

## Formal and informal carers' views on ICT in dementia care: Insights from two qualitative studies

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*M.R. Hastall, N.D. Eiermann, U. Ritterfeld. Formal and informal carers' views on ICT in dementia care: Insights from two qualitative studies. Gerontechnology 13(1):51-56; doi:10.4017/gt.2014.13.1.003.00* Formal and informal caregivers' views on the use of Information and Communication Technology (ICT) solutions in dementia care were assessed using semi-structured qualitative interviews. Both caregiver groups were very little aware of available ICT solutions and the technological progress in this area. The analysis revealed three overarching themes: (i) barriers of ICT use in dementia care, (ii) expected benefits, and (iii) desired ICT functions or characteristics. Informal and formal carers shared basically identical views regarding potential negative effects of using ICT in dementia care, but expressed very different ICT-related attitudes and expectations. Findings are discussed with respect to successful ICT development and marketing, and improved end user acceptance.

**Keywords:** attitudes towards ICT, dementia, formal caregivers, informal caregivers

Dementia is a far-reaching neurodegenerative condition with significant consequences for patients, their social networks, and health care systems around the world. 35.6 million people are estimated to live with dementia globally, and this number is expected to “double by 2030 and more than triple by 2050”<sup>1pvi</sup>. These prospects stimulated a multidisciplinary search for techniques to more effectively address dementia-related individual and societal challenges. Given the projected shortage of human resource capacity in the near future, technological solutions appear particularly promising. Despite enormous technological progress, most Information and Communication Technology (ICT) solutions failed to achieve sufficiently high levels of user acceptance and market success. This may come as no surprise, since “design requirements have been typically generated in a top-down fashion, rather than being user-led”<sup>2p221</sup>. The target groups' reluctance to adopt new solutions thus may be well-founded: “In most cases this is caused by wrongly designed technologies that have been developed without thinking about the real needs and capabilities of the end users”<sup>3p8</sup>.

The current exploratory investigation aimed to shed light on German end user expectations by examining informal and formal caregivers' attitudes towards ICT use in dementia care. Compared to previous investigations<sup>2,4-7</sup>, we were

particularly interested to learn about caregivers' individual burdens, resources, expectations and technology-related discomforts in order to obtain indications for promising ICT functionality and realistic usage scenarios. Further insights were expected by contrasting formal carers' and informal carers' perspectives. Formal caregivers such as nurses are important sources for health-related information and valuable role models for informal caregivers with regard to care techniques<sup>8</sup>. Finally, the current investigation is, according to our knowledge, the first examination of German dementia caregivers' attitudes towards ICT in care. Germany belongs to the top-five countries worldwide regarding its absolute number of people living with dementia<sup>1</sup> and is therefore one of the largest markets worldwide for related ICT solutions. As cultures differ considerably with respect to dementia diagnosis and care procedures<sup>9,10</sup> and as the “interplay between culture and health is truly complex and invites consideration of a kaleidoscope of causes, experiences, expressions and treatments for a plethora of human ailments”<sup>11p1</sup>, it is unclear to what extent related previous findings from other countries can be transferred to dementia care in Germany. Consequently, the current study aims to extend the current knowledge about caregivers' attitudes towards ICT use in several aspects in order to facilitate more successful dementia-related ICT development and marketing.

## METHOD

Semi-structured interviews were carried out from March to August 2012 with 17 informal caregivers and 20 formal caregivers. Participants were informed about the research objective, the purpose of the interview, and their right to withdraw from the study at any time, without giving any reasons. Interviews were audiotaped with interviewees' agreement. The methodological approaches used to collect and analyze the interviews from informal and formal carers differed in some aspects such as the interview location or the topics addressed, as explicated below. Main reason for these changes were foreseeable dissimilarities between both groups in areas such as actual and perceived care competence, age range, health status, perceived care burden, knowledge about assistive care technology, type of relationship with patients, and emotional involvement in care. Most interviews were conducted in the natural dementia care environments, i.e., at informal carers' homes or at the residential home for elderlies that the formal caregivers were working at.

## Formal caregivers

Formal caregivers (2 male, 18 female; age:  $M=35.8$  years,  $min=18$ ,  $max=60$ ) were recruited at two professional long-term nursing homes. The interview guide focused almost exclusively on interviewees' general attitudes towards ICT use in dementia care and particularly their perceived effectiveness of ICT to meet central needs of both caregivers and patients. Participants were first queried to indicate central as well as potentially strenuous areas of their daily care obligations. Afterwards interviewers inquired about the extent to which participants perceive technological solutions as factually or potentially helpful in order to facilitate dementia care. The potential of touch-based mobile devices such as tablet computers and smart phones to meet the identified needs was assessed in greater detail, as these devices became quite popular and more affordable within the last years and as they offer a several features possibly relevant for dementia care (e.g., music player, video player, picture viewer, games, internet access, social network apps, camera, wireless LAN, GPS, inbuilt sensors)<sup>14</sup>. The recorded interviews were fully transcribed, verbatim, and independently analyzed by two researchers to identify major concepts, themes, and categories. No significant disagreement was found between both coders and minor inconsistencies were resolved through discussion.

## Informal caregivers

Informal caregivers (4 male, 13 female; age  $M=69.5$  years,  $min=38$ ,  $max=91$ ) were recruited through a local dementia service organization.

All but two were primary caregivers and thus the person with the highest involvement in care. The majority (12) was either husband or wife of the person with dementia, with the five remaining caregivers being either son or daughter and living close to the person with dementia. The interview guide comprised several topics, including anamnesis, current overall situation, informal care situation, external support, caregiver burden and resources, and attitudes towards assistive technology in dementia care. Participants were asked about their knowledge about and experience with such technology, and prompted to indicate specific areas in which they are likely to find assistive technologies helpful to reduce the care-related burdens specified before. Three technology-assisted care scenarios were then brought up to hear about their perceived helpfulness and to uncover participants' criteria for evaluating assistive technologies:

- (i) An information retrieval system allowing patients to better manage aspects of his/her disease;
- (ii) A video-based communication system facilitating interaction among patients and carers and offering a basic patient monitoring function;
- (iii) A sensor-based system indicating time spans with no acute care demands to signal carers moments for relaxation or other activities not related to care.

The tape-based analysis approach was used to produce transcript versions of the interviews containing only the most "relevant and useful portions"<sup>12p131</sup> related to our technology-related research question. Thematic analyses and the identification of themes and patterns followed closely the principles outlined by Braun and Clarke<sup>13</sup>.

## RESULTS

The analyses revealed several differences between formal and informal dementia carers' needs and ICT-related perceptions. Formal caregivers indicated a more distant, professional relationship to the person with dementia and also showed a much deeper knowledge about typical courses of dementia diseases and effective caring techniques. Informal caregivers reported greater psychological burden, particularly due to patients' behavioral and perceptual changes and the transformations of their relationship. Formal and informal caregivers alike reported a general lack of time as most important stress factor. Formal carers perceived structural overloads as main cause (e.g., having to care for too many people with dementia simultaneously), whereas informal caregivers expressed a lack of sufficient time for valued personal activities such as spending quality time with friends, going to work,

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relaxation, or participating in cultural activities. Feelings of constant alertness and responsibility were mentioned by informal carers as equally distressing.

## Views towards ICT in dementia care

Although several of the brought up burdens of dementia care could be reduced through available ICT, participants were not even remotely aware of existing solutions and the technological developments in this area. The analysis of ICT-related statements revealed three overarching themes: (i) barriers of ICT use, (ii) expected benefits, and (iii) desired functions and characteristics. These themes emerged solely from the interview data and were not a-priori defined as interview topics (Table 1). While informal and

formal caregivers agreed on potential negative side effects of using ICT in dementia care, they indicated relatively dissimilar ICT-related expectations and usage motivations.

## Barriers of ICT use

Formal and informal carers showed huge overlaps in their perceived barriers for ICT use in dementia care. Among the most central worries were fears of a dehumanized care, safety concerns (e.g., potential harming of dementia patients in cases of ICT malfunctioning), and privacy concerns (e.g., through constant monitoring features). Formal and informal carers were unanimously convinced that the end users' lack of experience with ICT constitutes the main reason for a lack of acceptance and repeatedly

Table 1. Formal and informal carers' themes regarding the use of ICT in dementia care; +=high salience; -=low salience

Themes		Caregivers	
		Informal	Formal
<b>Barriers</b>			
For persons with dementia	Fear of 'dehumanization' of care	+	+
	Safety concerns	+	+
	Privacy concerns	+	+
	Lack of experience	+	+
For themselves	Lack of experience	+	+
	High initial and operating cost	-	+
	Fear of theft, damaging, loss	-	+
<b>Expected benefits</b>			
For persons with dementia	Better care	+	+
For themselves	Substantial time savings	-	+
	Greater personal freedom due to time savings	+	-
	A simplified care process	-	+
	Improved access to therapy-related information	-	+
	Simplified staying up-to-date on recent developments	-	+
	Enhanced mobility (going out without guilt or fear)	+	-
	Strengthening social contacts (friends, relatives, care givers)	+	-
	Strengthened self-confidence and motivation	+	-
	Increased feelings of energy	+	-
<b>Desired functions and characteristics</b>			
For persons with dementia	Monitoring (vital status, wandering)	+	-
	Leisure time activities (music, photos, newspapers, videos)	-	+
	Cognitive enrichment training	-	+
	Communication with (in)formal carers (videoconferencing)	-	+
For themselves	Ease of use	+	+
	Information and guidance	+	-
	Therapy information database	-	+
	Care documentation	-	+
	Personal therapy material collection	-	+
	Time management	-	+
	Overall handiness and practicability for daily care routines	-	+
	Integration of therapeutic materials (songs, picture books)	-	+
	Cost efficiency	-	+
	Communication	+	-
	Relaxation and recreation	+	-
	Reassurance and motivation	+	-
	Motivation and entertainment	+	-
	Fully customizable (care scenarios, personal preferences)	+	-
Time saving feature	+	+	
Ease of use	+	+	

emphasized the ease of use as most critical feature. Formal carers expressed additional worries with respect to the initial and operating cost of ICT use and worries regarding the possibilities of theft, damage, and loss.

## *Expected benefits*

Formal and informal carers generally believe that ICT solutions have a great potential to improve care for persons with dementia, but indicated very diverse benefits for themselves. Formal caregivers hope for time savings due to more efficient care preparation, care procedures, and care documentation. Informal caregivers, in contrast, request ICT solutions that enhance their personal freedom and mobility and reduce care-related worries and fears. Besides a wish for intensified social contacts with friends, relatives and other caregivers, informal carers envision psychological benefits in the areas of personal motivation, self-confidence, and energy.

## *Desired functions and characteristics*

The preferred set of features and main usage outcomes varies substantially between both end user groups. Consistent with informal caregivers' desire to be at least partially relieved from constraining care, they favor patient monitoring functions (e.g., wandering, vital status) that enhance the safety and wellbeing of the individual with dementia without being too obtrusive or privacy-invasive. The importance of ease operability for both patients and carers was highlighted by all interviewees. With respect to their individual needs, informal caregivers hope for ICT solutions that provide trustworthy care-related information, guidance, and reassurance. Enhanced peer communication and relaxation features are likewise highly demanded.

Formal caregivers, in contrast, consider meaningful leisure time activities and cognitive enrichment trainings for persons with dementia as important function. Communication features that allow people with dementia to contact formal carers and family members—including informal caregivers—are likewise perceived as vital features. Further ICT features perceived as helpful for formal carers' daily work include functions for more efficient care documentation and for a simplified access to care information and care therapy material collections. Favored is a handy device that seamlessly integrates different types of therapy material (e.g., songs, videos, books) from own collections as well as other sources.

## **CONCLUSION**

Using semi-structured interviews, the current study explored ICT-related expectations and attitudes from formal and informal caregivers in

Germany. The analysis revealed striking similarities as well as substantial differences between both groups, which are discussed below with respect to their implications for effective ICT development.

## **Main findings**

Both end user groups were basically not aware of already available ICT solutions or of the technological progress in the areas of care-related ICT. This unfamiliarity, typically coupled with negative experiences with technology use, fosters unrealistic expectations as well as fears. Formal and informal carers articulated several similar reservations regarding the use of ICT in dementia care. Fears of a 'dehumanized' care, fears of safety and privacy issues, fears of difficult to operate devices, and fears of wasting resources were often expressed.

It seems overdue to better inform the public—journalists as well as potential end users—about available ICT solutions. Aspects such as 'intuitive operability' and 'safety features' should be particularly highlighted. While possible time-savings and cost-savings are especially important to communicate to formal carers, informal caregivers demand solutions that promise high levels of 'psychological empowerment' (e.g., motivation, self-confidence, relaxation). Either way, communication strategies should be adapted to ensure (i) a broader dissemination of ICT-related information to the general public that is (ii) appropriate to diminish technology-related negative emotions and (iii) optimally triggers positive emotions as well as the desire to try out the solution. This strategy, however, requires substantial insights in human information processing and thus likely requires external assistance from, for example, communication experts.

Despite the mentioned reservations, the analysis revealed that both end user groups anticipate a huge potential of ICT to meet a diverse set of dementia carers' needs. Dementia care is perceived as extremely exhausting particularly by informal carers, suggesting a multitude of promising possibilities for physical, psychological, and social interventions. Interestingly, many of the desired features could be relatively inexpensively provided through smart phones that are extended with specific apps. The growing use of smartphones and tablet computers certainly will help to promote and to increase the acceptance of dementia-related ICT.

Findings also show that expectations and use scenarios do not only differ remarkably between formal and informal carers, but also within members of these groups. ICT solutions thus should be adaptive to very specific user requirements

and ideally offer the possibilities to expand and decrease the number of available features. Most important for market success, however, appears the ease of use, the safety, and especially the psychological benefits and time savings derived from its use. Formal and informal carers' showed a striking resemblance regarding perceived barriers and benefits of ICT for individuals with dementia, indicating crucial dimensions of carers' ICT evaluation that should be fully addressed in ICT development and marketing.

## Limitations

Several limitations of our study must be acknowledged. Different methodological approaches were used for conducting and analyzing the semi-standardized interviews with formal and informal carers, limiting the comparability of the findings. Even though the number of interviewed individuals was relatively high, a considerable variance in responses was noted. It is therefore not unlikely that interviews with other or further carers (e.g., carers with more technology-related experience) might have produced different themes or subcategories. Our conclusions are furthermore solely based on verbal statements and it is unclear to which extent these are influenced by social desirability considerations and linked to actual ICT use behavior. Especially since both participant groups had only limited knowledge about ICT solutions for dementia care, their statements are rarely based upon experience but rather on expectations. Interviewees' hands-on experience with ICT solutions is likely to alter the data base upon which conclusions are drawn.

Overall, however, findings clearly demonstrate that many important needs of dementia carers in Germany are still unmet, although most of them

could be relatively easily addressed through ICT solutions. The demands for effective solutions as their market potential appears to be relatively high.

Both end user groups, however, do not only see the potential of ICT to reduce numerous caregiving strains, they also anticipate severe problems and negative emotions with the use of ICT in dementia care. This emphasizes not only the necessities for a comprehensive end user participation in the development process<sup>15,16</sup>, but also for an improved overall communication with potential end users. For example, enhanced efforts are required to reach patients as well as care givers in order to inform them about available ICT solutions. In light of the observed widespread objections towards the usage of technology it appears of utmost importance to better understand the origins and diversity of defensive reactions towards technology-related information<sup>17</sup>.

Strategic communication activities should be grounded on evidence-based principles rather than on intuition to increase attention towards educational and promotional messages, and to minimize unwanted defensive reactions towards them<sup>18</sup>. Cultural and individual differences related to technology acceptance need to be better understood<sup>19</sup> in order to tailor communication activities according to relevant characteristics of the target groups.

An intensified interdisciplinary sharing of knowledge and best practice solutions among stakeholders from different countries appears particularly promising to discover more effective ways of developing and marketing ICT solutions that will make a positive difference in dementia care—for patients, carers, as well as the society as a whole.

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