



# Who Cared?

## Oral History, Caring, Health and Illness: Marking 60 Years of the National Health Service

2008 Oral History Society  
Annual Conference  
University of Birmingham  
4th – 5th July 2008

In association with the  
Centre for the  
History of Medicine



and  
University of Birmingham

UNIVERSITY OF  
BIRMINGHAM

# ABSTRACTS

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## **THE ELEPHANT IN THE ROOM: PHYSICAL AND PHARMACOLOGICAL THERAPIES AT FULBOURN PSYCHIATRIC HOSPITAL, 1950 – 1970.**

**John Adams, Lecturer, Anglia Ruskin University**

This paper uses oral testimony from doctors, nurses, social workers and service-users, collected for an on-going PhD study of the post-War history of Fulbourn Psychiatric Hospital, near Cambridge, to explore the part played by physical and pharmacological therapies in the treatment regime. Fulbourn acquired international fame in this period for the work of its charismatic medical superintendent, Dr David Clark, in developing 'work for all' and 'open door' policies at the hospital. Clark was also one of the pioneers of the 'therapeutic community' movement in the UK, and a leading supporter of 'social psychiatry'. An orientation of this kind, however, did not imply an immediate rejection of physical modes of treatment, such as insulin coma therapy and leucotomy. While both these treatments eventually lost their place in psychiatry, electro-convulsive therapy (ECT) and the new drugs (such as chlorpromazine and imipramine) continued to be very widely used. Oral testimony has shown that a simple categorisation into adherents of either a 'social' or a 'biological' model of psychiatry does not do justice to the views and practices of many Fulbourn clinicians, or provide a satisfactory account of the process of change in medical knowledge.

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## **A MATTER OF LIFE AND DEATH: CONVERSATIONS WITH PATHOLOGISTS**

**Sue Armstrong, writer and broadcaster specialising in science and medicine; Olivia Bennett, writer/editor/consultant specialising in oral history**

Pathology, which seeks to understand disease and disease processes, is the cornerstone of modern medicine – the science that underpins diagnosis and treatment decisions. It plays a crucial role in our lives, yet a large proportion of the general public is unaware of its importance. During the Alder Hey controversy, pathologists faced active hostility, and were dubbed "doctors of death" by the media. Yet misunderstanding of the pathologist's role has serious implications. Since Alder Hey, new laws have been enacted regarding the use of human tissues that are inhibiting vital research and teaching, and there has been a dramatic drop in autopsies, the 'gold standard' for determining cause of death.

To challenge damaging misperceptions, Sue Armstrong interviewed pathologists working in a wide range of international environments. These "conversations" have resulted in very personal portraits of the individuals – their earliest influences, motivation, inspiration and experiences. They bring to life the human impact of the science, as well as explore some of the issues - philosophical, ethical and practical - facing pathologists today. Among many other things, pathologists speak about investigating 'new' diseases like AIDS and variant CJD; unravelling the mysteries of cancer and pandemic flu; doubts about 'shaken baby syndrome'; how bodies decompose; and what effect their work has had on their philosophy of life.

With Olivia Bennett, Sue is producing an archive of the interviews as well as distilling the essence of the collection into a book. In this paper, we discuss why taking an oral history approach is important to deepening understanding of the profession, one of the few areas of medicine whose practitioners are not seen in a “caring” role, and what we have learnt from the project.

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## **”I WAS HAPPY AT MARKLUNDA” – MEMORIES OF A SWEDISH INSTITUTION FOR PRE-TUBERCULOUS CHILDREN**

**Malin Arvidsson, MA Student of History, Malmö University**

In the late 19th century, many western European countries formed tuberculosis programs. By founding sanatorias and funding research, the Swedish National Association Against Tuberculosis played a central role in this mobilization. Their initiatives were subsequently publicly financed, but the overarching aim remained to strengthen the nation by providing care and preventive measures. The preservation of children was a great concern of the anti-tuberculosis movement.

In this paper I will examine an orphanage that in 1930 started to receive children of the urban poor, in order to isolate them from their contagious parents. In the 1950s the admission became broader as the tuberculosis decreased. However, the institution’s care ideology – open air activities and nutritional treatments in a home-like and healthy environment – was sustained.

My understanding of this institution has been altered by the use of oral history. To regard the orphanage as a means of social control became impossible when listening to memories of fellowship and strong traditions. My informants told me about punishments and other characteristics of total institutions – and how they resisted them. The division between cared for and carer was not always distinct; several of the persons I interviewed have been both living and working at Marklunda barnhem.

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## **CARING HISTORIES: LAY CARERS’ ACCOUNTS OF CARING RELATIONSHIPS**

**Marian Barnes, Professor of Social Policy, University of Brighton**

The histories told in this paper are personal histories of giving and receiving care across three lifetimes. The context was a project prompted by two concerns:

1. that there has been a tendency within welfare systems to abstract care relationships from individual and shared biographies and thus to ignore the significance of lives before the necessity for ‘care’ evoked an ‘official’ response; and
2. the neglect or, in some cases rejection of ‘care’ as a value to be promoted in the context of social care services, consequent on the advocacy of rights and empowerment.

From my perspective as a researcher these concerns arose out of personal experience in relation to the care of my mother who developed dementia. This prompted me to reflect on and question positions I had adopted in relation to rights based ideologies from within the disability movement. I wanted to examine the apparently

opposed notions of rights and care and to see whether they were, in principle and in practice, irreconcilable. My discovery of a political perspective on an ethic of care (Tronto, 1993; Sevenhuijsen, 1998) provided the intellectual basis on which to attempt such a reconciliation by reference to the lived lives of caregivers (Barnes, 2006).

The three stories told here are those of Alan, who cared for his mother when he was a child and again when she developed dementia. Alan had worked as a nurse, social worker and care manager and reflected on the connections between personal and professional care. Nell's adult life was shaped by her experience of caring for her disabled son and this had led to her becoming active in a carers' organisation. Emily had not only cared for her husband when he developed dementia, but for her mother and her son. Her story spans a period from before the Second World War.

Barnes, M (2006) *Caring and Social Justice*, Basingstoke, Palgrave.

Sevenhuijsen, S (1998) *Citizenship and the Ethics of Care: Feminist Considerations of Justice, Morality and Politics*, New York and London, Routledge.

Tronto, J (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*, New York and London, Routledge.

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## **'DON'T MIX RACE WITH THE SPECIALTY' (RETIRED SOUTH ASIAN CONSULTANT GERIATRICIAN): INTERVIEWING SOUTH ASIAN OVERSEAS-TRAINED GERIATRICIANS**

**Joanna Bornat, Leroi Henry, Parvati Raghuram, Gail Wilson, The Open University and LSE**

Several of the pioneers, interviewed by Professor Margot Jefferys in 1990-1, who developed geriatric medicine during the mid-twentieth century make passing reference to the South Asian doctors who played a significant role in building the specialty. However, amongst over 50 geriatricians she interviewed, only one was from South Asia. A new project, funded by the ESRC, aims to make good this deficit by recording the experiences of South Asian geriatricians in the organisational and scientific development of the provision of medical care for some of perhaps the most marginalised groups of NHS patients, frail older people. The paper draws on these interviews to consider how opportunity, status and career are negotiated in oral history interviews in relation to such factors as racism and discrimination, particularly given the need to record personal achievement and professional reputation within what is a strongly hierarchised area of employment. It explores the constitutive role of this part of a global workforce in building up a National Health Service.

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## **“SOMETIMES THE HELPFUL BITS COME IN ODD PLACES” – THE CONSTRUCTION OF ROLES AND GOOD PRACTICE IN A THERAPEUTIC COMMUNITY.**

**Matthew Bowen, Clinical Nurse Specialist with lead responsibility for supporting training staff in therapeutic community practice, Henderson Hospital therapeutic community; PhD Student, Goldsmiths University.**

Henderson Hospital pre-dates and pioneered therapeutic community practice in the NHS. With a pre-eminent international reputation, it recently spawned two replications within the NHS. Both unique and a template, it has provided residential treatment for persons with a diagnosis of personality disorder.

This paper concerns the largest and arguably most influential body of clinicians within Henderson, who are also the most under-represented in the literature. Nurses and social therapists co-facilitate formal therapeutic groups, engage in the 24-hour a day informal social domain, and take part in managing the community.

Using a comprehensive series of semi-structured individual interviews, recorded in my role as clinician-trainer and as part of doctoral research, I examine nurses' and social therapists' narratives of experiences of good practice within the context of their personal and professional lives. The narratives present a construction of the roles of staff and clients that explore a number of emerging themes including: the place of staff feeling cared for by residents within a therapeutic community, the creation of a resident's career, the expectation on residents to provide therapy to their peers, the importance of play between staff and residents.

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## **'THERE'S STILL THE ORIGINAL WALL, WHICH WAS THE WORKHOUSE YARD': CARING AND CONFINEMENT IN GERIATRIC NURSING, 1955-1980**

**Jane Brooks**

The foundation of the National Health Service (NHS) in Britain in 1948 was meant to eliminate the second-class treatment of the chronically ill and elderly in their decrepit hospital buildings. Whether being cared for in a prestigious teaching hospital or the old poor law infirmary everyone was now to be provided with the same level of care; all were now patients, those in the poor law were no longer inmates. However by the mid 1950s the honeymoon period was over, the British government realised that savings needed to be made; the 'geriatric bed-norm' was invented, and was unsurprisingly woefully limited and under funded.

Although in more recent years there has been a growth of interest in the politics and health of the older person in hospital and the community, the interest from medical and social care historians has resembled that of the governments; limited. More critically, there has been virtually nothing on the nursing care of older people in Britain. Given the involvement of nurses in caring for the aged, this seems a gross oversight. This paper is based on an oral history project of twenty nurses who worked on older adult wards in general hospitals between 1955 and 1980 in the UK. There are differences in the testimonies that these nurses brought and some were certainly more positive than others, but the overriding themes were of struggle and incarceration. Using the seminal work of Erving Goffman, this paper will explore the notion of the geriatric ward as a 'total institution', in which the patients and nurses alike are subordinated by the hegemony of the acute hospital. This examination will consider the relations between the nurses and their patients and the struggles both faced in status, financial support and recruiting and retaining suitable staff.

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## **THE ORAL HISTORY OF UNDERGRADUATE MEDICAL EDUCATION IN THE CARE OF THE DYING AT BIRMINGHAM UNIVERSITY MEDICAL SCHOOL; 1930-1970**

**Rodger Charlton, Associate Clinical Professor in Medical Education, Warwick Medical School**

Introduction: Palliative medicine for the care of the dying is a new specialty following the pioneering work of the late Dame Cicely Saunders in the 1960s.

Method: In order to test the hypothesis that Birmingham students were not adequately prepared to undertake care of the dying oral history interviews were conducted with 10 doctors who graduated prior to 1970 and 5 members of the public. A qualitative analysis using a coded theme approach was applied to the transcribed interviews.

Results: The following themes were identified;

- (1) No teaching in the care of the dying.
- (2) Training has improved enormously since from being entirely rudimentary.
- (3) The lack of training led to problems after qualification.
- (4) A lack of communication with the patient about the truth of their illness resulted in a 'conspiracy of silence'.
- (5) Nurses played a key role in care and patients usually died at home.
- (6) Pain relief did not feature largely in patients' care.
- (7) Many patients prior to the NHS may have gone without palliative care for financial reasons.

Conclusions: Further research using oral history is required to ascertain what factors influence medical curriculum change and the factors that facilitate home care for the dying.

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## **MEMORY, STATUS AND SURVIVAL: THE LIMERICK CITY DISPENSARY 1930-1970**

**Dr Maura Cronin, History Department, Mary Immaculate College, Limerick**

The Irish Dispensary System, originating in the 1851 Public Health Act and modified by subsequent legislation (1946, 1953), was the main provider of medical care for low-income families up to 1970 when a 'choice of doctors' and medical card scheme brought some degree of equality to the health system.

The main dispensary in Limerick city (population rising from c. 50,000 in 1950 to c. 60,000 in 1980) was in Gerald Griffin Street, at the heart of the retailing and working class residential area. It was here that inoculations and routine medical examinations were carried out, where supplementary social welfare payments were made, and where working class life intersected with the health service.

The dispensary's clients were mainly women with their children. The recorded memories discussed in this paper allow the exploration of childhood perceptions of officialdom, matching and contrasting them with those of the adults. They also raise questions surrounding contemporary and retrospective attitudes to 'respectability' in a medium-sized Irish provincial city, and the difficulties faced by the researcher in

reconciling historical 'accuracy' with the feelings and sensibilities of local people. The paper also considers the difficulties faced by dispensary staff and officials (doctors, nurses, pharmacists, relieving officers) in dealing with a part-deferential, part-demanding clientele, as well as the nature of the social gulf (simultaneously both deep and bridgeable) between patients and officials. Finally, there is a discussion of the inbuilt social controls operating (religion, deference, familiarity); and the (largely female) survival mechanism of humour – both decorous and crude – in the face of material hardship.

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**'I PUT MORE TRUST IN CHLOE FISHER...THAN ANYBODY ELSE, SHE WAS ABSOLUTELY BRILLIANT.' WOMEN AND THEIR MIDWIVES, C. 1945-1970.**

**Angela Davis, Department of History, The University of Warwick**

The practice and development of maternity care between 1948, when the National Health Service (NHS) came into existence, and 1974, when a reorganisation of the service saw the local Public Health Departments being abolished, has been the focus of much debate. A number of questions were being asked throughout this period. These include the issue of whether there was such a thing as a normal pregnancy and labour; if so, where should the 'normal woman' give birth and who should attend to her; and did the mother or child need to be the principal focus of attention. Implicit throughout discussions on maternity care at this time was the question of whether pregnancy and childbirth should be medical questions at all. Histories of maternity care provided to women during pregnancy and childbirth in the twentieth century, both from a medical history approach such as Philip Rhodes' history of clinical midwifery and feminist interpretations such as those of Ann Oakley and Marjorie Tew, have detailed developments and debates surrounding maternity provision.<sup>1</sup> In addition, Jean Donnison has identified the inter-professional rivalries between midwives and doctors.<sup>2</sup> However research has often focused on clinical and professional developments rather than the thoughts and feelings of the women who were at the receiving end of maternity care. This paper will therefore look at how debates surrounding maternity provision in the decades after World War Two determined the services on offer to Oxfordshire women, and how women experienced this care. In particular, I will focus on the changing relationship between women and their midwives in context of the decline in domiciliary midwifery that occurred during the years between 1945 and 1970. I will argue that as a consequence of this diminishing role of the independent midwife women lost the ability to decide where they wanted to give birth.

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<sup>1</sup> Philip Rhodes, *A Short History of Clinical Midwifery* (Hale: Books for Midwives Press, 1995); Ann Oakley, *The Captured Womb: A History of the Medical Care of Pregnant Women* (Oxford: Basil Blackwell, 1984); Marjorie Tew, *Safer Childbirth?: A Critical History of Maternity Care* (London: Chapman and Hall, 1995).

<sup>2</sup> Jean Donnison, *Midwives and Medical Men: A History of the Struggle for the Control of Childbirth* (New Barnett: Historical Publications, 1988).

## **"HOW DO WE KNOW WHO CARED? AND WHAT THEY CARED FOR?" A LIFE STORY APPROACH TO ARCHIVES OF THERAPEUTIC ENVIRONMENTS AND THE PEOPLE WHO SAVED THEM**

**Craig Fees, Archivist, Planned Environment Therapy Trust Archive and Study Centre**

Innumerable therapeutic environments small and large have come and gone leaving no trace, except in the rapidly disappearing lives and memories of those who were in some way associated with them. When even some extremely important and influential places leave virtually no surviving archives for key periods and episodes - Summerhill School and the Cassel Hospital for their pre-war manifestations, the Northfield Military Psychiatric Hospital for the whole of its pioneering war-time existence - , and considering the conditions of therapeutic work in pioneering environments and the events and disasters affecting them over the last hundred years, the miracle is that some archive collections do survive. The question is How? Why? and What are the implications?

The Planned Environment Therapy Trust Archive and Study Centre holds a number of archive collections which have survived only because of the care of key individuals at critical times. Using interviews with and about these people, and internal evidence, this paper looks at the life story of several collections, and the lives of the carers woven through them, with a focus on the archives of the pre-war therapeutic Hawkspur Camp. How do archives survive? Why? Against what odds? And what does this tell us about the field of therapeutic care, and what we think we know about it?

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## **ORAL HISTORIES OF X-RAY WORKERS**

**Christine Ferris**

Standard explorations of the history of X-ray work focus on technological developments, the various uses of imaging technology and the input of a variety of scientists and doctors. Oral history has given voice to those not in power at that time and has uncovered the realities of everyday practice for those working closely with X-ray apparatus and other forms of imaging modalities since the 1930s. Nurses were among the first radiographers although many retained their nursing title. They worked with male radiographers and the physical tasks of examining patients with X-radiation became aligned to gendered bundles of skills. This presentation is based on the analysis of 32 oral histories from male and female nurses and radiographers whose combined practice spanned almost seven decades.

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## **"MUM HAD MULTIPLE SCLEROSIS": FAULTY CONNECTIONS?**

**Katrina Gatley, PhD Student, Wellcome Trust Centre for the History of Medicine at UCL,**

This paper considers the impact on two families of caring for chronically and progressively ill mothers through the eyes of their children: mothers with multiple sclerosis. It deals in particular with the way in which the assimilation of medical knowledge shaped the families' responses and attitudes to both disability and medical care after the Second World War. It also considers how the children, who are now adults, view the

role of self-help organisations and single disease charities in shaping and challenging medical knowledge and providing practical support for the cared and carers in the later part of the twentieth century.

These oral histories illustrate a pride in their mothers, themselves and their families and a sense loss, especially of their child-mother relationships. A comparison of the narratives shows how the children scripted their understanding of their lives in a medicalised world.

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## **INSTRUCTOR, DAY CARE OFFICER, COMMUNITY SUPPORT WORKER: WHAT'S IN A JOB TITLE?**

**Helen Graham, Visiting Research Fellow, Faculty of Health and Social Care, The Open University**

Substantial shifts in job title and job description have characterised the relationships between service users and staff in the London Borough of Croydon's day services for people who are now referred to as 'having learning disabilities'.

When 'Waylands Craftwork, Training and Social Centre' first opened in Croydon in 1967 the staff were called 'Instructors' and were referred to as 'Mr' or 'Mrs'. Many staff were recruit from industry and were expected to teach work skills as a core part of their job. The decline in industrial work within the day service was accompanied by a re-conceptualisation of the staff role as being more about social education – including social skills, personal care and independence skills. Following the Valuing People white paper (2001) the new 'Community Support Worker's' responsibilities have come to be primarily focused on supporting people to access their local community.

Drawing on oral histories with staff and people who have used Croydon's service – and interviews by people with learning disabilities with staff they have worked with – I will explore the substantial reconfiguration of roles and how people have made sense of these changes in the context of recent 'modernisation'. In particular I focus on how these changes are expressed – and especially on moments where dissonance between old and new ways of thinking emerges – in order to illuminate the complexity of the relationships between those who attended and those who were employed to work in the Day Centres.

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## **ASSISTED MEDICAL DECISION MAKING**

**Humphrey Gyde, CHIME, UCL**

Many methods capable of assisting an individual in the making of diagnostic or therapeutic decisions have been developed over the last 50 years as instructions on paper, punched cards, slide rules and more recently as computer programs. Interviewing important contributors in this field would provide an alternative and supplementary record of value to future researchers. As a number of these innovators have died it is important that this should be done now. A list of potential interviewees was selected and prioritised. Preliminary explanations and discussion regarding the scope of the interview and copyright issues led to informed consent. Hand-held digital voice recorders were used. Verbal consent including a copyright agreement was recorded at the start. The interview was part-structured: with a brief chronological survey of

the innovator's background and career, leading to details of the discovery or invention including evaluation or outcome and finally any vision of future developments. 24 interviews with leaders in the field have been recorded to date in North America, Great Britain and Europe; with one refusal. The recordings are being transcribed by dictation into a voice recognition program as well as conventional transcription for comparison, prior to delivery to the archive.

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## **HOUSEWIVES, NEUROSES AND THE DOMESTIC ENVIRONMENT IN POST-WAR BRITAIN: INDIVIDUAL PERSPECTIVES**

**Ali Haggett, Research Fellow at the Centre for Medical History, University of Exeter.**

This paper will explore the personal recollections of women who endured affective disorders (anxiety and depression) during the 1950s and 1960s. The oral testimonies are taken from the oral history component of her doctoral thesis on neuroses in post-war housewives. This paper will focus not only upon women's experience of symptoms – but specifically upon the ways in which they 'coped' with their illness, and, for those that sought medical help, their encounters with physicians. It will examine housewives' assessment of medical consultations, and, for those who were prescribed anxiolytics or antidepressants, the effects of psychotropic drug treatment.

Feminist scholarship since the 1960s has repeatedly alleged that educated housewives developed symptoms of neurosis as a result of the banality inherent in the domestic role. They further argue that psychotropic drugs were over-prescribed to women in order to 'adjust' them to the domestic role with which they were unhappy. The oral testimonies from this project have raised points of concern with this reasoning. Firstly, by and large the women interviewed did not locate the cause of their symptoms in their domestic role. Secondly, in contrast to the popular conception of housewives as 'victims' in these circumstances, the women demonstrated considerable agency, strength and resilience.

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## **FROM 'I AIN'T GOING TO THAT CRAP' TO 'IT REALLY FELT LIKE WE WERE ACCEPTED AND LOOKED AFTER'**

**Robert James, Birkbeck College**

Haemophilia was until the 1960s an untreatable and extremely painful condition with people often dying as children and those living into adulthood doing so with crippled joints and ongoing arthritis. The treatment made from thousands of blood donations that revolutionised the lives of people with haemophilia but also transmitted a number of viral infections. In 1985, 1,246 people with haemophilia were diagnosed with HIV in the UK, infected through contaminated medical treatment. Since then, over 800 have died. The Haemophilia and HIV oral history projects at the University of Brighton conducted oral history interviews with over 60 people very personally affected by these events.

These individuals have all had a lifetime of experience with the NHS either receiving treatments that were both life saving and life threatening or caring for a children or partner receiving treatment. Over the past 20 years they have used a number of different support systems from formal counselling at NHS clinics, religious

groups, disability organisations and self-help groups to alcohol and drugs to get through the physical and emotional challenges of their lives. Where and how people got support varied significantly from place to place. Many were very clear about what did not help which frequently included the existing formal support mechanisms from the NHS or the voluntary sector. Haemophilia and HIV self-help groups were generally felt to be better at providing useful support although the person's perception of what the group would be like often inhibited them from joining without external some pressure, usually a partner or parents. Generic HIV self-help groups produced diverging results with some people finding them hugely supportive outlets while others felt them inappropriate to their needs. The descriptions suggest that similarity of experience, homophobia or the lack of it, and religious beliefs were the most important features in identifying where people found support.

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## **DUST NARRATIVES: USING ORAL HISTORY AS A SOURCE FOR UNDERSTANDING OCCUPATIONAL HEALTH**

**Ronnie Johnston. Centre for the Social History of Health and Health Care, Glasgow Caledonian University;**

**Arthur McIvor, Scottish Oral History Centre, University of Strathclyde**

This paper focuses on how oral history can be utilised as a methodology for enhancing our understanding of the causes and consequences of occupational dust disease in the twentieth century. In our two studies of the history of occupational dust diseases (*Lethal Work: a History of the Asbestos Disaster in Scotland*, Tuckwell, 2000; *Miners' Lung: a History of Coal Dust Disease in the UK*, Ashgate, 2007), our research methodology combined oral history interviewing with archival evidence. Interviews have been conducted with 82 workers exposed to dust in their occupations (including miners and various occupations involving exposure to asbestos) from South Wales, the North East of England, and Scotland, as well as 12 occupational health professionals (company doctors, industrial hygienists and occupational nurses). The main themes we explore in this paper are oral history and the working environment, workers' lay knowledge of dust disease, the conflict between the need for maximum production and worker protection from occupational health risks, the impact of masculinity on occupational health and safety, and oral history as a way of understanding the impact of occupational disability. We argue that whilst oral interview material requires critical and sensitive treatment, nonetheless such narratives provide a wide range of insights into the employment-health interaction and can aid our understanding of work and health cultures, the body at work, as well as the mutating identities which ensued as a consequence of contracting serious chronic occupational diseases.

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## **TIME TO TALK?: FACTORS THAT CONTRIBUTED TO SUFFERERS OF CHILDHOOD TUBERCULOSIS DECIDING TO TALK ABOUT THEIR EXPERIENCES YEARS LATER.**

**Susan Kelly, Research Assistant, at Centre for History of Medicine Ireland (CHOMI), University of Ulster**

This presentation looks at thirty –three oral history interviews, that were recorded as part of PhD research into the experience of childhood tuberculosis sufferers in Northern Ireland. The interviewees had tuberculosis

between the period 1926 and 1963. Many of the children experienced long periods of hospitalisation and suffered emotionally as a result. Tuberculosis was a disease that engendered fear and while this remained it created stigma. Many sufferers felt this stigma. Whilst some children did talk about their experience others remained silent. Silence appears to have been an attempt by some to move on with their lives. For some this reticence continued into adulthood. The impact of emotional trauma and stigma are considered with regard to influencing a desire to talk or remain silent about past experiences. Reasons such as family complicity, continuing health problems and unresolved issues are all reviewed as influences. With the help of a follow up questionnaire this presentation considers whether the interview process had a positive or negative impact on the interviewee's attempts to deal with their past and whether it influenced their subsequent behaviour.

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### **'SHARING THE STRUGGLE': AN EXPLORATION OF MUTUAL SUPPORT PROCESSES IN A THERAPEUTIC COMMUNITY**

**Dr. Maddy Loat, Clinical Psychologist, Camden & Islington Mental Health & Social Care Trust**

This descriptive, qualitative study explored individuals' experiences of mutual support whilst they were resident in the Cassel Hospital, a therapeutic community for people experiencing severe emotional and social difficulties. Twelve participants were interviewed and the interview data were analysed qualitatively, using interpretative phenomenological analysis. Eight themes, each comprising a number of sub-themes, were identified from the analysis. These were organised into three higher-order domains relating to participants' experiences of being in the therapeutic community, the process of giving and receiving mutual support, and the impact of mutual support on their sense of self and perception of their difficulties. Overall, participants' experiences of mutual support were positive and the study identified a number of ways in which mutual support processes operated within the TC and the impact these had on individual members. The findings were highly consistent with the mutual support literature, providing further evidence for the benefits of this type of support. The outcome of the study has implications with regard to the provision and delivery of mental health services and highlights the importance of providing people experiencing mental health difficulties with opportunities to support one another, alongside the usual provision of professional support.

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### **PERCEPTIONS OF A LIFE IN SURGERY.**

**Iain Macintyre and David Wright, Royal College of Surgeons of Edinburgh.**

During 2006-07 we conducted video interviews with seventeen people who had worked in the National Health Service, in careers related to surgery. The ages of the interviewees varied from 61 to 94, (average 76). Three were women. Fourteen had worked as surgeons, one as an anaesthetist, one as a theatre nurse and one as an anatomist.

The interviews were structured, asking standard questions about early life, family background, schooling, factors influencing choice of career and recollections of university life. To record personal memories of professional life we asked about training, how working conditions had changed over the individual's working

lifetime and the impact of a professional career on family and social life. We asked about how attitudes to women in surgery had been perceived during their working life. Finally we asked whether interviewees would recommend a life in surgery (or other career where relevant) to those seeking career guidance now.

Our purpose was to build up an interview archive to allow insights into a life in a career related to surgery from the 1940's to the 1990's. The paper explores some of the trends which emerge in backgrounds, experiences and attitudes.

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## **VETERANS TALKING ABOUT LIFE EXPERIENCES- A PILOT STUDY**

**Erin McCarthy (1); Ha Luu (2), Neal Dandade (2), Charles L. Bennett (2,3)**

**(1) Columbia College, Chicago, IL, USA; (2) Northwestern University Feinberg School of Medicine, Chicago, IL, USA; (3) VA Center for the Management of Complex Chronic Conditions, Jesse Brown VAMC, Chicago, IL, USA**

How can we improve the comprehensive health of our aging veterans? How can we best attend to their mental well-being as well as their physical health? These were the questions that motivated Dr. Charles Bennett, an oncologist at Northwestern University, to explore the possibility of developing a narrative intervention for his cancer patients at the Jesse Brown Veterans Administration Medical Center in Chicago. Dr. Bennett was familiar with work that was done with written narrative interventions but wanted something more appropriate to his specific patient population- veterans with higher rates of economic distress, low functional literacy, and lower education levels than the general population. Dr. Bennett became increasingly convinced that participating in an oral history interview would benefit the veterans at the VA.

Prostate cancer is the most prevalent cancer in males. There are a number of choices for primary treatment, including surgery and radiation. Patients are routinely followed with laboratory measurement of their prostate specific antigen (PSA) levels following primary treatment. During this monitoring, a number of patients experience a rise in their PSA, termed "PSA failure." A rising PSA can have psychological implications with potential decision satisfaction and regret because there is no medical consensus or treatment guidelines on how to treat PSA failure. The National Comprehensive Cancer Network (NCCN) advises prescribing treatment on an individual basis. Treatment options are vastly different, ranging from "watchful waiting" to medical/surgical castration. It is not clear how to best support patients during this time. Patients with PSA failure have reported substantial anxiety and have expressed enthusiasm about receiving psychological intervention to address anxiety as well as other psychosocial issues.

Recognizing the limits of a written narrative intervention among patients with below functional literacy, the refinement and application of an oral narrative intervention in the methodology of oral history was more appropriate to our study. During the fall and winter of 2007, ten PSA failure patients at the Jesse Brown VA participated in an oral history interview. Using NVivo software, content analysis of the interview transcriptions will be conducted to reveal new quality of life issues that previous patient consultations did not address. Finally, the study will look at the results of an anonymous follow-up quantitative survey designed to determine how the patient feels about not only the oral history process, but also his feelings about his illness and treatment.

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## **THE UNFORGETTABLE FORGOTTEN REMEMBERED. ORAL HISTORIES OF THE SPANISH INFLUENZA PANDEMIC IN IRELAND, 1918-1919.**

**Ida Milne, PhD student, Trinity College, Dublin.**

The tragedies and disruption to Irish family and public life caused by the effects of the Spanish influenza pandemic in 1918 and 1919 has not been recorded by historians. Historians of the pandemic in Ireland have limited sources to work with, as many official records were destroyed during the revolution and civil war.

One source that does remain to study this topic is human memory. Through a series of interviews with people who lived through the pandemic, and with people who were handed down stories about the pandemic, this paper will look at how Irish society coped with the illness at family and community level in the absence of any grand central plan from the soon-to-be abolished Local Government Board for Ireland.

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## **ORAL HISTORY AND THE PATIENT: INTERVIEWING ILLEGAL DRUG USERS**

**Dr Alex Mold, Centre for History in Public Health, London School of Hygiene and Tropical Medicine**

This paper will consider some of the issues that arise from using oral history when attempting to uncover the patient experience within the history of medicine. Based on research conducted as part of an Economic and Social Research Council funded project on the history of voluntarism around illegal drugs and the emergence of the drug user group, the paper will examine the process of interviewing a particular type of patient – the illegal drug user. Gaining former or current drug users trust was found to be vital to conducting a successful interview, and this could often be achieved by allowing interviewees to tell ‘their story’ in a way that they felt comfortable with. Such an approach, however, sometimes made extracting useful information more difficult. The researcher’s needs, therefore, have to be balanced with those of their subject. It is argued that this is a finding of relevance not just to interviewing drug users, but to interviewing patients more widely. If the patient and oral history are to figure in the modern history of healthcare, sensitive methodologies must be developed.

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## **OUT OF PLACE: EXPLORING ETHIOPIAN NARRATIVES AND ORAL TESTIMONIES INTO HOW THE RESETTLEMENT EXPERIENCE AND TRADITIONAL HEALTH BELIEFS IMPACT ON MENTAL WELLBEING IN THE ETHIOPIAN COMMUNITY IN LONDON.**

**David Palmer**

There is very little research on the resettlement experience of Ethiopian forced migrants in London, UK; this is particularly so in the case concerning causes of mental illness and access to mental health care provision. This paper is based on narratives undertaken with an Ethiopian priest, community leaders, Ethiopians working in the health sector and Ethiopian mental health service users. It will focus on the resettlement experience; its aim is to attempt to better our understanding of the issues. Analysis suggests that this group

face multiple forms of disadvantage including poverty, destitution, high unemployment as well as frustrations about immigration status, which impact on mental ill health. A further interesting dynamic is the inter-relation between a lack of 'help-seeking behaviour' due to cultural norms with the problem of a lack of access and engagement with western treatments. The efficacy of religious mechanisms and cultural activities were also strongly reported to bolster coping mechanisms. Perhaps most significant was concern raised about the evident increasing suicide rates amongst this group with many respondents suggesting a direct causal link between suicide and maladjustment in exile, looking beyond a simple medical explanation and therefore placing a greater significance on social variables. The methodology utilised for this research was developed with the specific interests/needs of the Ethiopian participants in mind, importantly taking cultural considerations and traditions as key to its development. The use of oral narratives offered an in-depth approach and provided many interesting and insightful experiential observations often overlooked or unheard when more formal interview techniques are adopted.

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## **AN ORAL HISTORY OF NURSES WHO CAME FROM MAURITIUS BETWEEN 1965 AND 1975 AND STAYED TO BUILD CAREERS IN THE NHS**

**Alan Pringle, Lecturer in Mental Health Nursing, University of Nottingham; Dass Musruck, Trauma Therapist, Nottinghamshire Healthcare NHS Trust; Ramgopal Teeranlall, Pro-Vice Chancellor, University of Stafford**

To tackle the nursing shortage in the 1960's an approach to recruitment was decided upon that had two distinct strands. In one, a sustained national recruitment campaign to attract new staff was launched in an attempt to recruit more British nationals into nursing. In the other the Government, the Colonial Office, the General Nursing Council (GNC) and the Royal College of Nursing devised a joint strategy to encourage people from the Commonwealth to apply for work as nursing auxiliaries and trainee nurses in Britain. This involved a mounting a huge overseas recruitment drive, with senior British nurses visiting Commonwealth countries and local selection committees being set up, to encourage people to come, targeting particularly the Caribbean, South Africa, Hong Kong, Malaysia and Mauritius.

This paper reports on the initial stage of a research project collecting oral histories of staff who came from Mauritius between 1965 and 1975 and who stayed to build lives and careers in this country.

At a time when the idea of bringing staff from abroad has created vigorous ethical discussion this project explores the impact the process had on the people themselves and on their families and on the economy of the island as a whole.

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## **FINDING THE LOST CHILDREN OF CRAIG-Y-NOS**

**Dr Carole Reeves, Outreach Historian, The Wellcome Trust Centre for the History of Medicine, UCL**

Craig-y-nos Castle, in the Brecon Beacons, served for forty years (1922-1959) as a sanatorium for children and young women, at a time when the incidence and death rate of tuberculosis in the industrial areas of south Wales were the highest in Britain. All hospital records have since been destroyed.

Ann Shaw, an artist and writer who was a patient from the ages of nine to thirteen (1950-1954), and I are constructing the first ever collective account by patients and staff of life inside a TB sanatorium. Over eighty oral histories have been recorded from ex-patients and staff aged fifty-eight to ninety-nine. These cover the entire period of the sanatorium's existence. Many people had never spoken of their experiences until interviewed for the project and it is clear that the Craig-y-nos story is extremely complex with both positive and negative long term consequences for survivors.

We have also collected over 1200 photographs, most of which were taken by the children themselves recording their daily lives. Photos were exchanged as keepsakes between friends. Photographic exhibitions have been held at Ystradgynlais and at Brecon. Swansea Museum will host a summer (2008) exhibition. A reunion in September 2007 was attended by 120 ex-patients, staff and their families. Some of the 'children' themselves, now parents and grandparents, are passing on their experiences to schools and local interest groups as well as collecting further interviews and memorabilia. We have recently obtained an Awards for All Wales lottery grant to produce a print-on-demand book.

This presentation will explore relationships between children and children, children and staff, and children and visitors. Deprived of family life (visiting was only once a month and a number of children were abandoned by their parents), the children looked to each other for emotional support through months of bed rest, traumatic procedures such as artificial pneumothorax and gastric lavages, and the deaths of close friends.

Ann Shaw's daily blog: [www.craig-y-nos.blogspot.com](http://www.craig-y-nos.blogspot.com)

Online exhibition: [www.childrenofcraigynos.com](http://www.childrenofcraigynos.com)

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## **CONVERSATIONS WITH CONSULTANTS: ORAL HISTORIES OF MEDICAL EDUCATION IN PROVINCIAL ENGLAND, 1930-1948**

**Jonathan Reinartz, University of Birmingham**

This paper draws on a number of interviews conducted during the early stages of research for a history of Birmingham's teaching hospitals. All 20 interviewees both worked in the city's teaching hospitals and attended its medical school. Originally conducted as an orientation exercise and in order to collect material for a commissioned history of the medical school and its associated teaching hospitals, the interviews are being reconsidered in the context of a new Wellcome-funded project which considers the history of medical education in provincial England, c.1825-1948.

The paper will consider individual narratives of medical education in a number of contexts. However, given the paucity of archival material relating to medical students, it is being used primarily to reconstruct students' experience of medical school. It will contrast experiences of students before and after the construction of a new medical school in the city (1938), male and female students, dental and medical, among a number of other themes. Finally, it will consider the way in which this particular source material adds to and challenges existing histories of medical education.

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### **LONGITUDINAL ORAL HISTORY RESEARCH ON HIV**

**Wendy Rickard, Institute of Primary Care and Public Health, London South Bank University,**

Through extended UK oral histories and photographs recorded in 1995-9 and again with the same people in 2006-7, this paper presents some themes and tensions about witnessing and experiencing the impact of treatment changes as time moves on. It explores memory, looking at how people describe their lives differently between when they thought they had months or only a few years to live, to when they outlive their parents, give birth to a new generation of children, live long with chronic pain or face existential crises and unrivalled uncertainty. The paper considers possibilities of longitudinal methods in health oral history and looks at the development of original project outcomes. HIV is entirely preventable. The paper ends by considering the use of archival data for HIV prevention and health literacy initiatives.

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### **THE TURN TOWARDS CARING: AMERICAN BUDDHIST CONVERTS CONFRONT AGING, ILLNESS, AND DYING”**

**Kim Lacy Rogers, Dickinson College, Carlisle, PA 17013**

Our understandings of life, health, and happiness are ultimately linked to our understandings of illness, aging, and death itself. In this paper, I will discuss perspectives drawn from the oral history narratives conducted with ten Buddhist converts between 2003 and 2006. All lived, worked, and practiced varieties of Buddhism in New Mexico, a state that has emerged as one of the magnet sites in the United States for new religious communities and New Age seekers since the 1960s. All of the narrators were involved in either career in alternative health care, in practices in psychotherapy, or in work with aged, ill, and dying people. Their narratives revealed that early experiences as religious and cross-cultural seekers had drawn them to Eastern and South Asian philosophies and experiences while adolescents and young adults. Encounters with Buddhism and training with Buddhist meditation masters and teachers had then propelled converts into further explorations of consciousness, abetted by the rather open and egalitarian atmosphere of many New Age movements in Europe and America of the 1960s and 1970s.

Buddhism's emphasis on embodied experience, on the finite limits of life, and the importance of preparation for death, led these seekers into chosen practices of healing and palliative care as part of their spiritual work. Often, life experiences with health and spiritual crises and loss reinforced the Buddhist emphasis of sitting with the experiences of pain and grief, and in using emotional, physical and psychic pain as opportunities for practice. Careers in health services, and care for the ill led them to reject the restorative or restitution

narratives of American health stereotypes, and to develop personal narratives that emphasized conditional survival marked by and chronic illness and intermittent life crises.,. Thus, the turn toward an expanded consciousness and questing returned these practitioners to a broadened appreciation of life limits, losses, and an acceptance of death. Although this acceptance of the finite nature of life and the inevitable losses of aging has been recognized by a number of life cycle psychologists and developmental theorists, it stands in marked contrast to the mainstream American emphasis on life-long vitality and medical miracles.

Among the narrators of this paper are Joan Halifax Roshi, Musai Sydney Walter, Ralph Steele, Selah Chamberlain, Dr. Henry Chigen Finney, Dr. Paul Oryo Steutzer, Kate O'Neill, Sabina Shultze and Sean Murphy.

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## **WORKHOUSE, WELFARE AND WATERSHEDS**

**Dr Annie Skinner**

Prior to the inception of the welfare state admission to a workhouse, or later public assistance institution, was usual for older people who became frail or ill and were without financial or social resources. These institutions instilled fear in local communities and admission represented a failure in society. Pioneers of geriatric medicine in the 1930s and 1940s, had raised the profile of old people's welfare, and after the inception of the welfare state, in general, facilities for older people improved. However, much institutional care was provided in buildings inherited from the poor law, and for many, admission to these institutions still carried a stigma.

By using oral histories of relatives and professionals who cared for older people before and after the inception of the welfare state, this paper examines a community's experience of ageing. The paper will: explore responses to shifts in welfare provision during the process of transition from poor law to welfare state; examine shifts in cultural attitudes towards state care for older people after 1948; and identify influences leading to admission to a local institution (a former workhouse) for old people before and after the welfare state.

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## **TREATMENTS OF HOMOSEXUALITY IN BRITAIN SINCE THE 1950S – AN ORAL HISTORY: THE EXPERIENCE OF PATIENTS AND PROFESSIONALS**

**Dr Glenn Smith, Prof. Michael King, Dr Annie Bartlett**

Objective: To explore the experiences of aversion therapy in Britain since the 1950s with people who were attracted to members of the same sex, and those professionals who administered these treatments.

Design: A nationwide study based on oral history interviews with 29 former patients of treatments for homosexuality and 30 health professionals who practised these treatments.

Results: A range of treatments were developed to make homosexuals into heterosexuals, the most common being behavioural interventions practiced on the NHS. Although some participants chose to undergo treatments instead of imprisonment or were encouraged through some form of medical coercion, most were responding to complex personal and social pressures that discouraged any expression of their sexuality. While many participants found happiness in same sex relationships after their treatment, most were left feeling emotionally distressed. With hindsight, professionals realised that they had not appreciated the influence of social context on sexual behaviour.

Conclusion: The definition of same sex attraction as an illness and the development of treatments to eradicate such attraction had a negative long term impact on many individuals. Social and political assumptions sometimes lie at the heart of what we regard as pathology and serve as a warning for future practice.

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## **UNHEALTHY PROFESSIONAL BOUNDARIES? PRIMARY CARE TEAM-WORKING AMONGST DEPRIVED POPULATIONS REVISITED**

**Graham Smith**

In 2001 I conducted a small study intended to develop strategies and methods that could be used to explore the attitudes and actions of primary care team professionals in relation to inequalities in health care. Inspired by testimonies from an earlier and larger oral history of general practice, I was especially interested in collecting additional data from rank-and-file general practitioners (GPs), practice nurses and practice managers working with deprived populations in the east end of a large city.

Participants were encouraged to discuss their memories and changes in their understandings of health care inequalities as well as their attitudes towards, beliefs about, and characterizations of changes to:

- professional boundaries and wider identities;
- the localities they work in;
- the populations they serve.

An initial analysis was made immediately after each interview to facilitate the comparison of differences and similarities of the narratives that were recorded. The recordings were fully transcribed, digitised and a coding frame developed. They were then compared with the earlier and larger collection of full life history interviews with GPs.

This proposed paper explores the testimonies again in a different way. Revisiting the testimonies in light of current discussions about (a) interdisciplinary working and (b) social remembering it is striking how powerful an approach oral history can be in understanding change and lack of change in how professionals work together. In listening to professionals reflectively reviewing their careers it is also chastening to realise that experiences of interdisciplinary working in difficult circumstances can lead to disillusionment.

## **HYSTERIA AND MAYHEM: THE SOCIAL AND PSYCHOLOGICAL IMPACT OF POLIO EPIDEMICS IN ENGLAND IN THE MID-20TH CENTURY**

**Sam Sneddon**

Ranking as one of the most terrifying diseases of the mid-twentieth century, polio killed and crippled children at a time when most infections caused merely a brief bout of sickness.

Several accounts from polio survivors exist, but these are usually autobiographical and often cathartic, focusing purely on individual experiences. Whilst the impact of the disease on family or friends may be considered, few accounts view the experience of an epidemic collectively. Here I want to explore reactions to polio of the individual, their family, their community and the impact these epidemics had both socially and psychologically.

Using oral accounts from polio sufferers, their relatives, and contemporary medical professionals, I intend to capture this slice of historical epidemiology, which may well be lost if their stories are not gathered in the near future. I am especially interested in the social construction of the disease, whether there were any disparities in the understanding of polio between society and the medical orthodoxy, and how these shaped health responses to the disease.

Chiefly, this paper describes initial pilot research conducted whilst working on a more general history and geography of poliomyelitis. It will explore the intended methodology for a future research project and provide some tentative conclusions regarding the impact of poliomyelitis.

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## **ORGANISATIONAL CHANGE IN THE NHS: THE MANCHESTER EXPERIENCE, 1980-2007**

**Stephanie Snow, Centre for the History of Science, Technology & Medicine, University of Manchester.**

This paper examines the ways in which the last 25 years or so of policy changes and organisational shifts across the National Health Service has shaped and reshaped patterns of administration, clinical care and services in and around Manchester. Since 1980, the NHS in Manchester (like other English regions) has been reorganised nine times. With each reorganisation, offices and archives have been disbanded and personnel have left the service. As a consequence the NHS has developed 'institutional amnesia' where the historical roots of past policies and service configurations have disappeared into the ether. Based on interviews with clinicians and managers who have played a key role in the region's health services, the paper will argue that organisational change has been detrimental at service level because it has broken down established networks and relationships. It will show how individual agency has been a powerful element in the implementation and translation of policy at local level and concludes by examining how the history of the NHS in Manchester and long-established social, medical and political networks have combined to shape the future direction of services within the locality.

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## **WHO CARED? THE SEARCH FOR THE QUINTESSENTIAL ELEMENTS OF NURSING AT ST. GEORGE'S HOSPITAL LONDON**

**Kath Start Deputy Dean of Faculty of Health and Social Care Sciences Kingston University & St. George's University of London; Carol McCubbin Project Manager Nurses Voices Oral History Project**

In our presentation we will use audio extracts from the collection to explore the complexities of and reflections on 'caring as an activity'

For many nurses this activity defines their profession and lies at the heart of their working lives. Evidence of the skill of nursing care and the impact of it often proves elusive to historians. . Even distinguished nurses engaged in formulating and carrying out nursing policy often left few personal papers. It seems that many nurses from the past did not perceive their work as having any historical importance and yet their influence on the lives and values of the nursing teams that they lead was profound

The Nurses Voices Oral History project is an oral history project organised with and by current and former members of an institution whose working experience spanned the period 1929-2003.

The project sought to record the memories, experiences and perspectives of nurses and the nursing care provided at this prestigious London teaching hospital and developed a method that would assist in the exploration of the quintessential elements of nursing at St. George's.

We have analysed the interviews to identify aspects of the life within the building and the notion that nurses have a significant contribution to make in defining the character of a hospital through their approach to care.

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## **BUSY HANDS, HIDDEN VOICES: AN ORAL HISTORY OF LABORATORY TECHNICIANS IN BRITISH MEDICINE**

**E M Tansey, Wellcome Trust Centre for the History of Medicine, UCL**

Laboratory technicians and their contributions are frequently missing from accounts of modern biomedicine: they are rarely included in staff lists or accorded obituaries and are often not acknowledged, or credited with co-authorship, in the scientific work to which they contribute. In an attempt to locate these hidden voices, this paper reports the results of a study that included oral history interviews with more than 80 former technicians from four principal types of laboratories (academic, service, research and commercial), which have revealed, inter alia, details of their backgrounds, training activities, pay and conditions, the impact of professional trade-union associations and formal training and accreditation procedures. This research has significant implications for analysing and understanding teamwork in the biomedical sciences, in addition to contributing a unique record of a previously neglected community within twentieth century biomedical science. Additionally we have built up a valuable archival resource that will be available to other researchers.

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## **“THE STAFF ARE MAKING CANDLES AGAIN”: 15 YEARS OF THERAPEUTIC RELATIONSHIPS AND PSYCHOTIC VIDEOS FROM A HOUSE IN BOGNOR**

**Trish Thomas, Joanne Williams**

House No. 48 ('the Activity Centre') was set up in 1985, as a mental health day service rehearsal for NHS 'Care in the Community'. Following decades of institutional life in the local psychiatric hospital, 25 people were transferred to supervised accommodation in and around the community of Bognor Regis, with access to the Activity Centre. Days were 'structured', to the extent that staff offered a timetable of activities, but clients reported that they would often walk past the craft room, commenting, 'The staff are making candles again', before joining their friends 'for a smoke' in the lounge upstairs. This paper concerns the period from 1991, by which time the referral procedure and timetable had become more open. 1991 was also the year in which the first of a series of PsychOTic videos – including *Casabogna* and *The Wizard of Bog* - were created to provide a humorous record of NHS care. This presentation, by current staff and clients, utilises oral history, videos and documents to look at changing attitudes, and the achievements of our group, trying to maintain a therapeutic environment where, 'No one is in charge', as long as 'everyone is in charge of themselves', listening, talking, and learning together.

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## **ILLNESS STORIES IN A MULTI-CULTURAL SOCIETY**

**Hanna Ulatowska, School of Behavioural and Brain Sciences, University of Texas at Dallas; Lauren Candia, Speech-Language Pathologist, UT Southwestern, Dallas**

This investigation emerged from interdisciplinary interest in illness narratives in sociology, anthropology and humanistic medicine. The main concern of these disciplines is that doctors use scientific expertise to listen to patients and understand their narratives of illness. Doctors must be aware of how their patients conceptualize illness and how they respond emotionally to its presence. This is especially important in multicultural societies where patients' narratives reflect cultural perceptions of medical care.

The purpose of this investigation is to explore how people describe major life disruptions caused by illness and how culture shapes their perceptions of that experience. Fifty illness narratives from three American ethnic groups: Caucasian Americans, African Americans, and Hispanics, were analyzed. Analysis was performed to identify the main themes which were then analyzed for evidence of cultural influences in the construction of illness. The analysis revealed the following themes: Emotional reaction to illness manifested as chaos and fear, change of identity and dealing with loss as a consequence of illness; identification of support systems during illness, i.e. religion, family; and attitude to medical profession, i.e. degree of trust and compliance.

The theme of emotional reaction to illness was found in most narratives of all ethnic groups, attesting to the commonality of human plight to disruption of life. Cultural differences were found in the themes of religion and family which occurred in the majority of African American and Hispanic narratives but not in the Caucasian American narratives. Mutual understanding between patients and health care professionals is

based on the recognition of these cultural components. Moreover, compliance requires awareness of the importance of the patient's perception of the disease.

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### **COLLECTIVE BIOGRAPHY: THE PSYCHOSOCIAL AND THERAPEUTIC COMMUNITY LEGACY OF ANNIE ALTSCHUL, HILDEGARD PEPLAU AND EILEEN SKELLERN**

**Dr Gary Winship - Associate Professor, Centre for Human Relations, School of Education, University of Nottingham**

This paper reports on research that renders a collective biography of the contributions of Annie Altschul, Hildegard Peplau and Eileen Skellern, summarising the strands of convergence in the careers of the three best known founders of the modern profession of psychiatric nursing in Britain. Even though it is well known that Altschul, Peplau and Skellern were influenced by the development of psychosocial, group and psychodynamic approaches, it is often overlooked that all three had careers rooted significantly in the therapeutic community and milieu therapy movements. Based on recorded interviews and previously unpublished correspondence with various witnesses including Annie Altschul, Hildegard Peplau, Henri Rey, David Russell and Brian Woollatt, as well as analysis of texts and biographical data, this paper brings the largely hidden dimension of personal memory and experience into play to offer a fuller and more accurate account of the traditions of psychiatric nursing and therapeutic community practice in the UK, enabling nurses to re-claim a specific lineage of psychotherapeutic practice in their profession.

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### **LIFE STORIES IN END OF LIFE CARE: ESTABLISHING AN ORAL HISTORY SERVICE IN A PALLIATIVE CARE UNIT**

**Dr Michelle Winslow, Ms Kate Walsh, Dr Bill Noble, Academic Unit of Supportive Care, University of Sheffield**

This paper discusses a project delivering an oral history service in a palliative care setting which is enabling individuals in end of life care to produce audio life story recordings. We aim to provide a life story service for patients that is capable of enriching their experience whilst receiving palliative care.

We reflect on the potentially important role of life stories amongst people with life-limiting disease. At certain life stages many people feel the need to explore their own life-story and draw meaning from it. Particularly significant is the process of remembering, which has the capacity to reinforce identity at a time when life circumstances are rapidly changing (Bornat 1994). A strong motivation for patients who record life stories can be the opportunity to do so as a record for their families. A life history interview can also help patients feel appreciated as people, and assist practitioners in understanding patients more fully.

Development, delivery and evaluation of the service will be considered, with issues in conducting oral history interviews within a challenging end of life care environment. A particular focus will be on the interviewer/interviewee relationship as both create an audio record, often intended for an audience after the narrator's death.

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## **THE ESTABLISHMENT OF THE NOTTINGHAM NURSERY NURSING TRAINING CENTRE**

**Val Wood, Senior Lecturer on the BA (Hons) Early Childhood Studies programme at the University of Derby.**

This presentation outlines the establishment of the Nottingham Nursery Nursing Training centre in 1947. It explores the initial training and early careers of the first cohort of students, employees of the war time day nurseries in the city.

National regulation of training for childcare workers, achieved in 1945 through the NNEB (Nursery Nursing Examination Board) qualification provided scope for the professional recognition of women deployed in a range of day care settings for children. These settings were initially overseen by the Ministry of Health and in Nottingham were retained in the post war period despite the withdrawing of government financial aid in 1945. Eventually they transferred to the local authority to become social services day nurseries and at a later date family centres.

The presentation draws upon the oral testimony of women who studied at the centre in the late 1940s early 1950 supplemented by photographs. The presentation will explore the changes in post war childcare provision and the relationship between health, social care and education as stakeholders in the NNEB qualification in one urban locality during this period.

There are very few recorded histories of women who trained as nursery nurses and the presentation considers the reasons for this and hopes to prompt further discussion with conference participants.

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## **"THAT'S A SIN IN MY EYES": SETTING THE RECORD STRAIGHT - AN ORAL HISTORY OF HIV AND HAEMOPHILIA**

**Krista Woodley, Research Fellow, University of Brighton**

In the 1980s over 1200 people with haemophilia were infected with HIV through contaminated medical treatment in the UK. The Haemophilia and HIV oral history project conducted oral history interviews with people affected directly by this: people living with haemophilia and HIV, their families, and families of the many people who have died. Many interviewees took the opportunity to challenge what they saw as a history that had been "re-written" by the government about the background and causes of the events:

"I've feared for many years that what gets read in future generations about history won't be factual. It'll be what the government want you to believe or want the general public to believe. And that's a sin in my eyes, because history is the only way that we'll proceed in life."

The interviews were often emotional. The project used a support framework for both interviewees and the project team, including bereavement counselling for interviewees, which was readily accessed and valued. The support framework established provides a model of good practice for projects involving traumatic life histories.

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**CITY SICKNESS: ORAL HISTORIES OF HEALTH AND ILL-HEALTH IN THE MUSEUM OF LIVERPOOL**  
**Georgina Young, National Museums Liverpool**

How can urban history museums use oral history to interpret caring, health and illness? The Museum of Liverpool will open in 2010 with health and ill-health as one of the core subjects of its People's City Gallery. The name of the Gallery signals the Museum's intent to put people at the fore of its interpretation and use oral history and lived experience to explore the complex relationship between the city and the health of its people in the 19th, 20th and 21st centuries.

Liverpool's rapid urbanisation in the 19th century prompted significant firsts and innovations in public health and the city environment continues to impact on the lives and deaths of Liverpoolians now. The Museum of Liverpool will gather and present testimony from health workers, policy makers and service users to examine contemporary issues in the context of the history of health and ill-health in Liverpool.

This paper will explore the oral history collecting methodology that the Museum of Liverpool team has used to identify and gather stories about caring, health and illness in the city within living memory and discuss the interpretive strategy that will frame them in People's City.