Is there a medical anthropology of Rheumatic Heart Disease? A Conference Report

Conference Report

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Abstract

Context This paper was presented at the Rheumatic Heart Disease conference titled *Practice and Culture* in Darwin in 2013.

Issue There is no disputing the biological fact of rheumatic heart disease; an acute and chronic condition, requiring treatment and prophylaxis that causes morbidity and mortality. This disease is found in small numbers of marginalised, minority groups of people. The people affected often have grown-up in poverty, lived in over-crowded conditions and have been colonised not only by a bacteria. What could a medical anthropological approach offer in better understanding and banishing this disease of neglect and inequality? What agency do they have in changing their vulnerability? What are their views on the 'check-ups', medicine, injections, cardiograms, and mechanical valves offered to them? How does it impact on them growing up with a 'broken heart'? What do they understand of the health system and the clinicians who touch them? What sort of research would answer these questions? These questions are explored in this conference presentation.

Lessons Learned Connecting medical and Indigenous Australian cultures will be necessary to be able to prevent initial and ongoing episodes, improve uptakes of prophylaxis, and increase health literacy. A medical anthropological approach in research can be part of the solution.

Key words: Rheumatic Heart Disease, Rheumatic Fever, anthropology, Australia, conference

Context

In November 2013, Aboriginal Health Workers, health professionals, researchers, and policy makers converged in Darwin to discuss Rhematic Heart Disease (RHD). The title of the conference was 'Practice and Culture' and was organised by 'Rheumatic Heart Disease Australia' [1] in cooperation with the Australian Government Department of Health and Ageing and Menzies School of Health Research. The organisation 'Rheumatic Heart Disease Australia' was formed in 2009 as a national coordination unit to support and control RHD. Rheumatic Heart Disease and Rhematic Fever remain common in Indigenous people [2] and this paper addressed the question of how medical anthropology could assist with reducing RHD.

There is a considerable amount of literature on the biological antecedents, strategies and clinical interventions of this disease [3-5], and also on the shortcomings of these biomedical approaches [6, 7]. This journal has published one paper on RHD which aimed to use the moon cycle to remind people to regularly accept their prophylactic penicillin injection [8]. The idea was novel and had some limited success in increasing awareness for patients but more than reminder aids are needed. Medical anthropology can offer insights into RHD and in particular how this disease of poverty and disadvantage is understood and embodied by its sufferers. Medical anthropology may assist with lessening the burden of this disease by forming a wholistic understanding which may be translated into better primary health care and clinical services by incorporating people's agency, disease embodiment, language and symbolism into research designs. This paper addresses the question, 'What could a medical anthropological approach offer in better understanding and banishing this disease of neglect and inequality?'

Issues

Medical anthropology

Medical anthropology is a sub-discipline of anthropology, which is the study of cultures, both exotic and ordinary. Medical anthropology contextualises and deepens understandings of well-being, illness and disease. It rests on the foundation of a constructivist paradigm or how social reality is built. While bio-medicine offers proven cures or treatments from a positivist paradigm, in many cases, the human aspect of the implementation of the treatment or

intervention can fail. Theories are structured frameworks or models for investigating and understanding a problem, like RHD, and inform the methodology used in tackling a research question.

The three major theoretical approaches in medical anthropology include medical ecological theory, cultural interpretive theory and critical theory [9]. Ecological theory is a way of understanding human biology and behaviour as a set of adaptations to the environment. It is apolitical and sees disease as part of nature and not imbued with cultural qualities. 'Medical systems are seen as utilitarian social responses to intrusive natural conditions' [*ibid* p 22]. Cultural interpretive theory centres on meaning and suggests that 'disease is knowable, by both sufferers and healers alike, only through a set of interpretive activities. These activities involve an interaction of biology, social practices, and culturally constituted frames of meaning... and result in the construction of 'clinical realities' [*ibid* p 25]. Again systems of power are not seen as important. On the other hand, critical medical anthropology, a term used by Baer and Singer in 1982, focuses on the political economy and attempts to analyse disease and treatment within the context of the global capitalist system. It draws upon Marxist theory, the Frankfurt School, C Wright Mills and Foucault, to argue for the significance of powers within institutions, nations and globalisation processes. Consequently it becomes important to ask how power is expressed in the social relations of various groups and individuals, and to question what influence the political economy has on health and wellbeing.

Inequalities and health outcomes

RHD is most common in disadvantaged and vulnerable populations. It is not a disease of the wealthy, socially mobile, White, privately insured classes. The Menzies School of Health Research researchers understand that health and social problems are entwined. But care must be taken in how we explain the causation of this disease, as it not simply poverty but inequality that drives infections. Not all Australians live in poverty, only a few, a sub-group of Australians. Wilkenson and Pickett demonstrate in *The Spirit Level* that countries with large social gradients between rich and poor, experience the worst outcomes in areas such as teenage pregnancy, obesity, infant mortality, amongst other things. Those countries with smaller social gradients, where societies are more equal have better health and social outcomes [10]. Wilkenson and Pickett's thesis posit that unequal societies impact on feelings of selfworth, stress and ultimately behaviour – their epidemiological data seem to back that

up. Social relationships, lower levels of trust, violence and reduced community life are generated by competitive societies. Alleviating poverty is important, but equally run-away wealth is also bad. Heart diseases in the form of ischemia, hypertension, and infarctions are increasingly linked with a social gradient of poverty and that ones environment is highly relevant; 'life style' becomes a rather lame explanation. Medical anthropology explicitly includes sampling people who are marginalised and socially vulnerable, as well as including the context in any analysis.

RHD is a disease rooted in inequality, perhaps similar to tuberculosis. Paul Farmer is a physician and medical anthropologist at Harvard University who writes on tuberculosis. He speaks of human rights, social justice, building health systems that function for all people and the correct provision of medical technology to overcome suffering. He states that no-one should die in the 21st Century from tuberculosis because we have the knowledge already to overcome it: hygiene and sanitation measures; screening and testing; antibiotics; medical and surgical interventions and this is not dissimilar to RHD [11].

Agency and meanings

The social determinants of health are important but what do they mean for the people affected who often have grown-up in poverty, lived in over-crowded conditions and have been colonised not only by a bacteria but by a hegemonic invading culture? What agency do they have in changing their vulnerability? What are their views on the 'check-ups', medicine, injections, cardiograms, and the mechanical valves offered to them? Senior and Chenhall's 2013 article 'Health Beliefs and Behavour: The Practicalities of "Looking After Yourself" in an Australian Aboriginal Community', suggest that Indigenous people in the Northern Territory are not completely unaware of their predicament [12].

They state:

> *In explaining the poor health of River Town's [pseudonym] community members, social determinants of health perspectives place emphasis on factors such as poor education, housing, and low socioeconomic status. For both communities and governments providing services, these are important and relevant explanations for poor health; however, they explain very little about the everyday experiences associated with individuals' health beliefs and behavior. [p 156]*

They use cultural interpretive theory to critique the socio-determinanistic approach and explore how Aboriginal Australians take responsibility for their health, and the extent to which they are able to prevent illness. This compelling article set in remote Arnhem Land explicitly includes individuals' interpretations and meanings through ethnographic data collection.

Drawing on Kleinman, they go on to say the ethnomedical models not only include examination of patients' behaviours but how this is experienced in particular social and physical settings, as well as being able to describe cultural norms and interpersonal exchanges. An analysis of the personal, familial, cultural and institutional must be undertaken to order to understand 'how the social determinants of health are "lived" [p156]. Therefore to better understand RHD we need to include the patient's worldview, her personal interpretation of her illness, the meaning it holds for her family, and her transactions with clinicians; she needs to be observed at home, in the clinic and in her community. This is an anthropological research method.

Senior and Chenhall [*ibid*] found that in River Community some people did not trust the clinic, they felt ashamed to attend, they did not understand the medications they were asked to take, or the 'check-ups' on their bodies. Their concept of health was that if they looked healthy and could do all the activities that they wanted to, they were then healthy. They also believed that they could have little influence over disease, sorcery and death was inevitable. All of this has implications for the management of Rheumatic Fever and RHD. According to Senior and Chenhall, policies that "support health interventions that build on the skills and priorities of local communities themselves"… and are "culturally compelling" [p 171] to clients are likely to be more successful.

If one agrees that RHD is a chronic disease, then self-management is a desired outcome. Self-management assumes that the patient is the expert of their body. 'An expert patient is someone who: feels confident and in control of their life; who aims to manage their condition and its treatment in partnership with healthcare professionals; who communicates effectively with professionals and is willing to share responsibility for treatment; is realistic about how their condition affects them and their family; and uses their skills and knowledge to lead a full life' [13]. The Standford Model and the Flinders University Model of enabling patients to take more control were developed in the 1990s. These models support individuals or groups to identify their personal goals and provide them with the information and skills to do so.

Family members can attend too and the intervention is a seven week education program. Lorig [14] suggests that this works and is cost effective. Patient centred care or research would seem to hold some solutions for us in the Northern Territory.

The Guardian Weekly recently reported that patient centred care and research was on the agenda in the UK [15]. In a press article titled, 'Patient's voices are being heard' the journalist reported:

> *J, and 13 other people with a long-term medial condition, ranging from permanent paralysis through to incurable bowel disease to severe heart problems, have been part of a 'people's panel', attending a two-day conference recently on the way the NHS needs to change. [p 21]*

In the NT there is no forum in which Aboriginal people are in a position to tell the Government health system the way it needs to change; however in the NT there are community controlled organisations and health clinics. Medical anthropologists wonder if these services function differently to government controlled health systems, and whether they have more successful outcomes? This perspective of analysis is critical medical anthropology, where power is examined and obviously power is exercised differently in Aboriginal controlled organisations and government organisations. The structure of health systems becomes the focus of enquiry, not just the 'recalcitrant', 'resistant', 'non-compliant behaviour' of the patients.

Children and RHD

In a co-authored paper on Aboriginal parenting in the first year of life in northern Australia, we found that the worldview of Aboriginal parents was quite different to non-Indigenous worldviews and significantly influenced the acceptance of health and medical advice. We cited Humphrey, Weeramanthri, and Fitz [2001:62] who found that health care providers attribute non-compliance to: cultural differences between patients and providers, lack of patients'understanding, and communication gaps. They went on to say this was a type of 'victim blaming wherein health providers perceive Aboriginal culture as a barrier to good health outcomes.' [16] p 778

To be effective, health providers must engage with parents and families on the issue of child development and health in ways that respect and incorporate Aboriginal parenting

frameworks and worldviews. By using ethnographic work with women and babies in parts of Arnhem Land, we found that Aboriginal children were parented in culturally specific ways. It is important to understand the Aboriginal parenting paradigm because many children need care for RF or RHD. Some central points were: there are no routines; the child sets its own limits; to say 'no' or 'don't' 'squashes the child's curiosity' and damages their autonomy; to leave a baby to cry is unkind; and to separate a baby from family is cruel. This style of parenting which is child-led is the antithesis of Western parenting which is parent-led. Imagine the dilemma faced by Aboriginal parents whose child refuses to see the nurse or doctor, who spit out their medicine, who cry and cry when injected and refuse to go to hospital. What should a good Aboriginal parent do in these circumstances? Their predicament is vexed. To ask someone to act against their strongly held belief of correct behavior – to make a routine assumes that time is a shared concept and important, that the child has no say or understanding of what it needs, to force a child against its will, to make it sad to the point of distress and then to send it away from its family, are reprehensible ideas to many Aboriginal parents.

This type of parenting is likely to be thousands of years old and has been highly functional for Aboriginal families who wanted to raise happy children who could function well in a group. It is certainly documented in the 1960s in Maningrida by a fellow anthropologist Hamilton [17].

Embodiment, language and symbolism

Medical anthropology acknowledges the interaction of biology, social practices, and culturally constituted frames of meaning. But what does this mean? Consider the heart. For many clinicians the heart is a blood pump, a particular type of muscle, innervated, chambered, and valved. Humans have been dissecting, describing, exploring and modifying the heart for centuries: Galen, Vesalius, Harvey, Hugnagel, Barnard and DeVries, all contributed to our current biological knowledge. They were esteemed men of science, rational positivists who challenged ignorance and often the Church. In the 17th Century Descartes, a French philosopher, who laid the foundations of scientific analytical discourse, suggested a theory of mind-body dualism and interconnection. He saw the human body as a machine that contained a soul. This idea of the body as mechanical and automatic remains in strong in Western thought, and even today bio-mechanic experts exclaim that "The body is a fascinating machine" [18]. In 1965 mechanical devices were implanted into the human heart

and in 2004 a functioning artificial heart was developed. The technological development of bionic and nanotechnologies raises interesting question for the future. What are the ethics of prosthetics? What do our patients think when they are offered to be enhanced with mechanical valves? Are all patients equally offered the possibility? What does it mean to Indigenous people to accept prosthetics in this part of their body?

Medical anthropology also considers the symbolism of the heart which is culturally bound. The symbolism of a heart is not the same as a pancreas for example; it means something different culturally. The ideograph of the heart is a culturally recognised symbol. It means emotion, deep emotions such as love, devotion, courage, affection, desire, kindness and empathy. The stylised image of the heart is supposedly drawn from the herbal contraceptive and abortifacient- Silphium – which was a plant with a special shape that was depicted on ancient Greek coins. Silphium is linked with writings on sexuality, fertility and heraldry. What does the heart mean in Indigenous Australian culture both modern and customary?

Other culturally bound images include the sacred heart found in religions. Christianity, Buddhism and Yogic practices refer to the heart as a site in the body for compassion and there are many icons, rituals, and ceremonies which focus spirituality into this organ of our body. It raises questions about our patients' spiritual beliefs, who often practice syncretic forms of religions; New Age, Dreamtime, Catholic or Lutheran [19].

Lastly consider language, as language is at the heart of people's identity; it constructs meaning and has practical implications in cross-cultural health care[20]. In other languages the word 'heart' is used in special ways. The Thai word for heart is – *jai* and it refers to the spiritual centre, or soul - *jai yen, jai raai, jai dee* refer to states of emotion. It is important in Thai culture to control emotion, to conceal strong emotions which are considered 'hot' and it is the culturally competent person who can keep a 'cool heart' or their emotional equilibrium in all situations. Medical anthropologists speculate about the words which relate to heart in the multitude of Aboriginal languages and what special meanings they may hold. How do Indigenous people refer to their hearts and do they assign any particular significance to this organ? Body mapping research methods would be useful to uncover patient's knowledge and interpretations of RHD and find mutual vocabulary and avoid biomedical assumptions of anatomy and physiology.

Lessons learned

There is no disputing the biological fact of RHD; an acute and chronic condition, requiring treatment and prophylaxis, which continues to debilitate and kill. A medical anthropological approach can offer better understanding to banish this disease of inequality. This disease is found in small numbers of marginalised, minority groups of people who have different perceptions of their agency in health. The people affected often have grown-up in poverty, lived in over-crowded conditions and experience less power than their clinicians or other Australians. There is a need to understand Indigenous people's views on the various clinical interventions offered to them, and seek their explanations for their 'broken hearts'. Medical anthropology can assist to build responsive health systems, as well as educate clinicians to provide culturally compelling reasons for patients to engage in their health care. Connecting medical and Indigenous Australian cultures will be necessary to be able to prevent initial and ongoing episodes, improve uptakes of prophylaxis, and increase health literacy.

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