Digital Participation at the End of Life

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ABSTRACT
In this paper, we describe the barriers to digital participation experienced by those at the end of life, propose a framework in which to set these barriers, and discuss research directions in addressing them.

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

General Terms
Design, Human Factors.

Keywords
Digital inclusion, social networks, older adults, end of life, thanatosensitive design.

1. Introduction
Most of us will die in old age, after a prolonged physical and possibly also social decline, beset by multiple conditions. It is predicted that, by 2030, 86% of deaths will be of older adults (people aged over 65), and 44% of deaths will be of those over 85 [7]. While the concept of "*dying well*" is subjective, there is wide agreement that it depends in part on social support given by family, friends and carers [5, 6]. Yet as people move towards the end of life (*EoL*), they are likely to become increasingly socially isolated [13], and to face a complex set of barriers that limit access to friends, family, carers and support organizations. Isolation may be exacerbated for the over-70s, who are less likely than any other age group to use digital social networking tools [2]. The "*transformational impact of digital technologies on aspects of community life*" [12] has potential to alleviate this social isolation for both those living at home and those in EoL care institutions (hospitals, care homes, hospices). In this paper, we describe the barriers faced, highlight technology use that currently circumvents the barriers, and introduce ongoing work that seeks to mitigate them further.

2. Digital Participation
At EoL, digital participation may reduce isolation for some individuals – e.g. the dying, the bereaved and their respective support networks. Previous studies show that people in these groups have used Web 2.0 resources such as blogs [1], online support groups and social networking sites to connect with others, to describe their experiences and to seek support [4, 9]. This is, however, far from the norm for older adults. Most individuals at EoL do not participate digitally, and their *social death* will either precede or be synchronous with *physical death*.

2.1 Barriers to Digital Participation
A complex set of barriers can prevent those at EoL – particularly older adults - from digital participation, either as originators or recipients of information, communication and social contact. These barriers include: a lack of hardware (e.g. access to a PC or smart phone) and software (e.g. email), access (e.g. absence of broadband in remote communities), technology literacy and confidence, and absence of mentoring [2]. Further barriers may stem from physical or cognitive limitations or decline – e.g. a user's ability to use a keyboard may dwindle as their physical condition declines. Beyond these more obvious barriers, there are subtle barriers which arise from *stakeholder interactions* at EoL, and from the *organisational culture* of EoL care providers. It is on these that we focus here.

2.1.1 Stakeholder interaction
Communication between the individuals and groups (stakeholders) involved in EoL care is often poorly supported. These stakeholders include the individual at EoL, their core carers (a small group of family/ close friends), and the wider support network of family, friends, neighbors, colleagues, health and social care practitioners, spiritual advisors and Third Sector organizations. A recent study of an Australian 'Home Hospice' program highlights both the importance of interaction between the core carers and the wider support network, and the difficulty of sharing information across the network [5]. Our own preliminary conversations with highly regarded hospices and care homes suggest that they recognize (and in many cases wish to change) the barriers to EoL care caused when online and offline information is scattered amongst stakeholders, but not shared effectively.

Information sharing is further complicated by privacy concerns entailed in life-threatening illness. Previous research has highlighted individual families' desire that different information be given to different stakeholders, and also older people's fears that the Internet threatens privacy. Palliative care doctors have also expressed concerns about privacy – e.g. "*Blogging presents an important medium of communication with the outside world for patients who are bed bound and socially isolated, but raises important clinical, ethical and social issues relating to confidentiality and the nature of the physician-patient relationship…*" [8].

2.1.2 Organisational culture

Our conversations with EoL care providers suggest that their own organizational culture can create a further set of barriers to ICT take-up for patients at the EoL. Those conversations have highlighted (to the obvious disappointment of some caregivers with whom we have worked) that in care organizations, ICT:

- Is seen as an administrative tool for staff, rather than a facility for patients/client/residents to use as part of their care.
- Technical support is provided for staff, not patients.
- Represents a disruption when used by patients, and a potential risk to their moral wellbeing, and that of staff, therefore access by patients should be controlled.
- Should be secure. Delivery of / access to digital media (e.g. photographs) may be blocked automatically by security applications.

2.2 Reducing Barriers to Digital Participation

We propose that the barriers to digital participation at EoL can be set in a framework of overlapping factors, consisting of:

- Technology factors (lack of hardware, software etc.).
- The individual's physical and cognitive constraints.
- Sub-optimal information sharing amongst stakeholders.
- Organisational inhibitions amongst EoL care providers.

The areas in which ICT tools currently support the terminally ill and bereaved are those in which these barriers can be easily circumvented [13]. Specifically, ICT tools such as blogs and social media sites have been most rapidly adopted by technologically savvy (and often younger) users. Such users are likely to suffer less from the constraints of old age, and may have a very different notion of privacy than that held by the elderly [3]. Finally, the technologies introduced at the start of this paper, such as patient blogs or memorialisation on FaceBook, have flourished beyond the control of EoL care organizations such as hospices, hospitals or care homes [13].

3. Research Directions

Our ultimate objective in this area is to design practices and tools that *directly address* the barriers described above, to supplement existing practices and tools that *circumvent* the barriers - i.e. ICT's, ICT infrastructures and best practice that directly support the specific social interactions in which those nearing EoL are (and wish to be) involved. We will also take account of key organisational concerns surrounding EoL data protection and privacy.

At this early stage in our work, we are collaborating with partners in elder care homes and hospices to deepen our understanding of:

- The individual and group interactions that can mitigate (or currently promote) social exclusion amongst the elderly and terminally ill.
- The support for those interactions that can be provided by ICT tools tailored to the needs of the elderly/terminally ill, and their core/extended support networks.
- The key barriers to take up of those technologies.

We have begun to develop and assess ICT's [6,10,11] that directly address the complex set of barriers introduced in this paper. We will report upon that development and assessment in future papers and, in the meantime, welcome insights from fellow researchers and practitioners.

Quality of life depends on social relationships as much as the satisfaction of physical needs, yet research into the use of digitally assisted social contact for the elderly is currently limited [2]. Our aim is to initiate research into how ICTs can support the *social* life of those near the end of life, and mitigate their social isolation.

5. REFERENCES

1. Chung, D.S. and Kim, S. Blogging activity among cancer patients and their companions: Uses, gratifications, and predictors of outcomes. *Journal of the American Society for Information Science and Technology 59*, 2 (2008), 297-306.

2. Gibson, L., Moncur, W., Forbes, P., Arnott, J., Martin, C., and Bhachu, A. Designing social networking sites for older adults. *Proc. HCI 2010, Volume 1*, BCS (2010), 181-189 .

3. Gibson, M. Death and mourning in technologically mediated culture. *Health Sociology Review 16*, 5 (2007), 415.

4. Hoey, L.M., Ieropoli, S.C., White, V.M., and Jefford, M. Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling 70*, 3 (2008), 315-337.

5. Horsfall, D., Noonan, K., and Leonard, R. *Bringing our Dying Home : Creating Community at End of Life*. Little Hartley : Debbie Horsfall, 2011.

6. Johnson, P. and Hourizi, R. Memories Are Made of These: Life Stories. *Death & Dying in the Digital Age: Book of Abstracts*, (2011).

7. Leadbeter, C. and Garber, J. *Dying well*. DEMOS, London, UK, 2010.

8. Lowney, A.C. and O'Brien, T. Where Palliative Medicine meets the Social Network. *Death & Dying in the Digital Age: Book of Abstracts*, (2011).

9. Massimi, M., Odom, W., Kirk, D., and Banks, R. HCI at the end of life: Understanding death, dying and the digital. *Proc. CHI EA'10*, ACM (2010), 4477-4480.

10. Moncur, W. A model for the provision of adaptive ehealth information across the personal social network. 2011. Unpublished thesis, University of Aberdeen.

11. Nosseir, A., Hourizi, R., Middup, C., Nemetz, F., and Johnson, P. Towards Autonomous Systems that Collaborate: Investigation of a Proposed Collaborative Framework. *Proc. SEAS DTC '08*, SEAS DTC (2008).

12. Research Council UK. What is the RCUK Digital Economy theme? 2011. http://www.rcukdigitaleconomy.org.uk/home/the-research-councils-uk-digital-economy-theme.html.

13. Walter, T., Hourizi, R., Moncur, W., and Pitsillides, S. Does the internet change how we die and mourn? An overview (Forthcoming). *Omega: Journal of Death & Dying*, (2012).