

Northern Territory practitioners views on the use of Information and Communication Technology to improve the quality of life of carers and people with dementia

Mr David Heath
Charles Darwin University, Northern Territory, Australia
david.heath@cdu.edu.au

Dr Deborah West
Charles Darwin University, Northern Territory, Australia

Abstract:

Objective: This study investigated the use patterns and attitudes of practitioners in dementia and/or carer service agencies in relation to using Information and Communication Technology (ICT) to improve the quality of life of people with dementia and carers.

Method: In this descriptive, exploratory study, a purposive snowball sample of 61 practitioners working in dementia and/or carer service agencies in the ‘Top End’ of the Northern Territory were administered a questionnaire focusing on ICT: access, knowledge, awareness, learning, opportunities and skills.

Results: Practitioners in the sample frequently used technology for general tasks like e-mail but rarely for the formal therapeutic purposes that, according to professional literature, might be useful.

Discussion: Practitioners in agencies have a crucial role to play promoting the digital inclusion of carers and people with dementia. In the Northern Territory this role needs to be further developed at the theory, research and practice levels.

Key Words:

Carers, Dementia, Northern Territory, Quality of Life, Technology

Northern Territory practitioners views on the use of Information and Communication Technology to improve the quality of life of carers and people with dementia

David Heath & Deborah West

Introduction

Dementia is frequently portrayed as a ‘social death’ [1][2]. As a neuro-degenerative condition, dementia symptoms include memory difficulties, vagueness in conversation, limited enthusiasm, deteriorating social skills, neglect of hygiene, emotional unpredictability and inability to process questions and instructions [3][4][5]. These symptoms all potentially result in the social exclusion of people with dementia.

In 2006, the total number of Australian people with dementia was estimated at 171,000 [6]. Approximately half of Australian people with moderate to severe dementia live in residential care facilities [7]. For the other half outside residential care, carers often play an instrumental role in providing support and enhancing quality of life. The care-giving role is frequently carried out by family members and can be emotionally and physically demanding. Stress, depression, exhaustion and anxiety are common amongst carers [1][8]. Various respite services are available but not often used purposefully by carers to achieve a restorative mental break [8][9]. For carers, this entails temporarily leaving the care-giving world for their own world [10].

Information and communication technology (ICT) has significant potential to improve the quality of life of carers and people with dementia [11]. ICT is a broad term that encompasses many forms of technology, including telephones and the internet. Proposed applications of ICT with carers and people with dementia include: on-line support groups, informal communication with family, friends and agencies, streamlining daily tasks like shopping and bill-paying, information gathering, on-line education, personal security and cognitive stimulation [9][11][12][13][14]. Aged and dementia care agencies and practitioners have a key role in assisting carers and people with dementia to become aware of and utilise these resources.

In the Northern Territory, little is known about how practitioners in various support agencies and residential care facilities promote the ICT engagement of people with dementia and carers. Theoretically guided by the *Framework for Inquiry into the Technological Divide* [15][16], the present descriptive, exploratory study investigated ICT access; knowledge; awareness; learning opportunities; support; and, skills of practitioners in dementia and carer service agencies in the ‘Top End’ of the Northern Territory. Each of the above factors contributes to the capacity of people, like health practitioners, to fully utilise ICT [15][16]. In recognising the inherent leadership function of practitioners and agencies, the project aimed to inform policy, practice and further research that promotes the digital inclusion of carers and people with dementia.

Method

This study featured a purposive sample of practitioners employed by dementia and/or carer service providers in Darwin, Katherine & Nhulunbuy. Agencies in these major towns frequently provide visitational services to more remote communities and townships so the designation 'Top End' was adopted. Inclusion criteria were: location in the study region and paid employment in a role involving policy or practice with carers and/or people with dementia.

The research instrument in the study was a questionnaire. The questionnaire was designed specifically for the present study and was not based on any existing instrument.

In 2008 the social work department at Charles Darwin University (CDU) obtained ethics approval from the CDU Human Research Ethics Committee. The researchers then used local community service directories to identify carer and dementia service agencies. Telephone calls were made to the agencies and subsequently the questionnaires and accompanying participant information sheets were distributed to consenting agencies either in person or via e-mail depending on participant preference. Practitioners in each agency self-selected and consented to participation. Utilising a snowball sampling strategy, agency contacts were also requested to recommend other agencies potentially suitable to participate. These 'referred' agencies were then contacted in the manner described previously.

Completed questionnaires were either returned by fax, mail or E-mail, or collected directly from the agencies. Flexible questionnaire return methods were offered because practitioners were frequently busy or away on business during the data collection period. Participation at each level by agencies and individual practitioners was voluntary and no incentives were offered. Descriptive statistics were analysed using SPSS (version 16.0).

Results

Sixty-one practitioners returned the questionnaire. Partly because some questions related to carers and some to people with dementia, the response number varied between questions. All individual responses to questions were included in analysis. Forty-four participants (72.1%) were primarily located in Darwin, 16 (26.2%) in Katherine and 1 (1.6%) in Nhulunbuy. The mean experience that each practitioner had working with people with dementia and/or carers was 11.2 years. In terms of highest educational qualifications: 5 participants (8.3%) had not completed year 12; 3 (5.0%) had completed year 12; 16 (26.7%) had completed a Vocational Education and Training certificate; 21 (35.0%) had completed bachelor degrees and 15 (25.0%) had completed post graduate study. Common fields of study were nursing with 13 participants, aged care with 10 participants, social work with 5 participants and psychology with 3 participants.

At least one practitioner from 23 of the 27 agencies approached to participate in the study completed the questionnaire – an agency response rate of 85.2%. There were 14 participating agencies from Darwin, 8 from Katherine and 1 from Nhulunbuy. In a mutually unexclusive format 30 participants (49.2%) indicated that they worked in residential care, 23 (37.7%) had clients visit the agency temporarily, 24 (39.3%) visited clients, and 9 (14.8%) did not engage in direct practice with clients.

Access

Practitioners were asked about their agency provided access to a landline telephone (n = 55). Fifty-two (94.4%) had agency provided full-time access, 2 participants (3.7%) had shared access and 1 (1.9%) had no access. Fifty-seven practitioners indicated their access levels to an agency located computer with the internet. Forty-nine (86.0%) had agency provided full-time access, 1 person (1.8%) had shared access and 7 respondents (12.3%) had no access. The respondents with no access were principally people involved in practical roles such as personal care assistants.

Knowledge and Awareness

Practitioner knowledge and awareness of using ICT was investigated by asking participants about potential benefits (see Table 1) and barriers (see Table 2) associated with using ICT to improve the quality of life of carers and people with dementia.

Table 1: Participant perceptions about how ICT can improve the quality of life of people with dementia and carers (n = 59)

<i>Way of improving the quality of life of people with dementia</i>	<i>Yes n (%)</i>	<i>Way of Improving the quality of life of carers</i>	<i>Yes (n)</i>
Communication with family and others	74.6% (44)	Communication with family and others	94.9% (56)
Keeps the mind active	67.8% (40)	Social networking and informal support	86.4% (51)
Contact with helpful organisations	67.8% (40)	Information at fingertips	83.1% (49)
Social networking and informal support	64.4% (38)	Contact with helpful organisations	81.4% (48)
Easier communication with carer	55.9% (33)	On-line support groups	81.4% (48)
Personal security (e.g. locating people who wander)	55.9% (33)	Freeing up time for respite (e.g. paying bills via b-pay)	78.0% (46)
Reminding people of things that need doing	52.5% (31)	Self-confidence from learning new skills	78.0% (46)
Creating and maintaining life memory stories	52.5% (31)	Easier communication with care recipient	64.4% (38)
Reducing anxiety when separated from carer	50.8% (30)	Reduces anxiety when separated from care recipient	57.6% (34)
On-line support groups	50.8% (30)	Assistance in daily tasks	55.9% (33)
Self-confidence from learning new skills	44.1% (26)		
Assistance in daily tasks	42.4% (25)		

Table 2: Participant perceptions of barriers to using ICT to improve the quality of life of people with dementia and carers (n = 57)

<i>Barriers for people with dementia</i>	<i>Yes (n)</i>	<i>Barriers for carers</i>	<i>Yes (n)</i>
Dementia symptoms making ICT use difficult	86.0% (49)	Expensive for the carer to purchase technology	80.7% (46)
Expensive for person to purchase technology	80.7% (46)	Fear of new technology	68.4% (39)
Fear of new technology	77.2% (44)	Lack of awareness of the benefits of ICT	66.7% (38)
Limited general ICT skills of people with dementia	72.9% (43)	Carers are too busy	61.4% (35)
Limited ICT resources in remote communities	70.2% (40)	Limited ICT resources in remote communities	61.4% (35)
Lack of awareness of the benefits of ICT	64.9% (37)	Expensive for agencies to purchase technology	61.4% (35)
Lack of ICT trained facilitators in agencies	59.6% (34)	Limited general ICT skills of carers	57.9% (33)
Expensive for agencies to purchase technology	54.4% (31)	Lack of ICT trained facilitators in agencies	54.4% (31)
There is a current lack of helpful technology	28.1% (16)	Current lack of helpful technology	33.3% (19)
ICT has limited potential to help people with dementia	19.3% (11)	ICT has limited potential to help carers	5.3% (3)

Learning Opportunities and Support

Practitioners were asked to rate their own and their agency's supportiveness of ICT in their practice. This was on a seven point Likert scale where 1 represented 'not supportive', 4 represented 'moderately supportive' and 7 represented 'very supportive'.

Practitioners mean supportiveness for ICT use was 5.53. The mean perceived agency supportiveness was 5.22. Put another way: 16 practitioners believed their agency was more supportive of ICT use than they were; 21 believed their support exceeded their agency's support; and, 22 believed their own and agency's support levels were equal.

Skills

Table 3 presents data of respondent perceptions of their own skill level in conducting selected ICT based activities identified in the literature as potentially useful.

Table 3: Participants perceived level of ability to conduct selected ICT based activities

<i>ICT based activity</i>	<i>Perceived level of ability</i>				<i>Total n</i>
	<i>Very limited ability (n)</i>	<i>Limited ability (n)</i>	<i>Fairly good Ability (n)</i>	<i>High level of ability (n)</i>	
Use the internet for general activities like surfing or e-mail	5.7% (3)	7.5% (4)	43.4% (23)	43.4% (23)	53
Teach people basic internet skills	13.0% (7)	18.5% (10)	51.8% (28)	16.7% (9)	54
Conduct formal counselling or extended supportive conversations over the phone	21.8% (12)	14.5% (8)	50.9% (28)	12.7% (7)	55
Formal counselling using internet capabilities	41.2% (21)	39.2% (20)	17.6% (9)	2.0% (1)	51
Facilitate an on-line support group or similar	50.9% (27)	35.8% (19)	11.3% (6)	1.9% (1)	53

Under the *Framework for Inquiry into the Technological Divide* it is observed that maintaining proficiency in ICT use requires frequent practice of skills. Table 4 presents data relating to how often practitioners conduct certain types of ICT based activity.

Table 4: Frequency with which practitioners conduct selected ICT based activities

Telephone based activity	<i>Frequency practitioner conducts activity</i>				Total n
	Not at all (n)	Rarely (n)	A few times a week (n)	Daily (n)	
Talk to people in other agencies	7.3% (4)	14.5% (8)	18.2% (10)	60.0% (33)	55
Direct discussions with carers	17.8% (10)	17.8% (10)	23.2% (13)	41.1% (23)	56
Direct discussions with people with dementia	36.4% (20)	27.3% (15)	21.8% (12)	14.5% (8)	55
Speak directly to clients or carers in remote areas	29.1% (16)	36.4% (20)	20.0% (11)	14.5% (8)	55
Formal counselling	54.5% (30)	20.0% (11)	16.4% (9)	9.1% (5)	55
Internet based activity					
E-mail to colleagues in own agency	23.2% (13)	8.9% (5)	14.3% (8)	53.6% (30)	56
E-mail to other agencies	25.9% (15)	6.9% (4)	19.0% (11)	48.3% (28)	58
Information/resource gathering	10.7% (6)	23.2% (13)	42.8% (24)	23.2% (13)	56
Use the agency website to convey information to clients	48.3% (28)	34.5% (20)	13.8% (8)	3.4% (2)	58
E-mail to clients in remote areas	63.8% (37)	24.1% (14)	10.3% (6)	1.7% (1)	58
Conduct on-line counselling	77.6% (45)	17.2% (10)	3.4% (2)	1.7% (1)	58
E-mail directly to carers	39.3% (22)	39.3% (22)	25.0% (14)	0.0% (0)	56
Teach clients how to use the internet	78.6% (44)	16.2% (9)	5.4% (3)	0.0% (0)	56
E-mail to people with dementia	73.2% (41)	26.8% (15)	0.0% (0)	0.0% (0)	56
Facilitate on-line support groups	92.8% (52)	7.1% (4)	0.0% (0)	0.0% (0)	56

Discussion

This study was conducted utilising a theoretical framework that emphasises that digital inclusion is not simply a binary conceptualisation based on notions of access or non-access to technology. The framework asserts that access, skills, knowledge, awareness, learning opportunities and support are all components of digital inclusion [15][16]. The results of the study illustrated that whilst practitioners in the sample had quite high access levels to telephones and the internet, they rarely utilised these devices to conduct formal therapeutic activities which literature suggests could be helpful with carers and people with dementia. These activities included telephone counselling, teaching people to use the internet, facilitating on-line support groups, and conducting on-line counselling.

These findings are concerning because practitioners in 'Top End' dementia and carer service agencies in major centres like Darwin, Katherine and Nhulunbuy typically play a key role in servicing more remote townships and communities. If agencies and practitioners have not adapted their therapeutic and supportive activities to an on-line medium, this must limit service provision flexibility to people with dementia and carers in remote communities.

In addition, the observed dissonance between the literature and the perceptions of this sample of dementia and carer service practitioners raises questions about whether ICT is as useful in this practice field as the literature suggests. In the authors' view, this dissonance also indicates that practical and policy responses are required to improve the knowledge, awareness, skills and learning opportunities and support for practitioners in the study region so that ICT can be more fully utilised in service delivery. This is imperative when nearly twenty percent of the sample believed ICT had limited potential to help people with dementia.

Dementia and carer service agencies help promote and maintain the quality of life of carers and people with dementia. As this sample showed, 'Top End' agencies are staffed by professionals from a range of disciplines. Many practitioners in the sample believed ICT could improve the quality of life of people with dementia and especially carers. Yet these same practitioners did not necessarily actively promote its use or engage in ICT use with clients. This leads one to question whose responsibility it is to actively promote ICT in the dementia and carer service field in the 'Top End'.

There are significant gaps in the literature around the use of ICT with people with dementia and carers. This was a descriptive and exploratory study because little was known about how 'Top End' agencies incorporated ICT into their practice. This study begins to detail this picture and exposes the need for additional research. Research into how carers and people with dementia currently use technology would be helpful, as would research that investigates how agencies interact with carers and people with dementia in remote areas. Finally, evaluative studies of current or commencing ICT based interventions would assist in reducing the divide between theory and practice.

Key Points

- Digital inclusion requires access, knowledge, awareness, learning opportunities, support and skills.
- Literature suggests that ICT can help improve the quality of life of carers and people with dementia in a number of ways.
- Practitioners in the sample frequently used ICT for common daily practice and communication tasks, but rarely in a more structured therapeutic fashion.
- Practitioners and dementia service agencies have a key future leadership role in promoting the digital inclusion of carers and people with dementia.

Acknowledgements

Funding for this study was provided by the Australian Government through the South Australia/Northern Territory Dementia Training Study Centre.

Note

This study was an honours project carried out by the first author. Further information about the study and the research instruments themselves can be found at:

http://www.santdtsc.edu.au/media/docs/davidheath_final_report_nov08.pdf

References

- 1 Sweeting H, Gilhooly, M. Dementia and the phenomena of social death. *Sociology of Health and Illness* 1999; 19: 93-117.
- 2 Kirkman A. Dementia in the news: the media coverage of Alzheimer's Disease. *Australian Journal on Ageing* 2006; 25(2): 74-79.
- 3 Roller L, Gowan J. Dementia and Alzheimer's Disease. *Australian Journal of Pharmacy* 2007; 88: 65-69.
- 4 Alzheimer's Australia. *Progression of Dementia*. Available from URL: <http://www.alzheimers.org.au> (accessed 1 March 2008)
- 5 Miller E, Morris R. *The Psychology of Dementia*. Chichester: Wiley, 1993.
- 6 Australian Institute of Health and Welfare. *Australia's Health*. Canberra: AIHW, 2006.
- 7 Alzheimer's Australia. *Dementia Facts and Statistics*. Available from URL: <http://www.alzheimers.org.au> (accessed 1 March 2008)
- 8 Watts J Teitelman J. Achieving a restorative mental break for family carers of persons with Alzheimer's Disease. *Australian Occupational Therapy Journal* 2005; 52: 282-292.
- 9 Gottlieb B, Johnson J. Respite programs for carers of persons with dementia: a review with practice implications. *Aging and Mental Health* 2000; 4: 119-129.
- 10 Strang V, Haughey M. Respite: a coping strategy for family carers". *Western Journal of Nursing Research* 1999; 21: 450-471.
- 11 Vanderheiden G. Redefining assistive technology, accessibility and disability based on recent technical advances. *Journal of Technology in Human Services* 2007; 25(1/2): 147-158.
- 12 Cohen-Mansfield J, Biddison J. The scope and future trends of gerontechnology: consumers' opinions and literature survey. *Journal of Technology and Human Services* 2007; 25(3): 1-19.
- 13 Marziali E, Damianakis T, Donahue P. Internet-based clinical services: virtual support groups for family carers. *Journal of Technology in Human Services* 2006; 24(2/3): 39-54.
- 14 Marziali E, Dergal J, McCleary L. A systematic review of practice standards and research ethics in technology-based home health care intervention programs for older adults. *Journal of Aging and Health* 2006; 17(6): 679-696.
- 15 West D. Lenses for Digital Inclusion. *The International Journal of Technology, Knowledge and Society* 2006; 2(1): 121-129.
- 16 West D. *Bridging the gap: facilitating older people's participation in the use of technology*. PhD Thesis. Adelaide: The Flinders University of South Australia, 2003.