End-of-life Care in China: Ecology of Hope

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ABSTRACT

In this thesis I explore the current end-of-life care provision as experienced by older people with advanced cancer in three distinct care settings in Yunnan China: a hospice, an inpatient palliative care ward and a self-help organisation. In particular, I focus on the role of “hope” at the end of life, hope having emerged as a significant aspect of participant’s experiences. I took a “multiple-embedded case study” approach, employing mainly qualitative interviewing and observation to capture the richness and complexity of the experience of end-of-life care in different settings.

The findings show that mainstream health care for advanced cancer in China focused on curative western medicine and failed to alleviate prevalent pain and symptoms. Specialised palliative/end-of-life care services adapted from the western palliative care model contributed mainly to relieving cancer pain and symptoms. “Total care for the whole person” – the core of the palliative care philosophy, was an aggregate of the resources located in the family, health care and the broader sociocultural environment.

The study revealed the nature of hope as essentially affirming life in all circumstances and as situated and fostered in a “hierarchical social and cultural ecology of hope” (Feudtner 2005, p. S23) comprising an individual, his or her family, care providers and other physical, social and cultural elements. The fostering of hope, as a resource at the end of life, has implications for improving care and support at multiple levels – personal, interpersonal and social and cultural.

Hence, it is suitable to take the public health approach proposed by Kellehear (2005) to advance palliative care development in China because it endorses a compassionate approach to death and dying and loss and proposes that care for people at the end of life is a fundamental responsibility of not just health professionals, but also communities, governments and societies.
Growing up with HIV: Exploring the experiences of the first generation of young people perinatally infected in the UK

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ABSTRACT
This thesis explores the experiences of young people perinatally infected with HIV in the UK. Although advances in medical treatment have made a major difference to the life expectancy of these young people this may not be matched by their ‘lived experience’ insofar as they face the consequences of a stigmatised disease as well as an uncertain future. This is the first study to critically analyse young peoples’ accounts of growing up with HIV in the UK. This thesis considers the experiences of twenty-eight young people between the ages of fifteen and twenty-four recruited from a London hospital. Drawing on Bury’s (1982) concept of ‘biographical disruption’ and the concept of ‘critical moments’ (Thomson et al. 2002), it explores how HIV affects a young person’s biography.

Findings from the study demonstrate that a diagnosis of HIV disrupts biography and this experience is interspersed by ‘critical moments’ that serve to bring into sharp relief difference and forces young people to continually re-evaluate and make sense of being HIV positive. Young people make sense of disruption in order to construct and maintain a new identity as they become adults; this process is influenced by the stigma attached to HIV as well as by the disease trajectory. They use a range of strategies to adjust to and manage living with a stigmatised identity. This study raises important questions about the impact of HIV on young people, their families and their relationships. It demonstrates that most young people learn to ‘pass’ (Goffman 1963) as uninfected and conceal their HIV status. They withdraw from social relationships which increases their isolation and loneliness and affects their well-being. Findings also reveal that young people report little support to help them manage the impact of HIV. The study also highlights the urgent need for future research focusing on young people with HIV.

Keywords: HIV/AIDS, perinatally infected, born with HIV, young people, biographical disruption, critical moments
The holistic discourse and formalising education of non-medically qualified acupuncturists and homeopaths in England

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ABSTRACT

The overarching aim of this research study is to explore the way that Non Medically Qualified (NMQ) acupuncturists and homeopaths in England, as part of their efforts to professionalise and formalise their educational structures, negotiate holistic concepts that are embedded in their theory, practices and discourses. The thesis is the product of an in-depth, qualitative inquiry. Several data sets were used in this research: (1) Twenty-five in-depth interviews with acupuncturists and homeopaths in London and the South of England, including practitioners who are school principals and lecturers; (2) Participant observation of teaching a research methods unit in a BSc (Hons) Acupuncture in a private school for Chinese medicine; (3) A review of practitioners' professional websites, of professional bodies' educational and practice documents, and of 27 acupuncture and homeopathy course syllabi; and (4) Two non-participant observations of a day in an acupuncture practice and a day in a homeopathy practice.

Crucially, the holistic discourse which is interwoven in acupuncture and homeopathic philosophy, theory and practice, is a dynamic discourse, influenced by political and societal factors surrounding these therapies, as well as by the dynamics within the therapies themselves. This research study demonstrates the way practitioners 'narrow' and 'expand' their holistic narratives and practices according to the challenges that they face during the process of professionalising and formalising their education, as well as in relation to their consumers' expectations. This study suggests that the way by which practitioners often negotiate the tension that exists between increasing formalisation and the unique nature of their expert knowledge, can be described as 'pragmatic holism' through which practitioners try and make gains from the formalisation process, without losing their holistic approach and appeal. Furthermore, the entrance of Higher Education Institutions to the teaching of acupuncture and homeopathy courses seems to have accentuated some of the tensions that are part of the formalisation process, but it may also offer opportunities to increase practitioners' critical reflectivity in relation to their holistic discourses and practices and to expand the scope of their holistic awareness.

Keywords: Holism, professionalism, acupuncture, homeopathy
This is not a law: The transnational politics and protest of legislating an epidemic

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ABSTRACT

HIV/AIDS continues to pose some of the most significant social, political and legislative challenges globally. This project explicates the text-mediated processes by which many HIV-related laws are becoming created transnationally through the use of omnibus HIV model laws. A model law is a particular kind of regulatory text with a set of relations of use. Model laws are designed to be taken, modified and used by stakeholders in the creation of state laws. Because they are already framed in legislative language, model laws are worded in ways that can be expeditiously activated and translated into state law. The problematic of this inquiry arises from the activities of a constellation of legislative actors including human rights lawyers, policy analysts, academics and activists who have worked to critique aspects of the United States Agency for International Development/ Action for West Africa Region (USAID/AWARE) Model Law (2004) and subsequent state laws this text has inspired across West and Central Africa. I argue that mapping the origin and uptake of this omnibus guidance text is optimally achieved through a sustained analytic commentary on the institutional genre of “best practice”. Explicating the coordinating function of this textual genre is central to understanding the rapid spread of HIV/AIDS laws across at least 15 countries in West and Central African between 2005-2010. The work processes of legislative creation, challenge and reform under investigation demand an interrogation of complex ruling apparatuses regulated by text, talk and capital relations.

The USAID/AWARE Model Law is rife with contestation: from its name, scope, funding source and process of development, dissemination and domestication to its legislative content and role in protecting or violating women's rights and public health objectives. Many of the policy actors critiquing this USAID-funded initiative have been engaged in the development of alternative HIV-related model laws and the shaping of a global anti-criminalization discourse to respond to the increasing use of criminal law governance strategies to prosecute HIV-related sexual offenses and the rise in new HIV-specific criminal laws in and beyond sub-Saharan Africa. This study maps relations that rule, and makes processes of power understandable in terms of everyday transnational work activities organized by the language of law. My research method is informed by the critical research strategy of institutional ethnography. This complex legislative process was made visible through participant observation, archival research, textual analysis and informant interviews with national and international stakeholders. This has involved research in Canada, the United States, Switzerland, Austria, South Africa and Senegal (2010-2011).

Keywords: HIV/AIDS; legislation; transnational; model law; Africa; institutional ethnography
Enacting Biobanks: Governance as Scientific and Ethical Practice

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ABSTRACT
My PhD is dedicated to the phenomenon called biobanking—the creation, running and usage of assemblages of biological samples and data obtained from donors and patients. My thesis establishes the interconnectedness of notions of ethical governance and the practices that constitute biobanking for bioscientific research. My research connects enactments of biobanking and biological data, concepts or entities with their so-called bioethical concerns. Rather than thinking of biobanks as a priori entities that have an impact or must be managed in a certain way, I pose an epistemological question about what a biobank is and what it represents.

I discuss relevant literature from Science and Technology Studies, anthropology, the natural sciences and social science scholarship about genomics, concerning themes such as classification, social order and biological material and information. I connect to the discussion on governing biobanks a more wide-ranging one about the social and the biological. Alongside theoretical challenges, I present fieldwork from three sites that are involved in biobanking practices and, to varying degrees, in biobanking debate and regulation. I contribute to and challenge current understandings of biobanking and the biosciences in three ways. Firstly, I show how the construction of the categorisation of the social and biological is integral to making sense of governance issues and how this categorisation (re)frames these. Secondly, I reconceptualise biobanking as a practice and place the ethical and the governance within that practice. Thirdly, I query the relationships between people, materials and data within the domain of the “biosciences” that enact biobanking and, therefore its governance. Moreover, I question the status of this “biological” as it intersects with notions of biobanking, again through people, materials and information flows.

To dictate a “better” way of biobanking would attribute essential properties to both biobanking and governance, which my thesis refutes. Yet, it holds important lessons in practice for those governing and ethically ordering biobanks and for academics writing about ELSI of biobanks. I urge authors, scientists and policy-makers to consider their audiences, both in terms of scientific and donor communities and in terms of reaching relevant sites where biobanking “is being done”. Participants in activities of and debates about biobanking might miss important sites if they restrict their conceptions of biobanking to semantics, because scientists engage with and conduct biobanking through local practices and might not self-identify as “doing biobanking” according to standardised paradigms.

Instead, I suggest assessing the importance of biobanking as practice on social fabric and on roles within the bioscientific and biomedical sector. For instance, this reduces the likelihood of over- or underestimating the importance of biobanking across different contexts. Some scientists hold a view of biobanking as a domain of practice in its own right that is, however, carried out by a limited set of people defined as “biobankers”; other settings do not self-identify in this way, even though all professionals across the clinical and research domain are involved in the practices of biobanking at the site. Conceptualising biobanking as
a practice remains key to these deliberations and it also, finally, urges a focus on how
science and ethics work together to produce certain status quos.

To illustrate these points in contemporary biobanking debate, my thesis creates a
juxtaposition between the debate on whether or not results from biobanking research should
be returned to biobanking donors (and, if so, which types of results) with the debate on how
and whether access to donated samples and data should be granted to other research
groups within the bioscientific community. I argue that visions of the biosciences are often
shared and propagated between donors and scientists, while donors are also enlisted as
virtual allies in the alleged need to develop ethical data-sharing policies within science. On
the other hand, biobanking practices that do not share with donors results of the research
uphold and are often based on their enactment as a lay audience. Considering the two
debates together thus deconstructs any a priori status of donors and of bioscience by
questioning the social relations involved between donors and scientists and amongst
scientists across various governance challenges for biobanking.

**Keywords:** Biobanking and genomics, governance and social dimensions of biomedical
research
Spirituality in psychotherapy: A hidden dimension. An exploratory study

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ABSTRACT

Many in the caring professions consider spirituality to be a fundamental dimension of human experience and identity. Consequently, some claim that this dimension cannot be ignored in disciplines such as psychotherapy that deals with the human being and with human experience. Moreover, the increase in secularisation and the emphasis on the subjective and the personal in people's experience of spirituality and religion, have led to an increased interest in psychotherapy, counselling and other forms of activities and professions that deal more closely with the personal and subjective. Other themes that connect spirituality and psychotherapy include: spirituality is related to a person's mental health; people make meaning which assumes that they are spiritual beings; and spirituality and psychotherapy both involve enlightenment and meaning-making. For some, spirituality is manifest in psychotherapy either because of spiritual concerns that are raised by clients in the psychotherapeutic process, as a resource, or as a form of pathology. For others, therapy is a spiritual encounter.

The research is a qualitative exploratory study of the experience and perception of the spiritual dimension of psychotherapy of Maltese practitioners. The study was held with two groups of Maltese psychotherapists and clinical and counselling psychologists. Each group attended a series of four focus/study group sessions. Key areas explored include the participants' conception of spirituality and religion and their understanding and experience of the spiritual dimension in counselling and psychotherapy. Broadly, the study focused on the ways in which spirituality may become manifest and express itself in the psychotherapeutic process, the roles and experiences of the therapist and the client regarding spirituality in counselling and psychotherapy and the identification of the factors that may contribute to the spiritual dimension of counselling and psychotherapy.

The findings are presented as two main domains, that of 'understanding spirituality and religion in a postmodern context' and 'spirituality and psychotherapy'. The latter is divided into four themes that are facets of the domain 'spirituality and psychotherapy'. These are a) understanding spirituality and religion, b) the therapeutic relationship as sacred space, c) the being: it is who the therapist is that counts and d) applications in clinical practice. The findings are discussed in relation to the literature and to the Maltese context.
Touching work: a narratively-informed sociological phenomenology of Holistic Massage

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ABSTRACT

This thesis comprises an exploration of the practice of Holistic Massage, working across the sociological areas of complementary and alternative medicines (CAM), body work, emotional labour, sociological phenomenology and narrative inquiry. Holistic Massage is one of a plethora of practices encompassed by the field of CAM. While there has been steadily increasing sociological interest in CAM in recent years, much research has treated this diverse group as relatively homogeneous. This thesis looks at one practice in depth, in order to address issues specific to Holistic Massage - including what 'holism' adds up in to in practice, and the devaluation of knowledge based on touch(ing) - as well as those concerning CAM more broadly. Hence, whilst drawing on existing research on CAM, this research also addresses a lacuna within it via a novel methodology.

The thesis employs the conceptual tool of 'touching work', which brings together the concepts of 'emotional labour' (Hochschild 1983) and 'body work' (Wolkowitz 2006 and others) in a way that draws out relevant aspects of each around the fulcrum of touch, thus accounting for the latter in both its sensory and emotional meanings. In so doing, it also contributes to the recently burgeoning literature on the senses in sociology, and to an embodied sociology more generally. The thesis also draws on sociological phenomenology, in particular the notion of the intersubjective 'stock of knowledge' (Schutz 1963), and the understanding of talk as constitutive of the everyday social world. The overall methodological approach taken - which is outlined fully in the second chapter - brings together phenomenological theory with narrative inquiry, and specifically with the analysis of the form and content of talk. The analysis presented is based around data from loosely-structured interviews with ten women who do Holistic Massage. The interviews were analysed in terms of their overall shape and distinctive features (Chapter Three) and, in subsequent chapters, with respect to both what was said and how it was said. This analysis examines the constitution of a Holistic Massage stock of knowledge (Chapter Four) and how the practice is bounded (Chapter Five), and concludes in Chapter Six by taking a step back from the detail of the data to look at what can be known from it about Holistic Massage and touching work.

Piecing together the constitution by practitioners of a stock of professional Holistic Massage knowledge makes a significant contribution to the sociology of CAM, and thus to medical sociology more broadly. Also, by uniting phenomenological sociology and narrative inquiry, it provides a novel perspective on a form of work which is part of a small but significant contemporary occupational field in the UK. In particular, it draws out the multiple aspects of touch which can in fact be known and articulated through talk and challenges ideas about the supposedly ineffable character of touch. In this regard, it points to similarities between how practitioners talk about this and the Foucauldian challenge to the 'repressive hypothesis', which sees people as in fact talking readily and in detail about matters where they claim silence prevails.
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References


Caring towards death: A phenomenological inquiry into the process of becoming and being a hospice nurse

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ABSTRACT
This thesis seeks to illuminate the question of why nurses choose to work with dying patients, with the meanings nurses attribute to their experiences forming the essential material of the study. Adopting a hermeneutical phenomenological perspective, the study involved semi-structured interviews with 30 nurses working in English hospices. The results provide evidence of the ways in which narrative and experience inform one another in an active process of occupational identity formation. Through a search for congruence between ideals and working environment, the nurses had arrived at a point of equilibrium, having identified in hospice a setting in which their nursing ideals could be implemented.

A marked feature of the nurses' accounts was 'dichotomous perception' of the nursing care provided in NHS settings and that provided in hospices, with the dimensions of these contrasts representing ideals embodied in nurse education. Aspects of hospice nursing particularly valued by the nurses were opportunities to provide 'good' nursing care, 'hands-on' nursing, holistic patient care, 'being there' for patients and availability of time.

In the face of conflict between discourses of nursing care and management discourses focused on cost-effectiveness, these nurses remained uncompromising in their desire to provide 'good' patient care and were, in Maben et al's terms, "sustained idealists". However, the equilibrium they had achieved was perceived by some to be under threat, with financial restrictions and other factors challenging the nurses' identity as hospice nurses.

In developing an understanding of the way in which individuals set their personal narratives in the context of societal factors and engage their dynamic selves in ongoing conversation with themselves and others, the thesis illustrates that, as individuals, we can only make sense of our selves by taking account of the world around us.

Keywords: Hospice, palliative care, nursing, death and dying
Technological Innovation and Change of Nursing Work in an Emergency Department

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ABSTRACT

This thesis evolves around the identification and analysis of the particular sociotechnical factors and conditions that facilitate the implementation of new information and communication technologies (ICT) in complex clinical settings.

Today most national health systems around the world link the need for best healthcare provision with the overall efficiency of their institutions. Such orientations undoubtedly require outcomes linked to ICTs so as to assign them with criteria and measures of success. On the other hand, implementations of such technologies in healthcare organisations, particularly under the Connecting for Health (CfH) IT programme, have not been equally successful. As science and technology studies (STS) scholarship shows, these technologies, despite their technical robustness, do not guarantee successful implementations. It is rather the intertwining of people, machines and spaces at the local setting that determines the fate of the new system.

The four-hour waiting target (now a standard of hospital performance) for patients attending an Accident & Emergency Department (A&E) has undoubtedly become the most important catalyst of effective change towards a “whole system” approach in the provision of unscheduled care. This is, partially, because waiting times in A&Es have been acknowledged as one of the most prominent causes of dissatisfaction for patients interacting with the National Health Service (NHS). From the mid-1990s, Conservative and Labour, governments in the UK have developed and implemented a series of reform programmes to address this issue. After a long series of negotiations, which were intensified at the dawn of the new century, the Department of Health (DH), in accordance with the recommendations of relevant emergency clinical bodies and patient advocacy groups, stabilised, in 2004, the target (now a standard of hospital performance) to 98% of patients attending A&Es to be treated and admitted or discharged within four hours. During that time the DH also released a report with key recommendations on building layouts for these hospital departments in order to positively influence efficient patient care by appropriating circulation spaces for patients, clinicians and visitors.

This thesis is a case study of the implementation of a clinical information system for patient registration and tracking in the busy emergency department of a large Acute Care University Trust in East Midlands, UK. It explores the complexity of relations and subsequent negotiations between these heterogeneous elements during the formation of a new practice ordering for nursing work.

For this, I draw on the work of actor-network theory (ANT), firstly, within the broad field of geography. I conceptualise space and time as invaluable non-human entities that need to be enrolled and converged at the local level in order for the inhabitants (clinicians, administrators, managers) and the visitors (patients and their carers) of this temporal network to enact prescribed movements, interactions, communications and relationships.
From there, this thesis examines the way the above national policies (i.e. waiting time targets, built environment design) have come to facilitate the introduction, and subsequent stabilisation, of a clinical ICT in the local clinical setting.

Based on the findings from the analysis of 30 semi-structured interviews with nurses, change managers, system administrators and emergency department assistants as well as of relevant policy documents, internal reports, building blueprints and implementation studies, I argue that the re-engineering of healthcare practice with the diffusion of a new technology is not a fixed and linear process, but more of an interplay of various fluctuant, performative and co-constitutive technical and social factors. In particular, I first show that the DH strategically attempted at ordering the A&E towards specific outcomes of performativity by formalising procedures, interactions and generally the behaviours of these peripheral networks. Rooms and corridors were redesigned and timestamps are now being applied to every process so as to effect a new spatio-temporality in the planned circulation of patients and hospital staff. As a result, groups of users are being integrated or segregated according to particular (and rationalistic) conceptions of patient flows.

For the above purposes, the specific technology under examination (EDIS) arrives in the A&E as an efficient technological solution to a given waiting time problem. While issues of computer competence and interaction with complex technologies remained a concern for nursing staff during the implementation phase, these were substantially downgraded in the face of the new rigid policy. The technology was gradually translated and transformed into an invaluable ally. Conversely, success included not only the appropriate use of the system, but also the users’ high dependence on it and finally the network’s ability to act as a platform for continual, technologically mediated, reformation of its practices under specific strategic policies.

Through an ANT conceptualisation, the thesis concludes by arguing that despite the various negotiations that take part between the centre of calculation (DH) and the local setting (A&E) offering, to the latter, some room for manoeuvre and discretion, in the end, the former is constantly enhancing its instrumental and obligatory passage role in shaping local action. It does this by strategically organising the opening of the black-box of its constituted healthcare institutions through their enrolment, re-skilling and, after that, their mobilisation towards specific process outcomes.