

PROGRAMME

Monday 19th November 2012, 10.00am – 4.30pm

BSA London Meeting Room, Imperial Wharf

Venue details can be found at: <http://www.britsoc.co.uk/events/meetingroom.htm>

Theme: Death and the Family

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| 10.00 | Registration and Tea/Coffee |
| 10.20-10.30 | Welcome and Introductions |
| 10.30-11.00 | Varying meanings of the 'family' in the context of death and organ donation on Intensive care units
<i>Charlotte Kenten (King's College London), Magi Sque (University of Wolverhampton) and Myfanwy Morgan (King's College London)</i> |
| 11.00-11.30 | Through the Family Lens: how death illuminates the modern family
<i>Hannah Rumble and Kate Woodthorpe (University of Bath)</i> |
| 11.30-12.00 | Reconceptualising 'the' family and care-centric models: what can a sociology of personal life bring to death studies?
<i>Julie Ellis (University of Sheffield)</i> |
| 12.00-12.20 | Artist Presentation and Q&A with Sukey Parnell |
| 12.20-1.10 | Lunch (provided) |
| 1.10-1.40 | Death in the Family as a vital juncture? Intergenerational care and responsibility following bereavement in Senegal.
<i>Ruth Evans (University of Reading)</i> |
| 1.40-2.10 | 'We ARE family': disenfranchised grief, griefwork and perinatal loss
<i>Gayle Letherby (Plymouth University) and Deborah Davidson (York Univeristy)</i> |
| 2.10-2.40 | The loss of a parent in young adulthood: Understanding death's impact through the study of young peoples' mementos and relationships to family homes in the Netherlands
<i>Renske Visser (University of Amsterdam)</i> |
| 2.40-3.10 | Tea and coffee |
| 3.10-3.40 | The role of family carers in end of life care
<i>Laurie Dunn (University of Liverpool)</i> |
| 3.40-4.10 | Becoming the Older Generation: Love, Loss and the Midlife Transition
<i>Bethany Morgan Brett (University of Essex)</i> |
| 4.10-4.30 | Discussion and close (followed by informal get together) |



Convened by Erica Borgstrom and Kate Woodthorpe

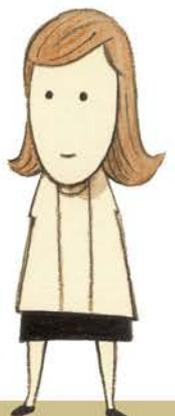
Symposium fees: Early Bird Registration for the symposium closes on **Monday 29th October 2012**. Fees are £25 for Postgraduates, £35 BSA members, £40 for non-members. Registrations after 29th October incur a £5 late booking fee.

Places are limited, so sign up early!

Please visit the event website http://www.britsoc.co.uk/specialisms/DDB.htm#_activity to register and for further symposium details.

For more details about the study groups please visit <http://www.britsoc.co.uk/specialisms/DDB.htm>

Please direct any administrative enquiries to the BSA office at events@britsoc.org.uk and any academic enquires to k.v.woodthorpe@bath.ac.uk.





Varying meanings of the 'family' in the context of death and organ donation on Intensive care units

Charlotte Kenten (King's College London), Magi Sque (University of Wolverhampton) and Myfanwy Morgan (King's College London)

The family in its multiple and shifting guises is a constant in the life course but often increases in prominence at specific points, including at the end of life. We will focus on one specific end of life experience for families, the death of a relative on an Intensive Care Unit (ICU) who is clinically suitable to be an organ donor. In the UK donation only proceeds if the family provide formal consent.

This paper examines the notion of 'family' around this time of acute bereavement and specifically in relation to breaking bad news, approaching for consent and decisions about organ donation with Black and South Asian minority ethnic groups. Qualitative research was undertaken involving semi-structured interviews with 13 donor families, over 100 interviews with ICU staff and observations across five English hospital Trusts undertaken as part of the DonaTE Research Programme. These data indicate how the 'family' is fluid and negotiated; beyond the immediate and usually biological family, it expands to include extended family, friends and acquaintances or contracts to core members depending on the phase of end of life care, the decisions that need to be made and closeness to death/donation. In contrast ICU staff, often perceived family in more rigid terms, tempered by legal definitions and practical considerations with, at times, limited or limiting cultural understandings of the role of 'family' at the end of life, and employed various strategies to manage the often large number of 'family' members and communicate with key decision makers.

Through the Family Lens: how death illuminates the modern family

Hannah Rumble and Kate Woodthorpe (University of Bath)

This paper argues that within sociological research into the modern 'family', the influence, impact and consequences of death have been overlooked. Drawing on a qualitative study that examined the experiences of those individuals from low income backgrounds who either cannot, or do not want to, pay for the funeral of a deceased family member, the paper suggests that examining who takes responsibility for a funeral and why, exposes the fragmented and fluid nature of 'family' today. In policy terms, this fluidity can exacerbate problems in accessing state support for funeral expenses and obscure identification of familial 'responsibility', both of which can add to people's emotional distress and day-to-day experience of financial hardship. The paper concludes that the reified heteronormative concept of 'family' implicitly associated with care, support and solidarity is a limited concept, marginalising and causing additional emotional strain to those who, for whatever reason, do not experience 'family' in this way when it comes to funerals.



Reconceptualising 'the' family and care-centric models: what can a sociology of personal life bring to death studies?

Julie Ellis (University of Sheffield)

In this presentation I will argue that there is surprisingly little work that stands out as 'seminal' in the sociological death literature which focuses primarily and explicitly on family or relational experiences of dying. I will draw attention to how often studies within the area of families and dying – especially those in allied health practice and professional fields – take a family systems approach to interpret family experiences of dying, or they have a care/ carer –centric focus. Unpacking this with examples from the literature and with reference to my PhD research, I will argue that as a consequence of viewing 'family' through these particular 'lenses', studies that focus explicitly on the experience of dying as it happens in the context of everyday family life remain uncommon. My aim within the presentation will be to demonstrate how theoretical concepts that have developed within family studies and the field of personal life more broadly, can offer important conceptual windows through which we can begin to think about the role of mundanity and the significance of the everyday within death studies.

Death in the Family as a vital juncture? Intergenerational care and responsibility following bereavement in Senegal.

Ruth Evans (University of Reading)

The death of a spouse or parent may have major emotional and material effects on family members and often leads to changing responsibilities for income earning, social reproductive work and decision-making within the household. Drawing on semi-structured interviews with 34 Serer family members of different generations who had lost a close relative, 7 religious and community leaders and 11 development practitioners and policymakers in rural and urban areas of Senegal, this paper analyses intergenerational caring relations and responsibility following the death of a close relative. I examine the ways that bereavement and the inheritance of material assets may represent a 'vital juncture' that leads to a transfer of wealth and responsibility between generations and/or genders in some families, while for others, a death in the family may lead to few, if any, changes in responsibility, intergenerational caring relations or access to resources. This has implications for how widowhood, orphanhood and social protection policies are conceptualised in a West African context.



'We ARE family': disenfranchised grief, griefwork and perinatal loss

Gayle Letherby (Plymouth University) and Deborah Davidson (York University)

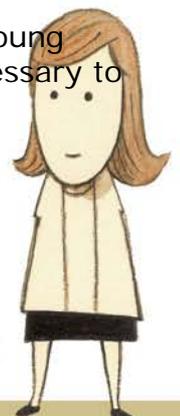
Online social support networks for bereavement have now become, more than ever, available on the WWW. The capacity of these fora to serve as devices for relationship building is well established in the research literature. Our particular domain of investigation is online social support networks for individuals bereaved by perinatal loss — miscarriage, stillbirth, and neonatal loss.

The goals of our research are to determine: the extent these networks offer support, and how the benefits of these communities might be accessed or deployed more broadly. We seek to characterize the social rules followed, social practices adopted, and social roles occupied within these online communities, as online participants collectively undertake the 'griefwork', or the labour shared and negotiated by grieving women and others. Studies indicate that bereaved adults suffer from an overall lack of support and would benefit from more caring overtures from those around them. Research demonstrates that the loss of a pregnancy/death of an infant causes profound grief, yet society often minimizes or ignores this grief. A common response is 'Never Mind, Better Luck Next Time' or even 'IT'S FOR THE BEST' if mother or baby are seen as less than 'perfect', OR as a solution to a problem if the 'time is wrong'. When 'trying for a family' or 'adding to one's family' is thwarted the status of parenthood and family can be challenged. Drawing on our data we explore the ways griefwork can be facilitated via the internet and the benefits, or not, of this type of support.

The loss of a parent in young adulthood: Understanding death's impact through the study of young peoples' mementos and relationships to family homes in the Netherlands

Renske Visser (University of Amsterdam)

The aim of this study was to gain insight on the impact of the death of a parent in young adulthood in the Netherlands. Eight young adults (aged 20-30yrs), who had each lost a parent, respectively a father or a mother, in their late teens or early twenties were interviewed about the ways in which they remembered their parent, the things they kept as memento and their relationship with their remaining parent and their parental home. This research has focused on the impact of a death both on a personal level and on an interpersonal level within a household. The loss of a parent affects an entire family and this was visible in this research. The loss called for a 'rebalancing' of relationships within a household. The roles within the family needed to be identified again as both parents and children needed to adapt to the situation. Sometimes parents had different ideas on the 'right' way of remembering the deceased parent than the young people. This tension was especially reflected in the parental home where parents often redecorated spaces whereas the young adults wished this space to be a stable core in which nothing changed. In some of the cases the remaining parent entered a new relationship. Here the young adults had to cope with another dynamic as 'space' in the parental home was necessary to make this new relationship feel at home. The tensions in the balance between remembering and moving on were most present in these cases.



The role of family carers in end of life care

Laurie Dunn (University of Liverpool)

The role of the family carer is often an unanticipated role, brought about by the onset of illness of a family member. Defining one's role can be particularly difficult for carers, who predominantly define themselves as a 'husband' or 'daughter' before a 'carer'. Indeed, family members may not define themselves as a 'carer' until much later in the illness trajectory, when the person they are caring for requires increasing levels of support in their day to day activities or their illness becomes more serious.

This paper draws on the experiences of family caregivers, gained from fifty narrative interviews with bereaved family carers. It explores the role of family caregivers in end of life care in home, hospital and hospice settings.

The paper will discuss the interaction between formal and informal systems of care, focusing on responsibility, power dynamics and the notion of 'experts' in different care settings (Thorne et al 2000, Nolan 2001) at end of life. The paper will argue that when formal and informal systems of care interact, it is possible to deliver the best possible quality of life for the patient and indeed for the carer. The paper will discuss areas where improvements may be made in order to improve the experiences of both patients and family carers at the end of life.

Becoming the Older Generation: Love, Loss and the Midlife Transition

Bethany Morgan Brett (University of Essex)

Midlife is a transitional phase in the life course that sees a shift in generational positioning that is the loss and increasing agedness of the generation above and changes in the lives of the generation below. This paper is based on a series of psycho-social interviews with 22 men and women aged between 39 and 58 years old. In this paper I look at how relationships between (midlife) children and their parents are negotiated during this transitional phase of the life course. I explore how relationships are (re)negotiated with parents in the midlife period on a practical, emotional and psychological level and as a result of changing demands, expectations and care responsibilities. I also focus on the psychological effect the movement of the generations and the death of parents has on those in midlife, how people feel about becoming the next older generation and how this impacts upon their own sense of aging and own mortality awareness. The paper will explore the complex human subjectivities around love and loss and their relation to contemporary social issues surrounding the life course, ageing, elder-care and intergenerational relationships.

