

BAAL Health & Science Communication SIG #healthsci16

Workshop Programme

28 November 2016

“Experiences of illness and death: learning from the discourses of realities and fictions”

Hosted by the Faculty of Wellbeing, Education and Language Studies
The Open University, Milton Keynes

“Any serious illness is a medical event, but it is lived in narrative terms” wrote Andrew Solomon in a recent article for The Guardian. This workshop will focus on these ‘lived’ and ‘narrative’ aspects of the experience of illness and death from a variety of disciplinary perspectives.

Accounts of illness and dying by patients, carers and healthcare professionals have been at the heart of the medical humanities for several decades. They have been called upon to better understand patients and to enable patient-centered care, to improve training and empathy in healthcare professionals and to begin to assist those who informally support and care for the ill. They have been investigated from the perspectives of history, sociology, literature, the visual arts and, more recently, linguistics. At the same time, these disparate approaches and applications, have tended to leave the field somewhat fragmented. The aim of this workshop is to bring together researchers of different backgrounds who examine and use experiences of illness and death to discuss and explore the methods and applications that allow us to get the most out of these rich and powerful sources of evidence.

Venue

The event will take place at the Open University Campus in Milton Keynes ([Directions to campus](#)). Registration and most sessions will be in the Christodoulou Meeting Rooms 15 ([campus map](#)).

Arrival:

- There is a dedicated bus service from Milton Keynes Central station to the OU campus in the mornings and afternoons ([schedule](#)) (travel time: 15mins, cost: £1).
- The local buses 11/11A/12/12A also go to campus. These take 20-30mins and cost £2.30.
- Taxis are also available from outside the station. Taxis will get you to campus in 10-15mins and cost between £6-£12. The cheapest local taxi company is Skyline Taxis (Tel: 01908 222111) - they can usually pick you up from the station within 5mins.

Note: it is possible to arrive by off-peak London Midlands trains from London for the start of the event.

Accommodation

For those looking to arrive in Milton Keynes the night before the conference, we recommend the following hotels, both within walking distance of the Open University campus:

- [Hilton Hotel Kents Hill](#) (The code **AOPEB** will give you access to a reduced rate of £69.00 for single occupancy in a Hilton Guestroom)
- [Kents Hill Park](#)

Programme Overview

Registration and refreshments available from 9:30

Time	CMR15	CMR1
10:00-11:00	<p>Welcome to #healthsci16 - Zsófia Demjén</p>	
	<p>Plenary Talk - Jonathon Tomlinson, GP, Hoxton, London 100 years of teaching and learning from doctors' illness narratives: from literature to lectures, where next?</p>	
11:00-12:00	<i>Break</i>	
	<p>Veronica Nanton - The threatened self: considerations of time, place and uncertainty in advanced illness</p>	<p>Korina Giaxoglou - "Dying to live": storying the everyday experience of death on blogs</p>
12:00-13:00	<p>Rachel Heinrichsmeier - Unwell but not (because of being) old: telling illness stories in the hair-salon</p>	<p>Kerry Jones - Parental Identity in Narratives of Grief Following Perinatal Death</p>
	<p>Dimitrinka Atanasova & Nelya Koteyko - Representations of recovery: Corpus-assisted qualitative frame analysis of mental health coverage in UK newspapers</p>	<p>Dariusz Galasinski - Time of death. Future perspective in suicide notes</p>
	<p>Nicola Hoppe - "You don't feel human anymore" – Metaphors of SELF and ILLNESS in online eating disorder narratives</p>	<p>Justyna Ziółkowska - The decision to kill oneself in narratives of patients who attempted suicide</p>
13:00-14:00	<i>Lunch</i>	

14:00-15:00		Sarah Collins et al. - "Remarkable Lines": adventures in linguistics, drama, poetry and music
	Plenary Talk - Julie Ellis, Sociologist, University of Sheffield Family Accounts of Life-threatening Illness: Stoicism, Humour and the 'Everydayness' of Feelings	
15:00-16:00	<i>Coffee break</i>	
	Antoon Cox & Kamran Khan - The dynamics of miscommunication in linguistically diverse A&E consultations	Petra Makela - From 'cocoon to the real world' after traumatic brain injury: A narrative case study
16:00-17:00	Sylvia Jaworska & Karen Kinloch - On 'bad' mothers and hormonal imbalances: Comparing discursive constructions of postnatal depression in lay, media and medical accounts	Rebecca Oxley & Arthur Rose - Exploring 'wheeze' in narrative breathlessness
	Malgorzata Sokół - Vicarious narratives of illness in blogs by healthcare professionals	Elena Semino - Visual images and narratives in communication about chronic pain
	Joelle Loew (Mitchell et al.) - Providing end-of-life care in general practice: findings of a national GP survey	Christine Douglass - Collaborative visual ethnography and breast cancer
17:00-17:30	Closing	

Keynote speakers:

[Dr Julie Ellis](#), University of Sheffield

Family Accounts of Life-threatening Illness: Stoicism, Humour and the 'Everydayness' of Feelings

I have argued that family experiences of illness and dying are made meaningful, through an immersion within the everyday and its mundane practices (Ellis, 2013). Drawing on data from an ethnographic study of everyday family life during life-threatening illness, I will present excerpts from in-depth interviews with families to 'ground' this assertion in lived experience. In my analysis of this material I attempt to problematise assumptions about the inevitability of crisis and emotional vulnerability in people's experiences, and draw attention instead to how individuals themselves explain their emotional approach to facing life-threatening illness in their day-to-day lives. In particular I discuss how accounts characterised by stoical pragmatism, humour and matter-of-factness suggest a more nuanced and contextual interpretation of emotionality in end of life contexts – an 'everydayness' of feelings – might be useful. Furthermore, I will reflect on my experiences as a researcher involved in the 'generation' and representation of these accounts. In particular I will consider some reflexive points about the emotional labour of identifying and then disseminating research findings which pertain to the 'everyday' in what are pervasively understood to be 'extraordinary' circumstances such as death and dying.

Julie Ellis is a sociologist and a researcher at the University of Sheffield. She is currently working on the ESRC project: ['End of or Start of Life: Visual Technology and The Transformation of Traditional Post-Mortem'](#). She is interested in medical sociology, the social and relational aspects of death and dying and material culture and everyday lives. Julie is a member of the Association for the Study of Death and Society (ASDS) and she co-convenes the British Sociological Association Study Group, Social Aspects of Death, Dying and Bereavement (DDB).

[Dr Jonathon Tomlinson](#), GP, Hoxton, London

100 years of teaching and learning from doctors' illness narratives: from literature to lectures, where next?

The experience of being a patient comes as a shock to doctors who are frequently surprised that years, sometimes decades as a clinician has taught them so little about the fear, loneliness, humiliation shame and powerlessness that comes with patient-hood. Many of them respond to this cognitive dissonance by writing narratives with the intention that their colleagues, trainees and students might appreciate what it is like, sooner than they did, before they become sick themselves. For the last 3 years I have been teaching 5th year medical students and GP trainees about doctors' illness narratives written over the last 100 years. The similarities are striking and suggest that their 'lessons from the other side' are not being learned. I will present a slightly abbreviated version of the lecture I give to medical students and invite the audience to discuss the issues raised and consider how to make more effective use of these narratives in medical education.

Jonathon Tomlinson is a GP in Hoxton, London. He is an undergraduate tutor, GP trainer and freelance lecturer. He has recently set up a course at UCL medical school about shame in clinical encounters and is interested in how to develop therapeutic relationships within the confines of a ten-minute consultation. He is an advocate for continuity of care and general practice in deprived areas.