

### Death and Time

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#### **Abstracts**

### Telling the time of death with clock, calendar and social time

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It is not always possible to know exactly when a person has died. If an individual is alone when they die and their body is found shortly afterwards the time of death in hours and minutes may be obscure. When someone dies alone and their body is not found for an extended period of time it may be impossible to identify either the time or the date on which they died. Does this matter? There are occasions when it may be important. For a family who wish to keep vigil with a relative whilst they are dying it may add to their grief to feel that they missed the moment of death. A precise date and time are important for forensic services in relation to deaths where there are suspicious circumstances, and death certificates in the United Kingdom require the date of death to be recorded. This paper will explore some instances where time of death is unclear. In doing so it will suggest that it would be helpful to rethink our approach to time of death and reframe it in terms that rely not only on the clock and calendar, but also on the concept of social time. The time at which a death is experienced as occurring may vary, depending upon who is involved; a coroner instructing the investigation of a suspicious death will understand the time of death differently to a family member who is experiencing the death of a loved relative.

# "Death is not the end": situating Buddhist and Hindu temporalities in advance care planning

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In this paper I explore the disjuncture between medico-legal trajectories of living and dying, where lives start and stop, and the cyclic comings and goings of Buddhist and Hindu bodies. Drawing on fieldwork with Buddhist and Hindu communities in Adelaide, I reveal the multiple spatio-temporalities that become implicated in end-of-life decision-making about where, when and how one might die. I trace how persons can be affected by what happens after biomedical death, including the handling of the body, how the living may encounter the presence of those who have passed, and how rebirth propels the dead forwards, their bodies and biographies becoming interwoven with new persons and things. In approaching death as a movement of opening (Ingold 2011), I make space for trajectories of living and dying that run counter to public policy instruments that focus on an irrevocable end to life.

# Clashing approaches in the time immediately before death: the management of death rattle

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In this paper we examine the management of death rattle in the period of time just before death. We will present this as a point in time where approaches emphasising a natural death meet in stark conflict with embedded practices of medicalised 'treatment'. This will be based on findings from a qualitative study which sought health care professionals' accounts of their experience of managing death rattle. Purposive sampling included: gender, years in practice, health care professional type and speciality. Data were gathered through eighteen qualitative telephone interviews. Analysis was conducted using the Framework approach and analysis was aided by multi-disciplinary research team interpretation workshops. The study participants' accounts revealed a tension in the management of death rattle at the time immediately before death. On the one hand they sought to reassure relatives and friends around the bedside that noisy breathing is a natural part of the dying process creating no discomfort or distress for the dying person. On the other hand, they wished to respond to the distress experienced by relatives, and the health care professionals themselves, from the sound of the death rattle. This led to the use of a medical 'treatment', the administration of antimuscarinic drugs, with the objective of treating the distress of the people around the dying person. This paper will consider this moment in time just before death and discuss whether the medicalized management of noisy breathing is a shift in the focus of treatment from the dying person to those affected by their death.

# Anticipating an unwanted future: Euthanasia and dementia in the Netherlands

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In the Netherlands, euthanasia is a legal, but strongly regulated practice. Rising numbers of requests for euthanasia by people with dementia are accompanied by lively public debates on how, and if euthanasia for people with dementia should be made possible. Requesting euthanasia is viewed as one of the possible ways to exercise control, in order to maintain dignity at the end of life with dementia. Without advocating any of the standpoints in the debates on euthanasia, I explore a request for euthanasia as an act of responding to, and preparing for, an imagined but unwanted future. The practice of anticipating death through euthanasia, then, discloses a worldview wherein death is seen as manageable, reflecting the increasing importance of the timing of death in contemporary western societies. Furthermore, it reveals normative ideas of a "good" end of life. Drawing from interviews with people with dementia with a euthanasia request, and their family members, I demonstrate that while choosing death over life with dementia through euthanasia can be seen as a way to prevent an otherwise inevitable, and for some apocalyptic future, it also constitutes an anticipatory temporality that encompasses both fear and hope. A strong fear for anticipated decay coincides with the hope for a better and dignified end.

### 'Every time I see him he's the worst he's ever been and the best he'll ever be': young people's accounts of losing their parent to dementia

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Improvements in medical knowledge mean increasing numbers of people being diagnosed with dementia, including young onset variants. Dementia is a terminal illness, with a declining and unpredictable trajectory. Families navigate a unique, and frequently prolonged, untimely grief journey.

Auto/biographical, narrative interviews conducted with 23 participants aged 7-32 years old who had experienced parental dementia highlighted profound and multifaceted loss that is not acknowledged.

Participants described experiencing their parent die over a protracted time period, noting the impact on the life course with their youth dominated by the disease and the biographical work required to make sense of it. Dementia's manifestations meant that young people effectively lost their parent, prior to physical death and that they were denied the opportunity to make reparations at the end of life. There was a sense of stigma, of lives being on hold and that, in common with other bereaved children, they would have to go through both the minutiae of life and landmark events without their parent. However, participants did not benefit from the social exemptions they might have received had their parent been dying/died from another disease. Public perceptions equating dementia with memory loss in older people led to it's terminal nature being overlooked. Young people's grieving status was denied if their parent was alive.

Our research emphasises the need for formal support for these young people and the importance of sharing grief narratives in order to inform the social scripts for those who are grieving in challenging circumstances.

#### The Generational Shift, Timeliness and the Death of Parents

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We are expected to die in order, the oldest generations first and then the next. When parents die in later life the generational shift sees the upward movement of the generations and places the (late) midlife group into the older generation. This can have significant consequences for the way in which family roles and relationships are arbitrated and can evoke a range of emotions, from increased sense of responsibility, maturity and wisdom to feelings of vulnerability, insecurity and anxiety. It can also have an effect on the way people think about their own ageing process and mortality. When the older generation dies and the midlife individual moves into the older position, there may be the sense that they are next in line and the generational buffer between them and death has now gone.

This paper looks at the effect the death of parents in later life affects the adult child. When there is a breakdown of the psychological barrier or buffer, which stands between midlife and death, what impact does this have on the individual? What are the psychological implications of moving up a generation and of witnessing the death of the generation above? And when a death is considered "natural" and "in order" why have these death experiences been disenfranchised (Doka, 1989) eliciting a less empathetic response from friends and family?

## **Telling Stories throughout Time: Sibling Bereavement Narratives over the Lifecourse**

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Riches and Dawson (2000, p.83) highlight that bereaved siblings are faced with the prospect of losing someone 'whose presence played a key role in defining his or her sense of self', whilst Forward and Garlie (2003, p.26) note that for surviving siblings 'the task of defining and stabilizing personal identity and concept of self must now happen in the absence of a principal agent'. As a result, they argue that the bereavement process requires searching for new meaning, reporting that participants felt they had permanently changed as a result of their sibling's death and, consequently, had to re-establish their life narrative and re-define their sense of self (Forward and Garlie, 2003). This presentation seeks to build on this literature with specific consideration of how people attempt to 'narrate' their sibling bereavement experiences. Moreover, as identity is not a fixed construct but an inherently social and continual process of self-identification (Jenkins, 2014), it is necessary to explore if and how these 'stories', their content and presentation are negotiated over the life course. It will draw upon in-depth interviews with bereaved siblings of various ages, which adopted a relational approach to researching long-term experiences of sibling bereavement over the life course. As this project conceptualises bereavement as an intrinsically social and relational experience, consideration will also be given to the role of the audience and how the narrative is adapted according to who is listening.

#### References

Forward, D. and Garlie, N. (2003) 'Search for New Meaning: Adolescent Bereavement after the Sudden Death of a Sibling', Canadian Journal of School Psychology, 18 (1/2) pp.23-53

Jenkins, R. (2014) Social Identity, 4th edition, Oxon: Routledge

Riches, G. and Dawson, P. (2000) An Intimate Loneliness, Buckingham: Open University Press

#### Time-related metaphors and pregnancy loss

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Far from being merely a rhetorical or artistic linguistic device, metaphor has been shown be common in all types of discourse (Steen et al., 2009). It is particularly prevalent in discourse relating to difficult or painful emotions or situations (Semino, 2011), when language users employ it as a tool to help them make sense of and express their experiences. Given this, it is hardly surprising that discourses surrounding bereavement are rich in metaphor. We are currently conducting an ESRC-funded study investigating the ways in which people who have experienced bereavement through miscarriage and stillbirth communicate their experiences to those who are there to support them. Our aim is to explore how they use metaphor to make sense of the trauma they are experiencing, both in terms of their own physical, bodily experiences and the reactions they have received by those around them. The current study focuses on time-related metaphors in a small corpus of language related to pregnancy loss. The corpus includes interviews with individuals who have suffered such losses, healthcare professionals, and patient information leaflets. We compare the ways in which the bereaved use time-related metaphors to talk about their experiences with those found in healthcare discourse, and demonstrate how such an analysis can be used to provide insight into the experiences of the bereaved. We conclude by exploring the implications of our findings for those in bereavement support roles.

### **Untimely Death: Perinatal Loss and Its Perishable Materiality**

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The timing of the loss plays a significant role in the very recognition of humanity and socially legitimate grief for parents experiencing prenatal or perinatal loss. The presentation is based on an ongoing qualitative inquiry (in-depth interviews with representatives of key involved institutions) in the Czech Republic into the practices related to the event (including last rites) with its implications for delimitation of the life itself. The significant clash in authoritative (expert and lay/lived) definitions of the timing of "humanity" (the moment of becoming a human baby – a subject) poses ethical and moral questions on current practices in prenatal and perinatal loss that are relevant for critical social science reflection. Powerful key social institutions form the ground. The Church, biomedicine linked to the legal setting, lived experience of the families affected – they all rely to a varied extent on time in their definitions of "conception" of life, possibility to "die" and in consequent care. The untimely loss is viewed and interpreted very differently depending on whether they situate humanity to the moment of conception of the egg and the sperm in case of the Church, follow the legal definition informed by biomedical practice measuring and calculating gestation weeks and weigh etc. demarcating a miscarriage of a foetus (or a cluster of cells regarded as human waste) or a birth of a (stillborn) child, the legal possibility to die only when there was the first breath etc. Yet, there is also a set of parental perceptions of their baby-to-be human existence, thus setting their own understandings of time in relation to human life and death.