

**Cecilia Trenter**

Linnaeus University, Sweden

**"Why did AIDS come to us at this time?" Explanations of a trauma and oral histories in the Face of AIDS Film Archive**

The paper discusses the mnemohistory of AIDS in order to understand how a social memory takes shape according to Jan Assmans theory of the transition from a communicative memory to an objectivized culture, and how the online archive "The Face of Aids Film Archive" (<https://faceofaids.ki.se/>) fits into this process. The archive content 600 hours of film material filmed in 40 countries during a period of 35 years divided in about 1800 videos documentation of HIV/AIDS by the Swedish filmmaker Staffan Hildebrand. The paper will look upon the filmic raw material as oral histories in order to learn how people in different situations and locations during the 1980s and 1990s defined and explained the existence of HIV/AIDS, and how they thought that the knowledge of the pandemic affected them. The archive delivers unique sources of perceptions of AIDS and HIV, conveyed in interviews with scientists, journalists, sexbuyer, people diagnosed with HIV, activists, anonymous people on the street, stigmatized groups such as homosexual men, drugdealers and sexworkers, and politicians in the health and care sector. The raw film materials mediate the interviews with interruptions and retakes which creates narratives characterized by repeats and variations in a way that corresponds with Assmans definition of a communicative memory.

**Vanessa Allen-Brown**

University of Cincinnati, USA

### **Triangulating Oral History for African American Women cancer survivors**

Preliminary findings in a community based research project indicated that African American women distrust medical professionals and are uncomfortable discussing personal health. Their reluctance to seek medical assistance negatively affects their long-term healthcare, an outcome that is particularly significant for survivors of breast cancer. Even after adjusting for differences in socioeconomic factors, baseline disease, and treatment variables, African American women have significantly lower survival rates than women of other races. Despite these poorer outcomes, the good news is that breast cancer can be treated successfully if detected early. This paper will address how Oral history, Narrative Medicine, and Photovoice were triangulated to study cultural factors to increase screening and treatment adherence to reduce breast cancer disparity for African American women.

The three methods, although different, share similar tools for data collection, principles for respecting the interviewee, and recognition that the story belongs to the narrator. In this study, Oral History allowed for more in-depth interviewing and with the knowledge of narrative medicine, we were able to create a comfortable environment for the individual to share their concerns about their illness and care. Then Photovoice, coupled with dialog and visuals, created rich data that was also triangulated.

Narrative medicine is an interdisciplinary field that challenges divisions between those who are in need and can access healthcare versus those who cannot. It creates an opportunity for the participants to voice their experience, recognizing the need to be heard and valued, while acknowledging the power of their narrative to change the way care is given and received. Photovoice is a participatory action research strategy which engages community members by encouraging them to take pictures of the communities in which they belong, engaging in dialog about the photographs, and use the photographs as a platform for policy change.

**Ella Leith**

University of Edinburgh, United Kingdom

### **Where's the 'I' in deaf? Understanding the personal as collective in British Sign Language life stories**

The history and culture of the British deaf community (i.e. those whose first or preferred language is British Sign Language) tends to be obscured by the disabling attitudes of wider society. Brought up in this 'hearing world' and often internalising these attitudes, many deaf individuals report that the discovery of their own 'culturally deaf' identity comes through the discovery of others' deaf identities, and the recognition that these mirror and provide context for their own. As such, the sharing of personal experience narratives and life stories within the community is a politically and emotionally charged act, enabling deaf people to challenge received wisdom about what their deafness 'means' and to assert collective resilience, capability, and cultural validity. Although these life stories are highly personal memories, they are also seen as constituting 'traditional' deaf narratives which 'extend beyond the personal to become stories of the life of an entire culture' (Bahan 2006:29).

This paper draws on a DVD corpus of signed oral histories collected from Scottish deaf people in 2010-2011. In addition to addressing the methodological issues involved in working with sign languages, including how to translate an un-writeable language of the body onto the page, it considers how the interviewees fit their personal life stories into an established framework – a shared 'deaf biography'. In particular, it analyses the recurring stock constructions and motifs which act as culturally loaded shortcuts to common experiences, and which also find expression in sign language poetry, storytelling, theatre, etc. To what extent is the individual's story their own, and to what extent does the narrator assume the role of a 'deaf everyman'? How can we interpret and represent the deaf 'I' in a personal memory when the personal is often tacitly understood as standing for personal, collective and traditional all at once?

## **David Caruso**

Chemical Heritage Foundation/Science History Institute, USA

### **Oral history, scientists with disabilities, and the Oral History Review**

The oral history methodology can be used in a multitude of disciplines, though it is most often employed within the context of social and cultural history, sociology, anthropology, and folklore studies. In this paper, I will discuss the ways in which this tool is essential for exploring the lived-experiences of persons with disabilities who have pursued a scientific career in the United States.

Traditional scientific publications contain no information about how scientists and engineers actually do their work, but merely the results of experiments, like data points and pictures of cellular structures. So it is impossible to develop a sense of the ways in which, for example, the spaces (both intellectual and physical) in which scientific work takes place have been unwelcoming or welcoming to scientists with disabilities or how having a disability shaped the experience of becoming a scientist and of participating in research. Using oral history interviews allows for a better understand of the ways in which these scientists and engineers have navigated scientific environments (both built and social) and research structures, the ways in which these environments and structures have changed over the last thirty years or more, and how persons with disabilities have understood their relationship with the scientific work they do.

Additionally, I will also be using this presentation to reach out to the global oral history community in my position as the (incoming, in January 2018) editor of the Oral History Review, the peer-reviewed scholarly journal of record in the United States for the theory and practice of oral history. My aim is to explain my editorial team's efforts to create a greater international presence in the journal and to answer questions on the article development process for prospective authors, with particular attention to authors for whom English may not be their primary language.

**Tom G McGorrian**

Middlesex University, United Kingdom

**'Hospice Stories' – Developing documentary practices for sensitive contexts –  
Video Ethnography in the UK Hospice Sector**

This film is being proposed for the IOHA's INTERNATIONAL CONFERENCE in June, 2018.

Any filmmaker who sets out to make documentaries faces multiple challenges, not the least of which is a set of ethical issues inherent in the process. How to portray the subjects of the film? What to shoot and what not to shoot? How to edit so that the film is true to its topic and subjects, yet also works as a compelling story for the audiences?

If a filmmaker is working in a sensitive environment, such as a hospice, how to represent people with dignity and sensitivity to that place, time and experience are added factors too. That said, the overall purpose of my research project was to use video ethnography in the Hospice Sector as a case study for developing documentary filming practices for sensitive contexts

My key aim was to explore how documentary and video ethnography methodologies can be utilized to help guide researchers as they navigate ethical concerns. A specific objective of my research project, partly conducted through interviews with people from a range of ages and experiences living out their last stage of life, was to identify the ethical issues relating to documentary recording of such sensitive subjects. It also intended to deliver evidence (in the form of both written material and film) about what quality of life means to people visiting day hospices, what specific practices, behaviours and attitudes have an impact on their quality of life and to capture the voices (through film) of those who are attending day hospices and expressing their views of a vision for care. Consideration was also given to how their input, and the process of recording and having on record such input, might influence practice in the future.

Tom McGorrian

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