An Interdisciplinary Lens: Design Challenges in Bereavement Support

Selina Ellis

HighWire DTC

LICA, Lancaster University

Lancaster, LA1 4YW

s.ellis@lancaster.ac.uk

Abstract

My emergent interdisciplinary framework has begun to reveal challenges facing internet technologies and related software applications aiming to support bereavement practices. Within this position paper I draw upon Death Studies, HCI, Sociology, Practice and Performance theory, to outline this framework and highlight how problematising grief and overlooking bereavement practices can have implications for the selection of design methodologies. While no concrete solutions to these two challenges are presented, I indicate some avenues for advancement and debate in these areas.

Keywords

Interdisciplinary, Design, Bereavement, Happenings.

ACM Classification Keywords

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

Introduction

The digital dimension of death opens up a number of potential avenues for the design and development of technologies aiming to support bereavement practices. It is within this context that my emergent PhD work has begun to uncover a selection of challenges facing

practice and research for End of Life technology development [17].

The selected challenges addressed in this paper stem from implications drawn from grief theories, which focus on the inner state of mind and the problematisation of grief within Western scholarship. Therefore this interdisciplinary synthesis opens for debate how these perspectives affect research directions and the selection of design methodologies.

Finally, the interdisciplinary nature of this paper and the mixed scholarship it draws upon instigates a space for reflection and discussion on the underlying tensions that different paradigms of inquiry inherently bring to interdisciplinary work.

Practices of Bereavement

Before engaging in theoretical discussions of loss and mourning, there are a number of key terms that I would first like to clarify. Within this paper I will apply "loss" to signify the rupture of a relationship instigated from a person's death, "Grief" as the complex response to loss, and "bereavement" the process of living with loss and grief [3,4,25].

The emphasis of this document is placed upon the bereaved and the discussion of *practices* which occur within the sociocultural context of bereavement. "Practices" in this vein refers to the death rites and mourning activities as responses to loss, which in turn make grief visible through a nexus of doings and sayings [23]. Posited as an adaptive response to the rupture of loss, death rituals and mourning practices can be cursory or extensive and exhibited through public or private spheres [3,12,14, 25].

My deployment of practice is not to create a dichotomy between the inner emotion and outer behaviour. Instead my approach is to emphasise that loss, grief and the practices it instigates are assembled in a myriad of ways within the sociocultural context of contemporary reality [25].

The Problem of Grief

Having briefly established key terms, I am moving on to discuss the recent critical interrogations on theories of loss. This work reflects the emergent post-modern view of loss and bereavement as being part of the sociality of our existence [25], one in which individuals respond in different ways within their frameworks of social and cultural practices [25].

This perspective differs from the previous theoretical emphasis in 20th Century Western societies that approached loss and grief with a distinctly modernist perspective [14,29]. Modernism here manifested through issues of 'normalcy' and theoretical perspectives which likened grief to illness [3], through defining 'healthy' responses, prescriptive approaches and stage models encouraging people to 'let it out' or 'let go' [2,3,29,33].

The postmodern decentering of posing 'grief as a problem' to solve and the 'return' to some prior 'normal', allows us to consider the impossibility of backwards changes and undoing death [3]. Instead 'normal' can only frame the bereaved's 'return' to the ordinary flow of life, rather than refer to altered inner realm of experience [3,25]. In this view, death rites and mourning practices offer avenues for the ruptures of loss and for accommodating bereavement over an extended period [3,4,]. They have been noted to

positively occupy the bereaved and be considered as creative responses that should be more fully legitimised [3].

Practice Ecosystem

Considering the importance of death rites and mourning practices for the bereaved, this has been an overlooked area of western study in its own right in comparison to the extensive work on the *internal* processes of loss amongst Death Studies [12,14]. Yet within the intersection between Death Studies and HCI literature, there are a number of sources exploring forms of online practice [1,16,18,31]. A characteristic thread here is discussions of memorialisation and the bereaved's interest in tributes and commemoration [31]. Yet if we tentatively consider practice as wide range of activities for responding to loss, it would suggest memorialisation is *one* practice focus in a broader practice based ecosystem concerned with loss and grieving.

Initial searches online offer a number of potential of venues where a wide range of practices centred on grief and loss are supported. Alongside social networking, special interest groups and memorial sites that have been previously dealt with within the literature (4,16,31), there are examples of blogs [15,28], websites, and forums [8,9,11,28,32] whose focus is not wholly centred on commemoration [4]. Wider searches expose a diaspora of photographic activity [6], video blogging [7], poetry [21], scrapbooking [5] and film making [20,22,10] activities within loss.

These examples suggest there is potentially a wide multitude of practices occurring online, which are not fully accounted for within the lens of memorialisation.

Here I would like to introduce the concept of 'Bereavement Happenings', to tentatively acknowledge those broader examples of practices, without out imposing definitions.

The concept of 'happenings' [13], drawn from Allan Kaprow's performance theories, refers to 'happenings' as being events and occurrences that just happen [13]. The notion of 'Bereavement Happenings', currently situated within the nexus of doing and saying, tentatively acknowledges a broader focus of unaccounted for activities and their potential for further consideration.

Designing Bereavement Technologies

I see a number implications arising from the theoretical discussions surrounding the problematisation of grief and its constrained focus on particular practice. Here I address three points of consideration for practitioners and researchers interested in End of Life technology development [17].

Designing for problems. Design has a central role in actively configuring, formatting and shaping the technologies the beavered engage with. Therefore careful consideration should be applied when selecting design methodologies and methods that potentially can frame loss as an implicit problem. Modernist design models or scientific methods aiming to offer 'solutions' for the bereaved as 'rational actors' engaging in 'goals' or 'tasks' is a potentially flawed construction [30].

Designing for practice. Design is approaching a multitude of potentially unexplored spaces for development. In light of this, participatory methods and design methodologies [26] could prove fruitful and aid

practitioners and the bereaved to reflect upon the design complexity and critique formulations which ultimately shape the technologies they actively engage with [26,30].

Designing for possibilities. A shift from problems to towards participatory approaches suggests the need for 'prepared *for-action' methodologies,* not guided by detailed prescriptive procedures [30]. Cyclic methodologies such a Co-design, Co-creation and Action Research may aid practitioners to explore possibilities dynamically through reflexivity and responsive methods [23,24].

Conclusion

Within this paper I have applied an interdisciplinary lens drawn from Death Studies, HCI, Sociology, Practice and Performance theory, to reframe loss outside of modernist discourse which problematises its presence, in order to suggest design needs to give careful consideration in the selection of methodologies that may inadvertently begin to re-problematise loss through practice.

By shifting the theoretical focus of bereavement away from the inner realms of experience and reframing it as a sociocultural form of practice, I have tentatively brought forth a multitude of bereavement happenings that suggest for further investigation. These happenings are of interest to designers, as they can be responsively explored by employing participatory methodologies within the design of bereavement technologies.

Finally, the interdisciplinary nature of this paper and the mixed theoretical perspectives it draws upon has opened a space for reflection and discussion on the underlying tensions that different paradigms of inquiry bring to interdisciplinary work around bereavement.

References
[1]   Carroll, B., Landry, K. Logging On and Letting Out: Using online social Networks to grieve and to mourn. *Bulletin of Science, Technology & Society.* 2010. 1, 30. 309-315

[2]   Currer, C. Is Grief An Illness? Issues of theory in relation to cultural diversity and the grieving Process. In: Hockey, J., Katz, J., Small, N. Eds. *Grief, Mourning and Death Rituals.* Open University Press. Buckingham, UK, 2001, 49-60.

[3]   Davis, D.J. *Death, Ritual and Belief.* 2nd Ed Continuum, London, UK, 2002, 43-61.

[4]   Doss, E. *The Emotional Life of Contemporary Public Memorials: Towards a theory of temporary memorials.* Amsterdam University Press. 2008. 5-25.

[5]   Good Grief Blog
http://www.goodgriefblog.com/

[6]   Grief and Acceptance.
http://www.flickr.com/groups/655682@N21/

[7]   Grief Chats: What to Do With the Shoes?
http://www.youtube.com/watch?v=IAqIGi1kqZw&list=UUgvg8uU1pCzdf1efHNEP8Qg&index=2&feature=plcp

[8]   MyGriefSpace
http://www.mygriefspace.com/

[9]   GriefShare
http://www.griefshare.org/

[10]   Grieving for Peter.
http://www.spokesmanreview.com/blogs/video/archive
.asp?postID=190

[11]   GROWW
http://www.groww.org/

[12]   Hockey, J. Changing death rituals In: Hockey, J.,
Katz, J., Small, N. Eds. *Grief, Mourning and Death
Rituals.* Open University Press. Buckingham, UK, 2001,
185-211.

[13]   Kaprow, A. Happenings in the New York Scene.
In: Kelley, J. Eds. *Essays on the Blurring of Art and
Life.* University of California Press. USA.1993.15-26

[14] Katz, J., Introduction. In: Hockey, J., Katz, J.,
Small, N. Eds. *Grief, Mourning and Death Rituals.* Open
University Press. Buckingham, UK, 2001,

[15]   Heybouer,k. Grief Blogging: Talking with the
blogger behind A Widow for One Year | NJ.com. 2008.
http://blog.nj.com/jerseyblogs/2008/04/grief_blogging
_talking_with_th.html

[16]   Lingel, J. The digital remains: Social media and
practices of online grief. 2011
http://www.kent.edu/slis/research/upload/the-digital-
remains-sopcial-media-and-practices-of-online-grief-
jessica-lingel.pdf

[17]   Massimi, M., Odom, W., Banks, R., Kirk, D.
Matters of life and death: Locating the end of life in
lifespan-oriented HCI research. *Proc. CHI 2011*, 987-
996.

[18]   Micalizzi, A. Mourning Network: new social
practices in on-line communities. *Digithum.* 2010.

http://openaccess.uoc.edu/webapps/o2/handle/10609/
8795

[19]   Mother Grieving Loss of Child.
http://mothergrievinglossofchild.blogspot.com/

[20]   Nine Years Later: our loss, grief, and moving on.
Youtube http://www.youtube.com/watch?v=75P3ueAx-
gk [

[21]   Pet Loss
http://www.petloss.com/poems/poems.htm

[22]   Remembering Josh.
http://vimeo.com/31956515

[23] Schatzki, T.R. *Social Practices: A Wittgensteinian
Approach to Human Activity and the Social.* Cambridge
University Press. UK. 1996. 89-90

[24]   *Schön*, D. *The Reflective Practitioner: How
Professionals Think In Action.* Basic Books. New York.
USA. 1983.

[25]   Small, N. 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.

[26]   Spinuzzi, C. The Methodology of Participatory
Design. http://flatfile.printobject.com/files/520204.pdf

[27]   Speed, C. An internet of things that do not exist.
Interactions. 18, 3. 2011.18–21.

[28] Still life with circles
http://stilllifewithcircles.blogspot.com/p/about-this-
blog.html

[29]   Stroebe, M. S., Hansson, R. O., Stroebe, W.
Contemporary themes and controversies in
bereavement research. In: Stroebe,*M.S.,* Stroebe,*W.,*

Hansson.R.O. Eds *Handbook of bereavement Cambridge University Press. New York. 1993. 457–471*

[30]   Stolterman, E. The nature of design practice and implications for interaction design research. *International Journal of Design, 2*,1 .2008. 55-65.

[31]   Walter, T., Hourizi, R., Moncur, W., Pitsillides, S. Does the internet change how we die and mourn? An overview. *Omega: Journal of Death & Dying* Forthcoming:http://www.computing.dundee.ac.uk/staff/wmoncur/publications/Omega2011.pdf

[32]   The Widdahood. http://www.thewiddahood.com/

[33]   Worden, J,W. Grief counseling and grief therapy: A handbook for the practitioner. 4th Ed. Springer publishing company. New York. USA. 2009