# Health Information Technology Design Guidelines Based on Caregivers' Information Behavior

Rachel A. Rutkowski, MS[a], Siddarth Ponnala, PhD[b], Andrea Gilmore-Bykovskyi, PhD RN[c], Eleanore Scheer, BS[a], Nicole E. Werner, PhD[a]

a. University of Wisconsin-Madison Department of Industrial and Systems Engineering b. DivvyDose c. University of Wisconsin-Madison School of Nursing

## Problem statement

16 million dementia caregivers [1,2]

18.5 billion hours of care [1,2]

5.8 million people living with dementia [1,2]

Caregivers encounter challenges managing **cognitive**, **behavioral**, and **physical** changes that characterize dementia progression [3,4,5]

Caregivers have **needs** that, if met, would better equip them to provide care [1]

Despite the **extensive research** on health information technology (HIT) design for dementia caregiving and **numerous** HITs developed, dementia caregivers continue to report **unmet information needs**
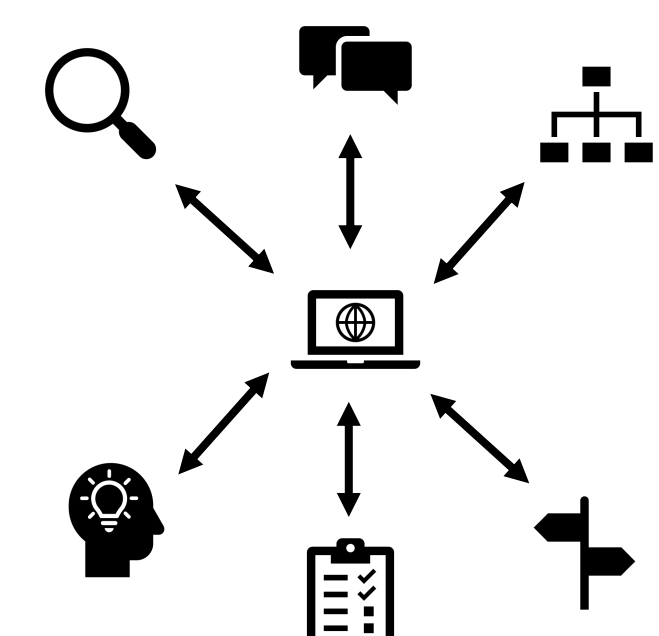
HIT must **seamlessly integrate** into how caregivers generated, acquire, manage, use, communicate, and seek information (i.e., **their information behavior**)

## Objectives

Identify HIT design guidelines based on dementia caregivers' information behavior

## Methods

**Design:** descriptive qualitative study

**Data collection:** semi-structured interviews

**Sample:** N=30
- Aged 47 to 90 years
- Cared for a parent (N=18) or spouse (N=12)
- Female (N=18)
- Caucasian (N=21); African American (N=5), Not disclosed (N=4)

**Analysis:** deductive and inductive content analysis
- Conceptual framework: processes occur within a sociotechnical system of inputs, processes, and outputs that feedback into the system and process [6]
- The process of interest: caregivers' information behavior as modeled by the information-seeking and communication model (ISCM) [7]

## Methods continued

**Deductive content analysis**
- Codes: information use, information provider, information product, information access, information assessment and processing, credibility, utility, and feedback [8]
- Team-based affinity diagramming to categorize codes into inputs, processes, outputs, and feedback (Figure 1) [8]

**Inductive content analysis**
- Focused on "feedback" which is the (un)intentional adaptation to system inputs and processes by system outputs [9]
- Reviewed each feedback excerpts and identified the associated inputs, processes, and outputs
- Documented the caregiver's information need, whether the need was met, and how the caregiver responded to unmet needs
- Team-based affinity diagramming to group similar unmet needs and responses to unmet needs
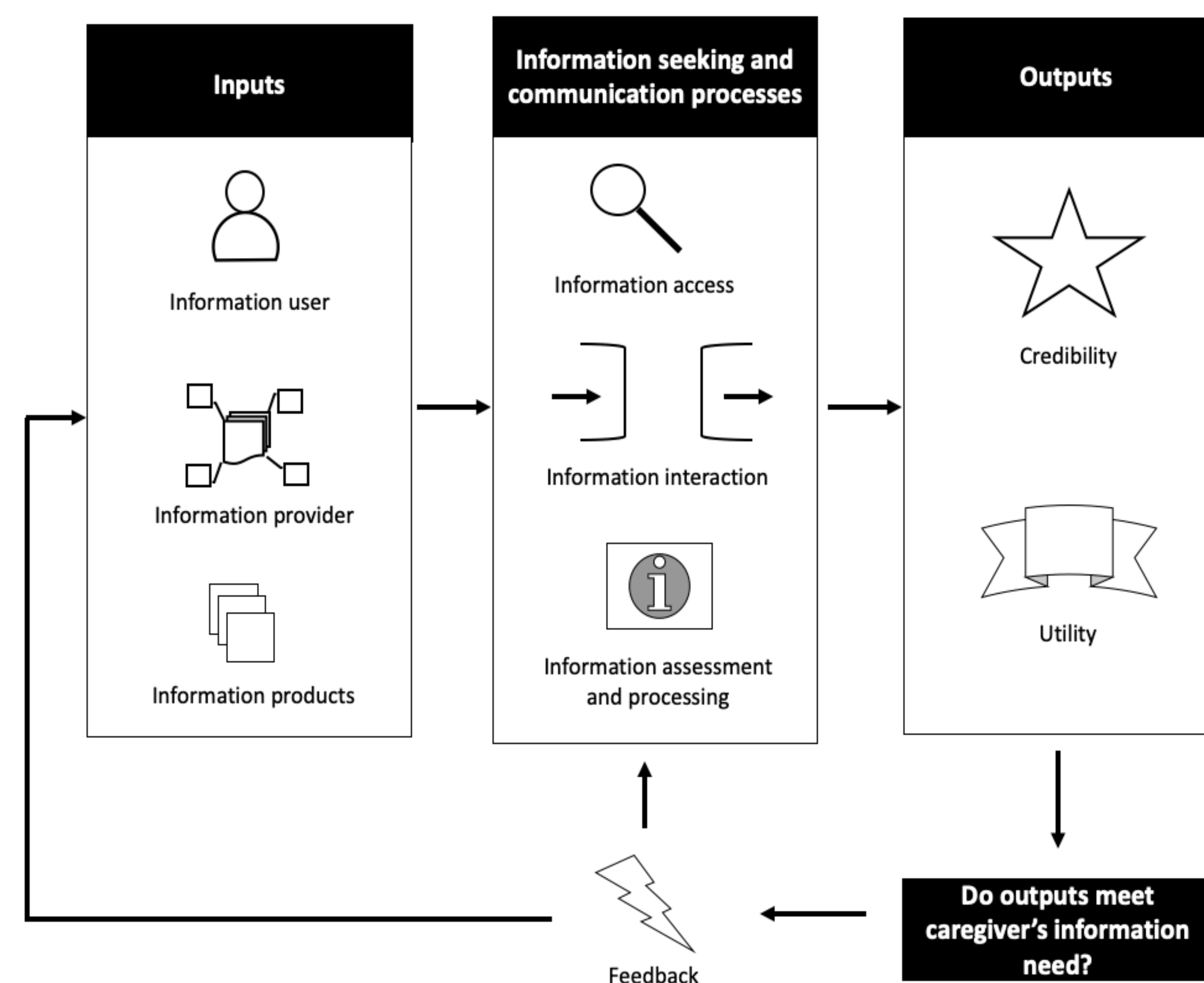


Figure 1: Sociotechnical-systems-based-process conceptual framework of information behavior resulting from deductive content analysis [8]

## Acknowledgments

## Results

**HIT design guidelines**
1. Timely access of information: instantaneous access to information as situations unfold
2. Shared situation awareness: shared understanding among the caregiver, the person living with dementia, and others involved in caregiving
3. Ability to engage support: accessibility of resources, caregivers' internal motivation to seek resources, and caregivers' perception of resource acceptability (e.g., websites with crowed-sourced information may be viewed as more/less reliable)
4. Access to specified knowledge: availability of information tailored to the context

## Discussion

- All design guidelines appear in previous literature [5, 10,11]
- Concurrent identification of guidelines suggests their interrelatedness and interdependence
- For HIT to address caregivers' unmet information needs in a way that appeals to their information behavior, it must adhere to all four guidelines

## Conclusion

Identified four HIT design guidelines that, if successfully integrated into HIT, would increase the likelihood of caregivers' information needs being effectively met

## References

[1] Alzheimer's Association (2019). ALZHEIMER'S DISEASE FACTS AND FIGURES. from https://www.alz.org/

[2] Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015: The Global Impact of Dementia*: Global Observatory for Ageing and Dementia Care.

[3] Boots, L. M., de Vugt, M. E., van Knippenberg, R. J., Kempen, G. I., & Verhey, F. R. (2014). A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry, 29*(4), 331-344.

[4] Boots, L. M., Wolfs, C. A., Verhey, F. R., Kempen, G. I., & de Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatr, 27*(6), 927-936.

[5] Werner, N. E., Stanislawski, B., Marx, K. A., Watkins, D. C., Kobayashi, M., Kales, H., et al. (2017). Getting what they need when they need it. Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms. *Appl Clin Inform, 8*(1), 191-205.

[6] Karsh, B. T., Holden, R. J., Alper, S. J., & Or, C. K. L. (2006). A human factors engineering paradigm for patient safety: designing to support the performance of the healthcare professional. *Quality & safety in health care, 15 Suppl 1*(Suppl 1), i59-i65.

[7] Robson, A. (2013). Building on models of information behaviour: linking information seeking and communication. *Journal of Documentation, 69*(2), 169-193.

[8] Rutkowski, R.A., Ponnala, S., Younan, L., Weiler, D., Gilmore-Bykovskyi, A., & Werner, N.E. (2020). A process-based approach to exploring the information behavior of informal caregivers of people living with dementia. *International Journal of Medical Informatics, 145*, 104341.

[9] Holden, R. J., Carayon, P., Gurses, A. P., Hoonakker, P., Hundt, A. S., Ozok, A. A., & Rivera-Rodriguez, A. J. (2013). SEIPS 2.0: a human factors framework for studying and improving the work of healthcare professionals and patients. *Ergonomics, 56*(11), 1669-1686.

[10] Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry, 193*(3), 240-246.

[11] Peterson, K., Hahn, H., Lee, A. J., Madison, C. A., & Atri, A. (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatrics, 16*(1), 164.