Conceptualizing caregiver workload: an exploratory study guided by NASA TLX

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ABSTRACT

Persons with dementia (PwD) are heavily dependent on the support of informal, dementia caregivers to fulfill their day-to-day care needs. Dementia caregivers, often friends and family members of the PwD, are unpaid, non-professional individuals who take on many of the care responsibilities. Due to the lack of formal training, social support, and information resources, among other factors, dementia caregivers are often at risk for negative outcomes such as stress and burden. There have not been any comprehensive assessment tools to predict these negative outcomes. Therefore, we employ the NASA TLX dimensions to conceptualize caregiver workload. This study operationalizes the NASA TLX dimensions in the context of dementia caregiving and illustrates examples for each of the dimensions. The results indicate that the NASA TLX does not include all of the factors necessary to conceptualize caregiver workload and prescribe a need for developing a robust caregiver workload assessment tool.

INTRODUCTION

The 5.7 million persons with dementia (PwD) in the United States receive a majority of their care from informal, dementia caregivers. Dementia caregiving – defined as unpaid and nonprofessional care – totals approximately eighteen billion hours of work per year (Association, 2018). Dementia caregivers typically lack the training, resources, and support that are needed to provide adequate care for PwD. Concurrently, dementia caregivers are faced with the challenge of maintaining their personal health and well-being (Gitlin, Kales, & Lyketsos, 2012). Further, the requirements and workload of dementia caregiving are continuously changing due to the neurodegenerative trajectory of the disease. Dementia caregivers are susceptible to an increased risk for negative psychological and physical outcomes, including higher levels of stress, burden, and burnout (Drinka, Smith, & Drinka, 1987; Yaffe et al., 2002). Decades of research on dementia caregiving have sought to mitigate these negative outcomes. However, a Human Factors and Ergonomics "work" approach may provide the missing link to supporting caregivers in mitigating stress, burden, and burnout by providing a way to measure caregiving workload.

Human Factors Engineering (HFE) conceptualizes dementia caregiving as *patient work*, or "exertion of effort and investment of time on the part of patients or family members to produce or accomplish something" (Strauss, 2008; Valdez, Holden, Novak, & Veinot, 2015). Patient work can generally be broken down into different lines of work such as illness work (i.e. medical tasks), everyday life work (i.e. household management), or biographical work (i.e., adjustments to occupation and identity). Patient work activities pose unique challenges to dementia caregivers which can be cognitive, physical or social-behavioral.

These challenges can further be conceptualized in the context of workload. Specifically, HFE conceptualizes well-being-related outcomes such as stress and burden through mental workload (Jex, 1998). Workload has been defined as "the difference between the amount of resources available within a person and the amount of resources demanded by the task situation" (Mark S. Sanders, 1993; Sanders, 1993). Specifically, in the context of patient work, workload has been defined as the demands associated with the burden of care due to an illness (Shippee, Shah, May, Mair, & Montori, 2012). This human-centered definition focuses on the characteristics (e.g. skills, behaviors perceptions) of the person (i.e. the caregiver), and how their characteristics interact with the requirements of task (i.e. the patient work activity) and the context in which the tasks are performed (Hart & Staveland, 1988). Workload demands can be expanded beyond the burden of care due to the illness, to encompass the demands in caregivers' lives, including everyday responsibilities, (Shippee et al., 2012). While conceptually workload demands are well-defined, we do not yet know what these workload demands are for dementia caregivers.

Therefore, having a way to conceptualize workload in the dementia caregiving context is a necessary endeavor to identify and understand the demands faced by caregivers in order to inform targeted workload intervention design, and both identify and address negative caregiving outcomes. As a first step, the present study seeks to determine whether the concepts used to capture the experience of workload through subjective measurement are able to robustly account for the workload experienced by dementia caregivers.

Workload assessment tools have been developed and shown to be useful in professional fields such as medicine, aviation, and education (Hart, 2006). Some workload measurement tools have also demonstrated utility in non-professional settings such as in assessing driver attention (Lee, Caven, Haake, & Brown, 2001). Because a dementia-caregiving-specific workload assessment does not exist, we looked to current literature to select suitable a workload assessment for this investigation.

The dynamic and complex contexts in which dementia caregiving occurs, along with the varied lived-experiences and demographics of dementia caregivers makes selecting a workload measurement challenging. These dementia caregiving considerations coupled with Sanders's preliminary human-centered definition of workload, led us to narrow our search to subjective measures of workload. Subjective measures afford researchers the opportunity to examine individual testimonies related to the perceived workload experienced during a task and draw estimated conclusions about overall workload (Eggemeier, 1981; Pauzie, 2008).

Among the commonly used subjective measures are the NASA Task Load Index (NASA TLX), and the Subjective Workload Assessment Technique (SWAT). These two subjective measures have been adapted successfully to assess workload in many different contexts (Hart & Staveland, 1988; Rubio, Díaz, Martín, & Puente, 2004; Stanton, Salmon, Walker, Baber, & Jenkins, 2006). The NASA TLX captures mental workload through its six dimensions: Mental Demand; Physical Demand; Temporal Demand; Performance; Effort; and Frustration. The SWAT captures mental workload through three broad categories: Time Load; Mental Effort Load; and Psychological Stress Load. A comparison of these workload tools revealed that the NASA TLX encompasses all of the dimensions within the SWAT and expands on emotional demands. Additionally, prior studies have shown that SWAT does not adequately account for individual differences (Rubio et al., 2004; Vidulich & Pandit, 1987). Given the heterogeneity of the dementia caregiver population we needed a tool that would be descriptive and sensitive to individual differences, which is why we used the NASA TLX for this study.

The present study represents a first step in exploring the concept of workload as it pertains to dementia caregivers. Our objective was to assess whether the six dimensions of workload as outlined by the NASA TLX robustly capture the patient work demands of dementia caregiving.

METHODS

Design

We conducted a directed content analysis using the NASA TLX dimensions as a framework on a secondary analysis of interview data from a qualitative study of dementia caregivers recruited from Wisconsin. Semi-structured interviews were used to accommodate the uniqueness and specificity that accompanies dementia caregiving by allowing interview questions to be tailored to the interviewee's individual circumstances. Interview questions were designed to develop an understanding of 1) the work performed by dementia caregivers, 2) strategies, tools, and resources used and developed by dementia caregivers to manage caregiving tasks, 3) unmet needs related to dementia caregivers' ability to perform patient work, and 4) the context (e.g., physical environment, social environment, family structures) in which dementia caregiving was performed. Participants were interviewed at their home or at a meeting place convenient for the participant (e.g., a public library). Interviews lasted approximately one hour and participants were paid 25 dollars for participation. Interviews were audio recorded, transcribed verbatim, and entered into NVIVO 11.

Participants

Data were collected from 20 dementia caregivers (female=12). Participants were between the ages of 49-82; cared for either a parent (N=11) or a spouse (N=9); and lived within 60 miles of Madison, WI. Participants were self-identified primary caregivers, which we defined as persons who provided the majority of care for PwD in their homes. All caregivers spoke and understood English.

Analysis

We conducted a directed content analysis guided by the six dimensions of the NASA TLX. While there are generally agreed upon definitions for the dimensions of the NASA TLX, for the purposes of this analysis we developed caregiver-specific, operationalized definitions for clarity and specificity (Table 1) (Hart, 2006). Two research team members (JG, RR) reviewed the transcripts and identified elaborative and contrasting cases for each of the dimensions of the NASA TLX, which were discussed within the research team until a consensus was established.

Table 1: NASA-TLX Dimensions and Caregiver-Adapted Definitions

NASA TLX Dimension	**Dimension Descriptions Modified to Fit the Context of Dementia Caregiving**
Mental Demand	How much mental or perceptual activity do caregiving tasks require?
Physical Demand	How much physical activity does the caregiver have to perform?
Temporal Demand	How much time pressure does the caregiver feel due to caregiving tasks? What is the pace at which these tasks occur?
Performance	How successful does the caregiver perceive their own caregiving overall or at specific caregiving tasks?
Effort	How hard does a caregiver have to

	work mentally and physically to perform caregiving tasks?
Frustration Level	How insecure, discouraged, irritated, stressed, and annoyed versus secure, gratified, content, relaxed and complacent does the caregiver feel during caregiving tasks?

RESULTS

Our results identified a wide range of examples illustrating workload specific to dementia caregiving for each of the six dimensions of the NASA TLX. Here we the describe variation within each of the six dimensions followed by examples from the transcripts.

Mental Demand

Participants described a broad range of mental demands. Several participants described intermittent but large memory requirements. For example, one caregiver described experiences that required her to obtain and understand information from her mother's doctor:

"Like I go to all of her doctor's appointments with her because, you know, she won't remember what they said or that." (Female, Daughter of PwD)

Several other participants described mental demand that was constant, requiring them to consistently think about their position as a caregiver. For example, another caregiver described the cascading effect of changes in her thought patterns as her husband required more time and attention. She described the ever-present internal, cognitive struggle of determining how to spend and manage her time:

"But I thought to myself, gee, I should…just be out, you know. But I don't do that, because I'm thinking all the time that I've got him to care for. You know, it changes your perspective on just going and doing something at will, you know." (Female, Spouse of PwD)

Physical Demand

Caregivers frequently referred to physical demands, and we found that caregivers often attributed physical demands to supporting activities of daily living such as bathing, dressing, and household chores. We found that the frequency of a physical task, and the progressive addition of physical tasks to their overall caregiving task list influenced caregivers' perception of low verses high physical demand. The degree of physical exertion did not influence their perception of workload. One caregiver described the progressive addition of tasks his caregiving responsibilities required him to complete:

"So working with her to use her walker with the dementia issues, learning is obviously a very slow process, if at all. And sometimes it seems like it's not at all, but doing that, carrying things for her through the house when she is using her walker…I've taken over doing much of the laundry. I've taken over cleaning up. One thing I notice is she no longer picks up after herself. And I'm sure it's just a, she forgets that she's put something down, and so I end up doing all of that." (Male, Spouse of PwD)

Another caregiver outlined her experiences of assisting her husband with his daily hygiene needs:

"And but it has gotten to the point now where he needed more help in the mornings. 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. He has developed incontinence, so I have been using Depends with extra padding at night. And he's gotten to the point where he was, he would come to the doorway, and because he's not talking anymore…So he would motion to me, and I would know that he'd have to go to the bathroom, and I would have to literally take him to the bathroom." (Female, Spouse of PwD)

Temporal Demand

Our results suggest that temporal demand can also range from low to high. Low temporal demand included fulfilling weekly time commitments, such travel time for as doctor appointments, whereas high temporal demands included requiring caregivers to forego personal commitments such as employment, and extra-curricular activities to accommodate patient work. Two caregivers described challenges of maintaining a full-time career and caregiving:

"And it got to the point where like, I couldn't have a job and do this, you know. And so I ended up, I mean, you know, for several reasons, but basically retired and, because I couldn't handle anymore." (Female & Male, Daughter & Son of PwD)

Another caregiver described the finite nature of his time, and how it was difficult to balance the relational pressure from his mother, and his personal prioritization of what should be done within his available time:

"Oh, well, like yesterday, my brother came over for the afternoon to be company for her and me. And the day, mid-morning, mother asked if we could go out back and clear out the shed of any extra items that we could donate before my brother got there. And I said it's, I struggle with trying to explain things so as not to upset her. And I try to explain, well, I've only got so much time. And I need to utilize that time doing this, that, and the other. And winter is coming. I have to get the outside ready for that. And she continued persisting and insisting that we do this...So that's basically every day to a different degree, amount of time." (Male, Son of PwD)

Performance

Our results suggest that caregivers do not perceive their own performance as success. However, caregivers did describe their performance in terms of continuous learning and improvement. For instance, one caregiver outlined his experience of learning more about caring for his father:

> *"But I'm learning as this is going on too about things." (Male, Son of PwD)*

Caregivers frequently referred to their performance as needing improvement. One caregiver reflected back on her experiences caring for her mother:

> *"Yeah, like what could I have done? I'm always looking back. And I probably didn't do that well, you know, I could have done that better, but…You do what you do at the time with what you know, and, you know, you've just got to live with it." (Female, Daughter of PwD)*

Effort

Participants described caregiving tasks as requiring a range of effort from low to high. They described both the mental and physical work that caregiving requires. For example, one caregiver described the mentally effortful process of guiding his father, step-by-step to stand and walk without the assistance of another person:

> *"I gave him social cuing like, okay, sit up, put your feet down. Make sure, you know, and then push up with the walker. I'll help him, but now I say, now focus. Instead of looking down, you need to look forward. Look straight at the wall. Grab your balance." (Male, Son of PwD)*

Another caregiver described the mental and physical effort associated with verbally and experientially explaining the complexity of caregiving tasks to her husband:

> *"Well, there would be days where, like I had to go to the doctor or groceries or whatever, and I'd tell him, you know, and he wouldn't want to go along. And, what took you so long? Well, then when he did go with me, he'd see what took so long, you know, for even getting in and out of the car for me is difficult. And I said, so this is what takes me so long." (Female, Spouse of PwD)*

Frustration Level

Caregivers frequently described situations where they experienced frustration related to both caregiving tasks and the symptoms of dementia. One caregiver describes the annoyance with her husband's memory loss:

> *"I told you about it at dinner, and I will tell you again, but if you ask me again, I'm going to say, gee, I don't recall because if it's not important enough for you to remember, then I think you're going to have to figure it out yourself." (Female, Spouse of PwD)*

Another caregiver described the frustration he felt with the types of tasks his mother required of him and with not knowing the best approach to caring for his mother:

> *"I would get frustrated, or I would get, you know, I would go visit my mom, and I would come out going, I don't know how much more I can do this, because I'm very frustrated. And I would get mad or upset…And then you take it on yourself, like, well, I should have caught that, or I should have seen that. Okay. So there's some of that with the caregiver [role]. You know, am I doing this right? Or, because there's no manual." (Male, Son of PwD)*

DISCUSSION

The present study sought to conceptualize dementia caregiving workload through the lens of the six dimensions of the NASA TLX. We were able to identify diverse examples for each dimension, which depict the vast range of workload experienced by caregivers across the dimensions. There was clear and distinct evidence that the workload experienced by dementia caregivers is, at least to a certain extent, informed and influenced by the dimensions of the NASA TLX; however, based on our current understanding of dementia caregiving, we believe the NASA TLX needs to be expanded to include other dimensions specific to dementia caregiving to comprehensively capture the demands of caregiving workload.

One such example is in the instance of multiple caregivers. Based on our analysis and the growing pool of research, dementia caregiving does not occur by a single caregiver, but rather a network of caregivers (Ponnala et al., 2018). Because patient work can be distributed across a caregiving network, evaluating each caregiver's testimony with the NASA TLX may not be effective in assessing workload associated with the patient work. From the literature, we know that members of caregiving networks can be categorized into three levels (primary, secondary, tertiary) based on relationship and frequency of interaction with person with dementia (Ponnala et al., 2018). The demands associated with role of the primary caregiver tend to be more varied. Primary caregivers are more susceptible to having their internal resources overcome by the demands of the patient work, resulting in work overload, compared to secondary and tertiary caregivers who experience significantly less variation in their demands. This variation in patient work demand severity and consistency is something that the NASA TLX is not equipped to identify.

Another gap is that of capacity (i.e. the amount of resources available within a person), the second component to the definition of workload. As caregivers adjust and spend more time in their role as a caregiver, they have the potential to develop capacity to more effectively manage the caregiving demands specific to the person for whom they are caring which can reduce their workload. The NASA TLX does not capture the characteristics of this development, nor does it capture how capacity has the potential to influence caregiver workload.

From the aforementioned points, we do not believe that the NASA TLX has the ability to robustly capture the patient work demands of dementia caregiving. Just as other fields have effectively demonstrated, we believe that the development of workload assessment specific to dementia caregiving, that includes, but modifies and supplements the dimensions of the NASA TLX is required (Pauzie, 2008; Wilson et al., 2011). To accomplish this, a next step is to conduct interviews with dementia caregivers to identify the specific demands of caregiving. Identifying these demands will provide a strong basis for the development of a workload tool specific to dementia caregiving.

This study had several limitations that should be noted. Our analysis did not consideration of how the NASA TLX dimensions are recruited and quantified within the context of the measurement through scoring, weighting or comparisons. For instance, the NASA TLX involves pairwise comparisons where participants indicate which of the two options contribute a higher workload. The results of the comparison then contribute the final workload measurement. The interaction of the dimensions within the context of applying the measurement was something that was beyond the scope of this study, but may be important when considering the future development of a dementia-caregiving-specific tool. In addition, because this was a secondary analysis, we were unable to probe for specific NASA TLX dimensions. As such, we analyzed caregivers' experiences that were collected with the motivation of understanding the broader context of dementia caregiving (e.g. work, tools, unmet needs, context) rather than dementia caregiving workload.

CONCLUSION

Given the prevalence of negative outcomes associated with dementia caregiving, there exists a significant need for the development of a caregiving workload assessment tool. This exploratory study identifies the merits of the six dimensions which comprise the NASA TLX. While the NASA TLX is a useful tool to capture instances of patient work within each of its dimensions, it does not capture the full context of dementia caregiving. The development of a caregiving-specific workload tool would enable dementia caregivers and clinicians to measure workload and identify caregiving-specific sources of stress and burden. Specific stress and burden identification will allow for the tailored recruitment of HFE and system-level intervention design to minimize the prevalence and severity of negative dementia caregiving outcomes.

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