CHAPTER 25

ETHICAL CHALLENGES IN THE ORAL HISTORY OF MEDICINE

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It is a mark of the contribution of oral history to the history of medicine that studies located within living memory are open to criticism if they fail to include oral history. Paula Michaels, in a review of a history of modern Chinese medicine, noted that

> an oral history component to this project would no doubt have yielded a less passive, more vivid picture of what it meant as a lived, everyday experience to study and practice medicine in early Communist China.[1]

However, oral history's contribution to the history of medicine is a complex one, and we will highlight this in an exploration of the history of professionals in medicine and medical professions, and in the emergence of the patient's story. We subsequently consider the problems of "shared authority": working with professionals when interviewee "power" is a factor and, conversely, our relationships with "patients" who may be viewed as "vulnerable" oral history subjects. Interwoven throughout this discussion is the question of ethics, and we raise some of the ethical challenges that arise within the history of medicine.

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The History of Professionals in Medicine and the Medical Profession

Part of the reason for the popularity for oral history among modern historians of medicine is the long-established use of biography and life history material in the subdiscipline. Before the 1970s, most medical histories were written from the perspective of men of importance—and the occasional woman—discovering new treatments and cures. In the mid-1950s, for example, Ralph Major published *A History of Medicine*, in which he described how "great" men "found" medical knowledge in a history that was an unrelenting intellectual progress from superstition through enlightenment to technological discovery.[2] While Major acknowledged the broader historical contexts in which his heroes operated, he presented historical change as a result of individual endeavors, rather than as a result of wider social history. In such a context it is unsurprising that oral history, even as early as 1960, had been adopted as a method of producing autobiographies of those great men.[3] By the early 1970s, though, Saul Benison, a pioneer oral historian and longtime member of the Association of American Historians of Medicine, was suggesting that the use of oral history in making hagiographies had its problems, since the focus remained firmly on the individual contribution to the progress of medicine.

The belief that the history of medicine was simply one of individual clinicians and scientists making medical discoveries became challenged with the rise of social history. In Britain, members of the *Society for the Social History of Medicine*, established in the late 1960s, combined an interest in the history of public health with social science methods, including social history. In a series of articles, Thomas McKeown argued, in what became known as his "thesis," that medicine makes no significant contribution to reducing the death rate when compared to the impact on the death rate of improvements in economic and social conditions.[4] It was a startling claim that has been subsequently the subject of periodic debate, but importantly it directed the attention of historians of medicine outwards toward broader historical change.

By the mid-1960s, historians of medicine were beginning to be influenced by the development of social history. While medical professionals like McKeown continued to dominate the subject area, often claiming that their clinical knowledge provided particular insights, it was academic historians and social scientists that set the intellectual pace. They were beginning to explore how social historical contexts shaped medicine, arguing for example over the significance of the French revolution in the rise of hospital medicine, which also marked a change in doctor-patient relationships.[5]

The study of individual contributions was giving way to examinations of the social forces that produced change in medicine. For many historians, this meant studying the rise of specialization and emergence of professions. As John C. Burnham later noted, "the idea of profession changed the writing of medical

history."[6] It also prompted many contributions to the growing critique of medicine and medical professionals that arose, at least in part, from the women's movement and as a backlash against medicalization; the turning of the conditions of everyday life into medical issues, and some have claimed a corresponding social control by health professionals.[7]

For oral historians, including Saul Benison, subjectivity was becoming increasingly important. An advisor on oral history for the U.S. National Library of Medicine, Benison in 1967 published an oral history memoir of Tom Rivers, a pioneering virologist.[8] In praising the book, a reviewer in the *American Historical Review* proclaimed that Benison "has clearly produced a new kind of historical document that is at once the memoir of an important scientific figure and the creation of a historian-interviewer who has framed all the questions and set the historical problems." Within a few years, Benison was noting:

> Actually, the collection of half-truths, myths, and prejudices is as valuable for history as pristine truth if they are appreciated and evaluated adequately. Often they lead to contradictions. In fact it is the contradictions that emerge from such material which pose the nicest historical problems.[9]

Understanding the significance of subjectivity would not only lead to identifying half-truths, but also contribute to understandings of how medical knowledge was historically and culturally made. By the 1980s, the construction of medical knowledge had become a central concern to historians of medicine. It was increasingly noted how the various medical professions and specialties differed in their views of the patient's body, of diseases, and of medicine itself.[10] By the early 1990s, for example, Lindsay Granshaw was writing about the differing perspectives of surgeons, anatomists, and the rise of the specialty of rectal surgery.[11]

Among the theories of knowledge that have proved important to historians of medicine was social constructionism, in its many varieties. For Ludmilla Jordanova, social constructionism in the history of medicine had a particular character: a sympathetic understanding of the "actors" whose beliefs and actions were shaped by professional interests, power, technology, and the content and contexts of their lived experiences. In this manner she identified the significance of the way language was used in medicine. For Jordanova, the prize was "A historiography capable of explaining the imaginative reach of ideas of health, healing, and sickness." Such a historiography was set to produce an antimodernist or antiprogressivist narrative that would be shared with other historians.[12]

Social constructionism was used to counteract what its advocates saw as scientism and Whig-like historical practices in existing accounts. But adopting an explicit position that privileged society as an explanatory category (rather than medicine or technology) signaled a particular disciplinary orientation. The history of medicine has always consisted of constituencies that are somewhat similar to those that have existed within oral history, what Dorothy Porter called "An eclectic mix of amateur and professional historians."[13] Adopting theories that emphasized

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An example of the approach in action can be found in Roger Cooter's application of a Weberian analysis to war and medicine:[14]

> If the relationship between war and modernity has been subjected to at least a measure of thoughtful and theoretically sophisticated sociological and historical analysis, the same cannot be said of the interaction between war and medicine... until very recently, this literature has been overwhelmingly dominated by practitioner-centred accounts of how medicine has benefited from and been advanced by war. Such triumphalist reckonings are as implicitly militaristic as they are naively positivist and partial.[15]

Cooter's explicit argument was that medicine did not simply service modernity. Instead, it was a midwife of modernity, helping to bring modernity into being. He was also implicitly arguing that the history of medicine cannot be left to clinicians, working or retired.

Why this should be important to oral historians of medicine is partially opportunistic. The way we collect and analyze subjective narratives lends itself in many ways to an approach that emphasizes the social. It also provides a number of challenges to the oral historian working in this area. These include locating the biographical narratives we collect within wider social historical contexts. As oral historians, our insights into the making of memory and consciousness equips us to undertake this task. We are practiced at gathering and using conflicting accounts; as well as how we relate to those we interview.

In the mid-1990s two major reviews of oral history in the history of medicine were undertaken: one in Britain by Paul Thompson, and the other in the United States by Nancy Tomes.[16] Thompson identified a range of different approaches being adopted, although he found that a great deal of oral history was being utilized in a supplementary manner. That is, oral history was simply an additional source used to illustrate or support existing documentary evidence. Thompson could identify few examples of oral history being collected to challenge existing documentary-based accounts. Instead, he found that oral histories were being collected to explore specific issues in the history of medicine, and included in-depth systematic auto-biographical approaches, mainly of doctors, as well as whole life history interviews. Such an approach was also beginning to be adopted in social science-type surveys.

In the United States, Tomes identified a similar pattern and added that oral histories exploring the histories of particular organizations, including hospitals, were much in evidence, as were projects documenting events and innovations, including the development of antibiotics in the 1950s. Somewhat inevitably, there were studies of the lives and works of leading medical scientists and clinicians. But she also noted attempts by some of those who were using oral history to demystify structure and bureaucracy, and so challenge ideas of "progress." While such histories continued to place emphases on human agency, there were also attempts at correctives, such as investigating the relationship between individuals and the informal "colleges" that

had been thus far hidden from history. There were even attempts to highlight the problems of particular developments, including the perils of medical specialization. In Tomes's survey we can see the growing convergence around subjectivity between the projects of oral historians and those of historians of medicine—a movement to include histories of the professions as well as medical professionals.

Repeating the surveys by Tomes and Thompson would now be an enormous task. Since 1995 there has been an explosion in the oral history of medicine throughout the world. Yet it is worth identifying a few examples of how the approaches identified by Thompson and Tomes have continued and developed. It is also worth noting that there have been a number of new developments.

In spite of leading historians of medicine being ever more critical of hagiographic projects, "greatness" and "progress" continued to be celebrated, especially in North America where testimony-based accounts about individuals abound.[17] It is particularly ironic that oral history continues to lionize the individual lives of medical grandees, when so many oral historians remain committed to history from below, and providing a voice to those who are too often hidden from, or by, historians. There are also publications that have attempted to go beyond this approach by concentrating on specialties, such as Allen Weisse's *Heart to Heart: The Twentieth-Century Battle against Cardiac Disease: An Oral History*.[18] There are also signs of unease among some of the biographers, such as Shelley McKeller, who brought a fine sense of irony to her portrait of the late Donald Walter Gordon Murray. Based on testimonies from his colleagues, the picture that emerged was of an audacious, dazzling, accomplished, flawed, and grumpy Canadian surgeon. She expressed her disquiet memorably in her introduction by describing her work as "dead white guy history."[19]

Ronald Bayer and Gerald Oppenheimer carried out an oral history study with doctors in the United States whose lives and careers were dominated by the AIDS epidemic, from the 1980s to 2000. They amassed important perspectives but came to understand that stories were multidimensional reflections on the epidemic's history. As interviewees spoke of events, they divulged personal meaning that changed over time as individuals gained experience, knowledge, and authority. In relating their personal interpretations of the significance of their experience of AIDS, contributors bore witness to horrors, not only in relation to patients and doctors but to societal stigma and taboo—including from within their own profession.[20]

Using oral history to supplement and inform documentary evidence has remained important, especially in the underresearched area of medical and health policy. Yet testimonies have been increasingly used with greater sophistication, most notably in Virginia Berridge's *AIDS in the UK: The Making of Policy, 1981–1994*.[21] In the historiography of AIDS/HIV, the study upon which this book is based on may be unique. The AIDS Social History Programme charted a national health crisis over time, remained unaffiliated from policy and pressure groups, and used oral history in the absence of government documentation. Berridge explored the challenges that the study faced, which included questions of relevance. Between 1987 and 1989 the collection of oral histories about policy decisions could have been seen as a frivolous diversion from alleviating suffering and searching for treatments.

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Mainstream medical sociology was attacked for "lacking in practical application, more concerned to develop general sociological theory than to have an impact on the course of the virus spread." One way around this was for social scientists to claim their research as immediately policy-relevant. As a result, as Berridge has noted, there was a more general "revival of positivist social science."[22]

Other research further has reinforced the significance of understanding policy through oral history without adopting a positivist position. This has included exposing the reasons for policy failure. An excellent example of this can be found in a history of the 1964 typhoid outbreak in Aberdeen, Scotland, by David Smith, H. Leslie Diack, T. Hugh Pennington, and Elizabeth M. Russell.[23] They described the complex relations between the health professionals, the media local authorities, and central government, and their different responses to the event. They convincingly argued that the outbreak reinforced regulatory approaches to the education of consumers and diverted attention from policy-making processes, as well as reinforcing the position of civil servants and their experts rather than politicians. Their conclusion is especially significant in understanding why subsequent large-scale food poisoning incidents occurred and why they were dealt with in the ways they were.

Oral history also continues to be used as correctives. Even when there is a vast amount of archival data, oral historians have shown how testimonies can provide alternative accounts. Anne Perez Hattori, for example, used evidence from Chamorro-speakers to provide a cross-cultural description of the U.S. Navy's health policies in Guam that was missing from the administrators' extensive archives of sanitation and hygiene.[24] Similarly, oral history has offered insights into how different communities made use of popular preparations and used pharmaceuticals and technologies in ways that manufacturers had never intended, including the self-treatment and "medicine" of isolated communities, such as those in Newfoundland.[25] Similarly, in examining the affect of birth control on women's lives, Kate Fisher has demonstrated the importance of oral history in understanding contraception in cultural and social contexts, particularly the interrelationship of gender and social class in the provision of contraception services.[26]

The Patient's Story

In addition to the impact of medicine and medical science on sections of the population, oral historians and historians of medicine have increasingly become interested in the patient's story., Roy Porter, one of those who set out to rectify a perceived imbalance in the history of medicine, observed that "We have histories of disease, but not of health, biographies of doctors, but not of the sick."[27] It was a complaint that oral historians were already familiar with. The number of oral histories of patients prior to 1985 was small and likely to be found in "health" in a broad sense rather than in medicine. For example, the journal *Oral History* has carried

articles on birth control and on opium use, but there was precious little else in the way of patient accounts and testimony.[28]

The delayed arrival of the patient in the historiography of medicine was not simply a matter of forgetfulness or ignorance. Not only had Roy Porter needed to locate new sources of information pertinent to the story, but he had to reject at least in part the idea that the "patient" was a construction of medical power. Porter's call for patient history was taken up by Flurin Condrau who commented that "how to write the patient's history, how to deal with subjectivity, experience and perhaps even choice, is still very much unchartered territory for historians of medicine."[29]

Oral history studies increasingly began to address the invisibility of recipients of medicine in the history of medicine, and oral histories of patients have rapidly grown in number. These include the stories of people who experienced particular diseases and treatments. A fine example is Sanjiv Kakar's history of leprosy sufferers and missionary medicine in British colonial India.[30] Other studies have involved patients in palliative care, documenting memories with people aware of their incurable medical conditions.[31]

While these approaches tend to display sensitivity to wider social historical contexts, they have not challenged medical constructions of "the patient" in the same way as those oral historians who have identified inappropriate medicalization and oppressive uses of medicine. Some of these counternarratives have even been published in clinical journals. Most notable is an article in the *British Medical Journal* that recounted the medical treatments of homosexuality in Britain from the 1950s on, drawn from testimonies of former patients.[32]

As well as people whose sexuality was diagnosed as unhealthy, oral historians have collected the life stories of those who suffered less from their disabilities and more from medical interventions (iatrogenesis). For example, Claudia Malacrida recorded the memories of survivors of a total institution for "mental defectives" in the province of Alberta, Canada.[33] She has noted how difficult that project turned out to be, and how barriers confronted her at every turn. She was initially denied contact with the survivors, and then refused access to the institution and its archive. Despite such barriers, Malacrida was able to record "rich and powerful testimony to the brutality of institutionalization" and to produce "an emancipatory history from the perspectives of those most oppressed by disability policies and practices." Kerry Davies's history of mental illness described how patients have been silenced by institutionalized systems but nevertheless found a way to express an "acceptable" voice via frameworks of loss. This loss was not solely through the effects of illness but also through a curtailment of liberty and their objectification as "the patient." In such narratives, there is a development of the self as a patient, survival, self-discovery, and a regaining of personal agency.[34]

Since the mid-1990s, oral historians have recorded testimonies with those who have suffered at the hands of medicine, and have also sought to promote changes in care. The Open University's pioneering Social History of Learning Disability Group has been especially active in making change. Their publications focused on the memories of people with learning difficulties, such as *Good Times, Bad Times: Women with Learning Difficulties Telli*

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Women with Learning Difficulties Telling Their Stories, and later included those of families and careers, including *Witnesses to Change: Families, Learning Difficulties and History*.[35] Both family members and those with learning difficulties were shown as active agents of change who challenged inadequate and poorly conceived health and social care. The result provided new ways of understanding disability in the past and new ways of influencing future policy. This has been reinforced by the group's use of oral evidence to argue that people with learning disabilities are able to direct their own lives as fully active members of their communities. The group has extended its work and collected accounts of self-advocacy from Australia, Britain Canada, and Iceland, which have been subsequently published as "testimonies of resistance."[36]

Oral history as a form of empowerment and advocacy has been taken up by other groups. Scope, a British national disability organization, has completed a pioneering oral history of people with cerebral palsy. Its monthly podcasts, *Speaking for Ourselves*, have drawn upon 230 hours of recorded testimonies by people with cerebral palsy over the age of fifty, interviews that have been deposited for public access with the British Library Sound Archive and the Wellcome Library.[37] The photographer Karen Hitchlock combined portrait images with oral testimony to give people living with multiple sclerosis an opportunity to express their own unique experience of living with MS, and of being a participant in research trials. She has cited the well-known expression that "science knows no boundaries," and stated that

> in fact scientists are very good at setting boundaries, obeying protocols and focusing on results. It is this type of knowledge that seems to matter to the scientific community. It is impersonal, public, productive and verifiable. But there is a weakness in this approach as it allows scientists to become more and more abstracted from their clients and their client's reality. It also encourages a dispassionate and detached approach, which is in conflict with the clinician's dual role as the objective researcher and the caring clinician.[38]

In their narratives of MS, participants raised issues important to them, finding common ground and mutual understanding of the impact of disease on their lives. Presenting stories in photographs and narrative encourages a reappraisal of the relationship between the research scientist and research volunteer, producing a shift of values that draws away from the analytical and impersonal method and moves toward personal experience.

The Nurse's Story

Oral history has long been used to document not only the lives of leading clinicians but also rank-and-file practitioners, especially those belonging to the "Cinderella" professions, including general practice and gerontology.[39] However, it is the history of nursing that has attracted the greatest use of oral history work. There are now

oral histories of numerous nursing specialties and many different aspects of nursing experience have been collected. In the United States, Jacqueline Zalumas used oral history for a history of critical nursing.[40] David Russell carried out a study of mental health nurses.[41] Duncan Mitchell and Anne-Marie Rafferty considered the work of learning disability nurses after the Second World War in the UK.[42] Sheryl Brennan described the "contradictory stories" that a cohort of nurses in Australia told when they recalled their 1960s training.[43] Helen Sweet and Rona McDougal detailed the role of community nursing in primary healthcare in Britain.[44] Challenging the assumption that nursing is an exclusively female occupation, Carolyn Mackintosh drew on oral history sources to present a history of men in nursing in Britain.[45] Other projects have established such archives as Nursing Voices in England and the Royal College of Nursing Archive in Scotland.

The Heritage Lottery Fund, a major funder of oral history projects in the UK, has supported a number of hospital-based projects, which combined testimony of nurses with patients, doctors, and other staff. Some of these include a project on Muckamore Abbey Hospital, Northern Ireland (2002); a community initiative to tell stories surrounding groundbreaking medical developments in Liverpool's Aintree Hospital (2005); the Royal Albert Hospital Archive recording the heritage of a long-stay hospital for people with learning difficulties (2005); the All Saints Heritage Project on the contribution to the Health Service in Wolverhampton of Black and Minority Ethnic communities working at the Royal Hospital (2007); Hospital Histories on Dartford isolation and mental hospitals (2007); and the Doncaster Gate Hospital Heritage Project, recording the history of a Rotherham hospital as it approached closure (2008).[46]

The Problems of "Shared Authority"

Oral history in medicine has raised a number of ethical issues. Until recent years, as the South African oral historian Philippe Denis has highlighted, the tendency for the humanities in most universities and research institutions was to view the ethical conduct of research as a matter for the conscience of the individual researcher. This has changed, and there is a growing movement to regulate researchers' use of private material and their relationships with the researched, as well as to develop ethical guidelines to reduce the risk of harm to participants in an interview situation.[47] Issues such as whether oral history is always good, whether interviewees always want to participate, why people tell their stories, what stories are told, what tensions exist around professional interest and patient autonomy, and the nature of the relationship between interviewer and interviewee are familiar to oral historians in any discipline but are discussed here in the context of medicine. Oral historians are increasingly required to be accountable to medical ethics committees about their research and their relationships with medical practitioners and patients.

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Where oral historians seem to be at their most comfortable in the history of medicine is confronting challenges of working with the disempowered, the marginalized, and those with very little presence in the historiography. "Shared authority," to use Michael Frisch's phrase, sees interviewer and interviewee working together reflexively to produce understandings of the past.[48] We have provided examples of projects—and there are many more—in which testifying has facilitated including those with learning difficulties, mental health problems as well as people who have been stigmatized by medicine. Great care has been taken to create partnerships and alliances with the less powerful. Such projects are often reflexive, as for example in the research of AIDS/HIV survivors by Wendy Rickard.[49]

In 1997, a notable development in the study of the history of medicine in the UK occurred with the commencement of the Wellcome Witness seminars. The seminars invited significant figures in twentieth-century medicine to gather together and discuss specific discoveries or events in recent medical history. Under the guidance of Tilli Tansey, they have covered a range of subjects including drugs in psychiatric practice, the development of cancer pain relief, and "Superbugs and Superdrugs: A History of MRSA."[50] Irvine Loudon, a historian of medicine, called these "oral history at its best":

> Regardless of your own areas of interest, all the volumes make compulsive reading because the participants tended to 'let their hair down' and talk more freely than they would have at a scientific meeting. They discussed openly the hidden realities of the evolution of medical practice and medical research. But the Witness Seminars are more than just fun to read. They are, primarily, important historical records.[51]

The immediacy of working with people whose histories we seek to (re)present has its own challenges in the history of medicine. Oral histories of policy, patients, and practitioners can produce particular difficulties in terms of "shared authority," which oral historians working elsewhere are perhaps less familiar with. This has been largely because medicine is a powerful social force in which practitioners, policy makers, and patients exercise differing degrees of power dependent on time and place. The relationship between historians of medicine and medical power or authority has also changed over time, moving toward more critical approaches that have attempted to place medicine within broader social and historical contexts. Oral historians have to make difficult choices about not only *whose* story should be told but *how* that story should be told.

Projects seeking to interview medical and health professionals during their career life will often come up against such sensibilities, particularly when their words will be read by an audience of their peers and possibly future employers. A project documenting the history of a London hospice encountered a number of concerns among professional interviewees, not least relating to representation of themselves and the organization.[52] Interviewees carefully checked their transcripts for information that might cast themselves or the hospice in a negative light, in addition to correcting "bad" grammar. The latter was negotiated with interviewees

to retain verbatim speech as far as possible, but preserving candid extracts of speech for publication was more problematic. A number of reservations could be allayed through reflexive communication with interviewees, but not all.

There may be a broader problem here in terms of differences in the way oral historians might see the history of medicine in contrast to the views of those they interview. The interests of historians can conflict with the ways in which men and women steeped in a particular view of medical history want to be remembered. In working with former clinicians or medical scientists, it is often difficult to contextualize their individual contributions to their professions, especially when such accounts neglect to mention broader structural and cultural changes. Prompting for details of such changes in interviews can lead to a sense of frustration, even insult, among interviewees.

Even when conducting an oral history with rank-and-file practitioners, it is sometimes difficult to produce a question or an account that satisfies participants. Graham Smith in his interviews with family doctors in a Scottish town noted how some participants were reluctant to discuss family and home life, or indeed to even be interviewed at home. Robert Perks highlighted a similar problem arising from interviews with business professionals, explaining that an unwillingness to reveal the real self behind the work persona was perhaps a survival mechanism in a competitive working environment. This should be an equal consideration in interviews with medical professionals.[53]

The general practitioners in Smith's study were also eager to keep the focus on their individual contribution to the profession and to keep "hidden colleges" hidden. During the interviews it became clear that some practices were able to access different secondary care for their patients with differing degrees of success. This was dependent on a variety of social networks, but exploring these networks was problematic. One doctor was extremely reluctant, even hostile, about talking about her social life, which included a Highland dance society. As it turned out, she was able to have older patients seen by the local gerontological service, when other family doctors struggled to do so. The service was widely perceived to have been overstretched at the time and difficult to access. That the local gerontologists were also enthusiastic Highland dancers proved an important factor: membership in the dance society was in short more important than clinical reputation in the successful onward referral of patients.[54] Drafts of the story of the social networks that shaped the way medicine was practiced, along with all other potential publications, were sent to all general practitioners who participated in the study. This encouraged additional information but also led to some puzzlement. Even when the interviewees saw the impact of the social, including family and friendships, in the ecology of practice, theirs was a grudging acceptance. While the tension could be creative and agreement could be reached, at times it felt less like "shared authority" than a mutual standoff.[55]

The lack of recognition of social factors in the history of medicine has a particular significance when medical ethics committees operate a governance policy, as they do in Britain. Under governance rules, researchers can be denied access to medical professionals if it is deemed that the research is not a good use of professionals' time.

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In a sphere in which such power can determine the significance of knowledge, it is important that clinicians are reminded of the social contexts in which they operate.

John Crellin, in a review of *History of Hospital Infection*, argued that oral history has the potential to raise important ethical concerns. He noted that oral history may point up ethical issues "such as hospitals wanting to keep infection data confidential amid the need for informed consent for patients.[56] It is easy to underestimate medical authority, and all too often medical ethics in different countries can silence voices. As mentioned earlier, access to mental health survivors in Claudia Malacrida's Canadian study was initially denied through legal guardianship orders.[57] The very powers intended to protect patients can be used to protect abusers and their institutions.

Interviewing those in receipt of medical care also brings the broader implications of using oral history in medicine into sharp perspective. In end-of-life care, oral history has benefits beyond recording histories, including sense of worth, finding meaning in life stories, and the projection of an identity as a legacy for family. Oral historians have also found remembering in a health care setting as having the capacity to build social relationships among patients and care providers, and to maintain identities where people are faced with loss and change.[58]

There are times when interviews can be potentially harmful, even dangerous. Farhat Manzoor, Greta Jones, and James McKenna explored ethical and professional dilemmas that typified nursing practice in Northern Ireland during the "Troubles." They based their work primarily on testimonies during the conflict relating to moral questions, choices and problems.[59] Moral and ethical issues include concerns about anonymity and permission to use material in published research. A less definable and more complicated issue is the potential harmfulness of an interview caused by recall of painful and distressing events. No oral history interview on any topic is free of such harmful possibilities since sharing both good and bad times in personal stories can bring traumatic memories to the fore. However, the potential to uncover painful stories that do harm is likely to be greater in the history of medicine.

There are circumstances in interviews in medicine when it is clear that an interviewee is in an emotionally vulnerable situation due to the nature of the topic, such as the palliative care project interviewing people with life-limiting diagnosis.[60] Obviously, a number of ethical considerations are part of working with the extremely ill, with an overriding question being whether oral history is ever therapy. Recall in interviews can have a therapeutic impact, but there is a difference between "therapeutic" and "therapy." Therapeutic reflects the beneficial process of talking at length with an empathetic listener, while therapy is an intervention that intends a health outcome. Leslie Lowes and Paul Gill have observed the cathartic outcomes that result from providing a nonjudgmental and confidential environment in which patients can talk in an open and unhurried manner with someone who is genuinely interested in what they have to say.[61] Since the interviews take place in a hospital ward, patients might also harbor concerns that nonparticipation could have negative consequences for their care and relationships with health professionals. Hence, oral historians make efforts to dissociate themselves from the clinical team

and informed potential interviewees that there no care-related relationship existed between the two.

Interviews carried out in a palliative care setting remind us that oral histories have focused on lived lives rather than dying. Interviewees talk of themselves prior to the disruption of their lives by serious illness, before disease irrevocably altered their lifestyles and how they are viewed by others. There have been exceptions, particularly when interviewees have negative experiences of health care. Narratives with people facing death from cancer contain consistent themes as the moment of diagnosis, subsequent treatment and sufferings, and the experience of medical interaction.[62]

In end-of-life interviewing there is an imperative to consider the bereaved and to have discussions with the interviewee about including oral material that could be potentially distressing for a listener. Such information might include accounts of extramarital relationships and children not knowing their adopted status. The notion of sensitivity is as subjective as the interview itself; hence it is desirable that interviewees listen to their interview as soon as possible after it has been recorded, to make sure that they are comfortable with their account. In circumstances where an interviewee is uncomfortable with their recording, interviewers must heed their instincts and suggest editing of problematic material, an ethically sound approach although it violates the oral history principle of retaining an unedited copy.

Nigel Hunt and Ian Robbins have reasoned that in developing a life story narrative the teller is more likely to be able to come to terms with traumatic life events. They view narrative as a critical component in attempting to find ways of dealing with traumatic information. Narrative development is an effective way of reducing the emotional stress of traumatic memories that flood into a traumatized person's mind in an uncontrolled fashion.[63] Those who want to tell their stories are often those who believe that talking about the past is therapeutic. People who are not prepared to be interviewed will often make the judgment that talking would be harmful; and oral historians must respect their decision.

The motives for taking part in an oral history are not always obvious. Memories and perspectives of events may be communicated in interviews with motivations that are not always apparent at the outset. Personal reflections convey how the narrator perceives the significance and impact of events and actions, and can reveal their attempts to make sense of the past. Reflective processes during an interview can add to the interviewee's original motivations for taking part in it, but it is good practice, in line with most medical research ethics, to advise participants that they can end an interview or a series of interviews at any time, without having to explain their decision to the interviewer.

As with oral history interviewing in general, patients have a variety of reasons for telling their life histories. Oral histories with patients can raise their self-esteem and sense of worth, attach meaning to their life experiences, create a personal family record, give recognition, and validate experiences. They also provide gains for clinical practice and health research: better understanding of day-to-day living with life-threatening disease; raised awareness of patient perspectives of hospice, hospital, and home treatment; greater appreciation of the impact of life-threatening disease

on identity and lifestyle; and insight into
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The relationship of narrative to medical ethics has been considered by Anne Hudson Jones, who sees the contribution through the content of stories (what people say) and through the analysis of their form (how they are told and why it matters). She advocates the study of both fictional and factual stories as aids to understanding in medical ethics, and believes that the techniques of literary criticism can be applied to the analysis of ethical texts and practices, shedding light on the different perspectives in an ethical dilemma. Listening to patients' stories, she asserts, can also help clinicians accept a patient's moral choices.[65] Such claims are, however, more easily made than they are proven.

The illness narrative has many potential interpretations, but the patients are the ultimate authors of their own text. Oral history offers them opportunities to produce a narrative with greater autonomy and input than is possible with other approaches. Participants become involved in the process of producing their own life histories. They recall personal experience in a whole life context, shaping their identity with a narrative that is comfortable for them. Oral history as a form of autobiography has advantages over written forms of narrative, such as diary writing and published illness stories, since it provides an opportunity for participation across a range of abilities, to people who may not wish to write but who can verbally tell their stories.[66]

The process of interviewing patients needs to be handled thoughtfully. An oral history usually involves, on one side, a healthy interviewer in paid employment who has a lifestyle independent of clinical needs, and on the other side, an interviewee with an illness that may be life-limiting, whose lifestyle has departed significantly from pre-illness circumstances, and who is encountering various degrees of uncertainty. This makes for a particularly unequal situation. It helps if there is time is available to form a relationship in advance of the interview, but that may not be the case if the interviewee is in poor health. Some who begin an interview talkative and outgoing can grow tired, withdrawn, and uncomfortable. With seriously ill people, interviews must be arranged and conducted on a short timetable and in short bursts, which can affect the quality of the interview. At worst, such interviews can err toward superficiality as the interviewer tries to draw out detail while the interviewee considers how comfortable he or she is engaging in a one-sided sharing of personal information.[67]

Can Oral History Make a Difference in Medicine?

In considering the role of oral history in the history of medicine, we can ask whether oral historians have made an impact on the practice of medicine. Some health professionals have recognized that oral history has a place in medicine.

Where patients are suffering loss, or attrition, of their sense of self, life history is a restorative intervention. In a textbook aimed at health professionals, Kathryn Boog and Claire Tester recommend life history as a nontherapeutic intervention in clinical settings:

> Where patients have very limited resources, making any form of physical activity unachievable, we need to help them change the emphasis of their view of themselves from that of a "doing" person to one of a "being." ... To help in this process, relating narratives of significant events in their life should be considered as a positive and meaningful exercise ... allowing patients to make choices about which stories to tell and how to tell them, and so encouraging the promotion of controlled self-expression.... The rediscovery of accomplishments and pleasures that may have been masked by subsequent negative episodes in that life leads to positive self-validation and improved self esteem.[68]

Writing about developing the profession of radiography with oral history, Sola Decker and Ron Iphofen have asked if lessons can be learned from the narrative of the career experiences of radiographer. They found that career experiences of radiographers can identify their unique strategies for coping with day-to-day work activities; that oral histories can act as a springboard for the socialization of entrants into the profession; and that interviews may inform policy making in education and practice. Narratives derived from the use of oral history create "an opportunity for reflection on professional activities."[69]

Oral history can make a critical contribution to articulating and understanding the meaning and transformations of mental health care from the point of view of families dealing with illness. Carlee Lehna's recordings with the twenty-two-year-old sibling of an eight-year-old diagnosed with leukemia highlighted the effects of a sister's childhood cancer on the sibling's life and home life at diagnosis, during, and after treatment. Fourteen years later, she observed that the themes of activity, closeness, anger, fear, worry, and spirituality that she had written about were "derived from the sibling's narrative." This suggested that health care professionals should take the emotions of the siblings of other children with cancer into account.[70]

Oral histories are also useful in resisting medical power including the power to shape the patient's story. Geertje Boschma's oral history accounts by family members in Alberta, Canada, demonstrated ambivalence toward the dominant biomedical explanation of mental illness. The stories illustrated mental illness as a culturally negotiated event, with agreements, for example, whether to frame a family member's behavior as mental illness. Boschma concluded that dominant cultural discourse affected how people enacted, accommodated, appropriated, and resisted particular ways of living with mental illness.[71]

We should also be clear that oral historians can contribute toward a critique of medicine and medical practice. Oral historians might be making a more significant contribution to well-being through helping to explore the history of

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medicine, than simply by offering medical professionals another tool in their encounters with the ill. There are those who claim that "oral history either on its own or combined with other interpretative research methods has the potential to guide the profession into the future," but oral history's first task is to critically examine medicine's past.[72]

Oral history in the history of medicine gives insight into past actions that allows their consideration in their contemporary circumstances. How were decisions taken? What were the options? What influences were at play? What actions ensued? Understandings of the successes and failures associated with these issues can enlighten present-day problems and further debate. A history of the hospice and palliative care movement in the UK found that accounts by health professionals and others involved in establishing services reflected what they perceived as personal achievements, what they still hoped to carry out, and what was left unfinished. Their contributions contained critical thought about the role of hospices within the spectrum of health and social care services, and offered reflections on future directions for hospice provision.[73]

Oral history has become established in the history of medicine, developing from "elite" histories of distinguished practitioners to explorations of what it is like to be "a patient." There is much room left for continuing the expansion of the oral history of medicine into new areas, such as contributing to a better understanding of embodied narratives, materiality, and social constructionism, as well as exploring everyday practice or ecologies of practice and their relationships to policy ideals. There remains much to do in appreciating the ethical challenges of working with both those in positions of power and those whose illnesses have brought a troubling realization of how little power they have over their own illnesses and their own lives. There is also the issue of how we generalize from our oral history research. Currently, oral historians of medicine are often engaged in small-scale local projects, which are very good for identifying local contingencies but less helpful for drawing generally applicable conclusions. The linking together of small studies through the reuse of testimonies will be one way of addressing this question. National and international studies in which the experiences of recipients and professionals of medical care can be compared and contrasted would also help, although the approaches required to do this are as yet underdeveloped.

We have deliberately chosen not to address legal, ethical, and governance oversight in this chapter. The differences in the ways in which ethics boards and committees, especially those in medicine and health, operate across the globe would have made the task difficult. In addition, a bewildering and growing myriad of laws, regulations, and guidelines that differ from country to country would have meant that any advice provided would have become quickly outdated. Instead we have tried to contextualize more broadly the ethical challenges faced by oral historians working in health and medicine.

There is a continuing need to be aware of the issues and debates faced by historians of medicine more generally. Such issues offer oral historians opportunities to recast our ethical concerns. So, for example, "giving voice" and "shared authority"

have an added complexity in working with current and former professionals, patients, and carers. Partly this is because relationships in health and medicine have long been imbued with power and belief. Interviewing in this area therefore requires additional understanding and sensitivity. However, oral history is now established as an important method and source in studying the recent history of medicine and health care.

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