

Death and Relationships

5 December 2019, University of Sheffield

Abstracts

Plenary

A Love that Never Dies

Jane Harris and Jimmy Edmonds
The Good Grief Project

This plenary session is based on Jane and Jimmy's latest documentary [A Love That Never Dies](#) and it will focus on relationships, Continuing Bonds and the work of [The Good Grief Project](#).

Placing death and dying: On the work of relationships in making place at the end of life

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End-of-life care is frequently concerned about the location of care, epitomised in phrases like 'preferred place of care' and 'preferred place of death'. This paper challenges the idea of 'home' or 'hospital' merely as a location. Playing on Douglas' thinking on 'matter out of place', the paper rethinks what makes a place, and what is deemed 'appropriate' for end of life care and dying.

The paper draws on 18 months of ethnographic observations of multidisciplinary team meetings of inpatient and outpatient palliative care teams, as well as 12 months of shadowing staff members in their daily work. Interviews with staff members, including doctors, nurses, social workers, occupational therapists, physiotherapists, patients and their families were also conducted.

Drawing on concepts and sensitivities derived from Actor Network Theory, we argue that a 'place' is always determined by a dynamic nexus of relations, interactions, activities of people, techniques and things. As a patient's sociomaterial network responds to changes in their body, sense of self and how they relate to others, place continually changes, even though they may remain in the same physical location. We highlight the work both professionals and patients takes to keep a place stable. Such efforts of 'placing', we propose, do not presuppose a pre-existing place, but highlight the making of place as a set of practices that (albeit only temporarily) enact a place. The research indicates the importance of acknowledging placing as a form of care done by palliative care teams.

Ending before it truly begins – the continuing relationship between bereaved parents and their baby as facilitated by a children’s hospice

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Since 1982, children’s hospices in the UK have provided services where families can care for their children at the end of life (EoL) in a less medicalised environment. More recently the services of many children’s hospices have extended to babies who have been transferred from neonatal units (NNUs). For some parents, this environment might be particularly supportive of their developing relationship with their newborn baby, enabling them to promote quality of life and making memories regardless of the shortness of the time. A Neonatal Care Pathway (TfSL, 2107) outlines ways of ensuring families are aware of their choices in a timely manner. Despite recent efforts to make the choice of a children’s hospice as a place for EoL care more widely available for families, evidence suggests most neonatal deaths still take place in hospital. Drawing on a larger qualitative study, this paper explores the experiences of three families (five parents) who availed of children’s hospices’ services either for EoL care or after the death of their baby. Narratives from parents reveal key aspects of hospice care that allowed them to feel connected with their babies, a connection which remains after death. Hospice appears to provide a physical space where parents and family members feel close to the dead baby and thus it enables them to protect their baby’s memory even though their life ended before it had truly begun.

‘We’re treating that person as that person, not as that illness’: The Relationality of Suffering in Palliative Care work

Natalie Richardson

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Existing literature observes suffering as a relational and social experience, one that involves a renegotiation of identity and a loss of ‘self’ or ‘personhood’. In suffering, our social relationships, social lives and roles are ruptured or altered in some way. This research seeks to explore suffering from the perspectives and experiences of palliative care workers, by adopting an ethnographic approach in a hospice setting. In this paper, I draw on the ethnographic data to suggest that many of the palliative care workers sought to provide personalised care to their patients, appreciating the patient as a person embedded in broader ties and relationships. Workers in the hospice came to know the patients’ traits, idiosyncrasies as well as their likes and dislikes, meaning that they could often tailor caregiving practices to each individual. I argue that getting to know patients as individual persons and carrying out small, personalised gestures helped to maintain some personhood and sense of self at the end of life. Moreover, relationships in the hospice were, at times, reciprocal, often going beyond clear divides of care giving and receiving. This paper hopes to explore these complex, personal and intimate relationships, in order to appreciate the work of palliative care workers in caring for the patient as a person at the end of life.

Relationship between HORFP and the deceased body

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During suspicious death investigations, the body transitions from being somebody to an object which is of legal, evidential and social value. One stage of the death investigation process is the autopsy, which is carried out by a Home Office Registered Forensic Pathologist (HORFP). This paper draws upon a series of interviews with HORFPs to explore their relationship with the deceased body. I locate the work of HORFPs within the broader framework of medical attitudes to the body, highlighting the influence of the dualistic separation of body and mind in the development of modern anatomy. However, I argue that this cannot capture the complexities of the HORFP's interactions with the deceased body. I explain this by situating the HORFPs' work and attitudes within a framework of embodiment. This describes the situation whereby the webs of science, law and social pressure under which the HORFPs role exists combine with the corporality of deceased human remains to produce a sense of duty to, and relationship with, both the deceased person and the bereaved. However, this model cannot explain the lack of moral value assigned to small amounts of tissue, highlighting the fragility of what a person or a body is and the potential for professional discourses to construct these.

Nurses' early and ongoing encounters with the dying and the dead: A scoping review of the international literature

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End of life care is high on policy and political agendas and in interdisciplinary academic and practice debates. Healthcare policy over the last 10 years has consistently highlighted deficiencies in the quality of end of life healthcare and much effort has been employed to improve the experience of care for patients and their families. Nurses are at the forefront of this care, caring for dying patients, 'managing' the dead body, and dealing with the corporeal, emotional and relational dimensions of death. Caring for the dying and the dead is arguably one of the most privileged, and yet challenging, aspects of being a nurse. And yet, despite being 'taught' the theory and practice of end of life care, we know little about nurses' prior experiences of death, dying and the corpse and how these shape their subsequent professional engagement and practice.

This paper presents the findings of an international scoping literature review to explore nurses' first encounters with, and reactions to, dying, death and mortality, and how these formative experiences shaped their understandings and influenced their practice. It focuses in particular on relational aspects including nurses' relationships with patients and their families; the body and the corpse; other professions, notably medicine; each other; and space. The evidence indicates there is still much more we could be doing to better understand the impact of death and dying on nurses and how this, and their own histories, shape attitudes and care.

‘Sticky’ Relationships with the Dead: An Adaptation of Continuing Bonds

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Since the publication of Klass, Silverman and Nickman’s seminal text in 1996, the concept of Continuing Bonds has been widely discussed by Death Study scholars. Within this literature, however, there is a tendency to ignore the potentially negative aspects of relationships and demonstrate an assumption that kinship ties are inherently positive in nature. This is despite Mason’s (2004) warning that relationality does not guarantee an equal, kind or fair experience. Continuing Bonds is also premised on the assumption that relationships with the dead are elected by those bereaved. In contrast, this paper draws upon Smart’s (2007, p.45) suggestion that relationships are ‘sticky’, noting that ‘it is hard to shake free from them at an emotional level... their existence can continue to influence our practices and not just our thoughts’. As such, this presentation will argue that it is useful to expand the notion of Continuing Bonds to consider the ‘stickiness’ of ties to the dead, as this idea recognises that they can continue to influence from beyond the grave, in both positive and negative ways, whether their presence is requested or not. This paper will draw upon 36 in-depth object elicitation interviews, conducted as part of a PhD project, with bereaved siblings who were aged between 19 and 66 years to make its points.

A relative absence: exploring professional experiences of funerals without a congregation

Nicola Turner

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When someone dies, it is usual for family, friends and associates to gather at a funeral to enact what Bailey and Walter (2016) term ‘relationships against death’. Through their presence, the congregation embody a collective act of eulogy for the deceased and make a communal stand against the finality of death. Yet some funerals take place without a congregation. For example, when someone who lived alone dies alone at home, it is not always possible to identify anyone who maintained social connections with the deceased person. In such cases, professionals who deal with the aftermath of a death are required to perform the appropriate social rites in the absence of the confirmatory power of a society.

Drawing on interviews with death care professionals and ethnographic observations of funerals without mourners, this presentation examines the performance of social rites against death when there is no-one to participate in them. I will explore how professionals understand their roles in dealing with a lone death, and how meanings are made tangible during the funeral service. Particular consideration will be given to the emotional labour undertaken in attempting to make good a death which is generally perceived to be bad. The broader significance of the funeral as a social rite against death in the context of a lone death, where the deceased person is assumed to have forgone social relationships prior to death, will also be explored.

Still caring, still faithful: relating life and death in pet cemeteries and crematoria

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Rituals and tributes of remembrance are paid throughout life to maintain connection with the dead, to show love and respect and to remind of close relationships. Perhaps to appease the anguish of grief, a form of communication is deployed which, in this instance, relates to the human bereft of a significant other, their deceased nonhuman animal friend. Carefully-planted carrots thrive around the grave of a loved pet rabbit, and a solar-powered candle streams light throughout real and metaphorical night, illuminating a cat's photograph embedded in her grave-marker. Meaningful words, phrases, poems and pictures honour those who are resting, have passed, departed, or moved on: words of action retaining connection rather than highlighting the passive immobility of dead, buried, and gone. Answers are sought as to why there might be need to keep caring for the animal deceased, and how such relationships of care might contribute to improving homeostasis in the bereaved and grief-stricken human. Hallam and Hockey speak of monuments standing as mediators in relationships with the dead so exploration of pet cemeteries and crematoria will demonstrate how such places of sorrow can enliven memories of past pet friends, bringing comfort to those left behind and enabling what Johnston and Probyn Rapsey term 'fidelity to the dead'. Ambros in Japan and Pręgowski in Poland have examined diverse human-animal life-death connections in those countries, so this presentation will attempt to add to thanatological research by investigating ongoing trans-species relationships in further spheres of privacy in public places.