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Getting what they need when they need it

Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms

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Summary

Background: Consumer health informatics (CHI) such as web-based applications may provide the platform for enabling the over 15 million family caregivers of patients with Alzheimer's Disease or related dementias the information they need when they need it to support behavioral symptom management. However, for CHI to be successful, it is necessary that it be designed to meet the specific information needs of family caregivers in the context in which caregiving occurs. A sociotechnical systems approach to CHI design can help to understand the contextual complexities of family caregiving and account for those complexities in the design of CHI for family caregivers.

Objectives: This study used a sociotechnical systems approach to identify barriers to meeting caregivers' information needs related to the management of dementia-related behavioral symptoms, and to derive design implications that overcome barriers for caregiver-focused web-based platforms. We have subsequently used these design implications to inform the development of a web-based platform, WeCareAdvisor,TM which provides caregivers with information and an algorithm by which to identify and manage behavioral symptoms for which they seek management strategies.

Methods: We conducted 4 focus groups with family caregivers (N=26) in a Midwestern state. Qualitative content analysis of the data was guided by a sociotechnical systems framework.

Results: We identified nine categories of barriers that family caregivers confront in obtaining needed information about behavioral symptom management from which we extrapolated design implications for a web-based platform. Based on interactions within the sociotechnical system, three critical information needs were identified: 1) timely access to information, 2) access to information that is tailored or specific to caregiver's needs and contexts, and 3) usable information that can directly inform how caregivers' manage behaviors.

Conclusions: The sociotechnical system framework is a useful approach for identifying information needs of family caregivers to inform design of web-based platforms that are user-centered.

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1. Background And Significance

Most of the over 5 million individuals living with Alzheimer's disease or related dementias (hereafter referred to as dementia) are cared for at home by an estimated 15 million family caregivers [1]. Family caregivers may be defined as nonprofessional and/or non-paid individuals. It has been estimated that family caregivers provide up to 17.9 billion hours of caregiving per year [1].

Caring for persons with dementia is complex, occurs over an extended period of time, and has psychological, physical and economic consequences for families [2–5]. Most families provide care without the requisite information needed to contend with the cognitive, behavioral and physical changes that occur with disease progression [5]. This is a particular challenge for families managing *behavioral symptoms*, a key clinical feature of dementia of any etiology. Behavioral symptoms may include aggression, agitation, depression, anxiety, apathy, disinhibition, hallucinations, delusions, sleep disturbances, aberrant motor activity, and other behaviors [4, 6]. Families are often left on their own to prevent and manage these behavioral symptoms [5]. In particular, the *information needs* of family caregivers are not being met such that they can effectively manage behavioral symptoms [7]. We refer to *information needs* as including information *access*, *retrieval*, *availability*, and *usability*. Currently, there is no widely-available mechanism that meets family caregiver information needs, including the ability for family caregivers to access and retrieve the information that may be most useful to them at the time that they need it.

1.1 Consumer Health Informatics Must Be Designed for the Family Caregiving Sociotechnical Context

Consumer Health Informatics (CHI) such as web-based applications have the potential to meet the unique information needs of family caregivers by providing them access to information on behavioral symptom management. The American Medical Informatics Association defines CHI as "informatics from multiple consumer or patient views, [including] patient-focused informatics, health literacy and consumer education. The focus is on information structures and processes that empower consumers to manage their own health [8]." However, for CHI to successfully meet family caregiver information needs, it is necessary that it be designed to account for the unique sociotechnical context in which family caregiving occurs [9, 10]. Sociotechnical context refers to the context within a purposeful system influenced by interacting components such as humans, technologies and environment [11, 12]. For example, the sociotechnical context of family caregiving includes the level of workload the family caregiver incurs, the social context of family caregiving, and the complexity of caregiving tasks [12-14].

1.2 Sociotechnical Systems Framework Can Be Applied to Understand Current Barriers to Family Caregiving Information Needs and Facilitate Future Design

A sociotechnical systems approach provides a framework for evaluating the system in which family caregiving occurs so that the design of CHI can be optimized to "fit" into the system [15]. In this way, the design of CHI by assessing the sociotechnical system can improve user experience and better meet the needs of the user. The sociotechnical system approach is particularly relevant to understanding how to meet the information needs of family caregivers given the complexity, unpredictability, and high workload associated with dementia care [3]. For example, family caregivers currently encounter barriers to successfully meeting their information needs. A sociotechnical systems approach can be used to identify the current barriers to information needs at the system level so that future CHI address those barriers in the actual design [15-18]. Addressing the sociotechnical context of those barriers in the design of CHI can provide critical information about how to optimize the design of CHI to facilitate family caregiver information needs by addressing optimal ways to design to fit into family caregiver workflows, how to best present information in meaningful ways, how the design should interact with other tools, and how the design should address where it is going to

be used. For example, the introduction of CHI into the sociotechnical system can change how the interactions occur within that sociotechnical system. These changes can lead to unwanted system consequences such as increased workload for family caregivers or stress induced by frustration with difficult-to-use technology [10-15, 19, 20]. Thus, it is critical to assess the sociotechnical system and the interactions that occur within the system prior to the design and implementation of CHI. Doing so will ensure that the system changes as a result of CHI implementation do not lead to unwanted system consequences, but rather facilitate intended outcomes [10-15, 21].

1.2.1 Conceptual Framework

The Systems Engineering Initiative for Patient Safety (SEIPS) is a sociotechnical systems model that describes an adaptive feedback system of interdependent elements that interact to conduct processes that produce outcomes, which feedback into the system [13, 14]. The SEIPS model can be used as a framework to evaluate processes and identify the barriers to those processes in a sociotechnical system [13]. In the study described here, the process we were interested in was caregivers' information needs related to behavioral symptoms and their management. We used SEIPS as a framework by which to identify barriers to caregiver's ability to meet their information needs related to behavioral symptoms [14].

2. Objectives

The purpose of this study was to apply a sociotechnical systems approach to identify barriers to meeting caregivers' information needs related to the management of dementia-related behavioral symptoms, and to derive design implications that overcome barriers for caregiver-focused web-based platforms. We have subsequently used these design implications to inform the development of a web-based platform, WeCareAdvisor,™ which provides caregivers with information and an algorithm by which to identify and manage behavioral symptoms for which they seek management strategies.

3. Methods

3.1 Procedure

We conducted four focus groups with a total of 26 caregivers at a large public university in a Midwestern state (Mean=7 participants per focus group). The focus group moderators (DW, BS) used a semi-structured interview guide of open-ended questions to facilitate a one-hour discussion. Focus group sessions were audio recorded and subsequently transcribed verbatim by a professional transcription service.

3.2 Design

The data reported in this study were derived as part of a larger multiphase NIH-funded research project for the design and testing of the WeCareAdvisor™ (NIH Grant #5R01NR014200–03), the purpose of which is to help caregivers better manage challenging behavioral symptoms based on an evidence-informed decision-making algorithmic approach to behavioral management [22, 23].

Participants were selected using a combination of purposive and network sampling to identify caregivers who currently provide care to persons with dementia or those with previous caregiver experience [22]. We also identified participants who had experiences (either currently or formerly) managing behavioral symptoms. The focus group moderators were an expert in mixed methods and qualitative research and professor of social work and psychiatry (DW), as well as a masters-educated research scientist with extensive experience in qualitative research and research in the area of aging. Both moderators have previous experience conducting research with family caregivers. Open-ended focus group questions explored caregiver perceptions of the following areas: 1) current experiences meeting informational needs related to managing behavioral symptoms, 2) how web-based appli-

cations could better meet informational needs around managing behavioral symptoms; and 3) what features they would hope to see in a web-based application. The specific questions used in the focus group are presented in ►Table 1. This study was approved by the University of Michigan Institutional Review Board.

3.2.2. Coding and Analysis

The SEIPS model was used to direct content analysis [13]. First-pass of broad coding was focused on the specific SEIPS elements:

- **Person:** The person or teams of persons that perform work in the system
- **Tasks:** The actions that constitute work performed by the person(s) in the system
- **Tools and Technology:** What is used to perform work in the system
- **Organization:** The work is structured in the system
- **Environment:** The physical space where work is performed

Coding directed by the SEIPS elements was targeted toward identifying barriers to processes related to information needs. Although coding was directed by the elements of the SEIPS model, we also allowed themes to emerge from the data. The first-pass coding identified a set of 9 overarching themes. We then conducted a second-pass coding to deductively identify focused codes within those themes to create the formal coding scheme. Those codes represented our final list of sociotechnical barriers related to information needs processes. The codes were used to direct a final pass coding to illustrate, explicate, and further revise the themes. The structural coding process occurred iteratively in which two researchers discussed the codes and themes identified until consensus on the coding scheme was reached (NW, MK). Both researchers coded all of the transcripts. The resulting themes were the categories of work system barriers. The research team found that data saturation was obtained during the structural coding process.

Barriers to processes can be viewed as challenges within the sociotechnical system that lead to imbalances between system elements. In other words, a barrier within one element leads to undesirable interaction between elements. Once barriers have been categorized within elements, the relationships between elements can also be examined. This is known as element *interactions*. The specific barriers that led to system imbalances between element interactions can support generation of design requirements for web-based platforms for caregivers. Design requirements were extracted by further analysis of identified barriers. Specifically, we identified the *interactions* between barriers of SEIPS elements of the sociotechnical system (e.g., an interaction between an organizational barrier and a tool and technology barrier). One researcher, a Human Factors Engineering expert (NW), examined all sections of each transcript that were coded as two or more SEIPS elements. The interactions were categorized and for each set of element interactions, the barriers that interacted were examined and initial design recommendations were developed. Other members of the research team (MK, LNG) vetted these requirements until a consensus was reached. Finally, we further analyzed the subsequent design recommendations to identify any common themes. Two members of the research team (NW, LNG) reviewed the resultant interactions and design recommendations and identified three overarching themes from these data.

4. Results

The 26 family caregivers (60% Female; 96% Caucasian; 4% African American) had an average age of 52 years (range = 24-76 years) and either lived with (9) or near (17) the person with dementia. ►Tables 2–4 provide details of caregiver and person with dementia demographic information. Caregivers noted that the 26 persons with dementia they provided care for (80% Female, 96% Caucasian; 4% African American) had an average age of 82 years (range =61–96 years). Eighty-one percent of the family caregivers identified as the primary caregiver, and 92% shared caregiving responsibilities. A majority of the family caregivers (96%) had some college education. All of the family caregivers had access to a computer, had internet at home, and had an email address. Most of the caregivers accessed computers at home (96%). Sixty-five percent of the family caregivers used email

several times per day. The use of internet enabled-devices included desktop computers (62%), laptop computers (69%), tablets (31%), and smartphones (54%).

4.1 Barriers to accessing information

Using the SEIPS framework to identify and organize themes, we identified 9 categories of barriers to accessing information on behavioral symptoms using a web-based platform that are described in ▶ Table 5 along with illustrative quotes. Quotations are referred to in-text using the relevant 'Q#'.

4.1.1 Person Barriers

The "persons" of focus were caregivers of persons with dementia who managed behavioral symptoms. Person barriers to meeting information needs related to behavioral symptoms included health literacy levels, the knowledge and skills the caregiver had, and the caregivers' level of trust in information. Caregivers expressed frustration at having to decipher medical terminology (Q1), difficulties identifying what was important information (Q3), and not being able to extrapolate the information available to their own situations. In addition, when searching for information on behavioral symptoms, caregivers explained that they often spent more time than they wanted to due to a need to find multiple sources to confirm the validity of a piece of information (Q3).

4.1.2 Task Barriers

The tasks related to caregivers' information were most often related to cognitive processes – processing information, identifying search strategies, deciding which information is relevant, and encoding the information. Task barriers were related to the ability to perform these processes. Barriers included: information underload, information overload, and high workload. Caregivers described challenges identifying information specific to their situations within large quantities of available information (Q5). Sometimes, caregivers encountered large amounts of information where there was a lot of information to sift through that pertained to their situation. Other times, caregivers struggled to find any information relevant to a behavior they experienced (Q4). Both situations often led to caregivers feeling overloaded. Meeting information needs was also a challenge due to the high volume of other caregiving demands, as well as the reduced capacity described by caregivers to handle high demands due to stress and burden (Q6).

4.1.3 Tools and Technology

Caregivers described using websites, general search engines, and caregiver-focused online discussion boards to meet information needs related to behavioral symptoms. Specific search engines and websites were not mentioned by name except for the Alzheimer's Association website. In addition, caregivers used books, senior care newsletters, and support groups to meet information needs. The tools and technology barriers included both the ease of use of information resources and the specificity of the information resource. For example, a major challenge for caregivers was the ease of use of websites and discussion boards specific to dementia caregiving (Q7). Caregivers felt some website designs led them in circles without being able to find the information they needed (Q7). They also discussed challenges with complicated searches and layouts that made sites difficult to navigate. The generalized nature of web sites also led to increased frustrations for caregivers (Q8). They felt that they searched for information about behavior management and the search did not result in the information needed. Sometimes this was because there was too much information, but other times it was because information was general and not tailored to their specific needs at that moment. This was also described as a challenge with books provided to meet caregiver information needs. Caregivers found books to be frustrating because they provided too much information. Specific book titles were not mentioned.

4.1.4 Organization

Organization barriers identified were focused on caregivers' experiences of isolation and lack of support. Caregivers described an isolated experience (Q9), with low frequency of available support from others, and difficulty finding time to go to support groups as barriers to meeting information

needs. Specifically, caregivers found it difficult to go to support groups due to a lack of family support (Q9), and the support groups being too far away from their home.

5. Discussion

5.1 Sociotechnical System Interactions: Translating Barriers to Design Implications

Based on these categories of barriers and the interactions between the elements of the sociotechnical system, design recommendations were extrapolated (►Table 6). ►Table 6 provides a detailed categorization of sociotechnical system element interactions, the specific barriers that interacted within those elements, and the design recommendations that resulted from those interactions. For example, although the caregiver may not have the information seeking skills for a task, this element *interacted* with a lack of family support (organization barrier). An additional interaction with a resource website to assist the caregiver that causes more frustration (tools and technology barrier) can further exacerbate the problem. Each barrier on its own can suggest relevant design solutions, but interactions among these elements can bring new complexity to design requirements.

The common design implications across all identified barriers to meeting caregivers' information needs are that caregivers need information on behavioral symptoms that is 1) **timely** – information needs to be available when they perceive the need to access it; 2) **tailored** – information needs to add value and be specific to the caregiver's own situation, and specific context in which behaviors occur; and 3) **usable** – information needs to be presented in language that is accessible (e.g., nontechnical), which does not add to workload and fits within their caregiving workflow.

5.2 Caregivers need timely access to information

Our findings suggest that critical to the success of the design of a web-based application is the ability to provide information to caregivers at any time they need it. In addition to behavior management, caregivers perform numerous tasks related to the daily care of the person with dementia, including the crucial management of health care such as medication management, as well as support of activities of daily living such as bathing and eating. Thus, it is imperative that information be provided in an optimal way that does not increase caregiver workload. This is in line with previous research conducted with older adults that found they required CHI with simple interface designs that supported decision making and other information processing [25]. One way to make this presentation optimal could be through the use of handheld devices. In a systematic review assessing the effectiveness of handheld computers and mobile devices that provide instant access to medical information for health care professionals, Mickan and colleagues found the use of handheld computers improved efficiency, reduced documentation errors, saved time, and enhanced work patterns [26]. The authors concluded that handheld computers provided timely access to information, which enabled accurate and complete documentation along with immediate access to evidence-based decision support [26]. Although there is evidence that web-based platforms built for medical professionals improve timely access to information and enhance care, web-based interventions for caregivers should be accessible and tailored to facilitate behavior management and caregiving duties. It will be critical for future research to investigate caregiver workflows over time to identify key information need points in their workflow so that CHI design can be optimized to fit these needs.

5.3 Caregivers need tailored information

Our findings also point to the importance of tailoring CHI to the specific situations of caregivers. Tailoring an intervention involves deriving individualized information and/or strategies specified to a person's unique attributes [27]. Web-based tailored interventions appear to be more effective than non-tailored interventions in inducing behavior change by providing content that is pertinent or relevant to one's situation [28-30]. A meta-analysis of computer-tailored interventions focusing on dietary improvement, physical activity, smoking cessation, and mammography screening found signifi-

cant overall effect sizes across the four, aforementioned behaviors. For family caregivers, research is needed to identify ways to tailor to specific information needs. For example, future research may explore the design of caregiver-focused search engines, as well as ways to process behavioral symptom inputs using lay (i.e., caregiver) rather than medical terminology. Future interventions should efficiently deliver information while taking into account the heterogeneity of caregiver characteristics and the differential disease trajectory or symptomatology [31].

In addition, tailoring of CHI should acknowledge that specific caregiving situations will likely change over time. As information needs change with disease progression, being able to access the specific information needed to manage behavioral symptoms along the care trajectory is important. As such, web-based applications designed to fit the needs of this population need to be adaptive to the changing needs of the caregiver.

5.4 Caregivers need usable information

We also found that caregivers need information in the specific amount they need it and that this amount may vary depending on the caregiver and the informational need. These findings are consistent with previous research, which indicates that most caregivers feel overwhelmed with the amount of information available and prefer receiving only relevant information to meet their current needs [32]. This requires not only the information at the right literacy level for the person, but also the correct tool design to provide access to the right information in an efficient manner. Previous research suggests that when successful in obtaining information, caregivers valued a quantity of information that was not "overwhelming", and Wald, Fahy, Walker and Livingston proposed a 'rule of threes' in order to help health professionals prioritize the vast amounts of information [33]. However, it is not clear how successfully the "rule of threes" would translate to web-based applications and whether specific tailored information could fit into this rule. Because caregivers and their situations are highly idiosyncratic in their needs, not only should they participate in the design in order to make the data useable, the tool should be able to learn from them. For example, caregivers can mark when they find information that fits what they need on a topic, as well as mark when they find content at the right level of detail or complexity for their comprehension. To address their informational needs, future interventions should be developed with a user-centered design or participatory methods. To promote high-uptake and usability, researchers should elicit feedback from caregiver-users throughout the design and iterative testing phases of web-based interventions. There is evidence confirming that the adoption of a participatory approach to designing web-based interventions enhances the usage of the e-tools, improves patients' health knowledge, and augments the effectiveness of systems [34, 35]. In addition, machine learning components that can tailor CHI to individual caregiver situations will be key to the success of CHI for caregivers. For example, tailorable CHI may "learn" for an individual user what amount of information is too much (i.e., overload), or too little (i.e., underload)

Several limitations of this study should be considered. First, it was conducted in one geographical area and may not be representative of all family caregivers. Second, this study focused only on informational needs and did not address other factors related to the successful design and implementation of CHI for behavioral and psychological symptom management such as training caregivers to provide the ability to appropriately apply the information, providing caregivers support systems (i.e., environment) that allows them to apply the information, consideration of other factors affecting tool usage such as prior comfort with and use of technological tools, and integrating effective measurements for outcomes that could feedback into CHI for optimized tailoring. We also note that additional limitations of this study include the use of two rather than three independent coders of the data as well as the lack of member checking.

Finally, we were not able to assess all of the elements of our framework with the data we collected. It is important to consider the potential implications of organizational and environmental barriers when designing for caregivers. Further, environmental aspects such as the home environment (e.g., whether there is a space to privately search), or the physical location of the home (e.g., in a rural area with challenging cellular service) should all play a role in design considerations made for this population. Generational and cultural considerations should also be addressed and could be critical to the

accessibility of the design. Future research in this area should specifically address the potential barriers within these elements.

It is important to note that assessing the needs of complex users such as caregivers of persons with dementia often requires extensive investigation, and there may not be instantaneous answers to all tailored questions. Questions such as what caregivers may be willing to give up in specificity for urgency and how we can sufficiently customize web-based platforms while facilitating community interaction among caregivers with similar situations are important questions for future research.

6. Conclusions

The sociotechnical systems approach was useful in identifying and categorizing barriers to information needs within caregivers' sociotechnical systems. The approach was also useful for leveraging those barriers to explicate design recommendations for web-based applications to support family caregivers' information needs in the management of behavioral symptoms. Family caregivers require user-centered information on behavior management provided just-in-time that can adapt to their changing needs over time.

Clinical Relevance Statement
Designers of web-based information systems may find the barriers identified through this study and their design implications helpful for advancing these tools and optimizing their relevance to family caregivers. In addition, the implementation of conceptual frameworks and design recommendations such as those provided here have the potential to advance intervention development through CHI for the over 15 million caregivers of persons with dementia in the United States. Finally, inclusion of family caregivers, individuals with dementia and healthcare providers early on in the conceptualization and design of web-based information systems is essential to assure relevance, acceptability and effectiveness of such solutions.

Conflict of Interest Statement
The authors declare that they have no conflicts of interest in the research.

Human Subjects Protection
This study was approved by the University of Michigan Institutional Review Board.

Table 1 Semi-structured Focus Group Questions

- How do you explain your family member's dementia to others in your family or to neighbors or to a child or a grandchild? Anyone can start.
- What do you think are some of the causes of the behavioral changes that you experience as a part of your family members' dementia? What triggers these behavioral changes?
- Do your family member's behaviors bother you?
- What are some of the strategies or approaches you use to cope with the behaviors, and what works and/or what doesn't work about those strategies?
  – How did you make a decision to use that particular strategy? What led you to that choice?
- Have you had to go to a doctor or other health care provider for help with managing the behaviors of your family members? If so, what influenced your decision to seek help? If not, why did you choose not to go to that health care provider?
- What would be most helpful to you in managing your family member's behaviors? What would really be beneficial to you as a caregiver?
- What kind of information would you like to see with regard to treating or managing your family member's behaviors?
- Would you be willing to use a computer-based tool that could help you learn to manage the behavioral symptoms?
  – What would prompt you to use the tool?
  – What features would be helpful to you in this kind of tool?

*The questions listed are a framework of question prompts used in the semi-structured focus group format. The exact wording of questions may have changed depending upon focus group participant discussions, but question topics were consistent across all focus groups.

Table 2 Family Caregiver Characteristics (N=26)

Characteristics	Mean (Range)	N (%)
Age	52 (24–76)	
Relationship		
Gender (Female)		60
Race/Ethnicity		
African American; Caucasian		4: 96
Lives with person with dementia		35
Years Providing Care		
<1 Year; 1–5 Years; >5 Years (%)		4; 69; 27
Primary Caregiver		81
Shares Caregiving Responsibilities		92
Education		
< High School		4
Some College/Vocational Training		27
Bachelor's Degree		38
Graduate Degree		31

Table 3 Person with Dementia Characteristics

Characteristic	Mean (Range)	N (%)
Age in Years	82 (61–96)	
Gender (Female)		80
Race/Ethnicity – African American; Caucasian		4; 96

Table 4   Caregiver Technology Use Characteristics

Technology Use Characteristic	N (%)
Regular Access to Computer	100
Frequency of Computer Use	
Few Times a Month of Less	4
Every Day or Two	31
Several Times Per Day	73
Places Access Computers**	
Work	19
Home	96
With Friends/Family	23
Library	27
Has Own Email Address	100
Frequency of Email Use	
Less than Every Day or Two	4
Every Day or Two	31
Several Time Per Day	65
Has Internet Access at Home	100
Frequency of Internet Use	
Every Day or Two	31
Several Time Per Day	69
Use of Web-Enabled Devices**	
Desktop Computer	62
Laptop	69
Tablet	31
Smartphone	54
Multiple Devices	69
Willingness to use web-based platform to meet information needs	
Yes	88
No*	8
Maybe	4
Sources Accessed for Information on Behavior Management Strategies**	
Alzheimer's Association	73
Doctor	58
Internet	81
Magazines	58
Radio/Television	23
Newspaper	19
Other	50

*Reasons provided for participants unwilling to use a web-based platform to access information on behavior management included discomfort with technology other than for email access and concerns about privacy.
**Could choose more than one item

Table 5   Sociotechnical system categorization of barriers to caregivers' ability to access information on behavioral symptoms using web-based platforms with barrier descriptions and illustrative quotes

Sociotechnical System Element	Barrier Impacting this Element	Description of the Barrier	Illustrative Quote Describing Barrier
Person	Health Literacy	Caregiver level of ability to understand and interpret medical information and/or terminology related to behavioral symptoms	Q1 "Then you get thrown into the medical community which is just full of acronyms...you're hearing about the x, y, z and the d, p, c and this and that. You know you're like frustrated...and you're madly trying to write down all these letters and remember this, that and the next thing...then there is no road map at all to help you." (P11, Focus Group #3)
	Knowledge and Skills	Caregiver current baseline level of knowledge and skills related to behavior management	Q2 "My mother went through some very aggressive behavior very early on. I wished I had had the knowledge at that time to know how to deal with it." (P8, Focus Group #3)
	Trust in Information	Caregiver confidence in source of information regarding behavior management	Q3 "[I want something] so that when I am looking I don't have to feel like this might be a 'Wikipedia' thing that I'm going to have to check, here, here, here and here [to verify that the information is accurate]." (P4, Focus Group #2)
Task	Information Underload	Insufficient or unavailable information	Q4 "We're stuck in this phase of just limbo-land you know like you can't find a lot of help on the internet for this [specific challenge] other than just go with the flow." (P2, Focus Group #4)
	Information Overload	Large quantity and/or excess amount of information given to caregiver	Q5 "After a while looking on the computer and reading more stuff my brain just starts to get kind of like overloaded." (P5, Focus Group #2)
	High Workload	Caregiver experiences high levels of workload that negatively affects ability to access information	Q6 "I can't get away from my wife. She's stuck to me like Velcro…It's very difficult to get away." (P1, Focus Group #4)
Tools and Technology	Technology Ease of Use	Caregiver has challenges navigating current technology to find the information needed	Q7 "Alzheimer's Association website is frustrating to some degree because I don't know it seems like you start clicking to find different pieces of information and it's just sending you back through the same crap again, and again, and again." (P2, Focus Group #1)
	Resource Specificity	Information sites not optimized to specific caregiver needs	Q8 "It's all out there but the right search engine that ties it all together, that's not Google. Because when I'm looking for a particular piece of handy dandy care for elders alarm system or something or information on drugs I want it (De-identified name)-ised. I don't want the PDR and all that fine print to go through." (P2, Focus Group #2)
Organization	Resource Limitations	Inability to access information from other caregivers due to low frequency of available support, distance from support groups, or difficulty finding time to go to support groups	Q9 "I think that there's such isolation for the caregiver because you often don't have someone to talk to unless you have a large family… support groups you know something that meets once a month doesn't do much good." (P5, Focus Group #1)

Note: No barriers associated with the physical environment were identified in our data

Table 6‚ÄÉCategorization of sociotechnical system element interactions, the specific barriers that interacted within those elements, and the subsequent design recommendations

Sociotechnical System Element Interaction (Primary element in bold)	Barrier Interactions (Primary barrier in bold)	Design Implications from Barrier Interactions
Person Task Tools and Technology	**Health Literacy** Information Overload Technology Ease of Use	• Provide information at accessible levels·Use lay terminology • Allow caregivers to assess language used
Person Task Tools and Technology	**Knowledge and Skills** Information Overload Technology Ease of Use	• Provide information at different knowledge levels • Integrate links to outside resources
Person Task Task	**Trust in Information** Information Underload High Workload	• Use trusted Information sources • Use evidence-based materials • Provide citations for sources of information and links to original materials
Task Person	**Information Underload** Trust in Information	• Identify the targeted amount of information needed through participatory design techniques • Integrate feedback loops and adaptations based on specific needs that may change over time
Task Person Person	**Information Overload** Knowledge and Skills Health literacy	• Identify the targeted amount of information needed through participatory design techniques • Provide the amount of information needed in targeted location • Design a caregiver-specified search feature
Task Person Organization	**High Workload** Trust in Information Resource Limitations	• Use of work analysis techniques to identify the optimal design to fit into caregiver workflow • Design content and interactions to minimize workload • Provide information when it is needed (i.e., at targeted times)
Tools and Technology Person Person Task Task	**Technology Ease of Use** Health Literacy Knowledge and Skills Information Overload High Workload	• Implement user centered and participatory design strategies to improve usability • Integrate usability testing into design process
Tools and Technology Person Person Task Task Organization	**Resource Specificity** Health Literacy Knowledge and Skills Information Overload High Workload Resource Limitations	• Design for information to be specific to individual situations • Feedback loops should be integrated to improve tailoring • Information should be adaptive to changing needs over time • Integrate feedback loops based on measured outcomes • Allow for adaptation in the technology over time
Organization Task Tools and Technology	**Resource Limitations** High Workload Resource Specificity	• Allow for real-time connectivity to other caregivers • Provide mechanism to support communication across caregiving networks

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