"You Cannot Offer Such a Suggestion": Designing for Family Caregiver Input in Home Care Systems

Pin Sym Foong[1], Charis Anne Lim[2], Joshua Wong[1], Chang Siang Lim[1], Simon Tangi Perrault[2,3], Gerald CH Koh[1]

[1]Saw Swee Hock School of Public Health, National University of Singapore
{pinsym, joshuawong, ephlcs, ephkohch}@ nus.edu.sg

[2]Yale-NUS College, Singapore
chariswork@gmail.com

[3]Singapore University of Technology and Design, Singapore
perrault.simon@gmail.com

ABSTRACT

Previous work has looked closely at the challenges of using patient-generated data to enable remote assessment and monitoring by healthcare professionals. In this paper, we examine family caregivers who act as proxies for patients who may not have the capacity of capturing the necessary data. We worked with occupational therapists to develop an application for remote assessment of the safety of patients' homes by occupational therapists with the assistance of family caregivers. We evaluated the application with family caregivers and found two features unique to communication between family caregivers and healthcare professionals: Caregivers want to be able to direct healthcare professionals' attention to support problem-solving at home, and they include their perspective on how to best meet the patient's health needs. We discuss the importance of these findings for home systems in the domain of long-term chronic care.

Author Keywords

Caregivers; healthcare; informatics; chronic care.

CSS Concepts

- **Social and professional topics~Personal health records**
- **Applied computing~Health informatics**

INTRODUCTION

Family caregivers are often described as "an important piece of the healthcare system" [39]. Recent estimates [48] in the United States show that there are 43.5 million informal caregivers who provide unpaid care. Accordingly, the economic value of unpaid care has risen steeply from USD375 Billion in 2007 to 470 Billion in 2013. When older adults have care needs, family caregivers undertake a significant and critical burden. In a meta-review of programs where family caregivers were explicitly integrated into post-hospitalization care, [36] showed clear medical benefits such as shorter rehospitalization and lower costs of care.

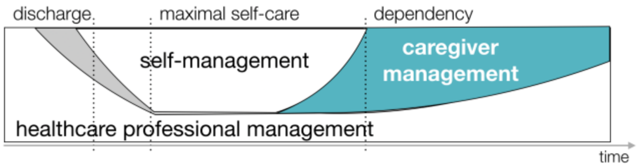


Figure 1. **Illustration of the changing health management roles of healthcare professional, patient and caregiver as chronic disease progresses.**

In Singapore, where this study was conducted, people are expected to spend an average of 10.6 years living in disability towards the end of life [30]. The work of family caregivers during these years consists of communication (35.1%), feeding (32%) and bathing duties (21.1%) [46]. As disease progresses, patient independence is compromised, and family caregivers often rise to take on increasing responsibility for the patient [12]. We illustrate this phase in Figure 1 (green, right), describing a period of chronic disease that we call "caregiver management".

Previous studies [28,29] have focused more on patients' self-management and their relationship with healthcare professionals, or on family caregivers alone [6,42,43], but less emphasis has been given to the relationship between family caregivers and healthcare professionals.

Previous research also showed that patients appear to be mostly open to caregivers accessing personal health records [20], even though there remains some tension between patients and caregivers regarding the use and sharing of data from patient portals [15]. There is also evidence that family caregivers may be unreliable reporters of systematic assessment outcomes [27]. Beyond this, there remain many open questions as to the **behavior of family caregivers when acting as patient proxies during their interaction with healthcare professionals.**

Due to the previously identified difficulties in the collaborative relationship between patients and healthcare professionals [1,28], our goal was to examine both the information elicitation needs of healthcare professionals and how information-gathering tasks are viewed by family caregivers. We used a user-centered research approach and developed a remote data gathering system in coordination with occupational therapists. The purpose of the system was

CHI '20, April 25–30, 2020, Honolulu, HI, USA

ACM ISBN 978-1-4503-6708-0/20/04…$15.00
https://doi.org/10.1145/3313831.3376607

to enable caregivers to gather home environment data for occupational therapists' (OTs) to remotely assess the home for safety for mobility-compromised patients. The target home user was the primary family caregiver.

We evaluated our system, *HomeAx*, with family caregivers who had brought home a patient with impaired mobility after discharge. We checked for system usability and interviewed caregivers on their caregiving experience and their response to the system. We analyzed the qualitative results using thematic analysis.

Similar to research on patients, our findings show a disjunct between what healthcare professionals see as important and the types of information that family caregivers feel the need to report. New in this study is the substance of this disjunct. Firstly, family caregivers seek to direct OTs to support problem-solving at home, regardless of whether it deviates from the requested information. Secondly, family caregivers wish to include their own perspectives on how to best meet patients' care and safety needs in their communication with healthcare providers. In our discussion, we look at the implications of these findings with respect to other work in this field, and on the design of at-home systems in the management of long-term, chronically ill patients in Singapore.

The contributions of this paper are 1) an implementation of a remote home assessment system 2) a description of proxy care reporting behaviors of family caregivers 3) design opportunities for supporting the management of long-term, chronic care at home.

RELATED WORK

Family Caregivers within Patient Care

On the left of Fig 1, we reproduced Pollack et al.'s [24] diagram from their study on patients' information and data needs from the hospital, through discharge and to the home. In this study, Pollack et al. indicated that information systems for at-home care needed to begin use in the hospital, before discharge [35]. We adapted their diagram to reflect the role of the family caregivers who accompany the patient in the hospital, through discharge and towards patient recovery [23,29,34,38].

In the middle segment of Fig 1, which we label "self-management", patients are sufficiently cognitively intact to engage in technology use, data analysis and reflection and discussion of their gathered data. In these circumstances, many studies have focused on 'personal informatics' and the gathering and use of personal health data [7,21,47].

In this phase of patient self-care, a large number of studies have identified various challenges that healthcare professionals have with patient-reported data. Healthcare professionals can find patient-generated data unwieldy – difficult to interpret, not clinically relevant and more mundanely, incompatible with their record-keeping practices [1,7,14,47]. For example, [13,28] identified a gap between the format and content that healthcare professionals want to collect and the type of data generated by non-medically-trained patients. Within the healthcare visit, Mentis et al. [28] described how patients and clinicians needed to work together to "reshape" data during a clinic visit.

On the patients' end, there are also a variety of issues with patient-healthcare professional reporting. Firstly, patients are not satisfied with what they perceive as the unappreciated work of gathering data. Despite their efforts, they report that physicians may trust patient-generated data less than lab-generated data [1]. Secondly, patients wished to expand the collected data to purposes *not* commissioned by healthcare professionals. For example, Nunes et al. [32] described how patients want to, but may not be able to put the data arising from self-care technologies to uses such as sharing and reflection.

Taken together, these findings have led to calls to innovate systems that allow for collaborative conversations between clinicians and patients over the reported data [14,16,28,41].

In longer-term chronic care and HCI, family caregivers are increasingly being recognized as an important stakeholder. They are often acknowledged as "collaborators in self-care" [8]. However, caregivers are often mentioned as one part of a "patient and caregivers" dyad. This treatment assumes full alignment of patient and caregiver perspectives and prioritizes patients as the main focus of the patient-caregiver-healthcare provider relationship. Some countering evidence suggests that family caregivers behave differently from patients in their purposes and sharing of patient data [15,20]. Family caregivers may also be inaccurate when assessing patient outcomes for healthcare professionals [27].

Since there exist circumstances in which family caregivers must assume primacy as the advocate and main caregiver of the patient [10,39,46], our goal was to examine deeper the behavior of family caregivers in this role.

Family Caregiver as Target User Group

In HCI research where family caregivers are studied, the focus has often been on the family caregivers' own needs. For example, Tixier and his colleagues [42–44] studied the social and support needs of family caregivers, particularly in regards to other family caregivers, and with the resources available in the community. This body of work called for online social support systems for groups of caregivers to share both instrumental and emotional concerns, and also for connecting caregivers to offline resources.

Another deep dive into family caregiver needs comes from Chen et al.'s [6] work on "integrality" and caring for caregivers. In this study, Chen et al. identify four "selves" in caregiving that should be served, outlining the multiple roles of caregivers in physical, emotional, social and reflective selves. We place our study of family caregivers as a closer examination of what Chen et al. call the physical self [6], addressing the activities and conditions of caregiving when they act as proxies for the patient at home.

To study this bridging role between care at home and healthcare professionals, we selected a project that involves these two parties. We partnered with occupational therapists who wanted to create a system to enable **remote home assessment** of a patient's home before the patient's discharge.

Background on Remote Home Assessments

Home assessments are conducted for patients who have heightened fall risk at home due to a loss of mobility [19]. During a home assessment, an OT's role is to use knowledge of patient and household composition to address functional deficits arising from the medical problem. The home assessment results in recommended modifications to the patient's or family's home. If there are difficulties with the recommendations, the OT helps to find alternative solutions [19]. A home assessment typically ends with a to-do list for caregivers which would include items like installing grab bars or re-organizing shower areas for independent bathing. When completed, these modifications are effective in decreasing the risk of home injuries and falls, especially for older adults [9,17,25].

Despite the proven benefits of home assessment, the time and cost of travel to the home can be prohibitive. Thus, previous work has suggested conducting remote home assessments with trained assistants who transmit synchronous videos to therapists [10]. More recently, a photo-based approach with caregiver-generated data [4] was proposed. Evaluations of these methods show that they are viable strategies, but each had some combination of the following limitations – the need for trained personnel to be on-site [10] which negates the travel savings, photos fail to show wet/slippery floors [4] and may not show everything an OT needs to see [4] due to occlusion or limited field of view. The combination of video and photo systems for this purpose has not yet been explored.

METHOD AND STUDY DESIGN

Given the difficulties with patient-reported data being incompatible with healthcare organization goals mentioned in the literature review, we sought to maximize the likelihood of a smoother collaboration using our system. Our goal was to reduce the friction over the formatting and specificity of the data collected.

In the first study, we conducted participatory design [18] sessions with OTs to gather the functional requirements of a system that requires caregivers to report data on the lived experience of mobility in the home. By observing simulated tasks and querying decision-making processes, we explored the requirements of healthcare professionals for reporting data on caregiving in the home. Then, we implemented the home assessment system *HomeAx* with these requirements. The app guides caregivers in taking a series of photos and videos at specific locations in the home.

In the second study, we evaluated our system with caregivers who have the lived experience of bringing home a family member with a change in functional mobility. We observed the process of using the system and analyzed the challenges faced by the caregivers.

Throughout, our goal was to use the findings and analyses to improve collaborative systems where family caregivers act as proxy reporters. We conclude by identifying the opportunities and challenges in supporting this relationship.

STUDY 1: PARTICIPATORY DESIGN WITH OCCUPATIONAL THERAPISTS

We partnered with 4 hospital-based occupational therapists (OT) from a public acute care hospital, and another 3 from a public acute and rehabilitation care hospital who work with long-term rehabilitation patients. The first group had a combined experience of 18 years among 4 OTs (mean = 4.5 years) while the second group had a combined experience of 5 years among 3 OTs (mean = 1.6 years).

Over two sessions of participatory design per group, we iteratively designed a low-fidelity prototype between sessions and conducted short user testing sessions with the OTs to gather feedback.

Our objective in this study was to 1) generate the requirements for a hospital-originated system that utilizes non-expert family caregiver input to document the home environment, and 2) understand current OT practice and values in conducting home assessments.

In the first session with the OTs, we walked through various items in paper-and-pen home assessment tools. The paper-and-pen tool was the "Fall Prevention and Home Safety Checklist" specifically developed by Singapore OTs for assessing apartments that form 80% of housing in the country (available in Supplementary Materials). Next, we asked the OTs to assess 4 photos of bathrooms taken from different angles. We focused on bathrooms as falls in bathrooms happen more often, with more serious results, compared to other locations in the home [12].

The therapists assessed the images based on two scenarios that they commonly encounter: "a patient who is newly wheelchair-bound" or "a patient who is returning home ambulant but frail", resulting in 8 annotated images per group of OTs (sample in Figure 2, top). The OTs were encouraged to discuss and explain their annotations, thus allowing us further insight into the thought process and goals of a remote home assessment.

To explore how OTs gain an understanding of conditions at home, we brought with us 2-dimensional home plans, and a spherical photo-taking app Bubbli[1].

Finally, we requested the OTs to complete two tasks on a prototype iPad application from a student project (Fig. 2 bottom). This iOS application was structured on the afore-mentioned Fall Prevention and Safety Checklist with an

[1] Bubbli (https://bubb.li/)

additional photo-taking and annotating function. Through this exercise, we could observe the challenges faced by OTs when the same task of annotation was conducted using a digital interface. While performing these tasks, we encouraged OTs to freely suggest additional features.

We used the insights to create low-fidelity prototypes. In the second session, we asked for feedback based on these prototypes.

Findings

Heavy User Burden

Recall that the initial prototype application was a naïve, digitized version of a paper-based assessment protocol with 72 tasks. The OTs' feedback was that a) completing the entire assessment may be too heavy a task burden on the caregiver, since caregivers have many other caregiving duties to attend to simultaneously, and b) OTs often conduct just a subset of these tasks, depending on the patient's unique needs. Thus, it would be a wasted effort to require caregivers to document the entire home. From here on, we focused on our efforts on strategies to minimize the data gathering tasks.

The Nature of Situational Awareness in Home Assessment

During a discussion of using blueprint-style plans as a way of arranging the gathered media, we were surprised to learn that the full details of the exact location of the room in the home were not important. Instead, it was more critical for the OTs' understanding of the potential mobility hazards at home to see the path traveled, leading up to each room.

Once a room was reached, it seemed important for the OTs to gain a thorough understanding of objects and the space around them. For example, in Fig. 2 (top), the OT annotated the figure with a request to see what is "behind the door". On another picture, the annotation asked, "What about on the left?" when the narrow field of view limited what could be seen.

We then discussed with the OTs the pros and cons of using a spherical photo as a possible solution to the limited field of view. After experimenting with this method of gaining contextual overviews of the home environment, the OTs raised the concern of privacy as a 360-degree image covers the entire home, including areas not relevant to the patient or task at hand. This technique was also less useful as the image was warped for perspective correction and distorted in the stitching process.

Thus, we concluded that the system should support videos for documenting paths between places. Videos will enable better contextual understanding but does not easily permit close examination. On the other hand, in places such as bathrooms and bedrooms, the system should require multiple photos from different angles.

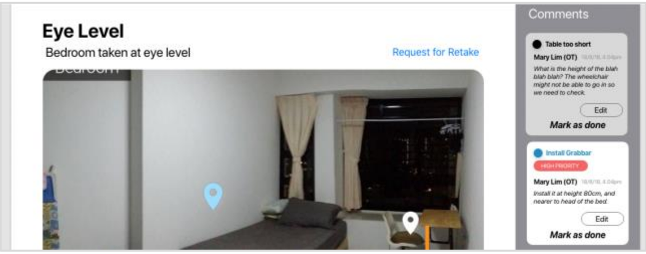
Figure 2. Outcome of the photo annotation activity on paper (top), and the outcome of OTs doing a similar annotation on our prototype iPad app (bottom).

Communicating Assessment Outcomes

When we discussed the bathroom image annotations, the OTs explained that they wanted to be able to point to an object, or circle an area, then annotate it with instructions for the caregiver. In the digital version, they indicated that the annotations should not overlap each other nor cover too much of the image. These occlusions block important information about the room's context.

The OTs explained that these image annotations have two benefits. For the caregiver, it forms a list of contextually displayed recommendations. For the OTs, it becomes a documentation of the assessment, which they can use in their record-keeping and sharing the recommendations with caregivers.

The OTs initially requested for a messaging interface where comments on the recommendations could be read like conversations. We implemented this feature in a visual, click-through prototype using Adobe XD (Fig. 3). In this suggested interface, both the OT and caregiver can write and reply to comments tagged to individual images/video frames.



Eye Level

Bedroom taken at eye level

Table too short

Mary Lim (OT)

What is the height of the blah blah blah? The wheelchair might not be able to go in so we need to check.

Install Grabbar

HIGH PRIORITY

Mary Lim (OT)

Install it at height 80cm, and nearer to head of the bed.

Figure 3. A visual Adobe XD prototype of a conversational space to discuss recommendations. This suggested function was rejected.

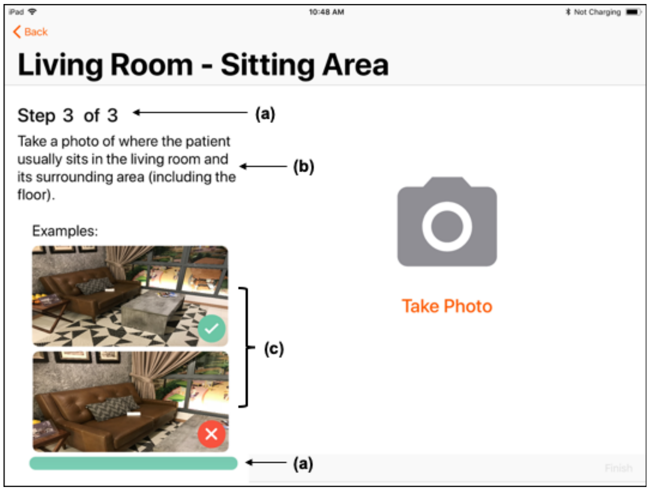
However, during the feedback session, all OTs became concerned that the conversational interface might "waste a lot of time" because the dialogue function opened up the possibility for the caregiver to ask questions beyond the scope of the home assessment. While unrelated topics are a common occurrence during a family caregiver consultation, having a messaging function seemed to open up their availability and obligation to reply, and to reply in a timely manner. Additionally, the OTs were also concerned that they could not be sure when the patient was going to see their comments on the platform or follow up with them. In all, the conversational interface became undesirable as it was likely to increase the OTs' work burden.

This led to a discussion of current communication practices. The OTs shared that their existing process is sub-optimal. Until about a year before the study, they had requested for photos using a locally popular messaging app, but this was stopped in order to comply with new hospital guidelines on data privacy. However, when they moved the conversation to email, our public hospital OTs were limited by the lack of storage in shared computers for data-heavy images. Additionally, this technique required a separate process of using software for marking up the image and resaving it. Phone calls supported 2-way communications, but not the efficient transfer of images. In summary, the OTs wanted the system to document and share the assessment outcomes in a way that was easier and quicker than current methods.

In the end, it was agreed that follow up conversations should still be constrained in time over the phone or face-to-face with both parties viewing the hard copy results of the assessment.

This envisioned process had the following advantages: limiting discussion time to the call or meeting and reducing the requirement for English and digital literacy for caregivers to view the annotations. As Singapore is a multi-ethnic country, OTs in Singapore often learn to speak multiple languages in order to bridge the language gap with clients. Reading in English and typing on a digital platform might limit access for some caregivers in Singapore.

Finally, the completed recommendation document should be in their standard report format, and available to the OTs as a digital copy for filing as part of the patients' medical records, and to initiate payment upon service completion.



Living Room - Sitting Area

Step 3 of 3

Take a photo of where the patient usually sits in the living room and its surrounding area (including the floor).

Examples:

Figure 4. Screenshot for photo-taking task for family caregiver. (a) text and visual progress indicator informing user on their progress. (b) text instruction informing user on the specific feature of the environment to be capture in the photo or video. (c) example of right and wrong image.

IMPLEMENTATION

We arrived at a guided data gathering approach that combines videos and photos for the caregiver to document the home environment in ways that the OTs need to see.

Although each home is different, there are locations of critical importance across every home. The OTs helped identify these locations as the home's entrance, bedroom, and bathroom. By focusing on these areas, we could minimize the number of tasks required to communicate the conditions at home.

Based on these requirements, we worked with the OTs to create a set of text instructions for each individual task. Next, we visited model homes at the Singapore Housing and Development Board (HDB) to take example photos/videos correspond to each text instruction, using the iPad camera.

Finally, we implemented *HomeAx* as an iOS application for iPads. The application supported remote home assessment by tasking caregivers with media capture tasks (Fig. 4). The text instruction and accompanying examples were displayed to the user for each photo or video task. For the photos, we included a good and bad example, but for videos, we only included a good example. This was because a single "bad example" video might not sufficiently capture all the potential mistakes. Even worse, it might confuse the users.

Once the tasks were completed, users would be given the option to accept or change the media. Once the user was satisfied with the input photos/videos, they would send the information to the OTs and the system will update the OTs interface for them to review and annotate.

STUDY 2: FAMILY CAREGIVER EVALUATION

Our research questions going into this study were: 1) *How has their experience of being a caregiver to a family member needing chronic care support been?* and 2) *Given this* *experience, what were their opportunities and challenges when using HomeAx to report data as requested by the OTs?*

Recruitment and Participants

Following ethics board approval, we recruited, using convenience sampling, individuals who were primary family caregivers. We put up posters at community centers and online via Facebook. We used the following recruitment criteria for care recipients (henceforth, "patient"): at least 65 years old and have had a history of at least one hospitalization followed by a return home with limited mobility. We also required that the caregiver in the dyad must have had consulted a professional about home modification and/or had an OT conduct a home assessment for the patients' home. People who met the recruitment criteria were given informed consent forms. A home visit was then arranged for the interview and prototype testing.

A total of 14 family caregivers, who were caring for 13 patients, participated in the study. One family had a pair of sisters who shared caregiving duties (P5a and P5b), so we decided to interview them together. Caregivers had a mean age of 56.8 years (SD=6.9, min = 47, max = 70) old. All participants could converse and read English fluently. 8 (61.5%) of the dyads lived together with the care recipient, while the other 5 (38.5%) caregivers did not. 11 (84.6%) of the caregivers were children of the patients. The remaining two were the nephew (7.7%) and the spouse (7.7%) of the patient. The caregivers had an average of 5.9 years of caregiving (SD=9.2, min 3 months, max 34 years).

All 13 of the aforementioned patients were female. Patients' mean age was 80.8 years (SD=10.8). All patients met the age criteria except for one who was 52 and bedridden. However, this dyad was included because her caregiver husband (P4) had met the main purpose of the recruiting criteria - he had extensive experience interacting with hospital personnel in the course of care for his bedridden wife.

In terms of mobility within the house, 5 (38.5%) of the patients depended on a walking-frame and had to be assisted while 4 (30.8%) were wheelchair-bound. 2 (15.4%) of them were ambulant but frail – they could walk independently but very slowly. 3 patients (23.1%) stayed in a multi-story house that required movement up and down the different floors, while the remaining 10 (76.9%) stayed in a single-level apartment or were restricted to a single level in a multi-story house. 12 out of 13 (92.3%) patients were additionally cared for by a foreign domestic worker, a common care option in Singapore [33]. Overall, the data matches with local and global informal caregiving statistics that have a high representation of females both as care recipients and as adult children caregivers [33,48]. A table of participants is available in the Supplementary Materials.

Study Design

Semi-structured interviews

We began the session with a short semi-structured interview focused on the participants' caregiving experience. We asked 1) *"Can you tell me more about your relationship with the care recipient?"* and 2) *"How long have you been a caregiver?"*

If the participant made no mention of their interaction with a hospital OT, we asked them if they had consulted an OT on home modifications, their experience on the consultation, and whether or not the OT's recommendations were implemented.

Finally, we asked participants questions about their experience during the transition of the care recipient from hospital care to home care: 1) *"What was the homecoming process like?"* or 2) "*Did you try to do something different (to prevent future falls)?"*

Usability and Acceptability Evaluation

To understand how family caregivers' caregiving experience influenced the way they report information to the healthcare professional, participants were given the following scenario and task.

"While the person you are caring for is in the hospital, your occupational therapist gave you an iPad and instructed you to task pictures and videos of [care recipient name]'s home using the HomeAx application. She wants to see whether the home is friendly and safe for the patient when he or she goes home. She also tells you that after you are done taking the necessary pictures and videos, she will receive them on her own iPad, and she will then assess the home for risk and possible modifications."

During the task, we observed and recorded notes on user behavior. Caregivers were instructed to 'think-aloud' [11] to provide insight into usability issues. Most participants completed the task within 20 minutes. When usage difficulties were encountered, we prompted participants to explore possible solutions before we provided assistance.

To compare the user experience between a paper-based home assessment checklist and our *HomeAx* application, we gave the participants the "Fall Prevention and Home Safety Checklist" to complete. Once again, we instructed the participants to think-aloud while they were completing the checklist and we recorded notes on the user behavior observed. Finally, caregivers completed a modified System Usability Scale [5]. We removed two items from the SUS that referred to a "system" so that we could compare results for both *HomeAx* (the digital prototype) and the paper-based checklist. We also added one question to the questionnaire - "The time needed to complete [method] was reasonable" in order to understand if our method was burdensome to use. All questionnaire items were rated on a 5-point Likert Scale, with higher total scores being better. Participants were also prompted to give direct feedback or suggestions. Each caregiver was compensated with ~15 USD worth of grocery vouchers.

Analysis

We calculated the average score across the eight SUS questionnaire items (max score 40), and we conducted t-tests to compare outcomes.

We used thematic analysis [3] to examine the interview data. Each interview and user testing session was audio-recorded and subsequently transcribed. Two authors individually coded two interview transcripts. Then, with two more authors, we created a coding scheme iteratively and reconciled themes across coders before coding the rest [4].

QUANTITATIVE RESULTS

The SUS was significantly higher for the *HomeAx* (t_{13}= 4.316, p=0.02, *HomeAx* mean=27.7/40 SD 2.89, Checklist mean=20.85/40, SD=8.47). *HomeAx* was perceived to have a more reasonable completion time, as compared to the Checklist (t_{13}=1.917, p=0.03, *HomeAx* mean=4.62, SD 0.51, Checklist mean=4.08, SD=1.04). We asked participants about their preference for *HomeAx* versus the current checklist method. 7 (53%) preferred *HomeAx*, 1 (8%) preferred the checklist, and 5 (38%) indicated that both had strengths that they would like to see incorporated. Specifically, participants liked the way the questions in the checklist helped them be more aware of the safety challenges at home.

Despite the participants' preference for *HomeAx*, we observed that participants seemed to not follow the instructions in *HomeAx*. In our analysis of the qualitative data, we found various motivations that seemed to explain this behavior. The following qualitative analysis expands on these motivations.

QUALITATIVE ANALYSIS RESULTS

We present the qualitative findings according to the themes that arose from the analysis. We note here that we have left colloquialisms in the text for reporting integrity, although they may not be grammatically sound.

Family Caregivers Filter Recommendations by Patients' Preferences

We found that family caregivers wanted to attend and respond to the patient's expressed needs and desires over the healthcare professional's recommendations.

P3 is a 53-year-old man who cares for his 76-year-old mother with limited upper limb mobility. He had removed previously recommended shower modifications because she had complained they were "in her way".

P11 is a 50-year-old woman. In this excerpt she relates her challenges when choosing medical equipment for her 83-year-old mother who had fractured her hip seven months ago:

> "We got her a rollator which is what she was using in the hospital initially. It is like a walker with wheels. When she saw it, she flipped. That was a cause of great tension initially… So actually we returned the item to the supplier because I thought we always have to struggle over that issue, and she was telling every single visitor about how sad she was about the rollator, 'Look, it's so high, I will fall'. And how 'it is really not my home anymore'. That was also recommended by the OT. And we had actually purchased it and it wasn't cheap also. And it was so hard to get one that had an adjustable level as well. I think, that was the hardest part. **Not so much putting the OT's recommendations into effect but rather how accepting she was of those changes. Because she just wasn't ready**."

In these cases, family caregivers who attempt to follow healthcare professional's advice were met with pushback by the patient for reasons that were not medical, but psychosocial. Eventually they decided in favor of the patient, without incident.

However, there were also instances where family caregivers encountered problems when not complying with OT recommendations. Some solutions had unintended, unexpected health consequences. P13, a 62-year-old woman with 10 years of experience caring for her 90-year-old mother related her learning journey:

> "In fact, I think we did all she (the OT) recommended. And maybe more. We installed a ramp outside as well as the bedroom toilet. There is a drop, so my brother did that. But subsequently, because (my mother) fell… something happened to her, she suddenly like couldn't move - she couldn't coordinate. All the food she eat, start(ed) dropping. We didn't know what is wrong with her, so that kind of set her back in her mobility as well. **Then we realised maybe we should not create ramp, she must be forced to move.** So we took out the ramp from outside the door and removed the one at the bedroom. *(Has it been better?)* Yah, she needs to step out. It's better for her."

The above example illustrates the importance of communicating care goals between healthcare professionals and family caregivers. When it takes place, this negotiation produces ideal problem-solving processes. P11's open communications with the OT about mobility solutions for her mother illustrates the ideal case:

> "In terms of furniture, I suppose the geriatric chair that was recommended - we talked about it a lot... Like we can flip it to a lying position and we can roll it about and all that - but she (the OT) recommended that we not get that because it was good to encourage my mom to start moving. If you have one chair that does everything, there is no need for the person to get out of the chair. The ideal is to recover as much of the ability my mom had before. So we got the cheap and simple but highly recommended geriatric chair."

Hence, while it may be intuitively appealing that caregivers should prioritize patient preferences, this finding on unintentional care outcomes cautions that the inherent knowledge limitations of informal caregivers should still be complemented by input from trained professionals.

Family Caregivers Sought to Direct OT Attention

As mentioned above, we saw seven participants (P3, 5, 6, 8, 9, 10, 11**)** who were not directly following the instructions. This mainly manifested through the behavior of ignoring instructions or using the app to take unrequested photos of areas and objects. Since the app was rated highly on the SUS scale, these issues did not seem to be usability problems. Instead, it might have been related to the app's perceived usefulness.

For example, P8 was thinking aloud while following the instructions to take pictures of the entryway to the house (front door). She decided to re-interpret the instructions to take pictures from the entrance of the building, including the stairs leading up to her apartment:

> "Entry. But I want to go more than entry. I want to go staircase. So, okay, I can interpret it as entry from the estate straightaway. I am assuming entry does not just mean the unit, but I will go downstairs and take the picture for the OT from the staircase because when she was at [rehab hospital], I specifically spoke to the OT to say we stay in a walk-up apartment, there is no lift, she needs to make sure she is trained to be able to walk up."

In this case, P8 was cognizant of a mobility obstacle that she knew her mother had to face in everyday life, so she had specifically directed OT attention to it both in conversations at the rehab hospital, as well as through the app. In another case, P11 summarized the need as wanting to "deal with the trickier places that require the OT's input".

P4, a 58-year-old man who had cared for his 52-year-old wife in a vegetative state for the past 1.5 years, had done extensive thinking about the problems he had to deal with in his house to enable a high level of care at home. His main purpose of interacting with OTs was to leverage another source of knowledgeable input, and not for recommendations:

> "So what I needed to do is to share with the OT what my house will need then she will agree or not agree, or (say) why not we do this or that."

We concluded that at different levels of caregiving experience, participants seemed to want to direct OT attention to achieve more competent care solutions. They seemed to expect the caregiver input app **to facilitate their problem-solving in the home,** and not just deliver what the therapists were requesting data for.

This finding suggests that one way to improve the usefulness of the system is to enable them to lead the process so that they can highlight the issues they encounter, rather than confining them to OT instructions to scan for issues most commonly encountered by patients and caregivers. P9's frustration with the generic types of information therapists ask for illustrates this need to lead the reporting relationship. At 61 years old, P9 has cared for 4 single, elderly aunts for 34 years. He described his previous interaction with OTs as being unsatisfactory due to a difference in focus:

> *"(Did you consult any OTs in the hospital for advice?)* No, they won't help me with these things. They will only help me with like - maybe that's one of the limitations. They will help me with things they know, things they are supposed to do - maybe grab bar, they have a list. But sometimes, you look at it and it's like, I don't care what your established checklist is."

Another four caregivers (P2, 4, 8, 11) reported experiencing similar limitations arising from medical experts' advice. This seemed to be the case when these tasks come from guidelines that address the common needs of most patients. However, family caregivers, due to their focus on one patient's needs, will often want to deviate from the requested tasks.

Family Caregivers Offer Home Care Expertise

The previous excerpts showed that at-home care involves a learning process and a series of daily challenges of attending and responding to patient care needs and adapting home life accordingly.

Over time, family caregivers' competence for care at home grows. This next excerpt is from P13, a 63-year-old woman who has cared for her mother for 7 years. She relates the learning process she went through and challenges she had to overcome in facilitating her mother's walk from the bed to the toilet:

> "We wanted to have a clear space in front of her when she (mother) gets up, she goes straight to the toilet so she doesn't have to manoeuvre. I think this one is commonsensical, we don't need the OT. But the bed frame - because she is heavy, she might not have the strength to get up, and our bed is not the hospital bed. So we had to go looking on the Internet for something to grab so she could get up herself… (Then) we realised … we need a lower bed. We never knew she would fall so she just slips because her leg was not quite touching the floor when she got up. The bed is not good so we swapped beds among the siblings. Then we realised since she is not steady, we needed a frame so that all came together. So that it's secure for her. … Very recently, because it happened near the bedroom, she passed her urine, the floor was wet then she almost fell… So I guess, it's always a learning process. The nurses, the OT won't teach us all these. What happens when she pass urine and the floor is wet? But then we realised there is a high probability the person will fall. The nurse won't alert you to all these."

From our work with the OTs, we know that slippery surfaces are part of the home assessment check. Nevertheless, this perception that the healthcare professionals cannot address certain issues due to their absence in the family members' daily lives was prevalent among our participants, as mentioned in the previous sections.

Together with the previous point of attention directing for problem-solving and prioritizing patient preferences, there is evidence here that family caregivers seem to take on the role of experts in patient care at home.

Care Needs of the Family Caregiver

Our findings showed one more element that is specific to caregivers' expertise. In our analysis of the interviews, we saw that long-term caregivers often learn to develop habits and practices that are sustainable over time.

For example, P4, the participant who cares for his vegetative-state wife, describes why he rejected an assistive shower device recommendation that he saw as unsustainable:

> "The caregiver doesn't just look at medical or person-centric needs. He also looks at the household needs. The OT doesn't have to worry that somebody has to wash the clothes, the poo sheet or change the curtain but we have to do that. They don't have to worry if somebody falls sick, then how? So since the caregiver is also the housekeeper and the cook and the person who buys the groceries, then I cannot be sick. So in the whole setup**, I also must cater for the wellbeing of the caregiver** …That's a lot of work we have to do every day… The caregiver will also be very tired and you burn the person out very quickly. So I said cannot, you cannot offer such a suggestion. It is not a good suggestion."

In a follow-up discussion with our OT partners, we asked how they respond to objections to their recommendations, particularly those based on the family caregivers' coping needs. Their response was that they usually promote discussion to find an alternative solution. There were no *a priori* measures to address family caregivers' needs.

DISCUSSION

Our findings indicate that family caregivers want to comply with patient preferences, and often prioritize those over instructions and requests from healthcare professionals. Daily interactions with the patient grow their ability to advocate for the patient, eventually turning them into the expert on home care. This expertise then influences how they liaise and negotiate with healthcare professionals.

This journey bears similarity to studies that describe patient self-management, e.g. [32,35]. Patients also grow in knowledge, resources, and efficacy to manage care. Furthermore, as with Chung et al.'s study on patient behaviors when sharing data, artifacts placed in the collaborative relationship between family caregivers and healthcare professionals have characteristics of boundary objects [7]. They are used for communicating, negotiating and aligning different needs. Similarly, we showed that family caregivers wanted to use HomeAx for asking for input and for negotiating care practice at home versus care practice as required by healthcare professionals.

However, this desire is in tension with our other finding that the OTs sometimes want to limit communications in order to manage workload. Resolving this tension is important so that we can move forward with better at-home care systems.

What differs between patients and family caregivers as reporters of at-home care is the advocacy position. Miller et al.'s work on the role of the caregiver in the hospital [29] suggests that this advocacy position begins in the hospital. Our study shows how, in the longer term, this role continues to develop. It encompasses patient needs, but additionally covers the needs of the household, the needs of sustainable care and the goals of the caregiver.

The importance of the advocacy role lies in the way the family caregiver becomes the channel through which patient care is filtered. Similar to patient behavior, family caregivers filter incoming information against patient needs. However, when information is outgoing, the mediation creates data that is influenced by the family caregivers' understanding of these multiple other needs. In reporting on raw, quantitative data this may not matter, but for qualitative, interpreted reporting, the caregivers' influence will be significant.

Given the family caregivers' mediating role, we conclude that there are two key points of consideration when designing systems for home care.

Implications for Design of Home Care Systems

1. Home care systems should recognize the "home expert".

Our findings suggest that home care systems are where medical expertise meets home expertise. We showed that both elements are important in the creation of sustainable care practices that benefit the patient. Yet, despite our best efforts, we continued to find a disjunct between what healthcare professionals want to elicit and what caregivers want to communicate. This suggests that there remain areas for alignment.

Potential alignment may arise from recognizing the role of the home expert. It is given that healthcare professionals, in their stance and knowledge, are mostly correct when directing caregiving practice to longer-term goals. They are the voice of the collective knowledge of medical practice and are trained to direct recovery and rehabilitation. At the same time, family caregivers live with the everyday implications of care practice. Hence, it is important that at home care systems recognize their role as the experts in the patients' preferences, the preferences of other co-resident family members, and in the demands of the particular context of each unique home.

The call for collaborative partnerships with family caregivers is not new in the health [10] and HCI [31,34] literature. We add to this call by suggesting that an explicit recognition of the role of the family caregiver as "home expert" can do more to reify the contribution of the family caregiver in advanced chronic care. For example, with *HomeAx*, after the caregiver evaluation, we redesigned the interface to have options for additional, open-ended reporting at every place or path in the home. Additionally, we re-organized the order of tasks to create three home tours that are led by the family caregiver. Our stance was to invite family caregivers to be the authority when it comes to reporting about care at home. When we demonstrated this design feature to our partner occupational therapists, they indicated that this approach supported their understanding of the home context better than a series of logically ordered, but not necessarily meaningful locations.

2. Home care systems are an opportunity for caring for the caregiver.

The findings suggest that there is an opportunity to incorporate care for the caregiver into at-home care systems. Incorporating care channels for the caregiver into patient care systems can seem to be an unnecessary dilution of purpose. However, it does bring the benefit of placing both family caregiver and patient under the same medical care umbrella. Schumacher et al., in a nursing review article on how to work with families of older adult patients, call for nurses to pay attention to caregiver strain and to assess when family caregivers are at risk for poor health outcomes [39]. The authors recommend that being in partnership with caregivers means that nurses support them in the following areas: caregivers' roles and responsibilities, caregiving difficulties, the caregivers' preparedness, the quality of care, the caregiver's physical and mental health and self-care activities, and the relationship between caregiver and care receiver.

Neither the number nor the reach of these recommendations is insignificant. It means that including "caring for the caregiver" in home care systems begins from the healthcare organization itself. This may be outside the scope of systems development. Our findings on the OTs need to manage work burden further sensitize us to the possibility that such care features also lead to an increase in the burden on healthcare professionals who operate these at-home channels. Furthermore, the recognition of the family caregiver as the expert at home risks increasing the burden of care for family caregivers, since it might mean that they are given even more care tasks.

Yet we argue that the parallel development of telecare systems for chronic care management may represent an ideal opportunity to support the home expert [26,45]. Increasingly, telehealth nurses act as the communications partner with the home [2] and are likely the right personnel for meeting the needs of an open channel of communication with the home. A growing recognition of the tremendous care burden on informal caregivers [10,44,46] may further increase the likelihood of such family caregiver initiatives.

LIMITATIONS AND FURTHER WORK

The results from the quantitative analysis may have limited generalizability due to the small sample size. Furthermore, our recruitment specifically seeks out individuals, both OTs and caregivers, who had some experience with a home safety assessment. Thus, the conclusions drawn from our data may have limited applicability to those who are new to such procedures. Further study will be necessary to understand if there are any differences in the requirements between experienced and inexperienced caregivers.

Our study was conducted in a multi-ethnic, Asian urban context. Still, it is similar to many other developed countries, because the country is grappling with demographic changes arising from a rapidly aging population and the accompanying rise in prevalence of chronic diseases. This improves the transferability of the finding on opportunities for family caregivers' care.

The transferability of recognizing the home expert should be balanced against some recent evidence suggesting that, among East Asian populations, worry about caregiving performance is higher compared to non-Asian populations [22,24]. This worry may provide a partial explanation for the finding on the family caregivers' need for problem-solving support from healthcare professionals. However, an examination of family caregiver studies from France [42], Germany [38], and the US [6] suggests that elements of these problem-solving needs are present within caregivers' social support needs and communication needs, but it is difficult to fully compare these findings since the relationship with healthcare professionals was not the focus in those studies.

We worked with allied health professionals in this study because, compared to hospital settings, clinicians (doctors and nurses) play a smaller role in chronic care at home. Nevertheless, future work is needed to connect this work to studies of family caregiver reporting practices with clinicians.

CONCLUSION

We presented *HomeAx*, a remote system to elicit family caregiver input for home assessments by occupational therapists. Through two studies, we showed that while *HomeAx* is more usable and is preferred over current paper-and-pen methods, there are unmet needs from family caregivers when it comes to communicating health and care practice in the home. Family caregivers grow into their expertise as patient advocates, and in this role, they want to be able to direct healthcare professionals' attention and to include their own perspectives on how to best meet patients' care and safety needs in their communication with healthcare providers.

ACKNOWLEDGMENTS

This research is supported by the Singapore Ministry of Heath's National Medical Research Council under the Center Grant Program – Singapore Population Health Improvement Centre (MNRC/CG/C026/2017_NUHS) and (NMRC/CG/M009/2017_NUH/NUHS – Telehealth Core). We also thank our occupational therapists and all our participants for their valuable time.

REFERENCES

[1] Jessica S Ancker, Holly O Witteman, Baria Hafeez, Thierry Provencher, Mary Van de Graaf, and Esther Wei. 2015. "You Get Reminded You're a Sick Person": Personal Data Tracking and Patients With Multiple Chronic Conditions. *J. Med. Internet Res.* 17, 8 (August 2015), e202. DOI:https://doi.org/10.2196/jmir.4209

[2] Jakob E. Bardram and Mads M. Frost. 2018. Chapter 10 - Double-Loop Health Technology: Enabling Socio-technical Design of Personal Health Technology in Clinical Practice. In *Designing Healthcare That Works*, Mark S. Ackerman, Sean P. Goggins, Thomas Herrmann, Michael Prilla and Christian Stary (eds.). Academic Press, 167–186. DOI:https://doi.org/10.1016/B978-0-12-812583-0.00010-9

[3] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 2 (January 2006), 77–101. DOI:https://doi.org/10.1191/1478088706qp063oa

[4] Svend Brinkmann. 2013. *Qualitative Interviewing*. Oxford University Press. DOI:https://doi.org/10.1093/acprof:osobl/9780199861392.001.0001

[5] John Brooke. 1996. SUS-A quick and dirty usability scale. *Usability Eval. Ind.* 189, 194 (1996), 4–7.

[6] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for Caregivers: Designing for Integrality. In *Proceedings of the 2013 Conference on Computer Supported Cooperative Work* (CSCW '13), ACM, New York, NY, USA, 91–102. DOI:https://doi.org/10.1145/2441776.2441789

[7] Chia-Fang Chung, Kristin Dew, Allison M Cole, Jasmine Zia, James A Fogarty, Julie A Kientz, and Sean A Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16*, ACM Press, San Francisco, California, USA, 768–784. DOI:https://doi.org/10.1145/2818048.2819926

[8] Sunny Consolvo, Peter Roessler, and Brett E. Shelton. 2004. The CareNet Display: Lessons Learned from an In Home Evaluation of an Ambient Display. In *UbiComp 2004: Ubiquitous Computing* (Lecture Notes in Computer Science), Springer, Berlin, Heidelberg, 1–17. DOI:https://doi.org/10.1007/978-3-540-30119-6_1

[9] H Daniel, P Oesch, Ae Stuck, S Born, S Bachmann, and Aw Schoenenberger. 2013. Evaluation of a novel photography-based home assessment protocol for identification of environmental risk factors for falls in elderly persons. *Swiss Med. Wkly.* (November 2013). DOI:https://doi.org/10.4414/smw.2013.13884

[10] Francine C. Ducharme, Louise L. Lévesque, Lise M. Lachance, Marie-Jeanne Kergoat, Alain J. Legault, Line M. Beaudet, and Steven H. Zarit. 2011. "Learning to Become a Family Caregiver" Efficacy of an Intervention Program for Caregivers Following Diagnosis of Dementia in a Relative. *The Gerontologist* 51, 4 (August 2011), 484–494. DOI:https://doi.org/10.1093/geront/gnr014

[11] Marsha E. Fonteyn, Benjamin Kuipers, and Susan J. Grobe. 1993. A Description of Think Aloud Method and Protocol Analysis. *Qual. Health Res.* 3, 4 (November 1993), 430–441. DOI:https://doi.org/10.1177/104973239300300403

[12] Pin Sym Foong. 2016. The Value of the Life Course Perspective in the Design of Mobile Technologies for Older Adults. In *Mobile Communication and the Family*, Sun Sun Lim (ed.). Springer Netherlands, 165–181. Retrieved February 11, 2016 from http://link.springer.com.libproxy1.nus.edu.sg/chapter/10.1007/978-94-017-7441-3_10

[13] H. Hong, G. D. Abowd, and R. I. Arriaga. 2015. Towards designing social question-and-answer systems for behavioral support of individuals with autism. In *2015 9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth)*, 17–24. DOI:https://doi.org/10.4108/icst.pervasivehealth.2015.259282

[14] Matthew K. Hong, Clayton Feustel, Meeshu Agnihotri, Max Silverman, Stephen F. Simoneaux, and Lauren Wilcox. 2017. Supporting Families in Reviewing and Communicating about Radiology Imaging Studies. ACM Press, 5245–5256. DOI:https://doi.org/10.1145/3025453.3025754

[15] Matthew K. Hong, Lauren Wilcox, Clayton Feustel, Karen Wasileski-Masker, Thomas A. Olson, and Stephen F. Simoneaux. 2017. Adolescent and Caregiver use of a Tethered Personal Health Record System. *AMIA. Annu. Symp. Proc.* 2016, (February 2017), 628–637.

[16] Matthew K. Hong, Lauren Wilcox, Daniel Machado, Thomas A. Olson, and Stephen F. Simoneaux. 2016. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), ACM, New York, NY, USA, 5337–5349. DOI:https://doi.org/10.1145/2858036.2858508

[17] Michael D Keall, Nevil Pierse, Philippa Howden-Chapman, Chris Cunningham, Malcolm Cunningham, Jagadish Guria, and Michael G Baker. 2015. Home modifications to reduce injuries from falls in the Home Injury Prevention Intervention (HIPI) study: a cluster-randomised controlled trial. *The Lancet* 385, 9964 (January 2015), 231–238. DOI:https://doi.org/10.1016/S0140-6736(14)61006-0

[18] Finn Kensing, Hronn Sigurdardottir, Arjen Stoop, and others. 2007. MUST-a participatory method for designing sustainable health IT. In *Medinfo 2007: Proceedings of the 12th World Congress on Health*

(Medical) Informatics; Building Sustainable Health Systems, IOS Press, 1204. Retrieved September 4, 2017 from https://search.informit.com.au/documentSummary;dn=783888507579978;res=IELHSS

[19] Susan I. Klein, Lois Rosage, and Geraldine Shaw. 2000. The Role of Occupational Therapists in Home Modification Programs at an Area Agency on Aging. *Phys. Occup. Ther. Geriatr.* 16, 3–4 (January 2000), 19–37. DOI:https://doi.org/10.1080/J148v16n03_02

[20] Celine Latulipe, Sara A Quandt, Kathryn Altizer Melius, Alain Bertoni, David P Miller Jr, Douglas Smith, and Thomas A Arcury. 2018. Insights Into Older Adult Patient Concerns Around the Caregiver Proxy Portal Use: Qualitative Interview Study. *J. Med. Internet Res.* 20, 11 (November 2018). DOI:https://doi.org/10.2196/10524

[21] Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A stage-based model of personal informatics systems. In *Proceedings of the 28th international conference on Human factors in computing systems - CHI '10*, ACM Press, Atlanta, Georgia, USA, 557. DOI:https://doi.org/10.1145/1753326.1753409

[22] Wee Shiong Lim, Wee Kooi Cheah, Noorhazlina Ali, Huey Charn Han, Philomena Vasantha Anthony, Mark Chan, and Mei Sian Chong. 2014. Worry about performance: a unique dimension of caregiver burden. *Int. Psychogeriatr. IPA* 26, 4 (April 2014), 677–686. DOI:https://doi.org/10.1017/S1041610213002445

[23] Birgitta Lindberg, Carina Nilsson, Daniel Zotterman, Siv Söderberg, and Lisa Skär. 2013. Using Information and Communication Technology in Home Care for Communication between Patients, Family Members, and Healthcare Professionals: A Systematic Review. *Int. J. Telemed. Appl.* 2013, (2013), 1–31. DOI:https://doi.org/10.1155/2013/461829

[24] Jinyu Liu and Mercedes Bern-Klug. 2016. "I should be doing more for my parent:" Chinese adult children's worry about performance in providing care for their oldest-old parents. *Int. Psychogeriatr.* 28, 02 (February 2016), 303–315. DOI:https://doi.org/10.1017/S1041610215001726

[25] Michael Lo Bianco, Sonja Pedell, Gianni Renda, and Ajay Kapoor. 2015. HCI Methods for Empowering Discussion on Person-Centered Fall Prevention with Older Adults. ACM Press, 255–263. DOI:https://doi.org/10.1145/2838739.2838767

[26] M. Luptak, N. Dailey, M. Juretic, R. Rupper, R. D. Hill, B. L. Hicken, and B. D. Bair. 2010. The Care Coordination Home Telehealth (CCHT) rural demonstration project: a symptom-based approach for serving older veterans in remote geographical settings. *Rural Remote Health* 10, 2 (2010). Retrieved August 22, 2016 from http://www.rrh.org.au/Articles/subviewnew.asp?ArticleID=1375

[27] Susan C. McMillan and Linda E. Moody. 2003. Hospice patient and caregiver congruence in reporting patients' symptom intensity. *Cancer Nurs.* 26, 2 (April 2003), 113–118. DOI:https://doi.org/10.1097/00002820-200304000-00004

[28] Helena M. Mentis, Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough, and Lisa Shulman. 2017. Crafting a View of Self-Tracking Data in the Clinical Visit. ACM, 5800–5812. DOI:https://doi.org/10.1145/3025453.3025589

[29] Andrew D Miller, Sonali R Mishra, Logan Kendall, Shefali Haldar, Ari H Pollack, and Wanda Pratt. 2016. Partners in Care: Design Considerations for Caregivers and Patients During a Hospital Stay. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16*, ACM Press, San Francisco, California, USA, 754–767. DOI:https://doi.org/10.1145/2818048.2819983

[30] Ministry of Health. Singapore Burden of Disease Report 2017. Retrieved September 20, 2019 from https://www.moh.gov.sg/resources-statistics/singapore-burden-of-disease-report-2017

[31] Francisco Nunes and Geraldine Fitzpatrick. 2018. Understanding the Mundane Nature of Self-care: Ethnographic Accounts of People Living with Parkinson's. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, ACM Press, Montreal QC, Canada, 1–15. DOI:https://doi.org/10.1145/3173574.3173976

[32] Francisco Nunes, Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik Grönvall, and Cristiano Storni. 2015. Self-Care Technologies in HCI: Trends, Tensions, and Opportunities. *ACM Trans. Comput.-Hum. Interact.* 22, 6 (December 2015), 1–45. DOI:https://doi.org/10.1145/2803173

[33] Truls Østbye, Rahul Malhotra, Chetna Malhotra, Chandima Arambepola, and Angelique Chan. 2013. Does Support From Foreign Domestic Workers Decrease the Negative Impact of Informal Caregiving? Results From Singapore Survey on Informal Caregiving. *J. Gerontol. B. Psychol. Sci. Soc. Sci.* 68, 4 (July 2013), 609–621. DOI:https://doi.org/10.1093/geronb/gbt042

[34] Laura R. Pina, Sang-Wha Sien, Teresa Ward, Jason C. Yip, Sean A. Munson, James Fogarty, and Julie A. Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing - CSCW '17*, ACM Press, Portland, Oregon, USA, 2300–2315. DOI:https://doi.org/10.1145/2998181.2998362

[35] Ari H. Pollack, Uba Backonja, Andrew D. Miller, Sonali R. Mishra, Maher Khelifi, Logan Kendall, and Wanda Pratt. 2016. Closing the Gap: Supporting

Patients' Transition to Self-Management After Hospitalization. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), ACM, New York, NY, USA, 5324–5336. DOI:https://doi.org/10.1145/2858036.2858240

[36] Juleen Rodakowski, Philip B. Rocco, Maqui Ortiz, Barbara Folb, Richard Schulz, Sally C. Morton, Sally Caine Leathers, Lu Hu, and A. Everette James. 2017. Caregiver Integration during Discharge Planning of Older Adults to Reduce Resource Utilization: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. *J. Am. Geriatr. Soc.* 65, 8 (August 2017), 1748–1755. DOI:https://doi.org/10.1111/jgs.14873

[37] Jon A. Sanford and Tina Butterfield. 2005. Using Remote Assessment to Provide Home Modification Services to Underserved Elders. *The Gerontologist* 45, 3 (June 2005), 389–398. DOI:https://doi.org/10.1093/geront/45.3.389

[38] Marén Schorch, Lin Wan, David William Randall, and Volker Wulf. 2016. Designing for Those Who Are Overlooked: Insider Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (CSCW '16), ACM, New York, NY, USA, 787–799. DOI:https://doi.org/10.1145/2818048.2819999

[39] Karen Schumacher, Claudia A. Beck, and Joan M. Marren. 2006. FAMILY CAREGIVERS: Caring for older adults, working with their families. *AJN Am. J. Nurs.* 106, 8 (August 2006), 40.

[40] Judy A Stevens, Jane E Mahoney, and Heidi Ehrenreich. 2014. Circumstances and outcomes of falls among high risk community-dwelling older adults. *Inj. Epidemiol.* 1, (March 2014). DOI:https://doi.org/10.1186/2197-1714-1-5

[41] Cristiano Storni. 2014. Design challenges for ubiquitous and personal computing in chronic disease care and patient empowerment: a case study rethinking diabetes self-monitoring. *Pers. Ubiquitous Comput.* 18, 5 (June 2014), 1277–1290. DOI:https://doi.org/10.1007/s00779-013-0707-6

[42] Matthieu Tixier, Gérald Gaglio, and Myriam Lewkowicz. 2009. Translating Social Support Practices into Online Services for Family Caregivers. In *Proceedings of the ACM 2009 International Conference on Supporting Group Work* (GROUP '09), ACM, New York, NY, USA, 71–80. DOI:https://doi.org/10.1145/1531674.1531685

[43] Matthieu Tixier and Myriam Lewkowicz. 2015. Looking for Respite and Support: Technological Opportunities for Spousal Caregivers. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (CHI '15), ACM, New York, NY, USA, 1155–1158. DOI:https://doi.org/10.1145/2702123.2702563

[44] Matthieu Tixier and Myriam Lewkowicz. 2016. Counting on the Group: Reconciling Online and Offline Social Support among Older Informal Caregivers. ACM, 3545–3558. DOI:https://doi.org/10.1145/2858036.2858477

[45] Reed V. Tuckson, Margo Edmunds, and Michael L. Hodgkins. 2017. Telehealth. *N. Engl. J. Med.* 377, 16 (2017), 1585–1592.

[46] Janhavi Ajit Vaingankar, Siow Ann Chong, Edimansyah Abdin, Louisa Picco, Anitha Jeyagurunathan, YunJue Zhang, Rajeswari Sambasivam, Boon Yiang Chua, Li Ling Ng, Martin Prince, and Mythily Subramaniam. 2016. Care participation and burden among informal caregivers of older adults with care needs and associations with dementia. *Int. Psychogeriatr.* 28, 2 (February 2016), 221–231. DOI:https://doi.org/10.1017/S104161021500160X

[47] Haining Zhu, Joanna Colgan, Madhu Reddy, and Eun Kyoung Choe. 2016. Sharing Patient-Generated Data in Clinical Practices: An Interview Study. *AMIA Annu. Symp. Proc. AMIA Symp.* 2016, (2016), 1303–1312.

[48] Caregiver Statistics: Demographics | Family Caregiver Alliance. Retrieved September 18, 2019 from https://www.caregiver.org/caregiver-statistics-demographics