

# **Dementia Caregivers' Engagement of Informal and Formal Supports and the Potential Role of Consumer Health Information Technology**

**Anna Jolliff,<sup>1,2</sup> Andrea Gilmore-Bykovskyi,<sup>3,4,5</sup> PhD, RN, Laura Block, BS,<sup>3</sup> Amy J. Kind, MD, PhD,<sup>4,5</sup> Nicole E. Werner, PhD<sup>1,4,5</sup>**

**<sup>1</sup>Department of Industrial and Systems Engineering, <sup>2</sup>Department of Counseling Psychology, <sup>3</sup>School of Nursing, <sup>4</sup>School of Medicine & Public Health, Department of Medicine, Division of Geriatrics, University of Wisconsin-Madison, Madison, Wisconsin, USA; <sup>5</sup>Geriatric Research Education and Clinical Center (GRECC), William S. Middleton Hospital, United States Department of Veterans Affairs, Madison, Wisconsin, USA.**

**Background.** Caregiving for persons with dementia (PwD) is not without negative consequences for the caregiver. Although both formal and informal supports are available, it is not clear how engagement of formal support differs from that of informal (e.g., family, friends) support, or what technological interventions are needed to increase support.

**Objective.** To understand caregivers' formal and informal support engagement.

**Methods.** Grounded dimensional analysis, followed by thematic analysis, was used to extract and elaborate upon themes from semi-structured interviews with 10 caregivers of PwD.

**Results.** We identified three overarching themes related to caregivers' engagement of informal and formal supports: 1) caregivers frequently engage formal supports, despite experiencing challenges; 2) caregivers rarely engage informal support, despite availability; and 3) expectations of formal supports can be filled by informal supports.

**Conclusions.** Consumer health information technologies (HIT) have great potential to overcome caregivers' challenges in engaging informal supports by acknowledging existing barriers to engaging informal support and working with and around these barriers.

## **Presenting Author:**

Anna Jolliff  
ajolliff@wisc.edu  
University of Wisconsin-Madison

## **Acknowledgments**

We would like to thank all of the caregivers who took the time to participate in this research. This research was supported by a grant from NSF (CHS CRII 1656927) as well as funding from the Wisconsin Alzheimer's Disease Research Center and the University of Wisconsin Institute for Clinical and Translational Research (CTSA UL1TR000427). This project was also supported by the National Institute on Aging 2P50AG033514-06 (Project 3, PI: Kind).

## References

1. Alzheimer's Association. 2015 Alzheimer's disease facts and figures. *Alzheimer's & dementia: the journal of the Alzheimer's Association*. 2015;11(3):332.
2. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-9.
3. Allegri RF, Sarasola D, Serrano CM, Taragano FE, Arizaga RL, Butman J, et al. Neuropsychiatric symptoms as a predictor of caregiver burden in Alzheimer's disease. *Neuropsychiatric disease and treatment*. 2006;2(1):105.
4. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Medical care*. 2009;47(2):191-8.
5. Covinsky KE, Newcomer R, Fox P, Wood J, Sands L, Dane K, et al. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of general internal medicine*. 2003;18(12):1006-14.
6. Takai M, Takahashi M, Iwamitsu Y, Ando N, Okazaki S, Nakajima K, et al. The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. *Archives of gerontology and geriatrics*. 2009;49(1):e1-e5.
7. Eppers L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Association of Nurse Practitioners*. 2008;20(8):423-8.
8. National Academies of Sciences, Engineering, and Medicine. *Families caring for an aging America*: National Academies Press; 2016.
9. Getting Help with Alzheimer's Caregiving [Internet]. National Institute on Aging. U.S. Department of Health and Human Services; [cited 2017Aug23]. Available from: <https://www.nia.nih.gov/health/getting-help-alzheimers-caregiving>
10. Pinquart M, Sörensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*. 2005;45(1):90-106.
11. Czaja SJ. Long-term care services and support systems for older adults: The role of technology. *American Psychologist*. 2016;71(4):294.
12. Caron CD, Bowers BJ. Methods and application of dimensional analysis: A contribution to concept and knowledge development in nursing. *Concept development in nursing: Foundations, techniques, and applications*. 2000;2:285-319.
13. Schatzman L. Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. *Social organization and social process: Essays in honor of Anselm Strauss*. 1991:303-14.
14. Strauss AL. *Qualitative analysis for social scientists*: Cambridge University Press; 1987.
15. Saldaña J. *The coding manual for qualitative researchers*: Sage; 2015.
16. Haley WE, Levine EG, Brown SL, Bartolucci AA. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and aging*. 1987;2(4):323.
17. Atienza AA, Collins R, King AC. The mediating effects of situational control on social support and mood following a stressor: A prospective study of dementia caregivers in their natural environments. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2001;56(3):S129-S39.
18. Fox S, Duggan M, Purcell K. *Family caregivers are wired for health*: Pew Research Center's Internet & American Life Project; 2013.
19. Werner NE, Stanislawski B, Marx KA, Watkins DC, Kobayashi M, Kales H, et al. Getting what they need when they need it. *Applied Clinical Informatics*. 2017;8(1):191-205.
20. Martins J, Carilho J, Schnell O, Duarte C, Couto FM, Carriço L, et al., editors. *Friendsourcing the unmet needs of people with dementia*. Proceedings of the 11th Web for All Conference; 2014: ACM.
21. Godwin KM, Mills WL, Anderson JA, Kunik ME. Technology-driven interventions for caregivers of persons with dementia: a systematic review. *American Journal of Alzheimer's Disease & Other Dementias®*. 2013;28(3):216-22.
22. Schorch M, Wan L, Randall DW, Wulf V, editors. *Designing for those who are overlooked: Insider perspectives on care practices and cooperative work of elderly informal caregivers*. Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing; 2016: ACM.
23. Aging NIO. *Next Steps for Research on Informal Caregiving*. U.S. Department of Health and Human Services; 2012.
24. Fitzpatrick G, Ellingsen G. A review of 25 years of CSCW research in healthcare: contributions, challenges and future agendas. *Computer Supported Cooperative Work (CSCW)*. 2013;22(4-6):609-65.

