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# Beyond Communication and Social Interaction: A Review on Designing for People with Dementia

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## Abstract

We reviewed 26 full papers on designing for people with dementia (PwD) in recent ACM SIGACCESS and SIGCHI proceedings. Through the lens of a conceptual framework for dementia care, we mapped the quality-of-life aspects addressed by and missing in the papers. Our findings show current HCI research focuses on

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communication and social interaction for PwD, and we discuss the gaps in the literature for future work.

## Author Keywords

Dementia; design; review.

## ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## Introduction

The HCI literature on designing for PwD is growing. A wide range of research projects have touched on various aspects of quality of life from dealing with wandering and wayfinding to supporting creating and sharing (e.g., [10, 12, 20, 23]). However, there is a lack of mapping between the HCI research conducted and the needs of dementia care. To this end, we adopted a conceptual framework for dementia care to examine the relevant ACM SIGACCESS and SIGCHI sponsored conference proceedings in recent years. We aim to map the existing literature and provide an overview of the research contributions and gaps regarding designing for PwD and their family and caregivers.

	No. of Papers
2010	3
2012	4
2013	3
2014	3
2016	5
2017	8
Total	26

Table 1: Number of papers in review by year of publication.

	No. of Papers
CHI	11
ASSETS	3
DIS	3
NordiCHI	2
APCHI	1
CSCW	1
C&C	1
ECCE	1
GROUP	1
HRI	1
TEI	1
Total	26

Table 2: Number of papers in review by venue of publication.

## The Conceptual Framework

The adopted conceptual framework for PwD and their caregivers highlights health-related quality of life elements specific to dementia across five conceptual domains:

- *Daily activities and looking after yourself*: getting around, keeping yourself clean, getting dressed, going to the toilet, using a knife and fork, etc.
- *Health and well-being*: global health, happiness/depression, contentment/frustration, enjoying life/enjoying nothing, confidence, etc.
- *Cognitive functioning*: memory for recent/distant events, concentration, communication, etc.
- *Social relationships*: treatment by others, social interaction, reciprocity, social integration, etc.
- *Self-concept*: self-esteem, presentation of self, sense of independence, feeling useful, etc. [26].

Incorporating the views of both PwD and their family caregivers, this framework presents a detailed picture of living with dementia and provides a holistic map for analyzing the interaction design contributions and gaps in the context of dementia care.

## Methods

We searched the ACM Digital Library’s full-text collection with the keywords "design AND dementia" OR "design AND Alzheimer" in all fields, and we refined with SIGACCESS and SIGCHI sponsored conferences. This initial search returned 80 results (as of January 2, 2018), and we selected the full papers among them. As a result, this review examined 26 papers (i.e., [1-5, 7-8, 10-21, 23-25, 27-30]) published during 2010 and 2017 (see Table 1) in 11 venues (see Table 2).

For each paper, we summarized the design outcomes, research methods, and participants involved. The design outcomes included tablet and mobile applications, smart homes, props, robots, virtual world prototypes, and tracking systems. Qualitative methods were most frequently used and typically involved a thematic analysis of interview, focus group, or design workshop transcripts and field observation notes. A variety of participants were involved in different research stages, including PwD, family and professional caregivers, art therapists, occupational therapists, and staff and volunteers of care facilities.

Then, we took a top-down approach and coded the descriptive components of the above framework based on the issues addressed by each paper. For example, a case study of a GPS tracking system used in dementia care [2] was coded for daily activity of “getting around”. It also discussed using technologies in professional dementia care and the self-esteem issue in value-sensitive design, so “social support” and “self-esteem” were also coded.

## Findings and Discussions

### *The components frequently addressed*

Overall, all five domains are addressed. The most frequently appeared components are “communication” and “social interaction”, followed by “getting around” and “sense of independence”. Other recurring components include “reciprocity”, “self-esteem”, “feeling safe”, etc. (see Table 3). It indicates that the HCI community has primarily focused on facilitating communication and social interaction for PwD, usually addressing them together. In addition, many projects share a common devotion to assisting PwD in getting around and maintaining their sense of independence.

<p><i>Social relationships:</i>  "social interaction" (19),  "reciprocity" (7),  "social integration" (5),  "intimacy and physical affection" (5),  "treatment by others" (4).</p>	<p>When helping PwD enjoy life and connect with people, researchers emphasize PwD's safety and self-esteem.</p>	<p>has a positive impact on PwD to maintain a sense of normality and keep up appearances [26], these everyday routines are worth investigating further. By facilitating such daily tasks as eating, shopping, housekeeping, and keeping personal hygiene, the design outcomes could help to improve PwD's autonomy and sense of independence, in turn reducing the caregiver burden.</p>
<p><i>Cognitive functioning:</i>  "communication" (19),  "place and person" (5),  "memory for distant events" (4).</p>	<p><i>The components less addressed and unaddressed</i>  The following components are addressed by no more than 3 papers: "getting in touch with people when you need to", "taking care of finances", "choice about how you spend your time", "global health", "happiness/depression", "confidence", "anxiety", "feeling lively, cheerful, relaxed", "memory for recent events", "concentration", "orientation in time", "making your mind up", "companionship", "social support", "other emotional relationships", "presentation of self", "satisfaction with past/present life", "hopes and aspirations for the future", and "feeling useful". Most components about daily activities are notably missing, i.e., "keeping yourself clean", "getting dressed", "keeping yourself looking nice", "going to the toilet", "using a knife and fork", "getting the things you need from the shops", "getting meals", "taking care of the house", "using money to buy everyday things", and "things that you want to do but can't". Other missing components are "contentment/frustration",</p>	<p>Researchers could also pay attention to all kinds of emotions and the mental status of PwD, increasing those positive feelings while reducing the negative ones. PwD value emotions as part of their well-being, but they might have to express their feelings in a concrete way of describing activities they enjoyed [26]. Therefore, it requires creative thinking and a keen eye to capture these subtle feelings in future study design, field observation, and data analysis. For example, a preliminary study on developing a smartwatch prototype for evaluating the emotional responses of PwD is a good start in this direction [9].</p>
<p><i>Daily activities and looking after yourself:</i>  "getting around" (10),  "getting where you need to go" (5),  "being able to enjoy what you want to" (4).</p>	<p>"embarrassment", "loneliness", "somatic complaints", "feeling irritable, angry, resentful, sad, distressed", "memory for names", and "clarity of thought".</p>	<p><i>Outside the framework</i>  During the coding process, we found some themes outside the framework appearing in several papers. In line with reducing reliance upon caregivers, personhood and autonomy rise from the discussions together with safety and independence, while technology could step in to balance the conflicts between those components [13-14]. The privacy and ethical issues of involving this vulnerable user group are noticed and respected. Furthermore, the case studies situated in the context of art therapy have expanded the horizons of designing for dementia by promoting entertaining, creative, and aesthetically-pleasing activities. These papers contribute to understanding the complex nature of</p>
<p><i>Self-concept:</i>  "sense of independence" (9),  "self-esteem" (7).</p>	<p>The above components reveal the possible gaps in the existing HCI literature. Except for getting around, the majority of daily activities are less supported. Outside the review scope, assistive technologies have been developed for daily routines, e.g., automatic task assistance in brushing teeth and washing hands for people with cognitive impairments [6, 22]. These projects have focused on AI challenges such as sensors and decision processes, instead of interface issues. As it</p>	
<p><i>Health and well-being:</i>  "feeling safe" (7),  "enjoying life" (5).</p>		
<p>Table 3: The descriptive components addressed by more than 3 papers (number of papers in the brackets).</p>		

sharing for PwD, designing novel and customizable tools for art therapy sessions, exploring a model of empathy and empowerment, and reflecting on epistemological perspectives for dementia and design [1, 7, 10-12]. Creativity is approached differently by a project exploring how to support creative thinking and problem solving by caregivers through a mobile application [30]. In a similar vein of person-centered care as art therapy, this app works from the angle of providing novel care in residential homes.

### Limitations

This review is limited to a small scale at this stage; in future work, we plan to expand to more ACM journals and conferences, as well as to other databases. The adopted framework could not cover every aspect of dementia care, and the coding relied on our interpretation which might be open for discussion. The research projects in review were conducted in different economic, social, and cultural contexts, so fitting them into one framework might overlook this diversity.

### Conclusions

In mapping the research contributions and gaps in this review, we find the current HCI research tries to help PwD with cognitive functioning and social relationships, as well as addressing some aspects of daily activities, self-concept, and well-being. With an aging population and an increasing number of families affected by dementia, the HCI community faces growing demands and responsibilities for designing for dementia care. Continuing to facilitate communication and social interaction and explore person-centered care, future research could seek inspiration and collaboration in related fields and expand to supporting more daily routines and attending to the rich emotions of PwD.

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