

Social Aspects of Death, Dying and Bereavement (DDB) Study Group

'The Impact of Death: policy implications in the 21st century' PROGRAMME

Monday 21st November 2011, 10.45am – 5pm BSA London Meeting Room, Imperial Wharf

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

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10.15 – 10.45	Tea and coffee
10.45 – 11.00	Welcome and introductions
11.00 – 11.30	The Impact of Policy on Death Erica Borgstrom, University of Cambridge
11.30 – 12.00	The Role of Advance Directives in the Lives of Patients towards the End of Life, Tikva Meron, Jane Seymour and Kathryn Almack, University of Nottingham
12.00 – 12.30	The Relationship between Palliative Care and Euthanasia: a comparison of the developments in England and The Netherlands during the Post-War Period Ellen van Reuler, University of Manchester
12.30 – 13.30	Lunch (provided)
13.30 – 14.00	Bereavement in Later Life: an emerging policy issue for the 21 st Century, Jodie Croxall, Swansea University
14.00 – 14.30	Bereavement and Workplace Well-being, Anne Corden, University of York
14.30 – 15.00	"Beyond Bereavement": the impact of unresolved grief on Gypsies and Travellers – implications for policy & practice Carol Rogers and Margaret Greenfields, Buckinghamshire New University
15.00 – 15.30	Tea and coffee
15.30 – 16.00	Paying the Price of Death: the challenges for British state funeral policy, Liam Foster, University of Sheffield, and Kate Woodthorpe, University of Bath
16.00 – 16.30	Finding the Future of the Cemetery in the Past: revisiting Victorian regulations on grave re-use, Julie Rugg, University of York
16.30 – 17.00	Discussion and close (followed by informal get together)

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Symposium fees: Early Bird Registration for the symposium closes on **Monday 31st October 2011**.

Fees are £25 for Postgraduates, £35 BSA members, £40 for non-members.

Registrations after 1st November incur a £5 late booking fee.

Places are limited, so sign up early!

To register <u>Click Here</u> and / or visit the event site for further symposium details: http://www.britsoc.co.uk/specialisms/DDB.htm#_activity

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.

We look forward to seeing you in November,

The Convenors

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ABSTRACTS

The Impact of Policy on Death

Erica Borgstrom, University of Cambridge

Since 2008, England has had a dedicated end of life care strategy supported by the Department of Health. This draws the political focus specifically on people's last year of life, their death and bereavement care. It was born out of a history of specialist palliative medicine and hospice care within the country and aims to build on and improve such services. The quality of care and context of end of life has contributed to the UK's international recognition as one of the best countries to receive end of life care in – that means one of the best places to die. Yet, this does not mean it is without complications, controversies or debate and the end of life care policy agenda can be seen to be straddling both mainstream and marginal politics. But what does this mean for those who are deemed to be near 'end of life'? This paper will describe what it is like to die in England today, drawing on ethnographic data of two local cases and the public discourse around end of life care and death. Recounting the last weeks of two people will demonstrate the ways in which policy is shaping the way people die. Moreover where the political objectives are not fully realised and how this fits with wider public debates will be outlined. Rather than asking how death is impacting policy, it will be a reflection on how policy is impacting death.

The Role of Advance Directives in the Lives of Patients towards the End of Life Tikva Meron, Jane Seymour and Kathryn Almack, University of Nottingham

Background

Socio demographic and epidemiological change means that the process of modern dying is often prolonged. Antecedent control over the dying process may be sought by recording choices about specific medical treatments through making an advance directive (AD). Israel is a medically developed country, but differs from most western countries in having dual religious and state laws. Controversies between the two affect implementation and understanding of ADs.

Aim

To examine experiences, beliefs and practices associated with the use of advance directives in Israel, in relation to patients with palliative care needs and their carers.

Methods

This paper presents one aspect of the larger study: case studies employing qualitative interviews with patients with a long term condition who have made an AD, and those relatives and/or health care professionals they wish to nominate. Eight case studies have been completed.





Findings

Patients viewed ADs as an incomplete response to their desire to control suffering at the end of life. There were discrepancies between patients and relatives' perceptions. Difficulties in communicating about wishes at end of life between physicians and patients were evident.

Conclusion

This study gives voice to a selective group of people not necessarily representative of Israeli society as a whole. However, the determination of this group is eminent. Interpretation of interview data raises questions about moral values, palliative care, and the role of family, health carers and society in Israel, in respecting patients' needs towards the end of life

The Relationship between Palliative Care and Euthanasia: a comparison of the developments in England and the Netherlands during the post war period *Ellen van Rueler, University of Manchester*

The relationship between the emergence of specialist care for people nearing the end of their lives and the availability of euthanasia is a contested one. The Netherlands attracted international attention by accepting euthanasia since the 1970s. During the same period, the number of hospices rose quickly in England. Although analyses of the development of palliative care services as well as euthanasia movements are available, the mutual influences of these developments have not yet been studied historically.

Several international commentators have argued that the availability of euthanasia in the Netherlands has resulted in the lack of an impetus to establish palliative care services. Based on a comparative study of the developments in England and the Netherlands, I argue that the relationship between the stance taken towards euthanasia and the development of palliative care is more complex than these commentators suggest and changed over time. The comparison of the two cases shows, for example, that other influences, such as the structure of the health care system and the emergence of other types of providers of end of life care, contributed to the dissimilar development of palliative care in the two countries. Additionally, during the second half of the 1990s we can identify an opposite relationship between developments related to palliative care and euthanasia than the one often asserted, because the Dutch government started to stimulate the provision of palliative care, because the legal codification of euthanasia was expected in the nearby future.





Bereavement in Later Life: an emerging policy issue for the 21st Century' Jodie Croxall, Centre for Innovative Ageing, Swansea University

Bereavement is a universal experience, however increased longevity and population ageing mean not only that it is more likely to become a commonplace experience during later life, but that it will engender new social needs particularly amongst older people. This paper draws on a PhD study which seeks to examine older people's needs for support during times of bereavement. Using a qualitative approach, the study explores older people's experiences of bereavement, and their perceptions of the adequacy of public, private (including family and friends) and voluntary sector agents in responding to their needs. Although research has long shown the pivotal role that social support plays in promoting well-being during periods of bereavement, the study argues that older people's needs for support during these times represent a neglected area in contemporary social policy agendas and raises implications of this policy neglect in the context of an ageing population.

The aim of this paper is to present initial findings from qualitative interviews conducted with two study populations; older bereaved individuals and service providers. Preliminary thematic analyses suggest that broader social changes, most notably within the family and community, have effectively reduced the potential availability of traditional, informal sources of support in later life. The study therefore points to the need for more formalized support for older people during bereavement, particularly as a means of avoiding social isolation and loneliness.

Bereavement and Workplace Well-being

Anne Corden, University of York

Despite significant bereavement occurring at any stage in a person's life, there is little information about the way in which this is dealt with in the workplace. For the bereaved person, issues include their experience (or not) of emotional support and understanding from managers and employers, and work colleagues, which may be of great importance in coping with loss and avoidance of complicated grief. Also important however, are practical and economic issues of taking time away from work while dealing with loss and grief – how is this negotiated? How much time is needed and allowed? What is the financial impact? For some people, the impact will include loss of earnings or annual leave, and there may be incentives to ask GPs to write certificates for absence from work due to ill health, which may have unhelpful consequences in the longer term. For managers and employers, issues include levels of awareness and support for bereaved employees; management of absence from work; and 'presenteeism' of people in work but affected by grief. We do not know how far employers understand an argument that there is a 'business case' for including bereavement issues within workplace systems and support, such that there are economic gains through improved productivity and workplace satisfaction.

The paper discusses these issues, what is known already, and the gaps in knowledge and understanding. The author, and colleagues at the Social Policy Research Unit, hope to fill some of these gaps in further empirical work.



"Beyond Bereavement": the impact of unresolved grief on Gypsies and Travellers – implications for policy and practice

Carol Rogers and Margaret Greenfields, Buckinghamshire New University

There are an estimated 300,000 Gypsies and Travellers in Britain and despite Romany Gypsies and Irish Travellers being recognised as distinct ethnic groups, in recent decades these communities have faced increasing challenges to retaining their culture and traditional nomadic lifestyle with significant impacts on their health and wellbeing. In addition to facing inequality and discrimination Gypsies and Travellers experience significant health inequalities and have a life expectancy which is between ten to twelve years less than for surrounding populations.

Bereavement is a significant health concern for Gypsies and Travellers with considerably higher levels of suicide, maternal and infant mortality, miscarriage and stillbirth than in wider society. Unresolved grief from multiple bereavements can have long term health implications including depression, anxiety and an increase in risk taking behaviours including alcohol and substance misuse.

The close knit nature of Gypsy and Traveller communities means that the death of a relative is felt with great intensity articulated by some research participants as an event with which they never come to terms. The significance of bereavement and loss within these groups can therefore result in a continuum of loss and unresolved grief throughout the lifespan, exacerbated by a lack of engagement with support services which are often seen as unapproachable.

This paper which builds upon Greenfields' earlier work in this area, presents emerging findings from Carol Rogers' on-going PhD (being undertaken in partnership with the Child Bereavement Charity) to explore the bereavement support needs of Gypsies and Travellers and how organisations can tailor their policy and practice to meet the needs of these 'hard to reach' populations.

Paying the Price of Death: the challenges for British state funeral policy Liam Foster, University of Sheffield and Kate Woodthorpe, University of Bath

The period immediately after death has too often been overlooked as a social policy issue for academics in the UK, particularly in relation to funerals. However, the challenges presented by projected increases in mortality rates mean that greater attention to funeral policy is required.

This paper examines issues around planning for funerals and the present provision of state support for funerals, via the Social Fund and Public Health Funerals, exploring ways in which these schemes need to be amended to best meet people's needs. In particular it highlights concerns about the value of the Social Fund, its complexity, the length of time taken to process requests, a lack of knowledge about how it works and associated stigma. It concludes that considerable changes are needed to current funeral policy.



Finding the Future of the Cemetery in the Past: revisiting Victorian regulations on grave re-use

Julie Rugg, University of York

The fact that the UK is rapidly running out of burial space is not surprising, but a solution to the problem has arisen through an alternative approach. It is possible to re-use consecrated cemetery space through simple recourse to 'Church' law. Under faculty – essentially Church of England planning permission – it is possible to remove remains from one consecrated grave to another, so leaving the existing grave open to use for further interment. This policy is currently being pursued at the City of London Cemetery, and is being considered by other boroughs.

This paper takes the opportunity to delve into early Victorian regulations on grave re-use, and demonstrates that the imperative to re-use graves was in fact intrinsic to the Burial Acts. Indeed, detailed guidance on the issue was published by the General Board of Health. A discussion of these regulations and response to their implementation at the local level demonstrates the considerable tensions which often arise in the cemetery as principles meet practice.

