



A Qualitative Study of Caregiving in Support of Aging in Place to Inform Analyses of Caregivers' Work and Design of Robot Caregivers

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Abstract. To design robots that meet older adults' caregiving needs, one would need to understand what caregivers do to support aging in place. Thus, analyses of caregivers' work are needed. To do so, one must first identify the type of work system in which such caregiving is embedded because that will determine the type of work analyses that should be conducted. Toward that end, researchers observed caregiving in older adults' homes, and interviewed caregivers. The resultant qualitative data were leveraged to address whether caregiving exhibited the main characteristics of a complex socio-technical system. The present data suggests caregiving should be analyzed via formative work analysis.

Keywords: Human factors · Caregiving · Aging in place · Work analysis · Robot

1 Introduction

To age in place, older adults often depend on caregivers [1]. Unfortunately, caregivers are in short supply [1]. To address that shortfall, one can develop robot caregivers [1]. Older adults are open to that possibility [2, 3], especially if robots allow them to regain independence [2]. In fact, there are many caregiving tasks for which older adults prefer being helped by a robot caregiver as opposed to a human caregiver [3].

To design robot caregivers that meet older adults' caregiving needs, one needs to understand what caregivers do to support aging in place. Unfortunately, our understanding about caregivers' work is incomplete. Existing literature does not provide detailed information about how most caregiving tasks are accomplished, a shortcoming that was noted in the U.S. National Research Council's report, *Health Care Comes Home* [1]. Accordingly, work analyses must be conducted. There are many ways to analyze work [4]. One's work analysis technique must align with the work system under investigation.

Therefore, to select a technique for analyzing caregiving in support of aging in place, one must understand the work system in which such caregiving is embedded.

Health Care Comes Home provided a model of possible human factors associated with enabling older adults to age in place. It suggested caregiving in support of aging in place requires the interaction of many people, technologies, and environments. In other words, that model suggested that caregiving in support of aging in place is embedded within a complex socio-technical system [4]. Such systems have nine main characteristics [4]. Workers in such systems 1) coordinate, 2) have diverse backgrounds, 3) may not be collocated, and 4) interact with technologies that automate work. Information in such systems is 5) imperfect, and 6) frequently filters through technology. Work in such systems 7) changes over time, 8) involves unexpected events, and has 9) serious consequences if not done correctly. Because of these characteristics, workers must perform different actions to accomplish the same goal depending on the system state, which has been referred to as “context-conditioned variability” [4].

To investigate whether caregiving in support of aging in place is embedded within a complex socio-technical system, we observed caregiving in older adults’ homes, and interviewed caregivers. The resultant data were leveraged to address whether caregiving a) stemmed from the interaction of people, technologies, and environments, b) reflected the nine main characteristics of socio-technical systems [4], and c) exhibited context-conditioned variability.

2 Method

2.1 Participants

Four older adults and 6 caregivers participated. Older adults’ ages ranged from 53 to 103 years (Mean = 76.00; SD = 19.14). On average, older adults scored 1.50 on the Katz Activities of Daily Life (ADL) scale (SD = 2.06) [5], 1.25 on the Lawton Instrumental Activities of Daily Life (IADL) scale (SD = 0.83) [6], and 11.00 on the Mini-Mental Status Exam (MMSE) 2nd Edition (SD = 6.44) [7]. One caregiver was the older adult’s parent; all others were paid professionals. Older adults and caregivers who were observed during work hours were not compensated. Caregivers who were interviewed outside of work were paid \$25 per interview.

2.2 Observation Procedures

During one of the initial home visits, the Katz Activities of Daily Life scale [5], the Lawton Instrumental Activities of Daily Life scale [6], and the Mini-Mental Status Exam 2nd Edition [7] were administered. For the remainder of that session and all other sessions, 1–3 researchers observed and took notes regarding caregiving activities. Free-form notes were taken because 1) the exploratory nature of the observations meant any observation recording sheet would need to be regularly modified, and 2) our Institutional Review Board (IRB) insisted on approving any observation recording sheet before its use. Our IRB did not allow us to document quotes verbatim.

After each observation, each observer transcribed their hand-written notes, including adding details they did not have time to record during the observation. When multiple

researchers observed the same session, they transcribed their notes separately and then met to compare notes and reach consensus about any disagreements, which were rare. After these sessions, each observer updated their notes.

The team conducted 28.5 h of observations. The mean, standard deviation, and range of the hours spent at a given observation site were 9.50, 3.12, and 6, respectively.

2.3 Interview Procedures

Interviews were scheduled during the caregiver's non-work hours. Typically, they were conducted outside of the older adult's home. Interviews lasted approximately 1 h. The research team conducted three interviews total, during which caregivers explained how they completed tasks, factors that would lead them to complete the task in a different manner than they previously described, how exactly those factors would change their approach to the task, and what specifically would performing the task accomplish.

3 Results

3.1 Inter-rater Reliability

Two researchers independently reviewed all notes. They first identified examples related to whether caregiving reflected the nine main characteristics of socio-technical systems, and exhibited context-conditioned variability. They then met to identify instances that best exemplified each characteristic. A third researcher then independently coded each exemplar. Those codes were then compared against the other researchers' codes. Codes were in perfect agreement.

The pair of team members also identified an exemplar regarding how caregiving stems from the interaction of people, technologies, and environments, including the associated people-, technology-, and environment-related factors. The third team member then independently coded each of those factors as being people-, technology-, or environment-related. Those codes were then compared to the other team members' classifications. Codes were in near perfect agreement, i.e., Fleiss' Kappa = .90.

3.2 Caregiving Stems from Interaction of People, Technologies, and Environments

What a caregiver will cook depends on people-, technology-, and environment-related factors. Regarding people-related factors, the to-be-cooked meal will be partly determined by the older adult's 1) physical state, and 2) mental state. For example, a caregiver might cook something indulgent in order to make the older adult feel better. The to-be-cooked meal will also be partly determined by the caregiver's 1) cooking skillset, and understanding of 2) the older adult's finances, 3) the older adult's life history (e.g., birthdays), 4) the older adult's food preferences, 5) the older adult's dietary restrictions, 6) the older adult's eating capabilities (e.g., finger food for an older adult who cannot see well), 7) available ready-to-eat food, 8) when the meal will be consumed, 9) desire to indulge the older adult, 10) the amount of time that has passed since the last indulgence, as well as, 11) desire to diversify the older adult's diet. The to-be-cooked meal

will also be influenced by the older adult's family's preferences (e.g., they may expect a vitamin-rich diet). Regarding technology-related factors, the to-be-cooked meal will be partly determined by the available 1) food preparation devices, and 2) food cooking devices. Regarding environment-related factors, the to-be-cooked meal will be partly determined by 1) the price of food, 2) care agency recommendations, 3) the number of billable caregiving hours relative to the amount of caregiving work left to complete, 4) the day of the week, and 5) the day of the year (e.g., holidays).

3.3 People Coordinate, Have Diverse Backgrounds, May Not Be Collocated, and Interact with Technologies that Automate Work

Regarding "people coordinate", our first example concerns coordination between a nurse and a paid caregiver. The nurse visited the older adult's home to refill medications. The nurse organized the medications so the older adult would know what medications to take and when. However, the nurse would explain the organization to both the older adult and the paid caregiver so the caregiver could provide reminders about the organization if needed. Thereafter, the paid caregiver monitored the older adult's medication administration, and provided updates to the nurse. The second example concerns coordination between an older adult's family member and a paid caregiver. The older adult's family member paid the older adult's utility bill. However, the family member occasionally forgot to mail the payment in time. In such cases, the family member contacted the caregiver and arranged for the caregiver to pay the bill in person.

Regarding "people ... have diverse backgrounds", our observations and interviews indicated the people who enable an older adult to age in place often have quite different backgrounds. Paid caregivers often, but not always, had little or no formal education; in contrast, nurses had extensive formal education. Further, both nurses and clergy had formal education, but their knowledge bases differed quite significantly.

Regarding "people ... may not be collocated", our observations and interviews identified several instances in which people who were enabling a given older adult to age in place were not collocated. Two examples have already been discussed in the "people coordinate" section. A different example concerns an older adult who emailed to schedule nurse visits or doctor appointments, and also used various Web sites to order medications and medical supplies. That older adult routinely coordinated with other people with whom she was not collocated in order to enable her to age in place.

Regarding "people ... interact with technologies that automate work", our first example concerns technologies that automate aspects of medication administration, which often involves reminding the older adult to take their medications at specified times. To do so, the older adults (or their caregivers) must remember the medication schedule, and track the older adult's adherence. However, pill organizers automate those activities. For example, one of our participants had several pill organizers, which were organized by time of day, and day of the week. All the older adult had to do was to take the pills that were in the appropriate section of his pill organizer; he did not have to remember his medication administration schedule or whether certain medications had already been taken. Our second example concerns technologies that automate aspects of entertainment. Caregivers often entertain older adults. For example, caregivers might turn on the television or talk with them or tell jokes. Devices such as Amazon's Echo can automate

certain aspects of that entertainment. For example, one of our participants used an Echo to search for and listen to 1) music, 2) news reports, 3) weather reports, and 4) audio books, as well as to 5) search for general information, and 6) tell jokes.

3.4 Information is Imperfect and Filters Through Technology

Regarding “information is imperfect”, one of our older adult participants spent a significant amount of her day sitting in a wheelchair, and could not verbally communicate well. Accordingly, her caregiver had to interpret the older adult’s behavior in order to gauge the older adult’s current state. Figure 1 depicts the caregiver’s decision process. For example, when the older adult shifted side-to-side, moaned, or both, the caregiver assumed the older adult was uncomfortable, and adjusted the older adult’s positioning. The caregiver then continued to monitor the older adult’s behavior. If the older adult stopped shifting or vocalizing, then the caregiver assumed that her previous assumption had been correct. Furthermore, one of our older adult participants did not speak English. Instead, he relied on his paid caregiver to translate for him whenever he needed to communicate with anyone who did not speak Spanish. Thus, the message received by the older adult may not have exactly matched the message conveyed by the English-speaking person who was talking to the older adult.

Regarding “information ... frequently filters through technology”, two of our older adults had difficulty breathing: one relied on a ventilator and the other supplemental oxygen when needed. Once activated, both systems monitored the older adults’ oxygen levels, displayed that information, and sounded an alarm if it fell below a given value. As such, the caregivers were not directly aware of the older adults’ oxygen levels; rather, information about those levels filtered through technology. Similarly, medical professionals often measured older adults’ vital signs during check-ups. They employed various devices through which information about the older adults’ health status filtered.

3.5 Work Changes Over Time, Involves Unexpected Events, and Has Serious Consequences if not Done Correctly

Regarding “work changes over time”, caregivers often performed different duties depending on the day. One of our paid caregiver participants provided services for 3 h per day, Monday through Friday. On Mondays, Wednesdays and Fridays, she would make and clean up after breakfast, clean the apartment as needed, bathe and dress the older adult, and encourage him to be active. On Fridays, she would also make sure the older adult had enough readily available food to get through the weekend. On Tuesdays and Thursdays, she did not bathe and dress the older adult, so she had time to perform other duties, such as grocery shopping or laundry. She also used that extra time to socialize with the older adult. Further, caregivers’ responsibilities often evolve as the older adult’s health changes. One of our older adult participants was largely self-sufficient when her caregiver began working with her. The caregiver’s primary duties were to provide companionship, be present if needed, and occasionally assist the older adult. Years later, that same older adult participant was completely dependent on her caregiver. The caregiver provided 24-h care, including but not limited to feeding, bathing, dressing,

and repositioning the older adult, as well as monitoring their medical conditions and coordinating with the older adult’s family and medical professionals.

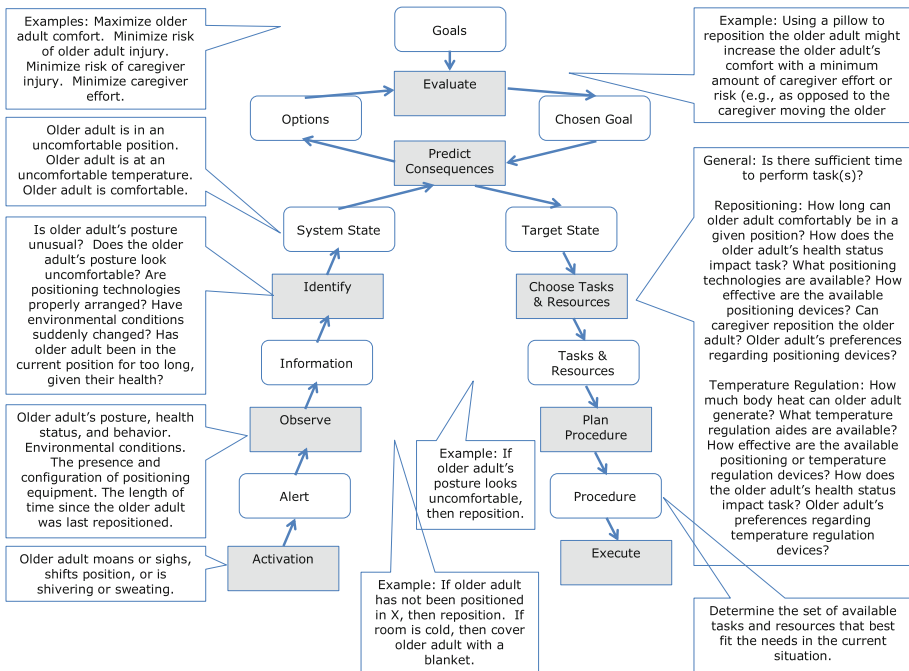


Fig. 1. A decision ladder representing a caregiver’s thought processes while deciding whether a non-verbal older adult is comfortable and if not how to make them comfortable. Sharp rectangles = information processing; Rounded rectangles = knowledge.

Regarding “work ... involves unexpected events”, one of our older adult participants recalled an instance when her motorized wheelchair tipped over and fell on top of her caregiver’s leg while attending an event. They were unable to free the caregiver’s leg, and had to recruit strangers to help them right the wheelchair and place the older adult back in it. Further, one of our caregiver participants recalled an instance when the carpet in the older adult’s apartment was being replaced. Workers had moved the older adult’s furniture, including a treasured family keepsake, outdoors so that they could work. It began to rain after the workers had left for their lunch break, prompting the caregiver to recruit neighbors to help her move the furniture back into the apartment.

Regarding “work ... has serious consequences if not done correctly”, two of our older adult participants sat in a wheelchair or laid in bed for significant portions of their days. One could personally adjust the inflation of her mattress to change the distribution of pressure points against her skin; the other relied on her caregiver to adjust her position. In both cases, if the older adults were not repositioned, then they would develop pressure ulcers (bed sores) where surfaces pressed against their skin. Further, one of our older adult participants relied on her caregiver to eat. The caregiver liquefied the food because the older adult had difficulty chewing, and tended to choke or aspirate unless it was

liquefied. If the caregiver did not prepare the food correctly, then the older adult could experience dire consequences. Finally, all of our older adult participants had medical conditions, and required some degree of assistance managing their medications and, in certain cases, maintaining and operating in-home medical equipment. Failure to take medications could worsen the older adults' medical conditions and shorten their life expectancies; incorrectly taking medications could kill.

3.6 Caregiving Exhibits Context-Conditioned Variability

Our research revealed many instances of context-conditioned variability. The following describes two examples. First, a caregiver ordinarily bathed an older adult on Monday, Wednesday, and Friday. However, baths might be skipped if the caregiver needed time for other caregiving tasks, such as grocery shopping or laundry, felt that it was more important to socialize with the older adult, or felt that the older adult was too upset to bathe (the older adult did not like to bathe). Second, one of the older adults was visually impaired and relatively sedentary, so he was instructed to walk inside his apartment for exercise (he could not walk outside safely without assistance). At times, he would do so without prompting. However, he would also pace around his apartment because he was anxious. When his caregiver saw him walking, she would assess why he was doing so. If the older adult did not appear anxious, and the caregiver was not aware of anything that would have made him anxious, then she would encourage him to continue walking. If the older adult appeared anxious, then she would encourage him to sit.

4 Discussion

Examples described herein suggested caregiving stemmed from the interaction of people, technologies, and environments, reflected the nine main characteristics of socio-technical systems [4], and exhibited context-conditioned variability. Thus, our study indicated caregiving is embedded in a complex aging in place socio-technical system.

Ways to analyze work can be categorized into three types: normative, descriptive, and formative approaches [4]. Normative approaches prescribe how work should be performed. Descriptive approaches convey how work is currently performed. Formative approaches detail the requirements that must be met in order to accomplish work.

Work analysts must choose the approach that is compatible with the type of work in which they are interested. The present results suggest analysis of caregiving in older adults' homes requires an approach tailored to the analysis of socio-technical systems. Normative and descriptive approaches are not adequate for the analysis of such systems because they cannot account for context-conditioned variability [4]. The former's prescriptions specify a single "best" way to perform a task. The latter's descriptions provide a snapshot about how workers accomplish their tasks while the system is in a given state, but cannot speak to how workers might accomplish their tasks when the system is in other states. In contrast, formative approaches are tailored to the analysis of socio-technical systems [4], and the context-conditioned variability that they exhibit. By identifying behavior-shaping constraints, formative approaches can capture work requirements without specifying exactly how that work must be done or who must do

it. As such, formative approaches are well-suited to the analysis of context-conditioned variability. For these reasons, researchers who analyze caregiving in older adults' homes to inform the design of robot caregivers should primarily use formative work analysis techniques and only use other work analysis techniques when they are confident that the work in question does not exhibit context-conditioned variability.

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