

Ethical telehealth design for users with dementia

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Purpose People suffering from dementia deserve to be treated with the same respect and dignity as other members of society, including in system design. An important part of inclusive system design is ethical consideration of stakeholders. **Method** From the 125 people who participated in the full study, 26 people suffering various stages of dementia actively used a system developed in the United Kingdom to connect to 109 family members across the USA and UK. **Results** The implementation of the system helped improve access to services, inclusion into the digital world, and for some people who had more severe dementia, provided a platform to use relatively intact intellectual skills to enhance their life quality. **Conclusion** Ethical design reduces stigma by causing cognitive dissonance between social perceptions of people with dementia and the reality of their use of telehealth systems to enhance their wellbeing, despite their disabilities.

Keywords: Alzheimer's disease, universal design, vulnerable

Increasingly there is a push by governments around the world to delay institutional care for seniors, because of the fiscal impact of such care on government funds. Trend data from many regions of the world suggests that these fiscal pressures will continue to increase. In the United States of America (USA) the proportion of the population aged over 65 years is projected to increase from 12.4% in 2000 to 19.6% in 2030¹. In Australia the number of aged care residents is expected to increase by 180-250% by 2044/45². Furthermore, European data shows that the number of people with dementia is expected to rise, for example from 207,000 in 2010 to 412,000 dementia patients in 2050 in the Netherlands, which, together with tight labor markets, is expected to jeopardize the quality of aged care, highlighting the importance of developing technology to assist caregivers³. Carer stress, where caregivers are available, is the strongest predictor of a move into residential care, and supporting carers can delay moves into care by up to two years⁴. This article describes how telehealth design can be used to empower people with dementia, whilst simultaneously reducing carer burden and care costs.

DEMENTIA AND TECHNOLOGY

A larger social network is a protective factor in dementia⁵. Networked support using communication technologies can help relieve carer stress and depression⁵. Use of telehealth improves the quality of life for dementia patients, when that involves familiar environments^{6,7}. Simple cognitive stimulation models have proven to be cost effective in dementia⁸ and some of these may well be suited for delivery using telehealth systems.

Creating user-friendly technology for those with dementia requires knowledge of the perceptual, cognitive and sensory-motor changes common with the disease⁹. For example, evidence suggests that visual-sensory functions such as visual acuity, color perception, and susceptibility to glare all decline with the onset of dementia and may require increased cognitive resource allocation¹⁰. Other cognitive changes may include slowed cognitive processing, decreased memory capacity and decline in working memory processes, as well as decreased attentional control¹¹.

VULNERABLE USERS

Sufferers of dementia are vulnerable citizens. Dementia is a progressive decline in mental abil-

ity, affecting memory, thinking, judgment, attention span and learning. There is no cure for the majority of the neurodegeneratives that cause dementia¹² and the focus of current clinical intervention remains on early detection in providing proactive support care, to maximise life quality.

Those suffering with dementia constitute a susceptible user population. Dehumanisation of dementia sufferers is also an ethically related concern¹³, because the stigma associated with dementia leads to increased social disability¹⁴. Vulnerability¹⁵ "is closely tied to identity" where people to assert any control in that situation "may believe (or think others believe) they are ... less than human". Vulnerability occurs because these people are powerless.

METHODOLOGY

Our project has been designed as a pragmatic, qualitative study with a focus on user feedback and engagement. Qualitative information was obtained from interviews involving participants and their families. The system was free to the end user and was funded by Newcastle Social Services. The project was reviewed by the Newcastle Social Services board and given ethical approval.

The aim of the system was to provide support to people who lived in their own homes. However, since this was the first time such a system was being introduced to older adults, most of whom had some degree of cognitive impairment, the system was initially introduced within a residential setting. An intermediate care facility where people in the community came for respite or as a step down from hospital was used. Once participants appeared confident that they were able to use the system without any anxieties they took the system home with them.

The project undertook to develop, in collaboration with Newcastle City Council, a comprehensive offering of software, hardware, broadband and service to help older adults to use internet-based videoconferencing to meet their care and social needs. A software development firm developed the peer to peer videoconference application with a user interface that was specifically designed for ease of use. The application was run on a touch screen computer and the end user needed to touch a picture of the person they wanted to connect to, in order to initiate a video conversation. The development utilized an ongoing iterative design process to refine the graphic user interface and associated hardware to implement the feedback collected over time. The videoconference system was demonstrated to participants without screening for cognitive function or ability. If it was felt that they may not

understand what was being offered or discussed, the team discussed the project with their family and formal caregivers, and made decisions in their best interests in accordance with current Mental Capacity legislation in the UK. If they consented to receive services through the touch screen videoconference system, the system was installed along with broadband and hardware in their homes. They were connected with friends, family and other users, as well as the 'Care technologist' who provided both in person and remote visits.

Selection of participants was not random, given the difficulty of gaining ethical clearance from sufferers of dementia and their carers. All residents in an intermediate care residential setting were approached and shown the system which had been installed in the care home. Potential participants were asked to sit in front of the screen and were contacted from another room in the building. If they were able to respond to the incoming call, they were offered participation in the trial of the system. If they were too confused, did not like the system, or felt it was inappropriate, they were thanked for their time. 125 people (86 women, aged: 20-72, and 39 men, aged: 32-74) in the wider carer network participated, and 26 people (18 women, aged: 72-100, and 8 men, aged: 78-94) suffering with various stages of dementia took the system home. All who did take it home had the mental capacity to make this choice. In the case that someone did not, a best interest decision was taken in consultation with family caregivers regarding implementing the system, with the participant being given assent to utilize the system at home.

Thus 125 older adults were provided with information about the system and shown how to use it. They were then asked to give written consent to participate in the project and their families gave assent for them to participate as well. All users required broadband.

26 individuals (18 women, aged: 72-100, and 8 men, aged: 78-94) took the system home and connected to 109 family members across the UK and USA. All participants were connected to a Care technologist for support. Users were also connected to each other and formed peer networks. The project duration was from September 2008 to March 2011. During that period one participant dropped out due to severe dementia-related challenging behaviours because the family felt that the participant could no longer use the system effectively. Two individuals moved into residential care during that period and therefore the system was given to other users.

Ethical telehealth

Four values of guided design

Beauchamp and Childress¹⁶ trace the philosophical theories of utilitarianism, Kantianism, rights theory, and communitarianism, to demonstrate that the four values of autonomy, non-maleficence, beneficence, and justice, lie at the core of moral reasoning in healthcare.

Designing for autonomy is about showing respect to the user and treating them as a valued member of society. It is about enhancing self-efficacy and independent agency. 'Non-maleficence' is derived from the Latin term 'primum non nocere'. Smith¹⁶ claimed that Hippocratic injunction to do no harm remains a guiding axiom for medical practice today. After reviewing recent and traditional views of beneficence, Beauchamp¹⁸ stated that the term beneficence is understood "to include effectively all forms of action intended to benefit or promote the good of other persons".

Beauchamp and Childress¹⁶ described the value of justice as one that emphasises fairness and equality among individuals. Slote¹⁹ linked this to an ethics of care which "seems to lie in an ideal that stresses connection over separateness. The Kantian emphasis on the autonomy of the moral person and the Rawlsian/contractarian assumption of separate individuals coming together to forge a social contract see us as basically separate from others, whereas an ideal of caring concern for others sees our (initial) actual historical and personal connections with others as the basis for a positive and caring response to such connection".

For Slote, the Rawlsian/contractarian assumption falls short of explaining why we have a moral duty to treat with fairness and equality persons with whom we have no direct link or emotional connection. This also includes which arrangements or technological solutions we as society can or must provide to persons with declining autonomy. 'For better or worse', he continues¹⁹ "we have to learn to live together in larger social units, and we cannot be intimate or even acquainted with every human being whose actions and fate are morally significant for us. So an ethic of caring that seeks to account for individual and social morality generally needs to say something in its own voice about social and international justice and about how given individuals can realize the virtue of justice".

System design

The initial iteration of the user interface (UI) was very simple and the design process essentially locked down windows. It was on with a 'blank' screen saver, causing participants to think that it had switched off when actually it was still on, although not connected to a call. Participants could 'wake up' the system by tapping on it. In two instances printed

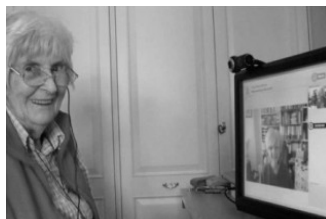


Figure 1. Connecting the user to a caregiver or clinician

prompts were printed on top of the screen to remind a particular participant that she needed to remember to tap the screen to wake it up when she wanted to make a call. Incoming calls had a prompt on the call button that said 'Tap here to talk to <name of person>'.
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The permanent, easy connection to caregivers and clinicians had the potential to be considered intrusive of a person's privacy (Figure 1). Three participants were cautious about whether having cameras was like 'spying' but when they understood the two-way interactivity of the system, this concern disappeared. Two others wondered whether this would make caregivers visit less often in person. However, the reverse occurred as visits both virtual and in person increased; the latter because crisis had been detected or the system had failed and required resetting.

FINDINGS

Due to the confidential nature of the data and potential to disclose the identity of participants, vignettes based on actual experiences with participants are used to exemplify the results of implementing the four guiding values in the design of the system.

Autonomy

Designing for autonomy is about showing respect to the user and treating them as a valued member of society. All users reported feeling empowered by using the system. They felt more in control and better supported. Six (5 women, aged 74-86; one man, aged 84) began using the system themselves to schedule calls to peer group members and felt comfortable in the new digital world. Another four (all women, 74-86 years old) asked to learn how to use the web and conduct searches. All the friends and family members connected to the users felt that the system provided users a means to communicate in real-time and also gave them the added satisfaction of being digitally included.

Non-maleficence

The team ensured both during design and during operations, that no harm was caused to participants. They minimised any potential anxiety of using the system by design with a simple UI and providing proactive IT support.

As stated above, one of the 26 participants (a man, 78 years old) during the 30 months of the project,

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returned the system as he was unhappy with it. It appeared that this was due to two reasons. Firstly, that the person had already developed severe behaviour problems related to dementia and there was a large degree of ongoing stress, which eventually led to his move into residential care. Secondly, the user and carer had expected a greater degree of contact with their relative who lived away. Unfortunately the relative was unable to support the user remotely due to issues of her own, and this lack of contact translated itself into frustration against the system. This was the only identified adverse event within the trial.

Beneficence

The aim of the system was ultimately to improve the quality of life of users by connecting them to peers and family, and to provide proactive prevention. Peer to peer connection was requested by eight participants (6 women, aged 74-100; 2 men, aged 78-82) as they had resided in the same care facility where they were introduced to the support system. In one instance, an 84-year old woman did not answer a scheduled call from her peer. She informed the caregiver of this lack of response and we contacted the participant who reported that she was unwell and an ambulance was called – it emerged that she was suffering from a stroke. The increased level of social interactivity meant that the peer network also acted as a monitoring network and eight peers began to support themselves and identify crisis early.

The system was introduced to a 74-year old gentleman in a care home who did not speak often and misidentified care staff as managers of the coal mine in which he used to work. As a result he was often defensive and spent most of his time sitting idly in a chair. As such he was not thought to be a good candidate for a technology-based intervention. To the surprise of the team and his carers, he used a simple drawing programme, coloured in a number of images and proceeded to play a simple memory game on the computer. He went on to use the system to interact with his sons who lived away, greatly increasing his quality of life.

Justice

People with dementia often face inadvertent social injustices. The system provided a platform for participants to use their relatively intact in-

tellectual skills to enhance their quality of life, by helping them make social connections. One 87-year old wheelchair-bound female participant who had no friends or relatives, and who was housebound due to long standing arthritis, had been receiving respite for social isolation in the residential care facility every 3 months for 2 weeks for the previous 15 years. With no relatives or friends she was extremely socially isolated and frail. Once she started using the system, it helped her make at least 4 friends, which then meant her previous lack of social connections was no longer a need for her to go into care. She stopped going into respite care because as she said, 'all her friends' were visiting her at home through the system.

Another illustration of justice as increasing social connection involved a participant with dementia who required her son-in-law to come to her house to prepare her dinner every evening as her daughter was herself house-bound due to arthritis. Due to her dementia she would follow her son-in-law around her house when he visited often intruding and asking repetitive questions causing great stress for her son-in-law. He was finding it more difficult to prepare her meals and attend to her housework due to her interference. Once the system was introduced, her son-in-law would start a video call between the participant and her daughter. While the two were engaged in conversation he found it easy to complete his care-giving tasks and found his level of caregiver stress greatly reduced. At the same time both mother and daughter felt more relaxed and engaged.

CONCLUSION

One of the main criticisms of telehealth has been that it does not consider the aspirations of end users, but instead addresses the needs of services to reach greater numbers, reduce costs. Our system, called 'Connect for Care' demonstrated how ethically designed services resulted in participants reporting greater autonomy, less isolation, and improved quality of life. The implementation of such services opens the possibility of reducing stigma by causing cognitive dissonance between widely held social perceptions of people with dementia being unable to learn new things, with the reality of their using telehealth systems to enhance their quality of life and communicate, despite their disabilities.

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References

1. U.S. Census Bureau. 2012 National Population

Projections: Midyear population, by age and sex, Table 094. May edition. Washington: U.S. Census Bureau; 2013

2. Tannous WK, Luo K. Ownership of Residential Aged Care Facilities in Australia. Sydney: Macquarie Economics Research Papers; 2006
3. Schikhof Y, Mulder I, Choenni S. Who will watch

- (over) me? Humane monitoring in dementia care. *International Journal of Human-Computer Studies* 2010;68(6):410-422; doi:10.1016/j.ijhcs.2010.02.002
4. Luppá M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia, A systematic review. *Dementia, Geriatrics and Cognitive Disorders* 2008;26(1):65-78; doi:10.1159/000144027
 5. Crooks VC, Lubben J, Petitti DB, Little D, Chui V. Social networks, cognitive impairment and dementia incidence among elderly women. *American Journal Public Health* 2008;98(7):1221-1227; doi:10.2105/AJPH.2007.115923
 6. Powell J, Chui T, Eysenbach G. A systematic review of networked technologies supporting carers of people with dementia, review. *Journal of Telemedicine and Telecare* 2008;14(3):154-156; doi:10.1258/jtt.2008.003018
 7. Brittain K, Corner L, Robinson L, Bond J. Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness* 2010;32(2):272-287; doi:10.1002/9781444391541
 8. Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam A, Woods B, Orrell M. Cognitive stimulation for people with dementia: A cost-effectiveness analysis. *British Journal of Psychology* 2006;188(6):574-580; doi:10.1192/bjp.bp.105.010561
 9. Nehmer J, Lindenberger U, Steinhagen-Thiessen E. Aging and Technology – Friends, not Foes. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry* 2010;23(2):55-57; doi:10.1024/1662-9647/a000016
 10. Schäfer S, Huxhold O, Lindenberger U. Healthy mind in healthy body? A review of sensorimotor-cognitive interdependencies in old age. *European Review of Aging and Physical Activity* 2006;3(2):45-54; doi:10.1007/s11556-006-0007-5
 11. Whitbourne SK, Meeks S. Psychopathology, Bereavement, and Aging. *Handbook of the Psychology of Aging*. 7th edition; New York: Elsevier; 2010; p 311
 12. Townsend M. When will Alzheimer's disease be cured? A pharmaceutical perspective. *Journal of Alzheimers Disease* 2011;24(Suppl 2):43-52; doi:10.3233/JAD-2011-110020
 13. Saunders T. Equality, discrimination and human rights. UK: Alzheimer's Society; March 2012; www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1674; retrieved July 21, 2015
 14. Sabat SR, Johnson A, Swarbrick C, Keady J. The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naeve and Kroll through the situated self. *Nursing Philosophy* 2011;12(4):282-292; doi:10.1111/j.1466-769X.2011.00485.x
 15. Baker SM, Gentry JW, Rittenburg TL. Building Understanding of the Domain of Consumer Vulnerability. *Journal of Macromarketing* 2005;25(2):128-139; doi:10.1111/j.1745-6606.2008.00115.x
 16. Beauchamp TL, Childress JF. *Principles of Bio-medical Ethics*. Oxford: Oxford University Press; 2009
 17. Smith CM. Origin and Uses of Primum Non Nocere — Above All, Do No Harm! *The Journal of Clinical Pharmacology* 2005;45(4):371-377; doi:10.1177/0091270004273680
 18. Beauchamp T. The Principle of Beneficence in Applied Ethics. In: Zalta EN, editor. *Stanford Encyclopaedia of Philosophy*. Stanford: Stanford University; 2008
 19. Slote M. Justice as a Virtue. In: Zalta EN, editor. *Stanford Encyclopaedia of Philosophy*. Stanford: Stanford University; 2010