

Death, Inequality and Social Difference

Friday 14 November 2014; 10.15am-5.00pm

BSA London Meeting Room, Imperial Wharf

Social Aspects of Death, Dying and Bereavement Study Group

List of Abstracts

What makes bereavement through a military death different

Elizabeth Rolls

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Drawing on a scoping study funded by a military support charity that explored the work of organisations who provide support to those bereaved through military death, and with a particular reflection on a current study with bereaved military parents, this paper will consider some of the specific features that make bereavement through military death different. Bereavement following a military death takes on a different shape for reasons associated with what Keegan (2011) describes as the 'cultural script of military life'. Like their civilian counterparts, military families grieve the loss of their relative in the context of a unique set of relationships and social world, but this can be seriously compounded and compromised by the inter-related features of the military life in which they have been located, including the impact of deployment prior to the death; the nature and timing of the death; those who have died and those who have been left behind; media coverage; the military culture and personal identity; and additional losses and changes. For bereaved military parents, there are additional burdens. Whilst parental loss is understood by many to be the most harsh and relentless loss of all (Brabant et al., 1997:255), parental grieving for the loss of a child as a result of conflict remains a 'central axis' in the lives of parents (Malkinson and Bar-Tur 2000). This experience is compounded by the complexities of the social, cultural, and political context that surrounds them.

Brabant, S., Forsyth, C.J., and McFarlain, G. (1997) The impact of the death of a child on the meaning and purpose in life. *Journal of Personal and Interpersonal Loss* 2:255-266.

Keegan, O. (2011) Bereavement- A world of difference. In D. Oliviere, B. Monroe, and S. Payne (Eds.) *Death, dying and social differences*. (2nd Edition). Oxford: Oxford University Press: 207-214.

Malkinson, R. and Bar-Tur, L. (1999) The ageing of grief in Israel: A perspective of bereaved parents. *Death Studies* 23:413-431.

Dying in prison in the neoliberal, carceral era

Marian Peacock

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In the last decade there has been a doubling of the prison population in England and Wales to around 86,000 in 2013, and prisoners aged over sixty are the most rapidly growing group, increasing by 122% since 2003 (Prisons and Probation Ombudsman 2013). For the small number of prisoners over seventy (some 881 in total in 2013) the increase is even sharper meaning that there are now over 10,000 prisoners over the age of fifty with growth predicted to continue. This expansion is primarily a product of a range of legislative changes and shifts in attitude to certain kinds of crime, rather than an increase in offending; what Wacquant et al (2011, p.10) have called "the penal surge". The changes have resulted in a rapid expansion in the numbers of older prisoners serving sentences from which they are unlikely to be released in the event of life-limiting illness. Thus a growing number can be expected to die in prison. Prisoners are disproportionately drawn from the most disadvantaged sections of society and have high rates of physical and mental health problems. Amongst older prisoners 40% are sex offenders, who are the most vilified of prisoners. This paper draws on the early findings from a study of anticipated death in prison and explores the connections between increasing inequality, neoliberal discourses and practices and the consequences for prison dying. Anticipated deaths are those from natural causes which are foreseeable and likely to require end of life care and it is these that have increased markedly.

Whose Death Matters? Bereaved Black Mothers and Social Inequality

Erica Lawson

University of Western Ontario

Maternal grief, translated into maternal politics, has often led to social change. Yet its full political possibilities are complicated by questions of social inequality. In particular, because black mothers and their families mourn black sons who are criminalized and viewed as disposable, their children's deaths and the grief that follow are disavowed. In her recent letter to the Brown family - whose eighteen year old black son, Michael Brown, was killed by a white police officer on 9 August 2014, in Ferguson, Missouri – Sybrina Fulton wrote – “if they refuse to hear us, we will make them feel us.” In truth, the settler nation-state is neither willing to fully hear or feel the pain of bereaved Black mothers because of

their precarious status as citizens within it. And this places limits on what maternal politics can fully achieve. Indeed, the extent to which maternal pain can be publicly expressed and socially validated is bound up in idealized notions of motherhood which black women are thought not to embody. Instead, Black mothers' expression of grief over the death of their children is interpreted through the apparatuses of the racial state. What requires examination then is how maternal grief and its political possibilities are mediated by the disposability of black lives, and how it is 'heard,' and 'felt' when black mothers express it.

Contested decision-making: negotiating death and ethnicity in UK organ donation

Jessie Cooper

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The introduction of end-of-life care criteria in the UK aim at standardising processes of care at the end of life, including how decisions on death are communicated to the families of dying and (brain) dead patients. In the setting of the Intensive Care Unit, these activities are often complicated by the biopolitical imperative to secure donor organs: where changes to donation services have seen the accommodation of organ donation procedures into end-of-life care routines. This has ramifications for understanding how medical decisions on death and dying are brokered with the families of 'patients' who have been categorised as potential organ donors. Drawing on an ethnographic study in England, this paper will document how communications around death get turned into a particular issue for the practice of requesting organ donation from minority ethnic families: a group who have become routinely constructed in problematic terms by transplant policy, research, and health promotion initiatives. We demonstrate how attempts to resolve conflicts between health professionals and minority ethnic families about a diagnosis of brain stem death, or the decision to withdraw care on potential donors are organised around practices of technological, authoritative, and religious brokering. We argue that these serve to facilitate a family's acceptance of their relative's death whilst also smoothing the pathway for a request for organ donation. The paper will conclude by offering further sets of questions which are afforded by the 'routinisation' of organ donation processes within end-of-life care procedures.

“Had he had cancer I’d have been fine”: inequalities in care provision at the end of life

Emily Moran, Sue Boase, Brooke Swash, and Stephen Barclay
University of Cambridge

Provision of high quality end-of-life and palliative care is becoming increasingly important within our aging population. Whilst only a third of patients die from malignant diseases, the term “palliative care” largely evokes the image of end-stage cancer patients, rather than incorporating patients with non-malignant diseases. The most recent VOICES survey has indicated that quality of care is higher for cancer patients than patients from different disease groups, suggesting continued inequities in care provision. Through extracts from focus groups and interviews of bereaved carers, GPs, and community nurses from the CAPE (Community Care Pathways at the End of Life) Study this paper explores people’s views on EOLC provision within different disease groups based on the care of recently deceased patients. All participants were in agreement that provision of EOL and palliative care differed between disease groups. Carers of non-cancer patients felt that receiving good care was often left up to “chance”, rather than planning. Clinicians admitted a reluctance to plan care with non-cancer patients, out of fear of taking away hope. There was disagreement as to whether specialist palliative services are appropriate and should be available for non-cancer patients. In this paper, the different experiences of care for different disease groups are highlighted, as well as the expectations of carers, patients, and professionals. Consequently, a greater acceptance of non-malignant diseases as palliative needs to happen on a societal level before provision of services can be truly equitable.

Negotiating personal networks: lesbian, gay, bisexual and trans older people’s networks of support towards the end of life

Kathryn Almack, Anne Patterson and Meiko Makita
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This paper examines how sexual orientation and gender identity can impact on experiences of end of life care and bereavement for older LGBT people. A legacy of institutional and historical barriers means that older LGBT people have been adept at organizing their personal networks in ways that minimize any vulnerability to discrimination. This may change in old age and in planning for and needing end of life care, which can introduce a whole new range of people and settings into one’s life, presenting new ‘layers’ of decisions about what to reveal and what to

hide. We draw upon the qualitative strand (60 in-depth interviews) of a two year UK project exploring the end of life experiences and care needs of older LGBT people, funded by Marie Curie Cancer Care Research Programme. Interviews included asking participants what support (practical and emotional) they could or would access. We consider the ways in which access to economic, social and cultural resources shapes later life experiences of LGBT people, which may impact on the sources and extent of support in old age. Our findings also contribute to debates about coming out and negotiating stigma for the oldest LGBT generations, where much previous debate focuses on younger generations. Participants' networks presented a complex diversity and richness including families of origin and of choice. It is clear however that older LGBT people's histories and pathways have ongoing profound influences on the means of social support available to them at the end of life.

Exploring responses to death in varying cultural contexts: adopting a reflexive approach

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Little empirical work has been conducted on social aspects of death and bereavement in the global South and death and bereavement studies have been rooted largely in medicalised and individualised frameworks developed in the global North to date. Based on our experiences of conducting a cross-cultural research project in urban Senegal funded by The Leverhulme Trust (2014-15), this paper explores some of the methodological complexities of researching responses to death in varying cultural contexts. We outline some of the problems of language and translation involved in a project in which we are working with three languages to undertake interviews with families of different ethnicities and socio-economic status in two cities. We explore the multiple positionings of the research team comprised of UK, Senegalese and Burkinabé researchers and interrogate our own cultural assumptions and understandings of responses to death, based on reflexive conversations and interviews about our own experiences of the death of a relative. In so doing, we highlight the benefits of adopting a reflexive approach and provide initial insights into the complex interactions between cultural and religious values and norms and responses to death in diverse socio-cultural contexts.

Battling the Invisible Death in the Nineties: New York's art photographers

Lauren Summersgill
University of London

The early nineties in New York saw an unparalleled shift in the social views of death. The eighties was rocked from the dream where death was a failure of medicine - a time when Phillippe Airès dubbed death 'invisible' – by the realities of AIDS and cancer. As the eighties turned to the nineties, euthanasia debates, abortion debates, and the death penalty brought death into the forefront of politics. Death was no longer invisible, and yet certain groups found that their death was being marginalized.

Andres Serrano and Nan Goldin were artists working in New York during this tumultuous time, and brought to the forefront two such groups – AIDS victims and police-related deaths. Using as case studies Serrano's Jane Doe: Killed by Police and Goldin's Cookie in Her Casket, I will argue that these artists attempt to reintroduce care to the dead, which were socially ostracized. This attempt to care for those dead that were otherwise discounted, however, raises serious ethical concerns. For Goldin the conflict of selling photographs of her dead friend is rarely breached by the critical reception of her work. In Serrano's case, Jane Doe's criminal identity raises concerns for those bodies that do not have a family to advocate on their behalf. Both artists use beauty to care for the dead, but does it cloud the reality of exploiting the marginalized dead? Do the benefits out-weight the consequences? Or is this the only way that art can critically engage with the issues surrounding these kinds of deaths?

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