

BAAL Health and Science Communication SIG Workshop

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

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At 10am on a gorgeous, sunny Monday morning, a buzzing crowd began to gather in the Christodoulou building of the Open University's Milton Keynes campus. It was time for the Health and Science Communication SIG's second event.

There is an increasing recognition that a serious consideration of accounts of illness and dying by patients, carers and even healthcare professionals improve quality of care as well as the experience of being ill. While such lived experience accounts have been investigated within a variety of disciplines (history, sociology, literature, the visual arts and, more recently, linguistics), the disparate approaches have tended to leave the field somewhat fragmented. With the aim of encouraging conversations across disciplines and exploring how we make better and more consistent use of these accounts, this workshop united linguists, sociologists, anthropologists, filmmakers, poets, actors, medical professionals and researchers, medical humanists and educators, service users, from Poland, Germany, Finland, Belgium, UK, working with interviews, everyday conversations, print media, observations, written notes, digital and social media, videos, photographs and Vlogs. In fact, the SIG committee was overwhelmed by the interest in this workshop. Originally intended as a small event with two keynotes and 7-8 short presentations, we ended up with two keynotes, 17 presentations in parallel sessions and over 50 participants. But the buzz even went beyond the confines of the two workshop rooms. Using the #healthsci16 hashtag, our presenters and attendees attracted the attention of many in the twittersphere, as the hashtag tracker stats below demonstrate:



The first keynote was delivered by Jonathon Tomlinson, a GP in Hoxton, London. He provided a timely critical reflection on teaching and learning from doctors' own published illness narratives,

suggesting that, while these are valuable in highlighting the fear, loneliness, stigma, powerlessness and loss of identity that come from being a patient, they have shared these same themes for the past 100 years. Why do these lessons still bear repeating? A flavour of Jonathon's thoughts on the matter is captured in his insightful blog post: <https://abetternhs.net/2014/06/12/lessons/>.

Issues of identity, self-presentation, representation and their acceptance or resistance by others were themes that continued in several of the parallel sessions after a short break. One of the panels explored these themes specifically in the context of death, dying and suicide, while the other included a range of conditions.

After lunch, the group was treated to an interactive, immersive performance of poetry, character and movement, demonstrating innovative strategies in medical education, before coming together for the second keynote of the day.

Julie Ellis, a medical sociologist at Sheffield University, delivered the second keynote of the day in a reflective and reflexive presentation on pragmatism, humorous banter and other examples of 'everydayness' in families' accounts of dealing with life-threatening illness. Julie problematised an underlying assumption that such accounts should be dominated by crisis talk and emotional vulnerability, suggesting that a more nuanced and contextual interpretation of emotionality in end of life contexts, based on actual accounts, would be useful. She also reflected on the issues and risks she encountered as a researcher in representing aspects of life-threatening illness experiences as 'everyday', when they are generally understood as 'extraordinary'.

A well-deserved break with coffee, tea and cake, and the group then headed back into the final parallel sessions of the day. One panel focused on accounts involving medical practitioners as participants or producers, while the other looked at narrative case studies, both verbal and multimodal.

It is difficult to represent the insights and energy from the event in but they are perhaps best captured in the Storify board created by someone enjoying the event from afar:

<https://storify.com/GlobalVStories/healthsci16>

To keep up-to-date about future events and to share relevant information with the growing Health & Science Communication SIG community, join our mailing list:

<https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=BAAL-HEALTHSCI>.