

HEALTH AND THE POLITICAL ECONOMY OF HOPE IN SOUTH ASIA
India Research Centre, Macquarie University
Building W6A, Level 7, Room 708

October 2, 2012

Special guests: Professor Tess Lea,
Associate Professor Kalpana Ram

Organisers: Dr Sumant Badami, Dr Victoria Loblay

Recent social science analyses have observed how hope has emerged as a crucial factor in health and illness. Whereas many of these analyses are based on research conducted in Western clinical settings, we are specifically interested in the ideological, legal, social and ethical questions related to the use of hope as a currency in the political economy of health provision in South Asia. We consider the construction of “hope” as both a political act and a social practice. In the political economy of hope, local practices between patient and practitioner intersect with global discourses and flows of capital whereby relations of inequality are often reproduced and reinforced. Hope for a cure, hope for medical or social inclusion, and hope for access to new reproductive technologies may be exchanged for patient data and/or co-option in biomedical research and practice. In what ways does the political economy of hope influence beliefs, attitudes and behaviours, and how does it construct cultural configurations of health, agency and identity?

Through a one-day workshop, we are seeking to critically engage with the way “hope” intersects with some of the shifts taking place in the provision of health care in the region. Ultimately, the theme of “hope” is designed to provoke a conversation about the imagined futures of health in South Asia, and our role as social scientists in contributing to, and critiquing such visions.

PROGRAM

9:30- 11am Session 1

Convergence of Spiritual and Biomedical Narratives

Discussants: Dr Sumant Badami and Dr Victoria Loblay

Michaela Stockey-Bridge

Ganeesh, grant us a baby! Australian parents and surrogacy in India

Since the legalisation of commercial surrogacy in India in 2002 there has been a steady increase in Australian gay and infertile intending parents travelling to India specifically to use ART's. In 2011 alone over 100 Australian babies were born in India as a result of gestational surrogacy arrangements, and in 2012 clinics in India are predicting more than 200 babies born to Australian parents. Intending parents from Australia frame their use of commercial surrogacy in India as their "last hope" in a long and fraught journey into parenthood. Over the last decade a growing community of individuals and couples using or having used commercial surrogacy in India has taken shape. The community exists largely online where networks are formed within forums and the blog sphere. However, small groups also meet up regularly in person both in India and in Australia. Within the Australian surrogacy community, hope is used as a social practise with which members offer one another support and comradeship. Images of the Hindu god Ganesh, the remover of obstacles, are often displayed on members' blogs and face book pages as a symbol of their hope for children and their commitment to "never giving up". Indian clinics are part of the Australian surrogacy community. Their own blogs appear as quasi advertisements on Australian commissioning parents' blogs. These clinic blogs explicitly set out to offer hope, displaying photos and blurbs of happy parents with their new babies and posting letters of gratitude from happy commissioning parents. While it is hope for a baby that drives commissioning parents in Australia to keep trying, clinics in India use hope as a marketing tool: to lose hope, they imply, is to give up while to hold on to hope is to keep trying at any cost.

Michaela is a PhD candidate in the Department of Anthropology, Macquarie University. Michaela's research focuses on commercial surrogacy in India. She follows intending parents from Australia to India and then back again. The thesis offers a multi-sided and multi-sited ethnographic account of Australians' fertile relationship with India.

Mythily Meher

Between hope and a hard place

This paper investigates expressions of hope in an environment where the prospect of a better life was limited. I draw on fieldwork in an Indian nursing home that ran on meager fiscal and human resources. Its residents – many of whom were infirm – engaged in the moment-to-moment practice of living in compromised ways. As they vacillated between realism and optimism, hope emerges not as a state of mind or a form of expectation but as one amongst many methods for coping. With a focus on

residents' agency in selecting and representing their aging experience, I examine hope's seeming incongruence with notions of naseeb (inevitable destiny) and the value of accepting one's circumstance, whilst also charting the influence of spiritual and bio-medical narratives that promote "positive thinking" in this context.

Mythily completed an MA in Anthropology at The University of Auckland (NZ) in 2011. Mythily's MA research considered the inter-subjective dimensions of love, care, aging and agency in an Indian nursing home. Her broader field of interest is medical anthropology, with a focus on how people navigate identity and emotion under duress. Mythily is currently at the University of Western Sydney working on a collaborative ethnography of emotions in restorative justice.

11- 11:15am Morning Tea

11:15am-12:45pm Session 2

Exchange and transactions of bodily knowledge

Guest Discussant: Professor Tess Lea

Dr Victoria Loblay

Evidence making and the Political Economy of Hope: Obtaining treatment in a global flow of tissues and knowledge on rare genetic diseases

The practice of enrolling patients in research trials to facilitate their treatment options is commonplace in India, and often thought to be an ideal solution for poor patients who would otherwise be unable to afford treatment. This paper considers the implications of this model of health care for patients suffering from a rare genetic disorder known as Mucopolysaccharidoses (MPS), who are part of a support group at the genetic counselling clinic in Chennai. For these patients, access to knowledge in relation to rare genetic diseases is structured by their location in a place where diagnostic facilities are inadequate and government funding for managing diseases is minimal. This position forces patients into a situation where their hopes for treatment and cure are contingent upon charitable programs of multinational pharmaceutical companies, as well as international research studies. The paper analyses how the support group, and the clinic staff who contribute to the work of co-ordinating the treatment and diagnoses for the patients form a specific node in a political economy of hope in relation to rare genetic diseases. By tracing the journeys of parents of children suffering from MPS, and considering their experiences as they struggle to create a sense of hope through access to treatment, I seek to elucidate the challenges involved in obtaining a diagnosis and accessing treatment through the realm of research. We see how the possibilities for hope are invariably subsumed by research agendas, and the rhetoric of bioethics effectively replaces the responsibility of the state in its provision of public health services.

Victoria completed her PhD in anthropology at Macquarie University earlier this year. Her PhD thesis, Embodied Encounters with Reproductive Technologies: Constellations of sexual difference and the boundaries of knowledge in the clinic, examined conceptions of gender in relation to public discourse on the issue of sex-selection in India and Australia. Victoria is currently affiliated with the India Research Centre at Macquarie University.

Jessica Hinchy

'They are reputed skilful in their mode of operation': Hijra medical knowledge, colonial physicians, agency and hope

Hijras were a deeply troubling yet fascinating medical oddity to nineteenth century colonial physicians. Hijras are male-born emasculated or 'eunuchs from birth' who identify as feminine or 'neither men nor women'; perform and collect alms in public and at households following births; and as infertile persons, are believed to have the power to bless or curse fertility. In the nineteenth century, hijras' bodies were sites upon which physicians demonstrated their 'scientific' expertise in 'deviance' and constructed pathologies of sexuality and gender. From the 1870s, physicians were also involved in the colonial government's surveillance and control of hijras and others classified as 'eunuchs.' Colonial physician's accounts objectified hijras and their bodies, but is it possible to move beyond the conceptualisation of the medical gaze as a dichotomy between powerful observer and passive, objectified object? How can we recover and theorise the agency of hijras in these medical encounters? What hope was there for hijras in interactions with medical physicians in the context of clinical examination, medico-ethnological research and colonial law enforcement? In this paper, I examine the knowledge of the hijra dais who performed the emasculation operation, and its recontextualisation in colonial physicians' accounts of the procedure. The interaction between colonial physicians and hijras was not merely between scientific observer and specimen, but was also an asymmetrical and power-laden dialogue between different forms of medical knowledge. Hijras' accounts of the emasculation operation, although appropriated to colonial purposes, nevertheless represent an assertion of communal knowledge and skill. Hijras perhaps exchanged the hope of knowledgeableness for the objectification of their bodies.

Jessica is a PhD candidate at the College of Asia and the Pacific, Australian National University. Jessica's dissertation examines north Indian and colonial political cultures, slavery, domesticity, colonial law and medicine through a case study of the impacts of colonialism and modernity on groups of eunuchs - including court and harem eunuchs such as the khwajasaras and transgender groups such as hijras - in eighteenth and nineteenth century north India.

12:45 - 1:15pm Lunch

1:15- 2:45pm Session 3

Consumption and Pharmaceuticals

Guest Discussant: Associate Professor Kalpana Ram

Anupom Roy

The ambivalent hope and the trajectory of medicine consumption in rural Bangladesh

The way individuals consume medication is closely connected with their illness experience and perceived outcome of the therapy administered. Studies have explored the roles of ethnomedical beliefs and socio-structural factors influencing individuals' use and disuse of biomedical therapy. These two streams of studies have contributed to a proliferation of compliance/adherence studies in social sciences while, to some extent, also fostering an idealization of medical behaviour of sufferers. Based on my ethnographic research into the consumption of medication of rural Bangladeshi sufferers of chronic breathlessness, I describe a deceptive perception of hope, generated by the pervasiveness of allopathic medicine, which motivates the trajectory of medication consumption in an area dominated by ersatz practitioners of modern medicine. This illusory hope for a cure was able to hide the chronic nature of the illness through a complex interaction between an image of a heroic and triumphant allopathic medicine, local sociocultural perceptions of the illness, and a cultivation of the self derived from the extant political rationality, and awareness of the uneven distribution of healthcare in Bangladeshi society. The temporal flux and complexities of sufferers' lives make the issue of compliance/adherence an unproductive discussion and instead impel us to seek a greater understanding of the political-economic structures of their suffering. Any attempt to focus only on cultural or structural factors of rural Bangladeshi sufferers' medication consumption would be reductionist and instrumental, and may just strengthen the authoritative nature of the allopathic medicine over sufferers' lives.

Anupom is a PhD Candidate at the Department of Anthropology, Macquarie University. Anupom's research interests are tobacco, political economy, and chronic illness. His current project looks into the experiences of chronic breathlessness in a rural Bangladeshi village with a focus on chronicity and control.

Dr Bianca Brijnath

Pills, Promises and Quality of Care: Health-seeking in India and Abroad

In this paper, drawing on ethnographic data from India and Australia, I show how middle-class Indian families, in Delhi and Melbourne, associate pharmaceutical drugs with hope and quality of care. From the elderly Indian couple who sought stem cell treatment for the husband's dementia from Cologne, Germany to the Indian women who bring in their 'stock' to Melbourne because their family doctors only prescribe Panadol®, innovative and diverse methods are used to obtain pills. I contend that the pursuit of such pharmaceutical intervention is closely linked to hope, the promise of

recovery, and embedded in the sub-continent's history of medical pluralism and health-seeking. Considerable power is located in medicines and a 'good' doctor is one who can offer patients quality of care and hope through drug prescriptions. Pills and social relations thus go hand-in-hand and the search for a pill is also the search for a 'good' doctor. I conclude by arguing that such practices of health-seeking require us to critically think about how culturally specific genealogies influence practices of health-seeking, poly-pharmacy and quality of care, at home, in India and in an increasingly transnational world.

Bianca is an early career researcher in medical anthropology, primary health care, and public health at the Department of General Practice, Monash University. Since completing her PhD, she is pursuing post-doctorate research funded by the NHMRC, which compares depression and health-seeking in Indian-and Anglo-Australian communities.

2:45-3pm Afternoon Tea

3-4:30pm Session 4

Competition between State intervention and Alternative Practices

Guest Discussant: Professor Tess Lea

Lesley Branagan

Medicine & God – a new model of healing and hope in India

In 2001, 25 people with mental illness died in a fire at a popular Sufi Muslim shrine in India with reputed miraculous healing powers. The Supreme Court issued suo moto intervention directives to address conditions at healing shrines and to reform mental health services and institutions. In response, the Gunaseelam temple in Tamil Nadu established a licensed rehabilitation centre that offers a combined 'medicine and prayer' model of healing, which is overseen by priests and a psychiatrist. This healing mode acknowledges that seekers of mental healing often take a pluralistic approach, informally combining biomedicine with alternative and religious therapies. Utilising ethnographic research undertaken at Gunaseelam, this paper considers how hope is reconfigured by patients and carers in the face of two different notions of cure – the biomedical model of psychiatry and its claims of 'truth' and credibility, and the 'folk' models of patients where spirit possession is an accepted cultural explanation, and where hope for a cure is directed at god. Do such tandem healing models leverage the hope and religious faith of patients and carers, in order to introduce biomedical treatment into the religious sphere?

Lesley completed her MAA at Macquarie University in 2011. For her thesis, she wrote about the impact of government mental health policies on faith healing temples in India.

Sumant Badami

La Perruque: The Black Magician as a Bricoleur

This paper provides a comparison between local practices and government mental health services as a way of understanding Indigenous cosmologies and social relationships in the recognition and treatment of suicide and distress. I provide ethnographic material describing and analyzing the manthravady (black magic) ritual used by the Paniay, a marginalised adivasi group in Kerala, Southern India. The manthravady mediates between local practices and global discourses to repair moral and social disruptions caused by dramatic social change. In this capacity the manthravady provides a counter narrative to public policy and practice and helps the Paniya to reauthorize distress on their own terms. The power of the manthravady comes from a complex understanding of life and self that draws heavily on their relationship with their deceased ancestors and helps to forge and maintain profound connections to places and persons.

Sumant's research is primarily concerned with the Paniy, an indigenous community in South India, who were slaves til the latter part of the 20th century. He is particularly interested in areas of health, development, indigenous identity politics, global governance, ethnomusicology, religion and ritual. He was recently awarded the Macquarie University Early Career Research Fellowship and is also affiliated with the India Research Centre.