A process-based approach to exploring the information behavior of informal caregivers of people living with dementia

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Abstract

Introduction and purpose: Informal caregivers of persons living with dementia have significant unmet information needs that, if met, would better equip them to provide effective care. Despite the existence of health information technologies, websites, resources, and organizations dedicated to dementia caregiving, caregivers continue to report unmet information needs. Caregivers' continued unmet information needs suggest a misalignment between information products, and caregivers' information behavior—how caregivers generate, acquire, manage, use, communicate, and seek information. Researchers have developed conceptual models for understanding caregivers' information behavior, but these models are limited in that they are task-oriented, and they assume that caregivers' information needs will be met if they engage in

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Summary table

What was already known before the study

Despite the existence of health information technologies and many information products, informal caregivers of persons living with dementia have persistent and pervasive unmet information needs that, if met, would better equip them to provide effective care. Conceptual models have been developed and demonstrated some utility for understanding information behavior.

What this study has added to the body of knowledge.

Informal caregivers of persons living with dementia engage in complex information behavior processes that can be modeled using a process-level, sociotechnical-systems-based approach.

We developed a usable and translatable information behavior conceptual framework that can guide the future design and development of information products, such as health information technologies, that align with caregivers' information behavior processes and support them in addressing their unmet information needs.

information behavior. To address these limitations, the present study sought to explore caregivers' information behavior as a sociotechnical-systems-based process.

Methods: We conduced semi-structured interviews with 30 self-identified caregivers to explore their daily experience of caregiving activities, including their information behavior. We applied a process-based conceptual framework that takes into account inputs, processes, outputs, and feedback mechanisms within a sociotechnical system to guide analysis. The process of interest was caregivers' information behavior as modeled by the information-seeking and communication model (ISCM). We conducted a deductive content analysis guided by the components of the ISCM. We then used team-based affinity diagramming to collapse and categorize the ISCM components into inputs, processes, outputs, and feedback.

Results: We developed a conceptual model to depict caregivers' information behavior as a sociotechnical-systems-based process of inputs, processes, and outputs that feedback into the system. The conceptual model consisted of three inputs (i.e., information users, information providers, and information products), three information seeking and communication processes (i.e., information access, information interaction, and information assessment and processing), two outputs (i.e., utility and credibility), and feedback.

Discussion and conclusion: Building on and addressing the gaps in previous information behavior models, our conceptual framework advances the previous task-level understandings of caregivers' information behavior into a comprehensive feedback-driven, process-level perspective consisting of context-based inputs, information seeking and communication processes, outputs, and feedback. A sociotechnical-systems-based understanding of caregivers' information behavior allows for misalignments between information providers and products, and caregivers' information behavior not only to be illuminated, but systematically addressed.

1. Introduction

Nearly 16 million informal caregivers (unpaid family, friends, and volunteers) provide an estimated annual 18.5 billion hours of unpaid care to the 5.8 million people living with dementia in the United States [1–3]. These caregivers encounter significant challenges managing the cognitive, behavioral, and physical changes that characterize dementia progression over an extended period [4–6]. Caring for people living with dementia is highly complex and has broad psychological, physical, and economic consequences [6–11]. Currently, caregivers have significant unmet information needs that, if met, would better equip them to provide effective care [2,10,12,13].

An information need can be defined as "*a recognition that [one's] knowledge is inadequate to satisfy a goal that [one] has, within the context/situation…at a specific point in time*" [14]. Information needs include information access, retrieval, and usability [6,15,16]. Caregivers have cited a range of unmet information needs including:

- Disease-specific information (e.g., understanding diagnosis, treatment options, prognosis) [16–19]

- Health and social/supportive services (e.g., nursing home options) [16,17]

- Patient care provision (e.g., behavioral symptom management) [15–17,20]

- Caregiver self-care (e.g., stress management) [15–17]

Without accurate and accessible information, caregivers may not understand important safety limitations, financial consequences, available services, and treatment options [16,20,21]. For example, when caregivers lack information about dementia disease characteristics or progression, they may make decisions (e.g., pursuing overly aggressive medical treatments) without understanding what options might be most useful in the long-run [22].

However, caregivers' unmet information needs do not appear to be due to a lack of information per se [16]. A multiude of information products are available for caregivers including health information technology (HIT), websites, and organizations (e.g., the Alzheimer's Association) [4,16,23–28]. Despite this abundance of information, caregivers continue to report unmet information needs. This suggests that the availability of information does not inherently meet information needs [16,18]. Caregivers' continued unmet information needs suggest a misalignment between information products and caregivers' *information behavior*. Information behavior is defined as the "generation, acquisition, management, use and communication of information, and information seeking" [29]. One potential cause of this misalignment is a lack of knowledge about caregivers' information behavior, and as a result, information products do not align with caregivers' information behavior. To address the misalignment, it is important to develop a comprehensive understanding of caregivers' information behavior. Such an understanding is needed to inform the design of future information products that align with caregivers' information behavior and minimize unmet information needs [30,31].

Researchers have begun to explore the utility of conceptual models for understanding caregivers' information behavior [32,33]. Available information behavior models are limited for understanding the specific context of dementia caregiving. Additionally, they assume that users' (i. e., caregivers') information needs will be met if they engage in information behavior. Existing models are also task-oriented, which may limit their ability to holistically understand caregivers' information behavior. These limitations constrain the usefulness of existing information behavior models in the development of information products for caregivers [33].

To address these limitations, the present study sought to explore caregivers' information behavior from a process-level perspective [34, 35]. The process-level perspective is grounded within a sociotechnical systems approach, which conceptualizes a process as the transformation of context-based inputs into desired outputs [36]. The outputs then feedback to inform future inputs and process. This approach explicates the process-level interdependencies among the individuals, tools, technologies, and contexts involved in caregivers' information behavior [46]. We posit that a process-level approach to caregivers'

information behavior will reveal underlying barriers in information seeking and communication processes that may prevent caregivers from having their information needs met. Thus, our objective was to explore caregivers' information behavior as a sociotechnical-systems-based process.

2. Methods

2.1. Sample

We used convenience sampling to recruit 30 self-identified, English speaking caregivers, who lived within 60 miles of Madison, Wisconsin (Midwest United States) (Table 1). Sample size was selected to achieve saturation [37], and data were collected and analyzed concurrently until no new concepts were identified [38].

2.2. Design and procedure

We conducted a descriptive qualitative study using semi-structured interviews to explore caregivers' daily experience of caregiving activities, including their information behavior (Appendix A). Participants were interviewed at home or a convenient meeting place. Interviews lasted approximately one hour, and participants received a $25 honorarium. Interviews were audio recorded, transcribed verbatim, and entered into NVIVO 11 for analysis. We received Institutional Review Board approval for this study (2016-0185).

2.3. Conceptual framework

Our conceptual framework is based on the understanding that processes occur within sociotechnical systems of inputs, processes, and outputs that feedback into the system [39]. The process was caregivers' information behavior as modeled by the information-seeking and communication model (ISCM) [32]. Although not specifically developed for caregiving, the ISCM integrates elements from foundational, cross-disciplinary information behavior models to depict information behavior as a continuous, sequential pathway of tasks involving information providers and users [32]. We chose this model because it: 1) was developed to capture information behavior complexity [32,40]; 2) includes contextual factors, making it adaptable to a sociotechnical systems framework; and 3) was validated in healthcare settings, suggesting it may be useful in caregiving [40,41].

2.4. Analysis

We conducted a deductive content analysis guided by the components of the ISCM while also allowing for the identification of concepts related to information behavior not captured with the ISCM [42]. We used team-based discussions to develop caregiving-specific definitions for each ISCM component (Appendix B) [43]. All transcripts were dual coded. The research team met monthly to review findings and discuss discrepancies until consensus was established [43]. To develop a sociotechnical-systems-based-process conceptual framework of information behavior, we used team-based affinity diagramming to collapse and categorize the ISCM components into inputs, processes, outputs, and feedback (Fig. 1) [39,44].

3. Results

Through our analysis, we developed a conceptual model of caregivers' information behavior as a sociotechnical-systems-based process of inputs, processes, and outputs that feedback into the system (Fig. 2). The conceptual model illustrates three key factors: 1) types and nature of inputs influenced the types and nature of caregivers' information behavior processes; 2) types and nature of processes influenced the types and nature of outputs; 3) outputs, and whether outputs met caregivers' information needs, directly informed system feedback, which subsequently informed future system inputs and process.

3.1. Process inputs

Our analysis identified three input categories of caregivers' information behavior: information users, information providers, and information products, and nine input subcategories (Table 2).

3.1.1. Information users—We identified four subcategories of information users (Table 2). First, we found that caregivers' needs, wants, and goals influenced information behavior. Caregivers described wanting to improve their ability to provide care and the person living with dementia's quality of life. Caregivers expressed a need for information to better understand dementia, how to provide daily care, dementia-related symptom management, and how to meaningfully engage the person living with dementia.

Second, caregivers expressed a range of emotional responsiveness, with some indicating that information behavior was emotionally over-whelming, while others reported that the process was empowering. Caregivers' level of emotional burden influenced their ability to emotionally sustain information behavior. One caregiver noted that she found information related to dementia progression depressing and preferred to forego that information in favor of maintaining emotional well-being.

Finally, caregivers exhibited a range of technological literacy, with some unable to engage technology and others engaging technology almost exclusively in their information behavior. Caregivers' willingness or ability to engage with technology influenced the nature and type of information seeking and communication processes they pursued and, often influenced whether information needs were met. For example, one caregiver described their dislike of computers and noted most of the information they received came from periodic in-person interactions with healthcare providers and experiential information gathering (e.g., developing care strategies based on experiences with the person living with dementia).

3.1.2. Information providers—Caregivers cited a range of small-scale and large-scale information providers. Some reported engaging primarily small-scale information providers such as the local Aging and Disability Resource Center or healthcare professionals (e.g., primary care physician). Others reported primarily engaging large-scale information providers such as national organizations (e.g., Alzheimer's Association). Finally, some described engaging both small-scale and large-scale information providers either to obtain more comprehensive information or because their information needs were unmet by one

type of provider. For example, multiple caregivers cited pursuing large-scale information providers when information received from healthcare professionals did not meet their needs.

3.1.3.   Information products—Caregivers described using a range of information products that were either technology-based or non-technology-based, with most caregivers using a combination of the two. Technology-based information products were primarily websites, but also included television and movies that featured dementia-related themes. Non-technology-based information products included conversations with individuals (e.g., social workers), written texts (e.g., books, brochures), and seminars. Caregivers noted a preference for engaging with mediums with which they previously had experience. Caregivers who used a combination of technology-based and non-technology-based information products did so to obtain more complete information or to source additional information products (e.g., using the National Institutes of Health's website to order paper books).

3.2.   Caregivers' information seeking and communication processes

Caregivers' information behavior included three information seeking and communication processes: information access, information interaction, and information assessment and processing. These occurred interdependently and transformed system inputs into outputs.

3.2.1.   Information access—Information access was either intentional or unintentional. Intentional access was caregiver-initiated and involved the conscious pursuit of information or engagement with information providers through actions such as searching the Internet, scheduling meetings, and attending seminars. Unintentional access was initiated by someone other than the caregiver (e.g., friend) and involved the coincidental or unsolicited receipt of information. Unintentional access included: newspaper articles identified while reading the daily paper, email subscriptions to national information providers' newsletters, mail subscriptions to local or national information providers' newsletters or magazines, and volunteered information from family or friends.

3.2.2.   Information interaction—Information interactions were initiated by caregivers or information providers and occurred across technology-based and non-technology-based mediums. Caregiver-initiated information interactions often targeted a specific information provider (e.g., healthcare professional). Caregivers used technology-based mediums (e.g., email, telephone), and non-technology-based mediums (e.g., in-person meetings) to facilitate interaction. When information interactions were initiated by information providers, communications tended to be generic and not specific to any one caregiver (e.g., sending an email to email list subscribers). Information providers used technology-based mediums like email and non-technology-based mediums like paper mailings.

3.2.3.   Information assessment and processing—Caregivers described information assessment and processing as difficult and burdensome because it involved either too little information or too much information. Minimal inputs resulted in caregivers feeling unable, unwilling, or unsure of how to access information, especially if available information was in a medium that did not match their preferences. Conversely, too much information resulted in

caregivers having difficulty discerning relevance. This predominantly occurred when information was accessed through technology-based information products.

3.3. Outputs of caregivers' information behavior process

System inputs were transformed by information seeking and communication processes into two types of outputs: utility and credibility.

3.3.1. Utility—We identified two challenges related to utility: 1) information was only available at suboptimal times; 2) information was irrelevant to caregiver circumstances. With respect to the first challenge, caregivers cited not having the information they needed when they needed it. However, caregivers' perceptions of when the "right" time to have access to information differed. Some caregivers found information most useful when it was available as circumstances unfolded (e.g., as the person living with dementia is exhibiting a symptom), while others described information as most useful either before or after an event occurred (e.g., before a clinic appointment). With respect to the second challenge, caregivers described frequently receiving information that was either too vague or incompatible with their present circumstances. For example, one caregiver described receiving information about what to expect in caring for a person living with dementia in the future. They noted that this information was "good" but not useful in their present circumstances.

3.3.2. Credibility—Caregivers perception of information provider credibility varied based on previous experience with the information provider. Also, perceptions of credibility were influenced by the extent to which the information provided aligned with the caregivers' lived experience or personal understanding of caregiving and dementia. Most caregivers recognized information providers as credible, especially when they were able to provide information to which the caregiver may not have had access. For example, many caregivers felt that information provided by healthcare professionals was accurate and relevant, trusting healthcare professionals as credible information providers. However, for some caregivers, the initial trust they had in information providers was damaged due to suboptimal experiences. For example, some caregivers explained that information provided by healthcare professionals was incomplete, inaccurate, or not applicable, which resulted in the loss of trust in healthcare professionals as credible information providers.

3.4. Feedback

Information behavior outputs either met or did not meet caregivers' information needs. We found that outputs most often did not meet their information needs. When needs were not met, caregivers responded in four ways (Table 3): 1) self-sufficing by attempting to draw upon previous experience to meet their information need; 2) engaging technology by searching websites or accessing personal health records; 3) engaging people such as family members and healthcare professionals to meet their unmet information need.; 4) not pursuing the information need (i.e., need remained unmet). Caregivers attributed unmet information needs to not having technological or human support; not wanting to further pursue information because it is too emotionally, cognitively, temporally or financially taxing; or their inability to identify the specific unmet information need (e.g., you do not

know what you do not know). Each of these responses served as feedback to inform system inputs and processes.

4. Discussion

We have provided a conceptual framework that transformed the previous task-level understandings of caregivers' information behavior into a feedback-driven, process-level perspective consisting of context-based inputs, information seeking and communication processes, outputs, and feedback [39,44]. Our framework exposes caregivers' information behavior challenges that often led to information needs being unmet. These challenges and how they manifest within caregivers' information behavior have implications for the design of information products to ensure they align with caregivers' information behavior.

Previous research explored caregivers' information behavior as a prescriptive set of tasks [33], often focusing on individual information behavior components (e.g., technologies used, seeking process) [5, 16–18,20,23]. Our study integrates and expands on previous research by providing a feedback-driven conceptual framework that organizes descriptive components of foundational information behavior models into a sociotechnical-systems-based process. Our framework has key implications for understanding and supporting caregivers' information behavior.

First, our framework provides an expanded understanding of feedback. Feedback is the intentional or unintentional adaptation to system inputs and processes by system outputs [45]. Existing information behavior models often feature tasks or outcomes that feedback to a single component of the model (e.g., information user) [32,33,40]. Our results suggest this singular feedback loop oversimplifies how caregivers respond to outcomes and how outcomes influence future information behavior. Our framework identifies whether caregivers' information needs were met, captures how caregivers respond to needs being met or unmet, and how caregivers' responses feedback to inform future system inputs and processes. The ability to comprehensively understand feedback is critical to developing a full understanding of caregivers' information behavior. Feedback can identify misalignments between inputs (e.g., caregivers' goals) and outputs (e.g., usability of information products) and suggest mechanisms to address those misalignments through (re)design [46]. Feedback represents a pathway for identifying where, when, and how to redesign information products and processes to address caregivers' dynamic information behavior [46].

Another key contribution is a usable and translatable information behavior conceptual framework that can guide future design and development of information products. Existing information behavior models are either too simplified or too complicated, making them difficult to apply and to interpret findings. The input-process-outcome-feedback structure of our conceptual framework draws upon sociotechnical system models designed to evaluate systems and identify opportunities for redesign [39,47]. Thus, our framework can identify and address misalignments between information provider/products, and caregivers' information behavior.

Addressing caregivers' unmet information needs would better equip them to provide high quality care without compromising their own well-being [2,10,12,13,18]. Supporting the sustainability of dementia caregiving is critical as society relies upon caregivers to provide a majority of care for persons living with dementia [2]. Caregivers are expected to become an increasingly important asset as the number of persons living with dementia is expected to nearly triple by 2050. Thus, ensuring their information behavior is supported will promote the health and well-being of both caregivers and persons living with dementia [2].

4.1. Limitations and future work

Our findings should be interpreted with certain limitations in mind. First, we scoped information users to informal caregivers. Future work should investigate how other information users both within and external to the caregiving network affect caregivers' information behavior [48].\Second, information providers were identified through caregiver self-report and may not be comprehensive. Future work could systematically identify information providers and their role in caregivers' information behavior. Third, the findings presented do not include information provider perspectives. Future work could use a dual-perspective approach to understand each party's information behavior and how that behavior interacts to either meet or not meet caregivers' information needs. Fourth, our sample may not be representative of all experiences of information behavior as data were collected in one region of one country and consisted of primarily white participants. Future work should aim to include a more racially and geographically diverse sample to further our understanding of caregivers' information behavior. Fifth, we did not systematically collect information about caregivers' health status or length of time caregiving, both of which may have the potential to influence information behavior. Future work should explore the physical, socioeconomic, and psychosocial factors that influence caregivers' information behavior.

4.2. Conclusion

In exploring caregivers' information behavior as a sociotechnical-system-based process, we developed a novel conceptual framework that expands our understanding of caregivers' information behavior. This conceptual framework can be used to guide future research to further explore caregivers' information behavior and to guide the design of information products to address caregivers' persistent and pervasive unmet information needs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

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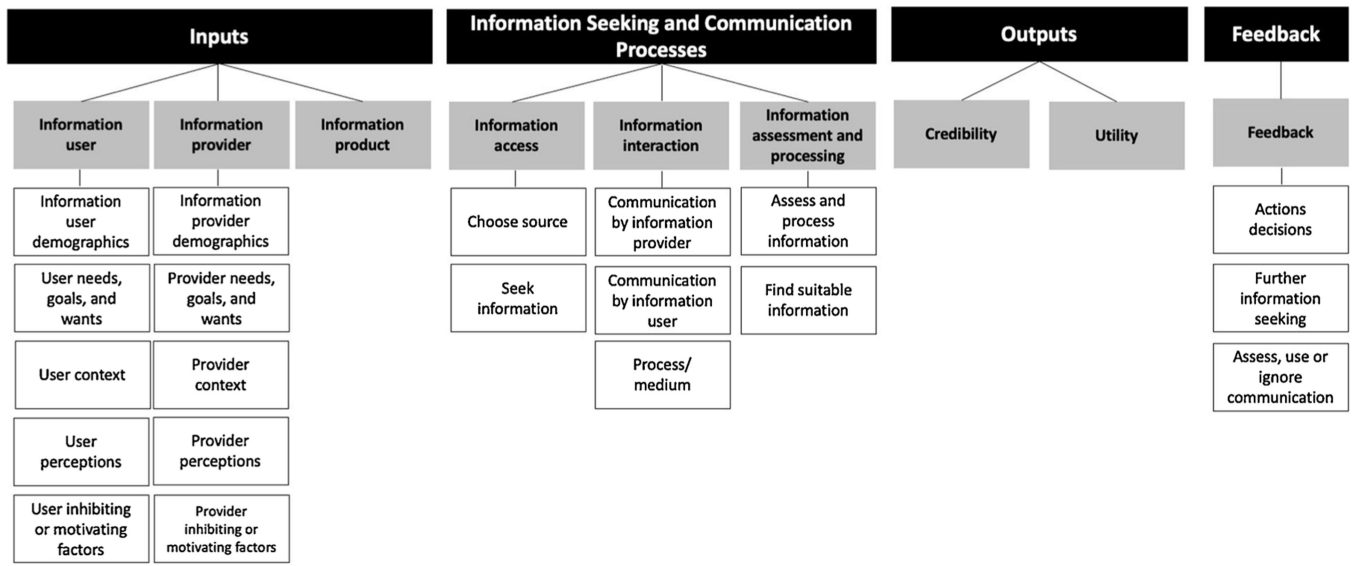
Fig. 1.
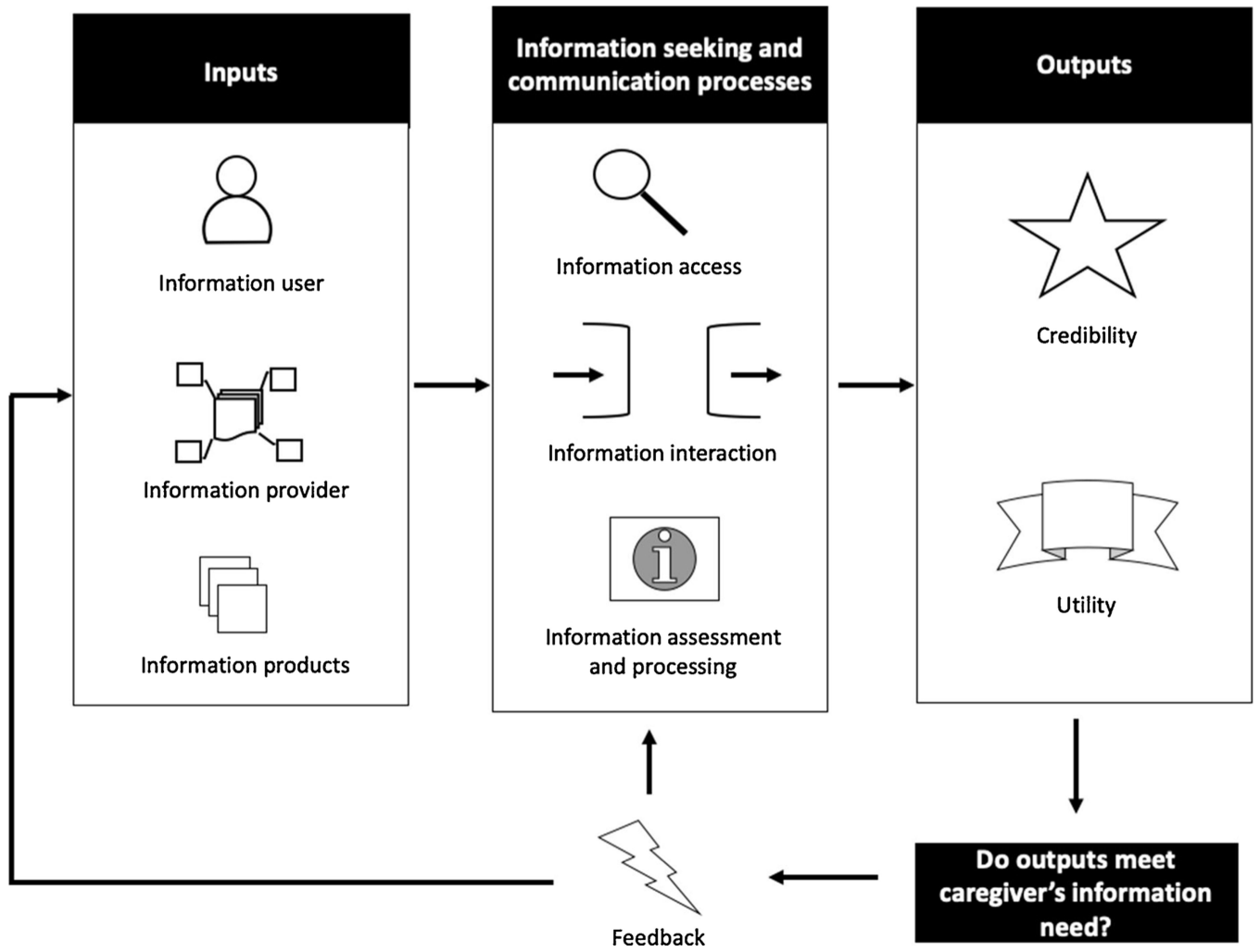Consolidation of 22 ISCM components into 9 representative conceptual model components.

Fig. 2.
Sociotechnical-systems-based-process conceptual framework of information behavior.

Table 1

Participant demographics.

Participants (n = 30)	
Gender of caregiver	
Female	18 (60 %)
Relationship to person living with dementia	
Spouse	12 (40 %)
Parent	18 (60 %)
Age of caregiver	
45–54	2 (6 %)
55–64	6 (20 %)
65–74	6 (20 %)
75–84	3 (10 %)
85–94	3 (10 %)
No age disclosed	10 (33 %)
Race/ethnicity of caregiver	
Caucasian	21 (70 %)
African American	5 (16 %)
Race/ethnicity not disclosed	4 (13 %)

Table 2

Information behavior input components and subcategories.

Inputs	Input subcategory	Subcategory definition	Illustrative quotation
Information user: A caregiver (e.g., family member, friend neighbor) that uses information	Caregivers' needs, goals, and wants	Caregivers' needs, goals, and wants related to information behavior processes	"I need to have some kind of, I was thinking of puzzles, but his vision isn't very good…And I need to find something that he and I can do together, which we don't do much of anything." Participant 694
	Caregivers' perception of urgency of the information need	Caregivers' perception or understanding of how urgent it is for them to fulfill their unmet information need	"For somebody in my position, it's like, well, you're sitting in the hospital wondering if [person living with dementia] going to live, and then you're starting to think in terms of, okay, she's going to live. Now what's coming? You know, what does the future hold and so on and so forth? So, yeah, as far as, yeah, you know, getting resources, boy, that's a really tricky thing." Participant 600
	Caregivers' level of emotional burden	Caregivers' response to emotionally taxing information and the ability to withstand the emotions associated with information behavior processes	"I try to read a lot about [dementia], and sometimes, it's just depressing. So sometimes I think it's better to just wing it." Participant 695
	Caregivers' technological literacy	Caregivers' understanding of and willingness to use technology during information behavior processes	"I can't figure [technology] out to start with. They drive me nuts. I want to throw the computer out the window sometimes." Participant 934
Information provider: Individuals, groups or organizations that produce, supply or communication information or facilitate access to it, as perceived by caregivers	Local information providers	Information providers that provide information within the caregivers' local community (e.g., county, state)	"I said I found this one thing from [local county] for the elderly, and I was going to look into that, in my collection of papers." Participant 694
	National or global information providers	Information providers that provide information at on a national or global scale	"I think we looked on WebMD, and I think we went to the Alzheimer's Association website." Participant 749
Information product: Outputs from information providers such as websites, brochures, blogs, etc.	Technological	Information products that come as a technological medium	"But I also, I mean, I did an incredible amount of reading on the Internet." Participant 503
	Non-technological	Information products that do not come as a technological medium	"I'm one of the few people on the street that get a newspaper yet. I get the [local] paper… They've got articles on Alzheimer's quite often." Participant 461

Note: Numerous quotations were identified during data analysis for each subcategory. The quotations included in this table were selected because they describe representative or exemplary instances of the subcategory.

Table 3

Information behavior feedback component and subcategories.

Feedback	Feedback subcategory	Subcategory definition	Illustrative quotation
Feedback	Self-sufficing	Caregivers innovated to address their unmet information need	"We kind of researched more, you know, to see what people had done with that and what was available gadget-wise to prevent her from going out the door again. But, you know, we thought of a lot of stuff on our own, just, or it was, it just came up, so, yeah." Participant 749
	Engaging technology	Caregivers engaged technology to address their unmet information need	"I go into MyChart when I have a problem…but I usually type it as if it's [person living with dementia]. It's so much easier." Participant 545
	Engaging people	Caregivers engaged others to address their unmet information needs	"The girls are helping me with all the paperwork because I'm not, I can't think. I'm not very good anymore sometimes with the paperwork, so they're very helpful…If I didn't have that support, I'd be in a loony bin." Participant 986
	Information need unmet	Caregivers' information needs remained unmet	"And then they had something that always call sundowning, and I don't know if that's what sundowning is or not. I never really looked it up." Participant 625

Note: Numerous quotations were identified during data analysis for each subcategory. The quotations included in this table were selected because they describe representative or exemplary instances of the subcategory in the data.