Characteristics of Family and Respite Care

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Abstract

When older adults develop certain medical or physical challenges, a family member typically fills the role of primary caregiver. These family caregivers can sometimes feel overburdened when juggling their caregiving responsibilities with the rest of their lives, and that can negatively impact their health. Respite care provides a temporary break to family caregivers. Even though there are benefits of using respite care, barriers such as uncertainty and mistrust exist. Our research is focusing on what trust issues caregivers experience and how information sharing through ICT could mitigate the issues and improve the quality of temporary care work. In this position paper, we present a summary of current issues and practices of family caregivers of older adults and respite care, and introduce our ongoing study to find ways to build trust through information sharing between family caregivers and respite care providers.

Author Keywords

Trust; Information Sharing; Communication; Cooperation; Family Caregiver; Informal Caregiver; Respite Care; Older Adults; Aging in Place;

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous; See [http://acm.org/about/class/1998/]: for full list of ACM classifiers. This section is required.

Introduction

As adults become older and develop complicating medical conditions, they often want to stay at home with their families as long as possible but cannot live completely independently [14]. Depending on their level of health or functioning, they may eventually need the aid of another person for to complete self-care tasks such as eating, dressing, showering, and going to bed. To make this possible, a family member typically has to step in and start providing care for them. However, when this care becomes long-term, family caregivers sometimes feel overburdened attempting to balance their caregiving tasks and other non-related responsibilities, which can result in physical and mental health issues.

To reduce the burdens of caregiving and maintain the level of care for older adults, it is essential for family caregivers to be able to reach out for help as they need it. Using respite care services allows family caregivers take a break from caregiving and take care of their own health [9]. However, there are barriers to adopting respite care. Some caregivers are reluctant to reach out for this care because of embarrassment about needing help, uncertainty about where to look for help, and mistrust of the quality of care their loved one would receive [12, 13].

Information Communication Technology (ICT) has the potential to not only to provide a way to reduce the barriers to respite care, but also to offer effective and appropriate methods for family caregivers and respite care providers to cooperate. CSCW and HCI research on this topic could provide ICT design ideas for a system for family and respite caregivers to trade off their work trustingly and effectively. This would allow family caregivers to have a proper break, which improves not only their health, but also their care recipient's health[2, 11, 26].

Our research focuses on what kind of trust issues caregivers face and how information sharing through ICT could temper the issues of trust and improve the quality of this invisible short-term care work. In this position paper, we summarize current the issues and practices of family caregivers of older adults and respite care. Considering trust and information sharing, we introduce our ongoing study to find barriers and ways to build trust through information sharing between family caregivers and respite care providers.

Family caregivers of older adults in the U.S.

About 34.2 million people in the U.S. have offered unpaid care to older adults in the prior year. Their care recipients have long-term health issues (59%) [16]. About half of those family caregivers offered care to older adults who need help with at least two activities of self-care [4]. For most of those family caregivers, caregiving work is a long-term obligation. The standard alternative is to move their loved one to a long-term care facility, which family caregivers generally want to avoid. However, prior research found associations between physical, physiological, and/or physical problems with caregiving work [4, 25]. Caregivers with emotional or mental issues related to caregiving work have a higher risk of mortality than non-caregivers [21].

Respite care

Respite care, which provides temporary relief to family caregivers, may help caregivers maintain their role as a primary caregiver for a longer period of time. It allows family caregivers to relax or have a "time-out" from their caregiving work regularly or in emergency situations [10]. There are several formal and informal forms of respite care (e.g. in-home respite care, respite care at day care center, respite care in a nursing home, etc.). [7, 8, 27]

Effectiveness

A systematic review concluded that there is some evidence that respite care benefits family caregivers, but that further research was needed to confirm their findings [22]. Even in situations where planned and well-coordinated community care interventions for a person with dementia do not extend their time outside of a care facility by much, it can significantly reduce the costs of care for those individuals [5]. Most importantly, caregivers themselves reported strong feelings that respite care had proven beneficial – with 93% saying they felt "invigorated" after receiving respite care services [19].

Trust

To have this type of invigorating experience, caregivers must first recognize their need for respite services and give themselves permission to step out of their role as a caregiver temporarily [17]. In addition to recognizing their need for respite care programs, they had to not only even regard accepting respite care, but also trust the individual care provider [7]. Caregivers generally prioritize the care recipient's experience when looking at respite care programs to try out, meaning caregiver's trust in a program is essential to its use [23]. In addition to concerns about their loved ones safety, caregivers often also have to deal with an unclear process to find and sign up for respite services [18]. These emotional hurdles must be dealt with by the family caregiver before they feel confident enough to try out respite care.

Information sharing

Information is one of the significant factors predicting respite care use. One of the most common reasons caregivers gave for not using respite care services was lack of knowledge of where to find those services [12, 13]. This indicates that it is important to share sufficient and reliable informa-tion to family caregivers [18]. While trying out a new respite care service, caregivers might want respite care providers to communicate with them proactively, but by and large, caregivers have to know what to ask in order to get information, and they might not know how to approach these conversations [13].

Sharing information through certain media (e.g. notes) can impact family caregivers' trust in care professionals [3]. An investigation found that receiving "Carer-Held Records" was beneficial to caregivers, provided care managers were willing to meet with and offer explanations and answers to caregivers [20]. Technology facilitating communication between family caregivers and medical professionals has helped address some of the issues surrounding tracking a patient's medical history and providing medical professionals with appropriate updates. This type of work draws from a broader target audience, demonstrated when Tang et al. designed a mobile application to help parents of preterm infants log their child's progress and report that information to healthcare providers in between appointments in consultation with both parents and medical professionals to ensure that the end product met both populations' needs [24]. Prior caregiving research has also made older adults independent by enabling caregivers to do more and helped caregivers find personal emotional or professional medical support [1, 2, 11, 15, 24]. However, research has not focused on the link between family caregivers and respite care workers who intervene temporarily and the gaps in communication between those specific parties.

When specific respite care workers cannot always be available for care recipients they have assisted in the past, communication between respite care workers becomes especially helpful. Unlike professional caregivers, volunteers do not necessarily have medical expertise, and unlike fam-

ily caregivers, they do not have shared history informing their interactions. However, they can often provide helpful, up-to-date information that can be used to facilitate future caregiver' interactions. Foong et al. focus on facilitating the transfer of knowledge between volunteers in the hopes that it can cut down on the burden of training programs for volunteer positions with high turnover rates [6]. This way, the lessons learned from one respite session might not be as easily lost by the next one.

Future Work

We have identified several key research areas that are important to care work involving family and respite care. We are currently working on research focused on trust and information sharing between family caregivers and respite care providers. Our research methodology includes 1-hour semi-structured interviews with open-ended questions. Our target populations are family caregivers and respite care providers of older adults. We are going to ask them the reason why they use or have not used respite care, their trust issues through respite care, and what kinds of information they share or did not share with respite care providers and/or other caregivers.

This ongoing research aims to find trust issues those caregivers have experienced and how information sharing technology could positively impact trust and the quality of temporary care work and information shifts among them.

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