

BAAL
Health & Science Communication SIG
Workshop
28 November 2016

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

Book of Abstracts

#healthsci16

Table of Contents

Introduction	3
Programme	4
Plenary Talks	6
Abstracts	7

Introduction

“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.

Programme

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	<p><i>Break</i></p>	
	<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	<p><i>Lunch</i></p>	

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	

Plenary Talks

[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.

Abstracts

Representations of recovery: Corpus-assisted qualitative frame analysis of mental health coverage in UK newspapers

Dimitrinka Atanasova and Nelya Koteyko, Queen Mary, University of London

While ‘the illness side’ of mental health - encompassing media representations of specific disorders and/or events involving mentally ill individuals - has received much attention, its ‘health side’ including recovery messages has been under-studied. Past research reports the presence of recovery themes in a share of the coverage (e.g. McGinty et al, 2016), but goes little beyond frequencies and proportions. Given this gap and recent definitions of mental health as a holistic construct involving both those experiencing mental health problems and seeking to recover and those maintaining their mental wellbeing (WHO, 2016), we analysed 1,412 UK newspaper articles (2007-2015) to evaluate recovery messages. Employing a novel corpus-assisted qualitative frame analysis approach (Touri & Koteyko, 2015), we identified frames of *stigma*, *economy* and *recovery*, of which *recovery* was the most predominant. We evaluate the *recovery* frame against the ‘illness model’ of mental health (Child, 2000) and the ‘mutual recovery’ concept (Crawford et al, 2013). We also discuss the view of recovery advanced by the *economy* frame and how it links to the broader neoliberal agenda.

References

- Child, N. (2000). The limits of the medical model in Child Psychiatry. *Clinical Child Psychology and Psychiatry*, 5(1), 11-21.
- Crawford, P. et al. (2013). Creative practice as mutual recovery in mental health. *Mental Health Review*, 18(2), 55-64.
- McGinty, E. et al. (2016). Trends in news media coverage of mental illness in the United States: 1995-2014. *Health Affairs*, 35(6), 1121-1129.
- Touri, M. & Koteyko, N. (2015) Using corpus linguistic software in the extraction of news frames: Towards a dynamic process of frame analysis in journalistic texts. *International Journal of Research Methodology* 18(6): 601-616.
- WHO (2016a). Mental health: strengthening our response. *WHO*, Retrieved from: <http://www.who.int/mediacentre/factsheets/fs220/en/> (Accessed 30 August 2016).

“Remarkable Lines”: adventures in linguistics, drama, poetry and music.

Sarah Collins¹, Helen Adamson², Jemma Drake³, Rebecca Goss⁴, Emmanuel Oladipo⁵

In our teaching and learning at Manchester Medical School in Patient-Centred Consulting, we employ creative approaches in exploring narratives and the lived experience of individuals’ and families’ encounters with significant illness, death and dying. Through interwoven dialogues that juxtapose discourses of realities and fictions, we investigate the ways in which acts of imagination and lived experience work off one another, and how this interplay can help us – whether as health professionals, medical students, patients, carers or family members – identify with what it means and what it feels like to have a significant or life-threatening illness.

We will open this presentation with an 8-minute performance of lines of monologue and dialogue, drawing on real, first-hand personal experience, creative interpretations and fictions, in narratives provided by medical students, patients and carers.

We will then illustrate, through a set of reflective, critical interrogations of the lines and words we have performed, the ways in which experimenting with narrative structures (in poetry, prose, dialogue and monologue), linguistic forms (lexical choices and prosody) and different media (music, written words, spoken words, movement, mime) can:

- a) shape and extend our interpretations of, and responses to, significant illness, death and dying;
- b) provide a rich, ethnographic and literary resource for training health professionals and supporting carers;
- c) motivate and inspire patient-centred approaches in clinical practice.

¹Senior Lecturer in Communication in Medical Education and Co-Director of the MSc Medical Humanities at the University of Manchester.

²Medical education partner, University of Manchester.

³Actor, simulated patient and teacher, University of Manchester.

*⁴Rebecca’s poetry collection *Her Birth* is about the death of her 16 month old daughter Ella, from congenital heart disease.*

⁵Junior doctor and performance poet.

The dynamics of miscommunication in linguistically diverse A&E consultations

Antoon Cox, Vrije Universiteit Brussel / King's College London and Kamran Khan, University of Leicester

Background

Due to the increasing diversity of patients in Accident and Emergency Departments (A&E), emergency physicians have to take history from patients with whom they do not share a language. Sometimes, these patients bring along companions with some (often-limited) knowledge of the hospital's language to support the communication process. While these companions are often helpful, they may add additional sources of uncertainties to the communication process and hence of potential miscommunication. This study aims to contribute to insights on the process of communication, by dissecting different levels of miscommunication and describing how they are interrelated.

Methods

We audio-recorded linguistically diverse multi party consultations in an A&E and collected the corresponding contextual information via ethnographic participant observation. The consultations were transcribed, translated, and multimodally analysed from both a medical, interactional sociolinguistic and social psychological or role dynamical perspective. Both talk and bodily movements were analysed with regard to miscommunication. We performed also member checking with the clinician in question, with members of the community of practice of emergency medicine and members of the speech community of the patients and their companions.

Findings

We identified a set of recurrent interaction patterns that lead to miscommunication at different levels. Based on these, we developed a taxonomy of different levels of miscommunication that lead to problems of clinical significance. Miscommunication was often ascribed to linguistic, social psychological and (non-)verbal reasons or aspects. Our taxonomy is dynamic in that one aspect may trigger or resolve the other one. We also noticed that a language barrier is not absolute. Depending on the questions asked, the tasks performed or the role dynamics, a language barrier can be at times thick and at other times thin during the same consultation.

Collaborative visual ethnography and breast cancer

Christine Douglass, Independent Filmmaker

In this presentation I want to problematise “the false sense of familiarisation” (Sontag, 2005) that occurs in clinical, social and cultural discourses surrounding breast cancer that leads, I will argue, to a silencing of individual experience.

Breast cancer is the most common cancer in the UK with high visibility at the level of the population. It is embedded in arguably the “most popular and influential social movements of the last twenty five years” (Klawiter, 2008), the Pink Ribbon movement which together with other homogenising regimes that surround the disease (for example, a single diagnostic label, an aesthetic of “normalising” through reconstruction, a paradigm of “survivorship” and culturally validated narratives of fulfilment) — have led to a detachment from engaging with lived experience at the level of the individual.

I will argue further that in healthcare research, contingent, predetermined themes, questionnaires and other hegemonic practices that situate diagnosed individuals outside of a study design, detract from giving insights into the complex, uncertain, fluid individual *realities* of living with illness. My visual ethnographic research explored the lived experiences of nine women diagnosed breast cancer. It developed in response to ethical concerns about the way we, as researchers enter into the lives of people with illness and make their experiences visible. Filming collaboratively for up to 18 months, nine films were produced that give highly individual accounts of living with breast cancer. These accounts challenge binary assumptions and linear causal thinking about the disease and offer insights not ordinarily detected in clinic-based research.

During the presentation I want to also discuss the status of this ‘experiential evidence’ and how it can feed into healthcare policy and practice.

References

Sontag, S. (2005) *On Photography*. New York: Rosetta Books. First published 1973. Klawiter, M. (2008) *The Biopolitics of Breast Cancer*. Minneapolis & London: University of Minnesota Press.

Time of death. Future perspective in suicide notes.

Dariusz Galasinski, University of Wolverhampton

In this paper I am interested in constructions of time perspective in men's suicide notes. I am particularly concerned with those notes which are written from the perspective of the future, that is to say representing the world in which the author of the note is already dead and his death happened in the past.

Assuming a constructionist view of discourse, I consider two ways in which the future temporal perspective is achieved: past references to the note author's death and the note addressee's experience of the death constructed in the present. I also argue that such notes construct a 'continuing presence' of the person who killed himself, and an acknowledgement of the difficulties the suicide brought onto those are left behind.

In conclusion I consider potential implications of such arguments. In particular, I touch upon current understanding of suicide, suggesting that its mechanistic approach to suicidal death ignores its social and experiential dimensions.

“Dying to live”: storying the everyday experience of death on blogs

Korina Giaxoglou, The Open University

Harvey and Kotyeko (2013, p.92) have called for the critical evaluation of narrative approaches to health with a view to gain a better understanding of illness stories proliferating in the general context of the “interview” context. This paper argues for the importance of extending narrative approaches beyond medical encounters or online patient peer-to-peer interaction to the study of the impact of (social) media on ways of telling and sharing stories of illness, death, and dying for the sake of the teller as well as for connecting to wider audiences.

Earlier linguistic research on narratives of illness shared on blogging platforms has pointed to the gendered, patterned ways in which tellers seek to connect to a community of users (Page 2011), opening up the way for further empirical narrative-oriented studies of health communication in mediated contexts. This paper contributes to this research direction by examining narrativity and audience reciprocity in accounts of dying by terminally ill patients of a young age on blogging platforms. Drawing on “small story” heuristics (Bamberg and Georgakopoulou, 2008), the analysis brings to the fore the particular linguistic and discourse strategies tellers deploy in their practices of positioning themselves vis-à-vis their past, present, and future, in an attempt to forge affective connections with networked audiences and to create their own digital legacies.

References:

- Harvey, K. and N. Kotyeko. 2013. *Exploring Health Communication*. London and New York: Routledge.
- Page, R. 2011. Blogging on the body. Gender and Narrative. In Page, R. and Th. Bronwen (eds.) *New Narratives: Stories and Storytelling in the Digital Age*. Lincoln and London: University of Nebraska Press.
- Bamberg, M. and A. Georgakopoulou. 2008. Small stories as new perspectives in narrative and identity analysis. *Text & Talk* 28: 337-96.

Unwell but not (because of being) old: telling illness stories in the hair-salon

Rachel Heinrichsmeier, King's College London

Many stories of illness and death emerge in research interviews (e.g., Heavey, 2015; Riessman, 2003; Williams, 1984) or in accounts given in medical settings (e.g., Heath, 2002). In this paper, in contrast, I draw on naturally-occurring talk collected for my doctoral research into older women's identity constructions in a hair-salon.

Chronic illnesses and disabilities, both mental and physical, become more common as people age (Age UK, 2016), to the extent that age may be seen as a – or the – reason for any particular ailment (e.g., Bond & Cabrero, 2007; N. Coupland, Coupland, & Giles, 1991; Degnen, 2012). Given these associations, it is not surprising that 'painful self-disclosure' (N. Coupland et al., 1991) is stereotypically associated with older tellers (Charalambidou, 2011; Matsumoto, 2009). Furthermore, hair-salons are stereotypically places where troubles get told in a supportive environment (e.g., Furman, 1997; Lee et al., 2007; Weitz, 2005).

Given the above stereotypes, we might expect tales of illness to be particularly salient in a hair-salon frequented predominantly by older people. The audio-recordings of hair-appointments in the site of my data collection, however, did not support this expectation. I illustrate this by examining what are analysably successive 'bids to tell' an illness story made by a 90-year-old client across the fifty-one minute duration of her hair-appointment.

In this exploratory paper, I suggest that analysis of the naturally-occurring interactions combined with wider observations in the hair-salon may point to a range of constraints on everyday tellings of illness stories, including orientation and resistance to stereotypical age/illness associations. This in turn raises questions about the kinds of identity constructions available to (older) people as ill/well and about the everyday support offered in terms of their health management.

“You don’t feel human anymore” – Metaphors of self and illness in online eating disorder narratives

Nicola Hoppe, University of Hildesheim

The state of illness is generally characterized by a loss of predictability over how our bodies react, which may endanger or even destroy the essential relationship between body and self (Frank 2010, 2002) that is crucial to human well-being. Eating disorders instrumentalize the body and thrive off a dissociation of the self from the body, often leaving those affected with a ‘lexicon vastly insufficient’ to properly articulate such inherently embodied experiences since ‘words lack shape and taste, temperature and weight’ (Hornbacher 1998: 275). Notwithstanding, patients must draw on language as an instrument of sense-making to communicate those bodily sensations. A cognitive linguistic approach focusing mainly on figurative language used in medical online diaries allows us to reconstruct how patients discursively negotiate their identities as ‘ill selves’, revealing a multilayered, entangled web of (dis)embodied self and split self metaphors (e.g. Emmott 2002, Demjen 2011) as well as various (contradicting) conceptualizations of the illness as a person (Senkbeil & Hoppe 2016) that touch upon aspects of death and dying, the mind-body-dichotomy prevalent in Western culture and the limited agency of a mentally ill person.

References

- Demjen Z (2011) Motion and conflicted self metaphors in Sylvia Plath’s ‘Smith Journal’. *Metaphor and the Social World* 1(1): 7–25.
- Emmott C (2002) ‘Split selves’ in fiction and in medical ‘life stories’: Cognitive linguistic theory and narrative practice. In: Semino E and Culpeper J (eds) *Cognitive Stylistics: Language and Cognition in Text Analysis*. Amsterdam: Benjamins, pp. 153–181.
- Frank A (2010) The body’s problems with illness. In: Kosut, Mary & Moore, Lisa Jean (eds) *The Body Reader. Essential social and cultural readings*. New York; London: New York University Press, pp. 31–47.
- Frank A (2002) *At the will of the body. Reflections on Illness*. New York: Mariner Books.
- Goffmann E (1963) *Stigma*. London: Penguin.
- Hornbacher M (1998) *Wasted. A memoir of anorexia and bulimia*. New York: Harper Perennial.
- Senkbeil K and Hoppe N (2016) ‘The sickness stands at your shoulder ...’ Embodiment and cognitive metaphor in Marya Hornbacher’s *Wasted: A memoir of anorexia and bulimia*. *Language and Literature* 25(1): 3–17

On 'bad' mothers and hormonal imbalances: Comparing discursive constructions of postnatal depression in lay, media and medical accounts

Sylvia Jaworska, Reading University and Karen Kinloch, Edge Hill University

Taking up the claim made by Partington et al. (2013: 12) that 'we are not deontologically justified in making statements about a relevance of a phenomenon observed in one discourse type unless [...] we compare how the phenomenon behaves elsewhere', our paper intends to demonstrate the benefits of comparing lay discourses around a mental health condition with discourses produced by medical authorities and the media. Such comparisons are important because they allow us to understand better the complex interplay between social and personal factors that constitute the lay experience of illness. When trying to give meaning to illness, people draw not just on their personal past experience of illness and consultations with medical professionals; they also engage with representations that are widely disseminated in society through traditional and increasingly digital media. They all constitute discursive resources that people appropriate when coming to terms with illness (Jones 2003).

Our study focus on the constructions of postnatal depression (PND), which is a highly stigmatised condition and the leading cause of maternal death in the UK (Oates 2003, NHS 2011). Using a comparative corpus-assisted discourse approach (CADS) (Partington et al. 2013), we examine the constructions of PND in four discursive domains including 1) lay narratives sourced from Mumsnet, 2) documents about PND disseminated by clinicians for clinicians, 3) information by clinicians for lay people and 4) articles about PND from British newspapers. We begin our analysis by retrieving keywords from each discursive domain. A selection of shared 'key keywords' including 'depression' and 'mother' are then examined in-depth using qualitative discourse-analytical techniques. Our results show the differences, similarities and absences in the ways in which PND is 'talked about' across the different contexts highlighting the specificity and subtleties of lay accounts. At the methodological level, our study highlights the relevance of using a comparative discourse approach to foster our understanding of the role that social and medical discursive resources play in constituting the lay experience of health and illness.

References:

Jones, R. (2013). *Health and Risk Communication*. London and New York, Routledge. NHS (2011). Postnatal depression often unreported,

<http://www.nhs.uk/news/2011/10October/Pages/call-for-postnatal-depression-support.aspx>

Oates, M. (2003). Suicide: the leading cause of maternal death. In: *The British Journal of Psychiatry* 183 (4): 279-281.

Partington, A., Duguid, A. and Taylor, C. (2013). *Patterns and meanings in discourse. Theory and practice in corpus-assisted discourse studies (CADS)*. Amsterdam, Benjamins.

Parental Identity in Narratives of Grief Following Perinatal Death

Kerry Jones, The Open University

This paper explores the myriad challenges bereaved parents face in claiming parental identity and meaning following perinatal death (stillbirth or neonatal death). It follows from research with bereaved men and women and their families in which a heuristic methodology frames the narrative inquiry employed to represent 'silenced' voices. In this framework stories may represent those of chaos and wreckage, but they are not necessarily about lives as they were lived, but as the experiences of those lives (Frank, 1995).

In these narrative accounts of the death of a child, the passage to parenthood represents a disruption and re-evaluation of identity as the incomprehensibility of the loss is negotiated. For many parents, these events may represent a part of the death of the self as well as that of the child they had spent time getting ready to welcome into their lives (Rando, 1991). Feelings of guilt, self-blame and self-doubt as well as anxiety and devastation permeate throughout parent narrations and are not uncommon.

Further, narratives which portray confusion expose the way in which a sense of self and identity is mediated by the cultural and social milieu to which parents belong and which are largely disenfranchising experiences when others fail to recognise the enormity of the loss. The consequences of course are such that if the death is somehow othered and considered invisible, this can contribute towards an ambivalent sense of identity and one which is betwixt and between that of nonparent and a bereaved parent of a deceased baby.

Re-framing parental identity following perinatal death is far more complex. In searching for meaning, parents find ways to narrate their experience and to memorialise as a way of maintaining a relationship with the deceased so that it co-exists in the survivor's daily life while they re-evaluate their identity (Klass, 1996:197).

From 'cocoon to the real world' after traumatic brain injury: A narrative case study

Petra Makela, University of Westminster

This presentation considers one man's narrated experience of the six months that followed his admission to hospital with a traumatic brain injury, exploring synergies and divergences in accounts of his own endeavours, support from his family and friends, and interactions with healthcare professionals.

This single case study, approached through narrative inquiry, captures the ways in which this man makes sense of the time in which he first became aware of his injury, emerging from 'post-traumatic amnesia' (O'Callaghan, 2006), assessments administered by healthcare professionals, and early attempts to leave the hospital ward. He contrasts the pen and paper tasks he was required to undertake in the controlled ward environment with the colours and sounds of the 'real world', in which he felt unprepared for being 'exposed to my weaknesses' and 'afraid to be alone'.

Collective strategies with his family, friends and other people who had experienced brain injury become key reference points in this man's accounts of navigating through the transitions following his discharge from hospital, travelling home to his family overseas, and later returning, alone, to attempt to resume his life prior to injury. During this time he endeavoured "to find my own voice, think about my own resources and project myself in the world", describing ways he interpreted his capabilities within social interactions to gauge his own progress in recovery.

The storylines identified within this narrative case study will be considered in relation to the predictive normative practices within healthcare professionals' ways of working with people following traumatic brain injury.

Reference

O'Callaghan, C., Powell, T. and Oyeboode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychological Rehabilitation*, 16(5), 579-593

Providing end-of-life care in general practice: findings of a national GP survey

Sarah Mitchell, Joelle Loew, Catherine Millington-Sanders, Jeremy Dale, University of Warwick

Background: The numbers of people living in the community with complex life-limiting multi-morbidity is increasing. GPs play a pivotal role in the provision of palliative and end-of-life care (EOLC). However with the GP workforce under unprecedented pressure, consideration must be given to improving the organisation and delivery of high quality palliative and EOLC. This survey provides insight into current experiences of delivering EOLC by GPs, particularly perceived facilitators and barriers to delivery of this care.

Method: A web-based national UK questionnaire survey was circulated via Royal College of General Practitioners, NHS, Marie Curie and Macmillan networks to GPs. Responses were analysed using descriptive statistics and an inductive thematic analysis.

Results: 516 GPs responded, widely distributed in terms of practice location. 97% felt that general practice plays a key role in the delivery of care to people approaching the end of life and their families. Four interdependent themes emerged from the data:

- Continuity of care; which can be difficult to achieve due to resource concerns including time, staff numbers, increasing primary care workload and lack of funding. Effective multi-disciplinary team working and communication were considered essential.
- Patient and family factors; challenges included early identification of palliative care needs and recognition of the end of life; opportunity for care planning discussions and the provision of support for families.
- Medical management; including effective symptom-control and access to specialist palliative care services.
- Expertise and training; the need for training and professional development was recognised to enhance knowledge, skills and attitudes towards EOLC.

Conclusion: The survey findings are in keeping with previous research, suggesting that limited progress has been made to enhance the quality of EOLC. They reveal enduring priorities for policy, commissioning, practice development and research, in the context of a pressured and changing primary care environment in the UK.

Reference

Mitchell S, Loew J, Millington-Sanders C, Dale J. (2016) "Providing end-of-life care in general practice: findings of a national GP survey" *Br J Gen Pract* doi: 10.3399/bjgp16X686113.

The threatened self: considerations of time, place and uncertainty in advanced illness

Veronica Nanton, University of Warwick

Objectives: Loss of self and the transition to patient-hood have been widely discussed in relation to the experience of advanced illness. Individuals however often maintain identities or selves beyond those demanded by the circumstances of being a patient. This paper explores the presentation of this 'non-patient' self or personal identity and interactions between intrinsic and extrinsic elements that support or threaten its maintenance. In particular the paper examines the impact of uncertainty on the representations of self and the part played by the patient's health care professionals and the systems in which they are embedded, in limiting or reinforcing its effects.

Methods: Complementary methods of ethnographic observation and serial narrative interviews together provided a cross-sectional overview and longitudinal perspective of the presentation of self by patients with advanced multi-morbidity, chronic illness and cancer. In total 36 interviews were undertaken with 16 patients. Analysis was guided by concepts of time and place, combining contextual data with the unfolding patient narrative.

Results: Good pain and symptom control was a necessary, but not sufficient, condition for the maintenance of a personal identity. Essential agentic elements included knowledge of appropriate and immediate sources of help. Also important were a sense of control achieved through a shared understanding with health care professionals of the condition and active management of uncertainty. In addition, the maintenance of self depended on keeping a connection with aspects of life associated with a pre-illness identity. Critically, this self was contingent on external recognition, acknowledgment and validation.

Conclusion: Professional relationships which focus solely on the 'person as patient' may be insufficient for patients' needs. Health care professionals should seek to recognise and acknowledge the personal identity that may be critical to their sense of self-worth. Through an ongoing relationship guiding the patient through the uncertainties they face, health care professionals may play an essential role in sustaining the 'patient as person.'

Exploring 'wheeze' in narrative breathlessness

Rebecca Oxley and Arthur Rose, Durham University

Breathing and breathlessness generate specific narratives about ways of being. For many living with chronic illness, sensations of breathlessness evoke a particularly unwelcome and distressful lived reality. These sensations are also often medically recognised as the 'first vital symptom' of respiratory disease [1, 2]. Yet describing and communicating these experiences can often be challenging in clinical and other contexts, where understandings, definitions and significance of terms can vary. For example, what does it mean to 'wheeze', a term with both a specific clinical definition and more general vernacular connotations?

Drawing from empirical research into the expression and experience of chronic breathlessness, as well as a literary account of breathlessness, found in John Updike's "Phenomena" [3], this paper explores accounts of breathlessness where 'wheeze' is evident, and how this can be approached as a relational, material experience. To articulate the meaning of 'wheeze' is to place this experience within a wider socio-cultural and linguistic milieu, while grasping more ephemeral strategic, subjective and embodied values. This paper uses interdisciplinary perspectives to consider the problem of conceptualising wheeze in narrative accounts of breathlessness, and in doing so, how this has the potential to uncover more about, and improve our understanding of, what it is like to live with chronic breathlessness.

References:

- [1] Currow, D. C., Johnson, M. J. Distilling the essence of breathlessness: the first vital symptom. *Eur Resp J* 2015; 45(6), 1526-1528.
- [2] Banzett, R. B., O'Donnell, D. Should we measure Dyspnea in Everyone? *Eur Resp J* 2014; 43: 1547-1550.
- [3] Updike, J. Phenomena. *Collected Poems: 1953-1993*. New York: Knopf 1993: 113.

Visual images and narratives in communication about chronic pain

Elena Semino, Lancaster University

In this talk I show how the production and exploitation of visual images can facilitate the telling of stories about the experience of pain. Pain is notoriously hard to express in language, and, like other subjective experiences, does not, in and of itself, have much narrative potential. This is a problem particularly in the case of *chronic* pain, where the cause of the pain cannot easily be established via medical tests, so that diagnosis and treatment rely to a large extent on successful communication between patients and clinicians. Against this background, I report on two projects that have explored the role of visual images in expressing the lived experience of pain and in improving communication between clinicians and chronic pain patients. First, I show how the creation of visual representations of pain in collaboration with an artist enabled a group of chronic pain patients to tell multi-modal metaphorical stories about their pain. Second, I present the findings of a study that investigated whether and how the availability of visual images in a specialist pain clinic affected the interactions between patients and clinicians during diagnostic consultations. I show how, when using visual images, patients make a bigger contribution to the consultation, engage in greater emotional disclosure and tell more personal stories about the impact of the pain on their own and others' lives. I conclude with some reflections on how the story-triggering potential of visual images could be exploited to improve clinical consultations about chronic pain.

Vicarious narratives of illness in blogs by healthcare professionals

Małgorzata Sokół, University of Szczecin

The aim of this paper is to investigate the form and function of vicarious narratives of illness in blogs by healthcare professionals. Vicarious narratives in focus are stories told by healthcare professionals about their patients' experiences of illness. In the study, I integrate a narrative-pragmatic approach and a socio-cultural linguistic approach to identity construction (Bucholtz and Hall 2005; Norrick 2013). The findings reveal that through vicarious narratives of illness healthcare professionals construct their relations with patients and legitimize their professional identity by communicating professional values, expertise and authority. They also share experience with their peers and educate potential patients. As regards the form, vicarious narratives of illness in blogs are vivid, often told in a humorous and entertaining way to involve the audience. They can be episodic, co-constructed and distributed across the post and comments, which is characteristic for storytelling in social media environments (cf. Page 2012; Georgakopoulou 2013).

References:

Bucholtz, Mary and Kira Hall 2005. "Identity and interaction: A sociocultural linguistic approach." *Discourse Studies* 7(4–5): 585-614.

Georgakopoulou, Alexandra 2013. "Narrative analysis and computer-mediated communication", In: Susan C. Herring, Dieter Stein, and Tuija Virtanen (eds.) *Handbook of the Pragmatics of CMC*. Berlin and New York: Mouton de Gruyter, 695-716.

Norrick, Neal 2013. "Narratives of vicarious experience in conversation." *Language in Society* 42: 385-406.

Page, Ruth. E. 2012. *Stories and Social Media. Identities and Interaction*. New York: Routledge.

The decision to kill oneself in narratives of patients who attempted suicide

Justyna Ziółkowska, University of Social Sciences and Humanities, Poland

In this paper I am interested in narratives about the decision to kill oneself. The data come from semi-structured interviews with 50 adult patients hospitalized in psychiatric wards after suicide attempts. Methodologically, the paper is anchored in the critically oriented discourse analysis.

I shall show that the decision to commit suicide is constructed as being outside of the informants' control, regardless of whether the respondents describe their attempt as planned or not. Most often the respondents talk about "something", "attack", or "thought" which are presented as responsible for the decision about their suicide.

In conclusion, I shall juxtapose the results of my analysis with preventive strategies in clinical practice that emphasize the control of the individual over his own behaviour. I shall end by stressing that qualitative discourse analytic research into experiences of the suicidal process, largely ignored in suicidology, can lead to new insights into current strategies of prevention.