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Conceptualizing caregiving activities for persons with dementia (PwD) through a patient work lens

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ABSTRACT

Informal caregivers are an integral part of care delivery for persons with dementia (PwD). Informal caregivers take part in a wide range of care activities both individually and collaboratively with other caregivers. Caregiving often involves high demands in the face of limited resources, which can lead to stress, burden, and burnout. To support caregivers, we need to conceptualize caregiving activities they perform, and the networks and roles through which they perform work. We performed a directed content analysis on interview data from twenty caregivers and applied a human factors approach to characterize informal caregiving work. Our results revealed 1) nuances in caregiving roles, 2) differences in caregiving networks, and 3) 13 categories of caregiving activities characterized by time commitments; physical, cognitive and socio-behavioral demands; and varying network dependencies. These findings can be applied in future studies to evaluate the needs of caregiving networks and how to better support them.

1. Applying human factors engineering to caregiving work

Since the Institute of Medicine's (IOM) 2000 report on the value of human factors engineering (HFE) in patient safety, healthcare systems have started to adopt methods and research from HFE to understand and improve the work done by healthcare providers (Donaldson et al., 2000). For many years, these efforts were largely focused on formal clinical settings such as the hospital; yet recently have extended into informal care settings including patients' homes (Czaja et al., 2006; Fisk et al., 2018). This branch of HFE has been coined as *patient-engaged human factors*, "or the application of human factors theories and principles to study and improve work done by patients and families" (Holden et al., 2013, p. 758). Patient-engaged human factors is particularly relevant when studying the management of complex illnesses in the home. These illnesses occur over long periods of time and often require the assistance of informal caregivers such as family and friends of the patient (Schulz and Czaja, 2018). In community settings, informal caregivers play a critical role in the safety and efficiency of care delivery for patients; yet they often remain under-supported and as such, can experience broad physical and mental health consequences ("Dementia caregiving in the US," 2017). HFE has termed the contributions of informal caregivers to patient care as *patient work, or* "work in which the patient and/or family caregiver is the primary agent, with minimal active healthcare professional involvement" (Holden et al., 2013, p. 28). We need a better understanding of the patient work informal caregivers perform to improve both caregiver outcomes and the care of patients.

1.1. Importance of studying dementia caregiving work

People with dementia (PwD) are one population of patients requiring prolonged, complex care in community settings; and these patients often have networks of informal caregivers involved in their care delivery. Informal caregivers are broadly characterized as individuals (i.e., family, spouse, and children) who are unpaid, non-professional, and assist with various PwD care needs (Reinhard et al., 2008). Annually, 16.1 million informal caregivers spend approximately 17.9 billion hours on caring for roughly 5.7 million people with dementia ("2018 Alzheimer's disease facts and figures," 2018). In the United States alone, informal care costs 277 billion dollars every year ("2018 Alzheimer's disease facts and figures," 2018). Providing care for someone living with dementia is complicated for a variety of reasons including the fluctuation of symptoms and needs of the PwD (Geda et al., 2013); the high prevalence of

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comorbidities such as fall risk; compromised vision; aging-related medical complexities ("2018 Alzheimer's disease facts and figures," 2018), the paucity of support available to informal caregivers (Brodaty and Donkin, 2009), and the management of behavioral symptoms (Bird and Moniz-Cook, 2008). Given the care-related challenges informal caregivers face, it is no surprise that over 35% of them report negative outcomes, such as stress, burden, and burnout ("2018 Alzheimer's disease facts and figures," 2018).

HFE is the study of work and has been applied to understand and reduce the risk of worker stress, burnout, and other negative outcomes in various work domains (Or et al., 2009). As informal caregiving can be conceptualized as 'work', HFE can be applied to better understand the characteristics of caregiver work and what can be done to mitigate negative outcomes associated. In order to mitigate the stress and burden, we need to understand the source, or the work itself. A broad conceptualization of caregiving work is necessary to identify areas where HFE techniques can be used to develop interventions that help mitigate work induced negative outcomes.

1.2. *Dementia caregiving is under-supported and associated with negative outcomes*

Caregiving for people with dementia is generally provided by multiple individuals operating in a network, composed of friends, family members, and volunteers (Tang et al., 2018). Much of the existing literature focuses on individual informal caregivers, and not their networks; and finds that individual caregivers may lack the adequate knowledge required to provide comprehensive care for patients (Lopez-Hartmann et al., 2012), and receive very little guidance from formal healthcare providers (Alrashed, 2017). Despite the presence of caregiving networks, caregivers often operate individually with little help from others for two reasons: 1) hesitation to ask others for help and 2) help unoffered from other individuals (Bossen et al., 2013). When informal caregivers, often the same age as the PwD, take on a majority of the care responsibilities individually, they neglect their own physical and mental health, leaving themselves vulnerable to becoming a patient (Goren et al., 2014). Informal caregiving for PwD is a challenge that needs to be addressed immediately to prevent further negative outcomes for both patients and caregivers. HFE can be applied to study the patient work done by caregivers to address the various challenges associated with informal caregiving for PwD.

1.3. *Current perspectives on caregiving work*

The field of gerontology or the scientific study of old age, the process of aging, and the particular problems of older adults – acknowledges that informal caregivers must support various activities to meet the needs of care recipients (Gill et al., 1995). Gerontologists have broadly conceptualized caregiving activities that caregivers perform or help support in three categories: Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and Self-Maintenance Activities ((Katz, 1983; Lawton and Brody, 1969)). ADLs are defined as daily routine self-care activities (i.e., dressing, bathing, and feeding); IADLs allow individuals to live independently in the community (i.e., managing finances, housekeeping, preparing meals); and self-maintenance activities supplement the ADLs and IADLS by fostering emotional and mental support for the caregiver (i.e., attending support groups, taking classes). While ADLs and IADLs capture a majority of the tasks that caregivers perform, researchers have acknowledged other types of mobility-related, emotional, and social activities caregivers provide to support persons with dementia (Katz & Stroud III, 1989).

1.4. *Dementia caregiving as patient work*

Other disciplines have categorized caregiving activities as patient work, defined as the "exertion of effort and investment of time on the part of patients or family members to produce or accomplish something" (Strauss, 2008, pp. 64–65). HFE as the study of work can provide further insight into defining, understanding, and supporting patient work. Recent HFE work has focused on chronic heart failure patients. This work was instrumental in identifying the categories of patient work, which include, illness related, everyday life work, and biographical work (Valdez et al., 2014). However, these findings were focused on one type of chronic illness, and have not been validated in other illness models. Further, dementia care has unique characteristics that might affect the work categories. For example, the PwD often doesn't participate in several aspects of care, the illness trajectory is long often spanning decades, as the condition changes, the nature of the work also changes, and caregivers operate as part of a network ("2018 Alzheimer's disease facts and figures," 2018; Kunkel and Applebaum, 1992).

Studying patient work in the dementia-care context will broaden our conceptualization of work done for dementia care beyond professional and collaborative work. Understanding the broad range of patient work categories will provide opportunities to support informal caregivers, to alleviate some of the burden they may face. One particular challenge of studying patient work is findings have to be situated within a great deal of context, which may be difficult to extract from the caregivers. Nevertheless, characterizing specific categories of patient work can provide insights on designing interventions aimed to support caregiving networks and help individual caregivers to more clearly realize the extent of their roles to mitigate negative consequences such as role ambiguity and role conflict (Hanson, 1993).

1.5. *Study objective*

Characterizing dementia-specific patient work and the networks and roles through which work is facilitated can provide insights on interventions aimed to support both individual caregivers and networks. Beyond this, improved understanding of patient work can maximize network roles and capacity, and mitigate burden and issues associated with caregiving (Hanson, 1993). To gain a deeper understanding of caregiving work, we aimed to 1) identify and categorize the distinct roles of informal dementia caregivers, 2) describe the networks in which dementia caregivers provide care, and 3) categorize and characterize the work performed by dementia caregivers.

2. Methods

2.1. *Participants*

Data were collected from 20 primary caregivers (PC) of PwD (female = 12). Participants were between the ages of 49–82; cared for either a parent (N = 11) or a spouse (N = 9); lived within 60 miles of an urban Midwestern city. Participants self-identified as primary caregivers, persons who provided the majority of coordination and care for the PwD in community settings. All caregivers spoke and understood English.

2.2. *Design*

We used semi-structured interviews to collect in-depth data on the high variability nature of informal caregiving. Following a semi-structured process, specific questions along with follow-up, probing questions were adapted to the participant and situation.

Example questions included asking what a particularly “good” or “bad” day as a caregiver might look like, what type of resources were helpful in providing care, and with whom they shared their caregiving responsibilities (Table 1). Further, some questions employed a name generation technique to identify other caregivers in the network (Marin and Hampton, 2007). Interviews lasted approximately 1 h and took place in a meeting place that was convenient for the participant, such as their home or a public library. Participants received 25 dollars for participation. Interviews were audio recorded and transcribed verbatim. The study was approved by the University's Institutional Review Board.

2.3. Analysis

2.3.1. Content analysis

Research team members analyzed interview transcripts using NVivo 11, a qualitative data analysis software. We used an inductive and deductive content analysis with the goal of understanding informal caregiving work in the PwD work system (Creswell and Poth, 2017; Hsieh and Shannon, 2005). A coding framework generated from Lawton's ADLs, IADLS, and maintenance activities and patient work literature (Corbin and Strauss, 1985; Lawton and Brody, 1969) guided the deductive content analysis. Two research team members conducted structural coding of passages in the transcripts (SP, AL). While we were using a deductive approach, we also allowed other codes to emerge from the data. Research team members then discussed the codes until a consensus was reached on the categories of caregiving work captured by the codes (SP, AL, LB, AH, NW). Two coders (SP, AL) identified elaborative and contrasting cases for each of the categories, which were discussed until a consensus was formed. Once consensus was reached on categories of caregiving work, the research team retroactively aligned the results with existing patient work literature ((Holden et al., 2015).

2.3.2. Network mapping

The research team mapped each caregiver's network to understand how different each network is with respect to number of people involved, and relationships to the PwD. The use of a name generation technique in semi-structured interviews yielded a list of caregivers who contributed to each of the 20 caregiving networks. A member of the research team (SP) accounted for every individual the PCs mentioned in the interviews. The research team assessed the frequency of each caregiver's interaction with the PwD, geographical proximity to the PwD, and communication style to place each caregiver in one of the following roles: primary (self-identified), secondary, or tertiary caregiver. Individuals who did not fit the criteria for the aforementioned roles, but were mentioned by the PC, were assigned the roles of caregiver allies. The criteria were generated inductively and are presented in the results. The research team then mapped each of the caregiving networks with the PwD in the center of the network as illustrated in Fig. 1.

3. Results

The results presented are a reflection of primary caregiver experiences and their descriptions of extended networks. We identify and categorize distinct roles informal dementia caregivers take on, 2) describe the networks in which they provide care and 3) categorize and characterized the work dementia caregivers perform. A content analysis identified that caregiving work can be categorized into 13 unique categories. The quotes in Table 2 were selected from different participants in this study. The de-identified participant codes are presented at the end of each quote to demonstrate they are from different participants.

3.1. Role delineation of informal caregivers

Primary caregivers described that not all of the caregivers within a network contributed equally or performed the same care tasks. Through an inductive approach, the research team delineated three roles within caregiving networks: primary, secondary, and tertiary. We also identified individuals beyond the network who are not directly involved in care activities, but act as “caregiver allies”, connected to the primary caregiver. Table 2 displays characteristics of each of the identified caregiver roles.

As demonstrated by the quotes in Table 2, Primary caregivers (PCs) explained that they provided care most frequently and were the most accessible to the PwD because they co-resided with the PwD or lived within close proximity. PCs also described their duties as continuous and explained how they were never relieved from their role; they further explained that it was their responsibility to communicate any changes in care, treatment progressions, and doctor visits with the rest of the caregiving network. PCs took on the responsibility for the overall well-being of the PwD. PCs also explained that they were required to manage other comorbidities that come with aging such as mobility, vision, and dental problems.

PCs described that *secondary caregivers* provided help with yard work, keeping the PwD accompany, cooking/having a meal or going for a walk with the PwD. Some secondary caregivers were described as being distant in proximity from the PwD, but involved in care through providing support to the PC. Typically, PCs reported that secondary caregivers made an effort to stay informed about the PwD and contribute in whatever way possible to the PC's care efforts.

PCs described *tertiary caregivers* as being in variable proximity to PwD's residence (some close by, others are further away) and having intermittent engagement with the PC and PwD. PCs described tertiary caregivers' communication patterns as asynchronous, meaning the caregivers only reach out to the PwD in an intermittent frequency. PCs further explained that tertiary caregivers may provide financial support occasionally for the PwD or PC and visit occasionally to check up on the PwD.

PCs described *caregiver allies* as individuals who often times are distant relatives, or friends to the PwD or PC. PCs explained that these individuals do not directly contribute to the care activities for the PwD. However, they are available to use as a resource when necessary. PCs mentioned reaching out to caregiver allies to share their experiences with these individuals as an avenue for venting their emotional and mental burden from caregiving.

3.2. Variation in networks

Based on the 20 Interviews, caregivers described informal care networks that varied in size, ranging from 2 to 12 caregivers. Fig. 1 displays examples of two caregiving networks (one large and one small). The caregivers are placed on different levels of the network map based on the criteria outlined in Table 2, with the PwD in the center. In the large network of 12 caregivers, there are many different individuals involved with varying relationships to the PwD: spouse, siblings, children, grandchildren, and neighbors. In the small network of 4 caregivers, the relationships include: spouse, two children, and a volunteer.

Table 1
Example semi-structured interview questions.

1. First, can you tell me (without using any names) who you've been caring for and how long you've been providing care?
2. Do you share your caregiving responsibilities with anyone else?
3. What does a usual day consist of?
4. How would you describe your caregiving activities during a typical day?
5. Do you have any strategies you use to help you carry out your caregiving activities, manage challenging [behavioral or emotional*] changes or challenging situations?
6. Is there anyone you talk to about caregiving or who may be important to you in your caregiving role?
7. Are there certain things that make caregiving easier or more challenging?

Table 2
Role Network level among Informal Caregivers.

Caregiver Role	Characteristics of Role	Illustrative Quotes
Primary Caregiver	1. Shares physical environment with PwD frequently 2. Primary channel of communication between informal and formal care networks 3. Provides care on a daily basis	"I'd get her pills and make sure she had her pills. And then we'd do the shower, and I'd help her get dressed. She wore support hose that I, you know, had to help her get on, and she needed help dressing."-5541 "I [communicate] through e-mail and sometimes by phone. And just try to keep [siblings] updated as much as I can to let them know where things stand … during the course of the last few years, any major changes or doctor visits, things of that nature." 7154 "I do all the driving now, and I've already told them that he's no longer a primary driver. Well, now he doesn't drive at all, because he can't move his feet quick enough". 4251 "So, I talk to [the PwD] her three or four times. You know, I call her in the morning and say, mom, time to get up, don't forget to take your pills, you know, just trying to keep her going. And I always called her at night just to make sure that she was safely back in her apartment and doing okay." 1452
Secondary Caregiver	1. Frequent interaction with primary caregiver 2. In close proximity to PwD's physical environment 3. Involved with communication of information about PwD	"My daughter and her son, my grandson has done a lot as far as helping me and helping him [PwD] with the yardwork and just, you know, getting things that I needed. … And the neighbors, I've got three neighbors that watch him, or did watch him when he was home, to see if he was walking to the post office or wandering somewhere else …" 3532 "There is one sister that has been more cooperative than the others that my daughter deals with and calls and e-mails" 3532
Tertiary Caregiver	1. Variable Proximity to PwD 2. Asynchronous communication 3. Intermittent contact with PwD and primary caregiver	"She [PwD] does have a friend who [stops by] two or three times a month they go to lunch, and then takes her shopping." 5920
Caregiver Ally	1. Individuals who are available to provide support for the primary or secondary caregivers but do not actually contribute to the caregiving activities	"I have a lot of friends to talk to, I have a friend in [location] who is retired RN, and I worked with her at one of the clinics. And I worked in the lab. She was an RN. So, I do talk to her." 3526

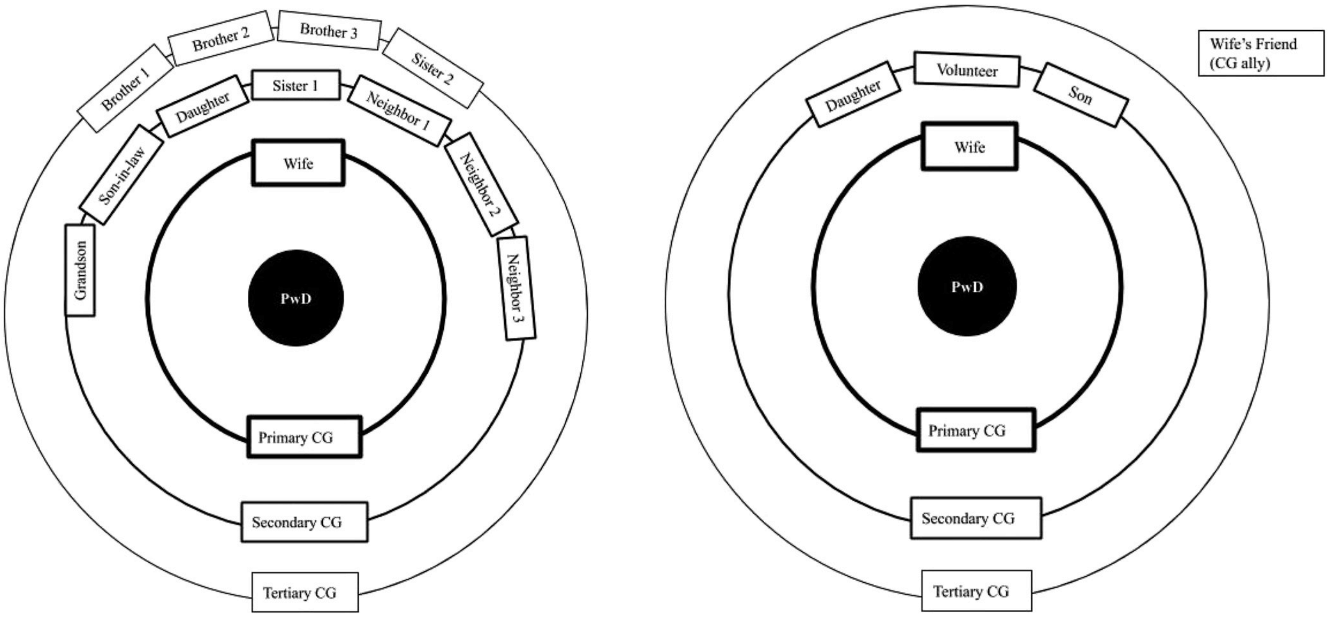

Fig. 1. Maps of dementia care networks.

Additionally, the wife's friend takes on the role of a caregiver ally.

Fig. 1: Examples of large (left) and small (right) network of caregivers for one PwD with many different individuals interacting and contributing at different levels.

3.3. *Categorization of caregiving work for PwDs*

The content analysis of the transcripts revealed that caregivers describe 13 unique categories of work to support PwDs which mapped onto, but extended beyond the classic categorization Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and self-maintenance (Table 3). PCs described: ADL work that can be delineated into clinical, functional, and cognitive categories; IADL work as decision making, house-keeping, information management, logistics, and transportation; and self-maintenance work as companionship, caregiver support, vigilance, pet care, and skill development. The quotes in Table 3 were selected from different participants in this study. The de-identified participant codes are presented at the end of each quote to demonstrate they are from different participants.

The categories identified through the content analysis were characterized by different time commitments, patient work demands, and network dependencies and aligned with existing patient work categories (Table 4). Caregivers often described their work as episodic or continuous in nature. Episodic work (Epi) was described as requiring intermittent effort on a daily or weekly basis (e.g., house-keeping or transportation). This is not to say that episodic work could still be required over a long period of time, but differs from continuous work (Con), which was described by caregivers as requiring around-the-clock effort (e.g., vigilance). For example, a functional task may be ambulation which requires caregivers to push the PwD's wheelchair. While this may occur multiple times throughout the day, it is not always occurring, therefore it is categorized as episodic. On the other hand, vigilance tasks such as watching the PwD to inhibit wandering out of the house, require around-the-clock effort.

Patient work categories were described by caregivers as illness-related work (Ill), everyday life work (Day), or biographical work (Bio). PCs described illness-related work described illness-related work as crisis prevention and management, symptom management, and diagnosis related medication management; everyday life work as routine work such as housekeeping, transportation, and other occupational work; and biographical work as managing the trajectory of the diagnosis such as skill development, and caregiver support.

PCs also described work demands as physical effort (Phy) (e.g., lifting, bathing, feeding, and housekeeping), cognitive (Cog) in nature (e.g., requiring mental effort in memory, coordination, multitasking) or Socio-behavioral (SocB) in nature, requiring social skills and positive behaviors.

PCs described the amount of work they take on changing based on the number of caregivers in a network and their interactions within the network. For example, if there are several siblings in a large network involved in caregiving and making decisions for a PwD, the PC is required to take on more communication and coordination tasks to garner feedback and discuss care options than in a small caregiving network. Additionally, the type of work itself may increase or decrease the work done by a single caregiver. The category of clinical work (i.e. providing medication) has a low (L) network dependency (reliance on the other caregivers in the network) than the category of decision-making work. In the case of clinical work, it typically can be done with one individual's effort. On the other hand, decision making (i.e., relocating the PwD to assisted living) has a high network dependency because it typically requires the collective effort of multiples caregivers in the network.

4. Discussion

In this study, we had three objectives: 1) conceptualize nuances between caregiving roles, 2) identify variances across caregiving networks, and 3) categorize and characterize dementia caregiving activities. This qualitative study revealed important nuances in patient work that may influence the quality of care delivered as well as patient and caregiver outcomes. Further, these results provide insight on the potential sources of negative outcomes such as stress and burden experienced by caregivers. We first identified differences in informal caregiver roles and variations across caregiving networks. Second, we categorized caregiving work in to 13 unique categories and then characterized each category by time commitment required by caregiver, type of patient work, work demands, and network dependencies. These findings expand on previous work on caregiving networks and caregiving work, by illustrating the complexities of informal caregiving for persons with dementia.

4.1. Interactions between caregiving roles and networks

Previous work has characterized tertiary caregivers and caregiver allies into the category of auxiliary caregivers (Tang et al., 2018). Other studies have only observed primary and secondary levels of caregiving networks (Carpentier and Ducharme, 2003; Consolvo et al., 2004). While these studies set precedent for our research, our findings expand on role levels of the caregiving network as presented in Section 3.2. Specifically, our data shows that the tertiary caregiver provides care for the PwD in a limited capacity, while the caregiver ally provides emotional and mental support for the caregivers as illustrated in Table 2. This finding illustrates the trickledown effects of the burden of caregiving for PwDs. Primary caregivers generally take on the majority of the caregiving work responsibilities, but the impact of caregiving reaches out to individuals (caregiver allies) beyond the boundaries of the caregiving network as illustrated in Fig. 1. When designing interventions to support caregiving networks, the needs of everyone involved, both directly and indirectly, in the caregiving processes should be considered.

Additionally, the size of the network has implications on specific categories of caregiving work (network dependencies in Table 4). The caregiving network size can increase or decrease work demands on individual caregivers. Large caregiving networks require additional coordination of caregiving tasks, and communication of relevant information regarding the PwD, but provide the ability to distribute caregiver work across multiple caregivers. On the other hand, small care networks may not have the capacity to distribute work. While we understand that caregiving work for PwDs is typically distributed across multiple caregivers (Carpentier and Ducharme, 2003), these results provide further insight into the complexities of each network and the differential level of interaction required to accomplish specific types of patient work (i.e., information management).

4.2. Furthering the conceptualization of caregiving work

Prior research has grouped work activities into three major categories: ADLs, IADLs, and maintenance (Katz, 1983). While these categories provide a foundational conceptualization of caregiving activities, they do not provide sufficient details about all the different types of caregiving work done by caregivers. Similarly, other conceptualizations of patient work have been described as illness related, everyday life, and biographical work (Holden et al., 2015). Our results expand on and integrate previous research to provide 13 concrete sub-categories with unique characteristics such as time commitment, and task demands (Table 3). Particularly our results recognize, the work associated with pets or pet care, information management, vigilance, skill development, and caregiver support, which have not previously discussed. Most importantly, our results found that the caregiving work categories have unique demands, that need to be understood to design interventions for caregivers. It is important to recognize the breadth of dementia caregiving work outside ADLs and IADLs that impose new challenges on caregivers.

Our data revealed that the time required for caregiving work cannot necessarily be quantified in minutes, hours, or days and that each type of work can be attributed to unique demands (Table 4). There are certain categories of work such as cognitive, vigilance, companionship, and skill development that are continuous, meaning they require around-the-clock effort by caregivers. Some of this work can be distributed to another caregiver, but work like skill development is unique to each caregiver. While there is the option to distribute some of the continuous or episodic work among caregivers, the act of transitioning of care between caregivers may give arise to additional safety concerns in care delivery.

Intervention designs to support caregiving networks need to be cautious about the time commitments and nature of different work to develop sustainable solutions. For example, to support the work category of companionship, designers may integrate exergames into the intervention (Brauner et al., 2015). While there are perceived benefits with these types of activities, they may require additional work such as communication and collaboration between the PwD and caregivers. Our results also confirm findings from previous research on ADLs and IADLS that some work can be cognitively or physically taxing, and a caregiver's

Table 3
Categorization of caregiving work.

Caregiving Work Category	Caregiving Tasks	Illustrative Quotes
Activities of Daily Living (ADLs)		
Clinical	• Providing medication • Medical tasks	“So, he’s used a catheter and a bag for years. He has handled those bags himself, but now I’ve taken over, and I’m rinsing them out, and I get them ready for him. And I’ll put one in his bathroom, and I’ll say, [PwD], this is your catheter set for the morning. And he says, okay, and he handles it then”. −6642
Functional	• Mealtime tasks (e.g., feeding, eating) • Daily hygiene and toileting tasks (e.g., bathing, dressing, grooming) • Physical ambulation	“I’ve been dressing him, waking him up. And he would, I would start his water, and he would go in the shower, and I would have his clothes all laid out. And but it got to the point where I’m literally dressing him all the time”. −1581
Cognitive	• Promoting orientation and awareness (e.g., time and day, names, location) • Providing conversation and answering questions • Providing updates on current events	“So basically, she had the same three, four, five questions constantly, just write them on a whiteboard, and then whenever she would ask the questions, you’d be like, well, it’s all written over here on the whiteboard.” −8644 “We have one bathroom that’s upstairs, but now he has to be reminded of where that is in our house because sometimes our house is confusing to him. Or he’ll think that there’s all these other people living in our house that aren’t. It’s just the two of us, I mean.” −6641
Instrumental Activities of Daily Living (IADLs)		
Decision Making	• Making decisions about medical and non-medical concerns with or on behalf of the PwD	“Since the aneurysm, or maybe it was shortly before, I don’t remember, but she actually put me on all of her accounts. So, I do have the power, if need be, to step in, which I don’t know that she would do that today if it came up”. −1513
House-Keeping	• Preparing Meals • Keeping house and yard • Shopping • Managing a wardrobe	“I’m basically doing what I can outside. He’s given up the lawn mowing. It’s just too much with this yard. So, I had to get somebody for lawn mowing, and I now have the same people will do snow shoveling if we have over three inches”. −6642 “I fix our meals, or up until just recently, we would go out, but, for meals, but it’s not, like he always eats the same thing. He loves cheeseburgers, and so it’s not much fun going out with him. There’s no conversation. We just kind of sit there and look at each other”. −3526
Information Management	• Managing and communicating information between person with dementia, other caregivers, and formal care teams • Communicating information regarding finances	“I take care of any payments or any things that have to be done around the house. If I have to call somebody in, I take care of paying them … Oh, I was keeping track of his checking, check account book, checkbook. And I thought, I’m going to keep it in my room, because sometimes we are looking for it”. −6642
Logistics	• Scheduling and reminding person with dementia about appointment • Ensuring timely delivery of basic necessities (e.g., food)	“I’d write down any appointments that she had so, you know, it was on her wall and, you know, she could look at it. Because I got the feeling that, you know, sometimes she, she was so regimented in the schedule, you know, that she would be looking to, what am I supposed to be doing? She was always asking, what am I supposed to be doing? But she wouldn’t look at it. So, she wouldn’t know. And then, of course, she got to that phase where she didn’t know what time of day it was or what day it was”. −1452
Transportation	• Driving or securing other modes of transportation for the person with dementia to and from the home	“I do all the driving now, and I’ve already told them that he’s no longer a primary driver. Well, now he doesn’t drive at all, because he can’t move his feet quick enough”. −4251
Maintenance		
Companionship	• Ensuring the patient has social interactions (e.g., conversations) • Providing stimulating activities (e.g., games, music)	“You know, we would go for walks in the hallway or even outside when it was nice, and that would always brighten her up, very much so, to go outside and just talk to other people in the building just even to say hello. You know, that changed her mood sometimes when, and I’d just tried to be positive”. −5541 “She has some friends that they pick her up. Oh, every so often, they go to a movie. Or there’s a bunch of them that used to bowl together, get together once a month for lunch. That’s about the amount of her socializing. And she enjoys that I know so”. -4165
Caregiver Support	• Supporting other informal caregivers emotionally and mentally • “Filling in” for other caregivers	“And I have one particular friend who I share a lot with. And he has a father who has different issues that he shares with me, and then so, it’s a good way to vent”. −5920 “Can you come in and sit with [PwD] for 2 h on Monday morning? And so, but he, one of his friends does come, but I only ask him if it’s something that I have to, it’s not for a social thing, if it’s some, if I’ve got a doctor’s appointment or something like that”. −3526
Vigilance	• Providing supervision during activities that may cause harm to the person with dementia (e.g., accompanist to post office, on walks)	“And the neighbors, I’ve got three neighbors that watch him, or did watch him when he was home, to see if he was walking to the post office or wandering somewhere else”. −3532
Pet Care	• Assuming care responsibilities for pets that may belong to person with dementia (e.g., walking, feeding, taking to vet)	“You’re not just caring for your mom; you’re caring for this little animal. And to separate the two, if I were to tell my mom, well, you know, we got to do something with your dog, it was as if I were asking her to donate her left arm … And fortunately, my youngest brother found a place, a good home for the dog”. −7154
Skill Development	• Seeking opportunities to build caregiver-specific knowledge and skills through self-reflection, attending classes, reading books, etc.	“But I’m learning as this is going on too about things.” −3625 “I actually joined the Alzheimer’s Association. I go, I’ve been to seminars. And whenever I get literature or something comes in the mail, I read it and share it with my sister, especially if it comes in e-mail.” −7946

Table 4
Characteristics of caregiving work by category.

Caregiving Work Characteristics														
Category		ADLs			IADLs					Maintenance				
		Clinical	Functional	Cognitive	Decision Making	House-Keeping	Information-Management	Logistics	Transportation	Companionship	Caregiver Support	Vigilance	Pet Care	Skill development
Characteristics	Time Commitment	Epi	Epi	Con	Con	Epi	Epi	Epi	Epi	Con	Epi	Con	Epi	Con
	Patient Work Category	Ill	Ill	Ill	Day	Day	Day	Day	Day	Bio	Bio	Bio/Ill	Bio	Bio/Ill
	Patient Work Demands	🧍	🧍	⚙ 🧍	⚙	🧍	⚙ 👥	⚙	🧍⚙	👥	👥	⚙	🧍⚙	🧍⚙👥
	Network Dependency	L	L	H	H	L	H	L	L	H	H	H	L	L

Time Requirement: Episodic (Epi), Continuous (Con).
Patient Work Type: Illness related work (Ill), Everyday life work (Day), Biographical work (Bio).
Demands: Physical 🧍, Cognitive ⚙, Social-Behavioral 👥.
Network Dependency: High (H) or Low (L).

mental and physical health may be compromised as a result (Kunkel and Applebaum, 1992). To effectively support caregivers in their work, it is important to have a detailed conceptualization of caregiving work as well as caregivers' motivations to adopt and accept interventions (Parker et al., 2008).

4.3. *Implications for future work*

There are many opportunities to develop our understanding of informal caregiving for PwDs based on the findings in this study. Firstly, we recognize work done by caregivers may induce both positive (i.e., satisfaction) and negative (i.e., burden) outcomes. To increase the likelihood of positive outcomes and negative outcomes, there is a need to assess the demands associated with caregiving work. To assess the risk of negative outcomes such as stress and burden, HFE has applied the measurement of *workload* in many different healthcare applications (Hart, 2006). Workload can be a useful construct to measure among caregivers to predict negative outcomes. However, since the context of patient work is different than professional work in terms of motivation and work itself, existing validated workload assessments may need to be modified to accurately capture the demands of dementia caregiving. Thus, there is an opportunity to further investigate the workload demands of caregiving work.

Additionally, the results in section 3.1 indicate that caregiving networks vary in size and relationships. To facilitate interactions within the network, caregivers have to share information through coordination and communication. These processes required to share information within networks present new challenges because information may be unevenly distributed. Since information is distributed, it is likely that individuals in the network have asynchronous awareness of the needs of the PwD and other caregivers. HFE has studied distributed situational awareness (DSA) in networks to model interactions and the flow of information in systems (Stanton et al., 2006). There is value in studying DSA in caregiving networks to identify barriers to communication and coordination of information within a network. This work can potentially inform the design of interventions to facilitate timely communication and coordination of information within caregiving networks mitigating the risk burden on one or more caregivers.

4.4. *Limitations*

This study has identified many insightful findings that improve our understanding of caregiver work for PwDs. However, there are a few limitations that need to be addressed in future research. Most importantly, we only interviewed one caregiver from each network, thus, we may not have captured all the categories of work done by caregivers. Further, we did not systematically collect information on how long each participant has been a caregiver and how often they provide care for the PwD. We recognize this limitation and recommend future studies collect data on caregiving history to understand how much experience the caregivers have had in their roles. While we began to scratch the surface of individual differences like capacity defining factors in caregivers (Giosa et al., 2014), it is important to account for those when designing interventions aimed at reducing burden and stress. Future work should strive to assess measures such as workload and identify individual differences to inform the design of caregiver support mechanisms.

5. Conclusion

Informal caregivers provide a majority of care for persons with dementia in community settings, and often report negative outcomes due to caregiving such as stress and burnout. Negative outcomes can frequently be attributed to the circumstances (i.e., work demands, lack of support) in which informal caregivers provide care. This study explores the networks of informal caregivers, and the different types of roles in a network. Further we identified 13 categories of caregiving work and characterized them by demands and network dependencies. These findings are valuable to inform work system design in informal care settings. Further the results from this study can also be used to develop design requirements for technology-based interventions. With these efforts, we hope to reduce negative outcomes such as burden, stress and burnout among caregivers and increase caregiver satisfaction as well improve quality of care.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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