8	83	female	BP	mild	low
P9	79	female	glucose	mild	moderate
P10	94	female	pain	moderate	moderate
P11	85	female	BP	mild	moderate
P12	84	male	wife's BP	mild	high
P13	91	female	-	moderate	moderate
P14	84	female	steps	none	high
P15	84	male	BP	mild	high
P16	100	male	-	none	moderate
P17	87	male	glucose	mild	high
P18	80	female	glucose	mild	high

Table 1. Characteristics of interviewed residents.

Site and participants

The CCRC where we conducted this research houses 400 residents and offers four levels of care: independent living, assisted living, memory care, and skilled nursing. We recruited participants from independent living. The independent section of the community houses 242 older adults, and includes a dining room where residents have one meal per day, a fitness room where residents attend group classes or individual sessions, and a health center where nurses provide basic health services, such as measuring blood pressure and applying dressings to wounds. Our site is located in the U.S. west coast, and its residents are of high socioeconomic status, a characteristic of most CCRCs that offer lifetime care contracts [64].

Independent residents lived in their own apartments or houses in the community property. They did not have significant cognitive impairments, but they had a wide range of physical disability, from being very active and regularly playing sports to needing to use assistive mobility devices such as a cane, walker, wheelchair, or electric scooter. Residents' movements and daily activities were not controlled or closely monitored. Many had cars and maintained active social lives inside and outside of the CCRC. The CCRC offered services for residents who could not drive, such as biweekly trips to supermarkets, rides to medical appointments, an on-site beauty salon, and on-site doctor visits at the health center.

Our participants were 18 independent residents and 5 staff members of the CCRC. Among the residents we interviewed, 11 were female. Their ages ranged from 74 to 100, with a median of 84. Each of them had at least one chronic illness, including hypertension, arthritis, cancer (in remission), diabetes, hearing loss, and gastrointestinal conditions. However, these chronic conditions are controlled without daily assistance from caregivers. These participants are described in more detail in Table 1. In the table, moderate disability refers

to not being able to walk unassisted for at least 15 minutes, and mild disability refers to not being able to walk unassisted for at least 2 hours. Participants who exhibited high technology use browsed the internet for 1 hour or longer at least 4 times per week, while those who had moderate use browsed the internet at least 2 times per week.

Among the CCRC staff, we interviewed: two social workers (S1 and S2), a computer technician (S3), a fitness trainer (S4), and a nurse manager (S5). The social workers' primary responsibilities were to ensure that residents were receiving appropriate care, and communicate with residents' family members. The computer technician assisted residents who had questions regarding computers and mobile devices, as well as technical problems. The fitness trainer led group exercise classes for the residents and provided personal training sessions. The nurse manager oversaw the nursing staff in independent living. Because our interviews focused on CCRC residents, and we interviewed only a few staff members to better understand the context, we are not able to extensively address other perspectives than the seniors'.

Data collection and analysis

We conducted semi-structured interviews with each of the participants. We asked residents about their technology use, their current health issues, and their health management practices. We also inquired about self-tracking and the care practices of the community. We asked staff members about their roles in the residents' health care, and about the different care practices of the institution. We first interviewed eight residents and one staff member, discussed the preliminary data among all researchers, and revised the interview protocols for the remaining interviews. The interviews were audio recorded and lasted 40 minutes on average. Each participant received 25 dollars for participating in the interview.

In addition to the interviews, we also observed the general practices of the CCRC and attended open events related to health or technology. These events were: three separate talks about hypertension, fall prevention, and nutrition; a residents meeting; a discussion circle about interacting with health providers; and a computer group meeting. Each event lasted between 40 minutes and one hour. The observations occurred before and during our interview phase over a period of 8 months. Observational data were collected in handwritten notes. In this paper we mostly present interview data, but observations were essential for formulating interview questions and conducting interviews. This study was approved by our institution's ethics review board, and informed consent was obtained from all participants. Prior to the data collection, one author met with the CCRC director and upper management and obtained authorization to conduct the study.

To analyze the data, we utilized a Grounded Theory-oriented approach [9, 58]. We transcribed each interview, and two authors separately coded a subset of the data following an open coding technique. Both sets of codes were discussed and combined, and one author proceeded to code the remaining interview and observation data. We used axial coding as our final analysis step. The categories we extracted with axial

coding include self-care and collaborative care, and they are discussed in the following section.

FINDINGS: CARE PRACTICES IN INDEPENDENT LIVING

Our data shows that resident health management is composed of several interdependent forms of care, including both self-care and collaborative care, wherein spouses, neighbors, health providers, and CCRC staff play roles in residents' care.

Self-care

At our field site, senior self-care involves managing their health care and health information as well as self-tracking health indicators including blood pressure and glucose. These activities are largely preventive, as they are used to prepare for emergencies or to identify worrisome changes in health indicators, such as spikes in blood pressure. Self-tracking is also used to check health indicators when feeling ill.

Managing professional care

As seniors face a variety of chronic and age-related health issues, managing their own health care is an avenue to assert their independence. This management tends to revolve around health records and information. Many residents keep organized archives of their health records, including prescriptions, test results, and medical preferences. Managing their health records allows residents to have easy access to them when necessary, and to keep track of how their condition evolves over time. These records are most often paper files, although one participant scans his records and keeps electronic copies, and two others are able to access their records through their health insurance's internet portal. Participants who are more proactive in their health care expressed that they habitually compare recent medical test results with their records, others primarily use them for their tax forms. These records are also kept for emergencies, as P6 said,

"I have a bulletin board right opposite the front door. And inside that, standing very clearly is, no CPR. [...] And I'm always making sure they update [my face sheet]. It's got all my medical history, it's got the people to contact, and to me that's insurance."

P11 explained how keeping health records became more important in old age, *"I haven't always done it, but as I've gotten older, probably the last ten years, I have thought it was much more valid."*

Tracking to monitor health indicators

To monitor their health and detect any undesired changes, many of our participants self-track health indicators such as blood pressure and glucose, and about one third of them share these data with health providers. Their self-tracking process is short, and consists mainly of checking whether the health indicator is in a predetermined range, as P11 explained, *"I know I have to keep [my blood pressure] in a certain range, that's all you worry about, really. And that works."* They expressed that self-tracking helps them to feel in control of their own health. P8 said, *"I think if I had a sudden spike in blood pressure, I would be very concerned. And maybe it's just a preventative thing."* P8 tracks her blood pressure daily, this habit allows her to be more confident about her well-being.

Interestingly, we found that participants who do not share their data with health providers are less likely to measure their health indicators regularly, or to register their data in writing. As P1 stated, *“I don’t write [my glucose] down. It’s not with a great regularity either.”* They are more likely to self-track more often when experiencing symptoms. P6 explained, *“Sometimes if I feel very low, I’ll take [my blood pressure].”* Similarly, P7 said, *“I check [my blood pressure] maybe once every couple of days. Unless I’m symptomatic, then I’ll check it every couple of hours.”*

Health, physical activity, and activity trackers

While our informants recognize the benefits of physical activity for their overall health and to maintain independence, monitoring of physical activity was not widespread. Only two of our participants use self-tracking technology to count their steps, and their goals were not to become more active. Those who are less active or have physical limitations expressed no interest in using activity trackers. P2 and P14 use pedometer apps on their smartphones, but they did not change their routine or increase the amount of exercise based on their step count. P14 said, *“I think it’s psychological more than anything else. [...] I like to know I’m moving, and you know, not just sedentary.”* P2 stated, *“Do I have a budget that I’m meeting everyday? No. I don’t.”* Both expressed that they ‘like to see’ their data, but the data does not encourage them to become more active.

Participants who are less active, and exercise to manage pain or to improve their balance, do not track their exercises. Instead, they use time to measure their activities (e.g. walking for 20 minutes) but do not record them in any way. Balance training is one of the most common exercise sought by the seniors to maintain their autonomy, as S4 said, *“Most just want to remain independent. So it definitely comes into functional fitness, which is just to continue doing daily activities with ease. [...] Balance is a key issue.”*

According to the fitness director, activity trackers and other self-tracking tools are not beneficial for functional training for two reasons: first, they do not measure relevant data; second, they provide less motivation than the direct results of the physical activity. As she explains,

“a lot of what we do is getting people from a walker to a cane, and from a cane to walking independently. [...] That includes weight shifting, that includes balance, that includes strengthening the legs and keeping them flexible. So in that mode, a pedometer or heart rate monitor is not going to affect their outcome.”

The benefit provided by exercising, namely reduced pain or increased mobility, is tangible, and more powerful than motivation provided by self-tracking could be. S4 explained, *“If they’re feeling better they are going to know it, they are going to feel it and it’s going to be obvious, and they won’t need to sign in a sheet.”* For instance, P10 walks in the mornings to manage her pain: *“It helps to take the pain away. And by noon or one o’clock the pain is gone, and I have no more pain the rest of the day or at night.”* P1 participates in balance training classes, and he notices how that helps him. He

said, *“I occasionally lose my balance temporarily or reach too far or something, and I find that I do get responses, correction responses with [balance training classes]. So I guess I will continue with those.”* These tangible benefits provide motivation to keep exercising.

In addition, pedometers are not seen as potentially helpful in a recovery process, but heart rate monitors (HRM) are used by seniors with heart conditions to prevent overexertion. For instance, P18 was recovering from a hip surgery at the time of the interview, and while she was walking unassisted, she had not fully recovered. She owns an activity tracker and planned to use it when she was able to be more active, but she did not think that it could help in her recovery. She explained, *“I do have the Fitbit, but I haven’t gone online to activate it yet because I didn’t think it was much use doing it when I am not back to my normal self, but soon I’ll do it.”* P18 walked without assistance at the time, but in her perception the activity tracker would not be useful until she could walk 10,000 daily steps again. According to S4, older adults who have heart condition often use HRMs when exercising to make sure their heart rate is in a safe range. However, she stressed that she does not find it useful for other goals, since many older adults take medications that affect their heart rate.

Overall, we found that activity trackers are associated with fitness goals of young people, and they often do not fit with older adults exercise needs. This sentiment was expressed by S4 and most of the older adults interviewed. The seniors who use these devices are physically able and active, and use them only to reaffirm their own activity levels rather than to change their behavior. This barrier was both functional and conceptual, as these devices are not designed for the particular needs of older adults and are most often perceived as not useful by seniors who have special needs.

Collaborative care

While self-care practices are an important component of CCRC residents health management, these practices occur alongside a number of collective care practices. We have observed that residents collaborate with the CCRC staff, with their health providers, with peers, and sometimes with family members to engage in what we call collaborative care. Collaborative care activities involve different levels of agency, but they help to keep residents well and safe, and provide support for emergencies.

CCRC care practices

The retirement community has care practices that aim to ensure the safety and well-being of seniors in independent living. These practices allow the CCRC staff to understand the needs of each resident, and to help the older adult remain in independent living as long as possible. These practices are also designed to detect and prepare for emergencies, such as falls. While independent living residents are not closely monitored, the CCRC does provide quick access to medical care in case of emergencies, as S5 explained: *“We do a lot with the paramedics across the street, [...] they’re here at least once a day. Because we have such a big population.”* Accounting for approximately 400 residents in four levels of care, these emergencies occur often.

While the residents are not closely supervised, CCRC staff maintain an awareness of residents' general status through their day-to-day interactions. If they see something that they find different or worthy of a note, they will document it and discuss in a staff meeting, as S2 explained:

"we talk about how the resident is behaving with other residents. We talk about whether the resident is doing isolating behavior and just staying to themselves. We talk about the resident's temperament, ability to walk, ability to self-care, ability to do their own shopping, cleaning."

These behaviors are mostly observed informally, rather than assessed in a formal setting. CCRC nurses and social workers have informal conversations with residents when they meet in the common areas of the property. After these encounters, these employees will sometimes add notes to the resident's files if they notice a change in mood or behavior. This informal monitoring helps to determine seniors' overall health and wellness status, and to inform decisions regarding their care.

In order to assess whether they are still fit to live independently, each resident has their cognition, mental health, fitness level, and overall health formally evaluated once a year. According to the nurse manager, this assessment is particularly helpful to monitor the most independent seniors who do not use the health center frequently: *"it gives us a chance to touch base, especially with the ones that are extremely independent, who don't like to go to the nurses for any reason."* Residents understand the purpose of the test, and find it important for their own well-being. Health monitoring by CCRC also allows some residents to track their health conditions over years. As P14 said,

"you have a chance to see where are you now in comparison to what you did or said last year. [...] I'm not as quick as I used to be. There's a whole lot of difference between 69 and 84. And so you expect to have some measure of slowing down or not being able to do as many things as you did previously or as rapidly."

On the other hand, the cognitive test generates anxiety in older residents. The test carries high stakes because a poor performance means that they are experiencing decline, and that might cause them to move to the next level of care. According to S2, *"there is a great number of residents who are older, maybe in their 90s, who tend to get anxious about it."* This anxiety is still present in seniors who perform well on the assessment, as P5 stated,

"I've been very fortunate, I've been above where I'm supposed to be all along. So it makes it even harder, because you want to keep achieving that goal, and the day comes when you're not going to be able to."

The test includes tasks such as subtracting a number from 100, or recalling a list of 5 words after a few minutes. Seniors strive to maintain their independence, and in order to maximize their results they prepare for these tasks by teaching themselves techniques to perform well. P13 trained for

the subtracting task, as she explained, *"I can subtract 7 [from 100] to 0 today. Last year I only did it 3 times, I think."*

The health center staff members also monitor residents' ongoing health issues and communicate with seniors' health providers. The community staff has both an electronic medical records (EMR) system and a paper-based medical records system that they use to keep track of the residents' health. They keep copies of services that the seniors receive both in the health center and from other health providers, including doctor's appointments and examinations. For instance, if an older adult goes to the health center to get their blood pressure checked, that data will be registered in the CCRC's records, as S5 reported: *"we keep a copy of that because it's good information to have. And we make sure with them it's okay to keep."* According to S5, the health center communicates directly with seniors' doctors: *"we have their name and phone number. And it's plastered all over our EMR and our blue chart. So if we needed to get a hold of them, we could."* Doctors are informed when seniors experience an emergency and are sent to the hospital, when they want to change medications, and when they have other relevant updates. The health center also keeps a face sheet for each resident with their basic demographic and health information, and that document accompanies seniors who are sent to the hospital. Maintaining this information allows the health center to be aware of the health status of each older adult, to understand what their needs are and to make sure that they are being cared for.

The CCRC has two electronic monitoring systems in place for independent older adults. The daily check-in system can identify seniors who may have had an accident or health issue in their residence. Residents have a 'check' button in their bathroom (Figure 1) that they are required to press every morning, between 5:30 and 10:00AM, to signify that they are doing well. This system allows the staff to monitor the well-being of seniors through minimally invasive means. Every morning an employee of the community calls those that have not pressed the check-in button. If there is no answer, a nurse goes to the apartment to check on them. Our participants understand the purpose of this process and value it, as P14 said, *"it's a benefit to know that people know I'm okay."* There are many instances of people who forget to check-in, but according to S5 the community staff always contacts them: *"and there's always some people that don't, they forget. [...] Very rarely, when we go up we find that somebody has fallen or gotten sick. You never know. But it's something that we do every single day without fail."* Oldest seniors associate forgetting to press the button to a memory decline. To them, the check-in is not only a safety system, but it also reminds them of aging-related issues. P13, who is 91, said, *"I am embarrassed when I don't do it in the morning. [...] I noticed in the last year and a half they have to call me. And I hate to slow down mentally, but there I am."*

For emergencies and other urgent needs, each senior has a pendant with an emergency button that they can wear on their neck or wrist. Anywhere on the community property, the button will alert the staff of an emergency, and send the approximate location of the user along with the alert. Although seen

Figure 1. Morning check button.

as extremely important, there is significant resistance to wear the device, as the nurse manager reported: *"It is a wonderful thing when they wear them, but it's really hard to get them to wear them. They don't like it, they feel it's a tie to us and they want to be independent. [...] They know that they're declining, [...] they struggle for every ounce of independence."* For our participants, the button is an unwelcome reminder of aging, and the problems that could occur. They also do not like its size and appearance, as P18 explained, *"I do not wear the pendant, and I know I should. [...] I couldn't sleep with it because I thought it was choking me and I was scared that I was going to roll over and press it."* According to S5, the button was pressed unintentionally *"nine times out of ten"*. During the fall prevention event, another senior said that she stopped wearing the pendant after it was triggered in her sleep.

Combined, these different factors lead to high levels of non-use of the emergency pendant amongst older adults. Although they did not want to wear the device constantly, a couple of our participants placed the pendants in strategic places instead, such as P12: *"I don't wear mine nor does my wife, but I have them down low in the bedroom and down low in the living room."* Since the check-in device in the bathroom already has an emergency cord, P12 used his and his wife's pendants to add this resource to two other important rooms in the house. P12's solution reduces burden, reduces accidental activations, and removes discomfort caused by wearing the device. Most other participants also did not wear the pendant for similar reasons. In the study, we found that seniors who are more afraid of falling, such as P1 and P10, are more likely to wear the pendant regularly, as it provides a sense of security to them. Interestingly, privacy did not seem to be a significant issue for our informants, as none of them mentioned privacy concerns with the CCRCs monitoring. We also found no correlation between attitude towards the pendant and attitude towards technology in general.

The care practices of the CCRC are highly collaborative, as they require active participation from the seniors. Collaborative care allows the retirement community to provide care in a minimally invasive fashion that significantly preserves their agency. The challenges involved in these practices arise from older adults striving to maintain their independence. The con-

Figure 2. P9's blood pressure log (left), P10's pain log (right).

sequential nature of monitoring gradual functional decline and stigmatizing care, such as the emergency pendant, cause tensions between older adults and CCRC staff.

External health providers' care practices

In addition to their day-to-day interactions with staff members, independent living residents of the CCRC tend to interact on a regular basis with a number of doctors and other health providers who are not affiliated with the CCRC. Many of our informants describe their interactions with their doctors in collaborative terms.

In order to communicate with health providers, approximately one third of our participants who self-track register their data on paper and share them with doctors. The most common health indicators tracked are blood pressure and glucose. Most participants bring logbooks to doctors' appointments, but some send their measurements regularly through fax or by phone. P5, when discussing how he tracks blood pressure, said, *"when I get a sheet full I send it to the doctor's office. If he wants a change he'll let me know."* For some participants, such as P9, self-tracking is temporary: *"my blood pressure in the last month has been up a little bit and we don't know why, so I am checking that daily. [...] I will probably call [my doctor] next week and give him a reading of the past week."* P10 uses a notebook to keep track of her pain and physical activities (Figure 2), she reported writing about *"the pain I have in the morning and how long it lasts, how much I walk. [...] So then I can tell the doctor for when I go."* Her purpose is to describe her pain patterns to her doctor.

Seniors also use electronic spreadsheets or documents to keep track of their prescriptions and medical histories, so that they can communicate them to a new doctor. S3 commented that

"[a few seniors] have a spreadsheet or a document where they are tracking prescriptions that they can give to another doctor. [...] They have written out what's gone on over the years so that they can introduce that information to another practitioner."

These older adults maintain succinct health histories in electronic files that they can update when needed, and use to share information with doctors. These documents can be particu-

larly helpful for older adults who may need to communicate a significant amount of information to new health providers, such as multiple chronic conditions, past surgeries and other procedures, and a long list of prescriptions. We observed that self-tracking enables different forms of collaborative care between seniors and healthcare providers, enhancing communication of symptoms and medical histories.

Friends' and family members' care practices

In addition to care from health providers and the CCRC, our participants might also receive care from other older adults, family members, and part-time caregivers. These additional care activities are less comprehensive than what is offered in the next level of care (assisted living), but they help seniors to maintain their independence.

Four of the older adults interviewed live with a spouse; the others are widowed, divorced, or single. Three married participants reported receiving or taking care of their spouses. For instance, when asked about how often he used a blood pressure cuff, P12 responded: *"on myself hardly ever, occasionally on my wife"*. P5, whose husband has mild cognitive decline, reported that she watches for any symptom progression, since they are more noticeable from an outsider's perspective. Most participants have family members who live nearby, such as children and grandchildren, but P1 was the only participant who reported receiving care from family members other than a spouse.

Being at a CCRC offers a sense of community for seniors, in the study we found that residents often provide care for each other when there is an emergency, or when someone needs advice or emotional support. For example, P3 became friends with a neighbor after helping her through the recovery process after a fall, as she explained, *"I went over because I knew she didn't have any family. We became very close friends, because I was her advocate."* Many seniors talk about their health with others, most often close friends. For instance, P14 talked with people who had the same condition in order to inform her own decisions:

"when I had breast cancer, I was very open about it. And I found that there were so many people who came to me when they knew I was facing surgery, and informed me that they were cancer survivors. And that was very encouraging. [...] And it was very helpful to just dialogue with them. You know, what did they do, how did they experience it."

Older adults in the retirement community help to care for one another, as P3 explained, *"we all kind of look out for each other. [...] So it's not just the [health center], or the nursing staff in any of the facilities. it's kind of a communal, to watch out for each other to make sure that nobody is in danger."* However, other seniors prefer to be more private, as P7 expressed, *"many times people get together on the table solely to discuss a change in their symptoms. [...] I don't sit with those people."*

Some of our participants who have mobility impairments receive assistance regularly from part-time caregivers or family members while still living in an independent apartment. For

instance, P1's son helps him with errands and chores, as he said, *"I have a son who comes in three days a week and he does my grocery shopping, and buying the medications, and any kinds of other errands, light housekeeping."* P10 has a hired part-time caregiver: *"I have somebody come in to help me twice for two hours every week, every day of the week. And they fix my breakfast, they make my bed, and if I have any laundry to do, and they run my errands."* These seniors require assistance with a few activities, but less than what is provided in the next level of care, assisted living. They are able to self-care and to conduct their activities of daily living, such as eating and bathing. They are able to remain in the independent section because of the additional help they receive with chores and errands. We observed that collaborative care with relatives, friends, and part-time caregivers was flexible and adaptive to the evolving needs of older adults.

How different forms of care are connected

These different aspects of care are highly interconnected due to their collaborative nature. As a consequence, it can be difficult to separate one form of care from the others. For instance, self-tracking a health indicator and sharing the data with a clinician to support treatment decisions is at the same time self-care, and collaborative care with the clinician.

Self-care is connected to each of the other aspects of care. For instance, many participants reported going to the CCRC's health center to have their blood pressure or glucose measured when their own device failed or ran out of batteries. Others who do not have a measuring device do the same (e.g. those who are only tracking temporarily by a doctor's request). A few participants who self-track regularly also share their records with the CCRC health center. Thus, the CCRC plays a supplementary role in senior self-care. Clinicians also often instruct seniors to self-track, and married participants who track sometimes talk informally about their measurements, or receive help with tracking devices from their spouses. Additionally, a few participants 'self-track' the results of medical exams and the CCRC's annual assessments. Through collaboration, other forms of care can facilitate older adult self-care.

Similarly, we found that the CCRC and external health providers collaborate with one another. The CCRC communicates directly with health providers. While they do not employ any physicians, a few come to the CCRC to see residents regularly, and those have a closer relationship with the health center. The health center employs nurses who provide medical care to the seniors, whose information is shared in both directions - the health center updates physicians on instances relevant to their specialty, and the health center receives information about prescription changes and exams.

Seniors' friends and relatives often recommend physicians, give rides to doctor's appointments, and accompany them during appointments or medical procedures. They also discuss health insurance options and provide advice and support to one another. Family members, and in particular the designated power of attorney for health of a resident, communicate often by phone with the CCRC's social workers, and share information about the well-being of the older adult.

In contrast with self-care, the CCRC care practices are less empowering for the seniors. Self-tracking activities are either initiated by the individual person, or recommended by a doctor who deems it appropriate for a particular person. CCRC care is more general, as it is intended for all independent older adults. When not recommended by doctors, self-tracking is seen as “opt-in”, each person having the autonomy to decide whether it is needed. Not wearing the pendant, however, is seen by the CCRC staff as non compliance. More active and independent seniors are more likely to want to participate actively in their health management, and not to wear the emergency pendant. A tension lies in the negotiation of the care practices between residents and CCRC staff. From the seniors’ perspective, self-care activities such as self-tracking provide more agency and less stigma in comparison with external monitoring systems. From the perspective of the CCRC, monitoring systems provide older adults with additional protection. We did not find any instances of non compliance with the other CCRC care activities.

Overall, in this study we found that although seniors live independently, senior care is highly collaborative in nature and it involves self-care as well as care from the CCRC, from doctors, relatives, neighbors, and part-time caregivers. These different forms of care are interconnected and complimentary. Nevertheless, CCRC collaborative care practices led to tensions due to seniors desire to remain independent.

DISCUSSION

The care of seniors in the independent living facility involves a variety of stakeholders and practices. These care activities are focused not only on maintaining their health and safety, but also their independence. These twin goals form the core of research into technologies and systems to support aging in place. We argue that investigating the intersection of self-tracking and monitoring can help to support independence in this population. These systems have to be adaptive to the needs of the users, and should be tested in real settings in order to understand how the meanings associated with monitoring impact their effectiveness. Furthermore, the needs of older adults to monitor their health indicators through self-tracking should be better supported.

Interplay of self-tracking and external monitoring

The health management of our participants involves both self-tracking and monitoring by others. While frequently seen as separate, we recognize that these activities are often interconnected, collaborative, and provide complimentary benefits to seniors. For example, collaborations involving self-tracking [15] and health record management [13, 48] between health providers and patients have been studied in the context of chronic illness management. In the case of seniors, this process can involve other stakeholders, including family members, the staff of a retirement community, or peers who care for one another. CSCW has an essential part to play in this space, as these care practices are inherently sociotechnical, and the balance between individual control and safety is nuanced and heavily dependent on context [17]. While previous work has investigated older adult care among seniors living with caregivers [44, 53] or living on their own [42], as

well as health management practices specific to a particular illness [57, 32, 44], they have not addressed the complicated and nuanced needs of independent seniors with diverse conditions in a retirement community. Thus, our findings could inform the design of sociotechnical systems for aging in place by characterizing the challenges and successes of collaborative care systems in a retirement community setting.

Collaborative care practices have been discussed in the literature in different contexts, including spouses managing a chronic condition [19], Parkinson’s patients and caregivers [44], careworkers and family members [14, 33, 53], patients and clinicians [23], and independent elderly neighbors [49]. We observed care practices similar to each of these, as married participants care for their spouses, seniors collaborate with their part-time caregivers, with the CCRC staff, with clinicians, and with neighbors they had befriended. In this context, the CCRC is responsible for part of the coordination work usually conducted by patients with their clinicians, and seniors also use self-tracking to facilitate this work [62, 50]. While Nunes et al. [44] have shown the collaboration between older adults with Parkinson’s and their caregivers, we found similar dynamics between independent older adults and the retirement community.

Both external care and self-care are collaborative. Older adults as well as those responsible for their monitoring play important and active roles in both self-tracking and monitoring. Monitoring relies on active participation from older adults. The morning check, a monitoring system geared towards identifying seniors who need immediate help, requires each senior to push a button everyday at a particular window of time. Self-tracking health indicators such as blood pressure is often part of being monitored by health providers. These collaborative dynamics have two main complimentary advantages. First, they enable older adults to have agency over their health management. Second, they allow others to ensure their well-being through minimally invasive means.

Furthermore, collaboration can improve the effectiveness of care activities in multiple ways. For instance, we observed that seniors who share their data with health providers self-track more consistently, which might improve their self-care. Training for the annual assessment may also characterize self-care, as previous work suggests that cognitive training can delay the progression of cognitive impairments in seniors [5]. Having access to patient-generated data can also be informative for health providers. Our findings suggest that the accountability that arises from collaborative care can benefit all stakeholders. However, since our interviews focused primarily on older adults, future work should further investigate other perspectives in collaborative care, such as those of health providers, caregivers, or retirement community staff.

In addition to the benefits we found in collaborative care, combining monitoring and self-tracking in a collaborative process could facilitate the adaptability required to support the gradual aging process of older adults. The independent living section of the CCRC is an “in-between” setting [8], a transitional space between the home and assisted living. It houses people in different health conditions, and there is a

nuanced interplay of agency and safety between independent and assisted living. While evolving needs for assistance can gradually reduce the capacity of the user to self-track or actively participate in their own monitoring, it is important to preserve agency for more independent seniors. Combining monitoring and self-tracking could allow a gradual shift that accompanies the aging process of the older adult.

The fear of being dependent affects monitoring systems

Although the monitoring practices for independent seniors were designed to be minimally intrusive, they are associated with an undesirable impression of dependency, and thus face resistance from older adults. While our informants perceive monitoring to be important for their safety, they still resist being monitored. In our study, this issue was most evident in the case of the emergency pendants. For the CCRC staff, the devices allowed seniors to maintain their independence without compromising safety by providing them the ability to summon help only when necessary. Residents, however, resist wearing the pendant, due to the device being unattractive, inconvenient, error-prone, and, more importantly, being a reminder of aging. Similarly, the annual cognitive assessment also causes anxiety among some older adults, and leads them to practice to increase their performance. Seniors also associate forgetting the morning check-in with a cognitive impairment. Technologies meant to support independence and aging-in-place face the inherent friction that, in addressing the functional challenges of aging, they also often serve as unwelcome reminders of the users' senior status. These findings indicate that monitoring technology should aim to avoid triggering these negative perceptions.

Older adults have an emotional response to their interaction with these systems. Their data has meaning, it reflects their abilities, which may be in decline, and impacts the decision of whether or not to move to a more advanced level of care. The meaning attached to the data affects the perception of and interaction with the system [2, 29, 61]. Furthermore, emergency systems such as the pendant can be stigmatizing [7, 55], and their non-use is prevalent [35]. Non-use of devices due to stigma has been discussed in HCI literature focused on people with disabilities. A proposed way to overcome such issues is to use mainstream devices that provide the same functionality [55]. In the case of the emergency pendant, it has a simple functionality that could be integrated into popular mobile devices such as smartwatches and smartphones.

Another way to mitigate these negative associations might be to monitor actions or instances that have positive connotations. For instance, a study found that self-tracking days when one resisted an urge to smoke produced significantly better results than self-tracking days when one smoked [40]. The check-in system in the CCRC did have a positive connotation, as it monitored the seniors' well-being. For this system, the negative association was not related to the monitoring itself. Instead, it was about how it is designed - the fact that it requires older adults to push the button every morning, when memory issues are associated with old age. Designers of technologies for aging in place must acknowledge these emotional responses, and investigate how to mitigate them.

Because older adults want to retain a sense of independence, technologies designed for their care should provide it.

Unmet needs of older adults in self-tracking systems

We observed that self-tracking is an important aspect of self-care among seniors, and their practices are influenced by the purpose that led them to track. Those who track their blood pressure or glucose want to find if these indicators are at a good level (i.e. inside their target range). The older adults who use the data to communicate with health providers are more likely to self-track regularly, and register their data in writing. Older adults generally do not use technology for self-tracking beyond the medical devices that are required to measure health indicators such as blood pressure [27]. Instead, most register their data on paper. However, there are design opportunities to assist the communication between them and their health providers, and help them to see patterns in a longer term. If the data was made available for medical research, it could also be used to find earlier signs to illnesses than what is currently known [6].

Furthermore, we observed that seniors seldom use self-tracking to promote physical activity, and they perceive electronic activity trackers to not be useful for other purposes. Many older adults' primary reasons for exercising are symptom management and functional training. However, activity trackers are designed with the assumption that the users' primary goals are to become more physically active. This issue is also connected to seniors' perception of activity trackers, as these devices are largely marketed for younger users. This perception is a cultural barrier to the adoption of these systems. Real improvement is more important than registering data about their activity, and our participants repeatedly expressed that they do not think that activity trackers can bring them real improvements in their particular goals. However, these devices have been used for broader purposes, such as tracking progress of post-surgery recovery [18]. Improving seniors' adoptions and perceptions of these devices requires investigating how they can be used by older adults with mobility impairments. Because our findings suggest that balance training is important for seniors to conduct everyday tasks and maintain their independence, studying how to use wearable devices to support this particular kind of activity could be a promising focus of aging in place research.

CONCLUSION

This paper investigates the health management practices of independent residents of a retirement community, and how the combination of monitoring and self-care allows them remain independent for longer. We discuss how these practices can inform technology that aims to assist a broader population of older adults who live on their own, and allow them to extend their independence. We have found that seniors' health management involves collaborative care that includes the retirement community, health providers, friends, and family. We argue that the intersection between monitoring and self-tracking is a promising space to investigate minimally invasive monitoring of independent older adults. Furthermore, the meanings associated with monitoring systems focused on

aging need to be acknowledged and addressed in the design of more effective systems for this population.

ACKNOWLEDGMENTS

The authors thank each study participant, in particular the CCRC staff who allowed us to collect data about the institution and its residents. This study was funded by a CAPES Science Without Borders fellowship and by National Science Foundation Grant No. 1219197.

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