

The Ethico-political Dimension of Thanatosensitive Design-orientated Research

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This paper considers the ethico-political dimension of technology embedded in thanatosensitive design-orientated research in order to discuss how ‘framings’ of design situations could perpetuate the marginalisation of groups and topics within sensitive research contexts such as death. As a practitioner-researcher, I draw from the literature and my own critically reflective practice as a designer to outline framings, raise ethical and political aspects of their enactment and propose questions for consideration by the HCI community in sensitive contexts.

Reflexivity, End of Life, Thanatosensitive Design, Bereavement, Ethico-political, Complexity, Interdisciplinary

1. INTRODUCTION

This paper will consider the ethico-political dimension of technology design at End of Life. I propose this as an important topic for HCI research within the theme of sensitive contexts, as the emerging presence of death within interactive technologies is a vital consideration for contemporary society. Within this paper I will focus on thanatosensitive¹ design-orientated research and discuss the role of designers in configuring and shaping technologies for End of Life, in order to open for consideration an ethical dimension which has emerged through personal meta-reflection on my role as a design practitioner-researcher interested in bereavement support technologies.

This paper will begin by discussing the role of thanatosensitive design in configuring and shaping technologies within the context of bereavement, before moving on to outline the importance of thanatosensitive design taking a wider ethically and politically engaged position, particularly when working for groups and subjects within sensitive research contexts. To do this I will draw upon an inter-disciplinary lens that I have developed to inform my own practice in this area, including STS (science and technology studies), HCI, design and in particular, recent ethico-political literature from Lucas Introna and Philip Brey.

¹ In Greek mythology, Thanatos was the personification of death.

2. DESIGNING FOR BEREAVEMENT

Dying, death and bereavement are aspects of the human life-span increasingly being taken into consideration by technology designers and researchers (Banks, et al 2011). There are numerous examples within the literature of the interesting ways that technology has intersected with mortality (Banks, et al 2011; Hourizi, et al 2011), including terminal illness support websites, the re-appropriation of social networking platforms for End of Life needs (Algie, 2012), augmented funeral services (Gilbert, 2012), to the service management of estates, assets and preferences (Banks, et al 2011; Hourizi, et al 2011).

Practitioner-researchers engaging with dying, death and bereavement as a concern have begun to adopt a ‘thanatosensitive design’ methodology to configuring and developing technologies for the End of Life arena (Charise & Massimi, 2009). As with any research activity within a sensitive context, design needs to take a reflective and considered approach when touching upon deeply personal experiences, emotive subjects and the sacredness around death (Liamputtong, 2007; Woodthorpe, 2011).

My own thanatosensitive design-orientated research questions: how can design support the bereaved in ways which are morally and ethically respectful, alongside taking into account and

reflecting the diversity of mourning practices within bereavement.

My focus on “Practices” refers to the death rituals and mourning activities the bereaved engage in as responses to loss, which make grief visible through a ‘nexus of doings and sayings’ (Schatzki 1996). As adaptive responses, death rituals and mourning practice can and have been increasingly more personalised and diverse, with a range of vernacular responses to death emerging online (Algie 2012; Ellis 2012; Feiller 2012; Walter 1997).

While my doctoral research continues to take a grounded approach to investigating the diversity of vernacular mourning practices online, literature offers warnings against attempting to predict or structure how any individual will engage in mourning practices (Feifel 1988; Small, 2001; Walter, 1997).

3. DESIGN COMPLEXITY

Design as a discipline, therefore, has been invited to consider bereavement as a space in which there are likely to be vast differences in activities, values, assumptions, beliefs and interests around loss (Small, 2001; Walter, 1997). Configuring and designing technologies to support such diverse practices within bereavement presents a number of design challenges, recognised in what Stolterman defines as ‘design complexity’ or ‘*the complexity a designer experiences when faced with a design situation*’ (Stolterman, 2008). I would argue that this area is similar to other complex design situations which present ‘potentially infinite and limitless sources of information, requirements, demands, wants and needs, limitations, and opportunities’ (Schön, 1983; Stolterman, 2008). Practitioners are required to make all kinds of judgements and decisions iteratively, including how to frame a particular situation by choosing what to explore or dismiss in the shaping of the actual design (Brey, 2009; Stolterman, 2008). Without this pragmatic framing, design cannot operate and enact changes in interactive technologies used at End of Life. Framing and closing a design process is an inherent part of the negotiation process of change, aiming to resonate not only with the communities it is working to support, but also with a wide variety of stakeholders such as clients, financiers, and technology specialist involved within a design process (Introna, 2007; Stolterman, 2008).

4. POLITICAL FRAMING

Whenever practitioners work to frame a design situation, configure potential design spaces, and iteratively refine a creation, this activity is engaging with politics surrounding the End of Life. Power is present in the enactment of these framings and

such decision-making processes that directly impact upon potential users (Introna, 2005). This occurs not just in the delineation of the people to be accounted for or discounted within a design activity. These framings reflect values, judgements and interests which subsequently become ‘enclosed in increasingly complex socio-technical networks’ (Introna, 2005). In this sense, thanatosensitive design extends beyond the situation at hand and is involved in shaping social possibilities which can be considered as part of the active socio-cultural, historically located, and politically contested, landscape at the End of Life.

While we have addressed the activity of framing in the HCI community (Brey, 2009; Brey 2000; Stolterman, 2008), there is also tentative work which has begun to touch upon the indeterminate and intangible quality of these framings. Carvalho Pereira and Maciel (2012) explore the beliefs and taboos around death within software development. They found within their critical analysis that ‘communications were observed to be permeated by beliefs, moral, religious and ideological values, which may influence the development of thanatosensitive design solutions’ (Carvalho Pereira & Maciel, 2012). This discussion brought awareness to how socio-cultural arrangements of death transfer into socio-technical landscapes, to highlight and reflect upon the extent which design activities may be affected by our culture or history (Carvalho Pereira & Maciel, 2012; Small, 2001).

This recognition of the enactment of taboos and beliefs suggest the need to take into account as fully as possible the impact of a practitioners’ own value systems upon the framings applied within their design activities. I argue that engaging with values should be an ongoing consideration of practice, including entering into a dialogue on how these are permeating framing activities. Such considerations will enable practitioners to reflect upon and reshape action in relation to the values being enacted and the impact on the End of Life.

Although it should be acknowledged that when employing critical and retrospective reflection, there will always be people affected by grief who find their voices, practices and realities not reflected within technologies (Introna, 2007). That alongside potentially supporting and facilitating strong personal norms about the way to grieve, framings also have the potential to disturb sensitivities through strange and seemingly irreverent actions.

5. THE ETHICO-POLITICAL DIMENSION

This draws attention to an ethical dimension of technologies at End of Life, where ethics shifts from treating technologies as value neutral. Where any

ethical issues of their use are considered in isolation from the practices of their production (Brey, 2009). Instead the ethical dimension develops from notions of complexity and framings which are enacted with the potential to impact negatively upon people in sensitive contexts. It is in the recognition that whatever is instigated at the level of code can turn into social practices of death and eventually into the production of social orders (Introna, 2007).

While the idea of technologies embodying values is not a new concept to HCI, it is the silent nature of these processes and framings that deserves consideration (Brey, 2009). To forget that this occurs serves to mask an important ethico-political dimension (Introna, 2007). Without critical reflexivity around both design *and* use of technologies, can potentially have far reaching consequences for those we are aiming to support. This is especially key if we are considering how to approach the richness and diversity in the field of mourning and loss, without imposing orthodoxies or frameworks for bereavement.

As engaged practitioners we do not set out to marginalise or impinge upon the sensitivities of those we aim to support. It is for this reason my research is considering, how can we research and design End of Life technologies with this ethico-political dimension as an on-going consideration of our practice? How can thanatosensitive design-orientated methodologies explore the embedded values in the design of technology?

None of these questions have obvious pathways forward, nor are they presented with the expectation that they contain resolvable tensions. I simply uphold the desirability of making the ethico-political dimension an on-going and visible consideration in the development of thanatosensitive design-orientated research in light of its potential to affect those who are vulnerable.

6. CONCLUSION

This paper considers the ethico-political dimension of technology design at End of Life, in recognition that what is instigated at the level of design and framing activities eventually translates into practices and the production of social orders (Introna, 2007). The danger here is not that there is a political and ethical dimension within design situations, but that we forget that these are already present within our practice and therefore fail to take into account how they may impact on those we aim to design for.

My reflection therefore leads to my proposition that HCI researchers need to: take into account as fully as possible the impact of framings applied within design activities, to be critically aware and reflexive

around what is being enacted and the ramifications of these enactments.

While the ethico-political dimension has been introduced for discussion for the thanatosensitive design arena, it is an ongoing concern that underpins my practitioner-researcher agenda into supporting mourning practices online and an area I will be revisiting as my PhD work progresses.

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8. REFERENCES

- Algie, J (2012) How Facebook has turned the normal processes of dying and grieving inside out. The Next Web. Available [Online] <http://thenextweb.com/facebook/2012/08/11/facebook-ok-dead-dying/>
- Banks, R., Kirk, D., Odom, W and Massimi, M. (2011) Matters of Life and Death: Locating the End of Life in lifespan-oriented HCI research. CHI 2011, Vancouver BC, 987-996.
- Brey, P. (2012) Anticipatory ethics for emerging technologies. *Nanoethics*, 6:1–13.
- Brey, P. (2000) Method in Computer Ethics: Towards a multi-level interdisciplinary approach. *Ethics and Information Technology* 2: 125–129.
- Brey, P. (2009) 'Values in technology and disclosive computer ethics,' In: Floridi, L. EDs. *The Cambridge Handbook of Information and Computer Ethics*, Cambridge University Press, Cambridge.
- Feifel, H. (1988) Grief and Bereavement: overview and perspective. *Bereavement care*. 7(1):2-4
- Feiler, B. (2012) Mourning in a Digital Age. The New York Times. January 13, 2012. Available [online]<http://www.nytimes.com/2012/01/15/fashion/mourning-in-the-age-offacebook.html?Pagewanted=all>
- Carvalho Pereira, V, C and Maciel, C. (2012) The Influence of beliefs and death taboos in modelling the fate of digital legacy under the software developers' view. CHI12:Workshop paper. Available [online] <https://sites.google.com/site/chi2012eol/accepted->

papers/chi2012EAMacielandPereira.pdf?attredirects=0 [Retrieved 9th June 2012]

Charise, A. and Massimi, M. (2009) Dying, death, and mortality: Towards thanatosensitivity in HCI. CHI 2009, Boston, 2459-2468.

Gilbert, M. (2012) Grief and technology: PowerPoint, Skype and other technology add to some services. Herald Mail. 2012. Available [Online] http://articles.herald-mail.com/2012-01-26/lifestyle/30669298_1_skype-slide-show-technology

Hourizi, R., Moncur, W. Pitsillides, S., and Walter, T. (2011) Does the internet change how we die and mourn? Overview and analysis. *Omega: Journal of Death & Dying*, 64 (4).

Introna, L. D. (2007) Maintaining the Reversibility of Folding's: Making the ethics (politics) of information technology visible, *Ethics and Information Technology*, 9(1): 11-25.

Introna, L. D. (2005) Disclosing the Digital Face: The ethics of facial recognition systems, *Ethics and Information Technology*, 7(2): 75-86.

Liamputtong, P (2007) *Researching the vulnerable*. Sage Publications. London.

Moor, J. H. (1985) What is Computer Ethics?. *Metaphilosophy*, 16(4): 266-75.

Schön, D. (1987) *Educating the Reflective Practitioner: Toward a new design for teaching and learning in the professions*. Jossey-Bass Publishers, San Francisco, CA.

Stolterman, E. (2008) The nature of design practice and implications for interaction design research. *International Journal of Design*, 2(1).

Small, N. (2001) Theories of Grief: A Critical Review. In: Hockey, J., Katz, J., Small, N. Eds. *Grief, Mourning and Death Rituals*. Open University Press. Buckingham. UK. 2001. 20-48.

Walter, T. (1997) *The Revival of Death*. 2nd Ed. Routledge, London.

Woodthorpe, K. (2011) Researching Death: methodological reflections on the management of critical distance. *International Journal of Social Research Methodology*, 14 (2), pp. 99-109.