



The inequalities of medical pluralism: Hierarchies of health, the politics of tradition and the economies of care in Indian oncology

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ABSTRACT

India has an eclectic health system that incorporates biomedical as well as traditional, complementary and alternative medicine (TCAM). Our understanding of the co-existence of these therapeutic modalities in this diverse, postcolonial and developing nation is extremely limited, and in the context of cancer care, to our knowledge no sociological work has been carried out. Contemporary Indian oncology represents a fascinating site for examining the interplay and articulation of forms of tradition/modernity, economic progress/structural constraint and individual beliefs/cultural norms. In a context of an increase in the prevalence and impact of cancer in an ageing Indian population, this paper reports on a qualitative investigation of a group of oncology clinicians' accounts of 'pluralism' in India. The results illustrate the embeddedness of patient disease and therapeutic trajectories in vast social inequalities and, indeed, the intermingling of therapeutic pluralism and the politics of social value. We conclude that notions of pluralism, so often espoused by global health organisations, may conceal important forms of social inequality and cultural divides, and that sociologists should play a critical role in highlighting these issues.

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Introduction

Contemporary postcolonial India is an intriguing mix of nostalgia for tradition and the pursuit of modernisation and economic development. Medicine, in India, epitomises this complex dialectic, reflecting a diverse and stratified country engaging in processes of nation-building and identity (re)construction, but also straining under the weight of a burgeoning population (Alter, 2000; Hammer, Aiyar, & Samji, 2007). As is the case in other South Asian nations, medicine is intimately interwoven with religiosity and ethnic identities in India (Tovey & Broom, 2007). Common therapeutic modalities like Ayurveda and Unani are deeply embedded in local cultural sensibilities and religious ideologies, producing a complex interplay of medicine, culture and identity (Alavi, 2005; Alter, 2000). Despite India's global significance, recent postcolonial evolution, and intricate array of therapeutic modalities, there has been little sociologically-informed research focusing on the interplay of Indian forms of medicine (see for exceptions Bala, 2007; Bode, 2006).

Whereas the dynamics between biomedicine and complementary and alternative medicine (CAM) in Western contexts has been defined by exclusive State legitimisation of biomedicine (Broom & Tovey, 2008), in India, many traditional practices are supported and, at least in part, funded by the State, and have been the primary providers of health-care for centuries (Cant & Sharma, 1999; Khan, 2006). Moreover, there have been sporadic but concerted efforts to encourage traditional practices including the efforts of Mahatma Gandhi who pushed for State support (Alter, 2000). Importantly, the interplay of biomedicine and traditional practices has gone through various permutations, reflecting a complex dynamic associated with the postcolonial predicament. That is, traditional medicine and systems of knowledge may on the one hand be celebrated as indigenous forms of knowledge to be cherished and actively promoted by the State, and yet, in many Indian contexts, biomedicine has achieved hegemonic status, framing illness and determining institutional credibility (Naraindas, 2006). Thus, medicine in India is rather more diversified than in Western contexts, and is deeply embedded in nationalist sentiment and (post)colonial discontents (Arnold, 1993; Khan, 2006).

The context of cancer in India is in many ways quite peculiar to the Indian sub-continent, although it has some parallels with issues facing other developing countries. Increased wealth (although stratified) has in turn increased life expectancy through better

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standards of living and reduced communicable diseases in certain populations (Hammer et al., 2007). Cancer has thus shifted from being of limited importance, in health policy terms, to being a considerable issue with an ageing population (Pal & Mittal, 2004a,b). Yet, the majority of the Indian population do not have access to biomedical cancer facilities (Pal & Mittal, 2004a,b), and those who do have access bring with them a complex history of engagement with a multiplicity of therapeutic modalities and paradigms of care (Naraindas, 2006; Pal, 2002).

In order to begin to explore these complex and multilayered issues, the current study takes as its point of departure the experiences of oncology clinicians whose everyday work is embedded in these complex historical, cultural and socioeconomic conditions. Set within a wider international health policy context of 'embracing diversity' (WHO, 2001, 2005b), in this paper we explore 'pluralism' as perceived and experienced by a select group of biomedical clinicians.

Background

At any one time, there are an estimated 2 million people who have cancer in India (Kishore, Ahmad, Kaur, & Mohanta, 2008), and the majority of those who are diagnosed have late stage incurable disease (75–80%) (Pal & Mittal, 2004a,b). Approximately 80 percent of people in developing countries like India will die from their cancer as compared to around 50 percent in developed countries (Pal & Mittal, 2004b). Out of the million diagnosed each year, 50 percent will die within 12 months, and less than 10 percent of those in need will receive biomedical palliative care (Pal & Mittal, 2004b). Deaths from cancer in India are predicted to rise significantly by 2030, to nearly 1.5 million annually (WHO, 2005a).

The plethora of therapeutic practices used in India makes a comprehensive overview impossible, but some reflection on the most common practices is useful. Ayurveda (Hindu), Unani (Muslim), and Siddha (Hindu) are the most common traditional practices and Homeopathy is widespread and virtually considered 'indigenous' by Indians despite being introduced from Germany in the 19th century (Frank & Ecks, 2004; Prasad, 2007). Likewise, practices such as yoga, acupuncture and meditation, viewed as perhaps exotic in some Western contexts, are normalised forms of everyday life and health practice (Alter, 2004). In terms of terminology, biomedicine is conceptualised as 'allopathic' and indigenous practices as 'traditional' or 'alternative'. As a category 'complementary' is less common than in Western contexts, although it is sometimes used to describe the use of 'traditional' or 'alternative' practices in combination with biomedical care. For most Indians, using a traditional or alternative practice constitutes a normal part of everyday life, as opposed to the perhaps more 'exotic' perceptions of CAM use evident in Western contexts (although this is changing).

Theoretical context: postcolonialism, tradition and the modern Indian State

The sociology of CAM has a strong literature base, now making a substantial contribution to our understanding of the dynamics between health professionals, patients' lived experiences, and shifting paradigms of health and illness (e.g. Broom & Tovey, 2007a, 2007b, 2008; Cant & Sharma, 1999; Goldstein, 2004; Hirschhorn & Bourgeault, 2005; Mizrahi, Shuval, & Gross, 2005;). For sociologists, this proliferation of CAM in Western contexts has raised complex questions regarding processes of de-medicalisation and the movement away from the centrality of 'scientific' medicine. Among other things, this emergent pluralism has been viewed as reflecting a 'cultural turn' of sorts situated within a broader waning

in public scientific knowledge and an increasingly individualized and subjectified cultural landscape, characterised by reflexivity (Beck, 1992; see also Cant & Sharma, 1999) and scepticism toward expert knowledge (Lupton & Tulloch, 2002). Yet, the majority of this work has been focused on Western, developed contexts in which biomedicine dominates mainstream healthcare delivery and non-biomedical practices largely occupy a position of 'outsider' in ideology and in service delivery.

The sociology of traditional, complementary and alternative medicine in the more diversified health systems seen in the developing world is virtually non-existent (Bode, 2006; Tovey & Broom, 2007) and any work that has been done in the social sciences has tended to be historical or anthropological in nature. The focus has thus tended to be on the historical evolution and cultural practices associated with traditional medical systems (Alavi, 2005, 2008; Alter, 2000; Frank & Ecks, 2004; Khare, 1996), rather than issues of professional practice, access to care, or experiences in specific disease contexts (Bode, 2006). We wanted to extend on the work that has been done on the sociology of CAM in the West to explore the Indian postcolonial therapeutic landscape (see Khan, 2006). This shift to a novel socio-cultural and economic context requires a new set of conceptual tools. Against this background we introduce a range of ideas which are useful in interpreting the accounts presented. These conceptual points can broadly be described as ideas about identity politics and medical pluralism; professions and social hierarchies; and lastly, tradition and the modern State.

A critical concept in many developing countries, and in Indian society in particular, is the complex interplay of identity, culture and medicine. In Western contexts, disease or ill health is often characterised as primarily physiological and medicine as transcending politics/culture. In the context of colonial and contemporary postcolonial India, medicine and its use is intimately and explicitly interwoven in caste, class, gender and religious dynamics (Arnold, 1993; Khan, 2006; Pati & Harrison, 2001). As such, therapeutic decision making can be informed as much by notions of 'effectiveness', as by conceptions of place, community and identity (see Nisula, 2006; Sujatha, 2007). Thus, priorities in and around therapeutic decision making can be quite different to health decision making in Western contexts. This is not to say that medicine in Western contexts does not express values and reinforce identities. To the contrary, notions of modernity, mastery and physicality (rather than say, mysticism or vitalism) imbue healthcare delivery in many Western healthcare contexts. Rather, it is that medicine-as-culture is more pronounced in India due to the plurality of modalities operating, many of which existed long before the presence of biomedicine. Although in many ways changing in urban India, biomedicine is often not the fundamental point of reference; that is, it is not the sole paradigm through which other practices are measured (cf. Naraindas, 2006). Its centrality is limited by the fact that it is not the only State-legitimated medicine (Ayurveda, Unani, Homeopathy, and other practices are also supported) thus creating a more diversified and open therapeutic environment. Finally, in a postcolonial India, localised and indigenous practices are held up by some as integral to contemporary Indian identity politics (Khan, 2006). As such, politically and culturally, non-biomedical practices are situated within a much different sphere than CAM in the West.

This intermingling of identity, culture and medicine necessarily shapes hierarchies and dynamics between professional groups and systems of medicine (Naraindas, 2006). Biomedicine is relatively new to India and the dynamics between TCAM and biomedical practitioners are constantly evolving and are differentiated according to the region examined. It is evident that TCAM practitioners hold certain forms of cultural capital and local knowledge that are acknowledged, if not supported, by many practising

biomedical clinicians (Nisula, 2006). While efficacy in a biomedical sense may be disputed, there is widespread acceptance of the fundamental assumptions underlying many practices that would receive little recognition from the biomedical community in Western contexts (Homeopathy or Ayurveda, for example) (Frank & Ecks, 2004). As such, biomedical clinicians' approaches to TCAM are embedded as a set of cultural sensibilities that tend to embrace traditional and other non-biomedical treatments. Forms of therapeutic engagement also denote notions of class (who can access certain practices), faith (use of religious healing practices), and socio-cultural status (having access to biomedicine). Consumption of medicine can thus interplay with the (re)production of class and urban/rural distinctions (Khan, 2006). For the individual, therefore, medical pluralism may be transformed into 'hierarchies of health', mediated by existing social inequalities including those of class, gender, age and place.

Lastly, understanding the role of the State is critical for situating medical pluralism in India and, in particular, the politics of tradition and regulatory devices of modernity (Attewell, 2007; Benner, 2005; Cant & Sharma, 1999; Jeffery, 1979). Notions of medical pluralism can tend toward the reification of tradition as a repository of 'authentic' knowledge and practice, fixed and immutable across time and space (Das, 1999a, 1999b). In India, and in other countries, 'tradition' has also been politicised and strategically deployed; it has been reshaped and appropriated to suit contemporary sentiments and ideological trajectories (Alam, 1994; Alter, 2000; Gupta, 1998). While we do not suggest this means traditional practices in their current form are thus inauthentic, any analysis of traditional medicine must incorporate the role of the State within and around what is 'traditional'. The championing of Ayurveda and Unani, for example, is deeply embedded in political and ideological objectives (Alavi, 2005; Benner, 2005). Gandhi pushed for a coming together of traditional and modern medical systems, to alleviate some of the tensions between communities. Yet, he simultaneously praised India's cultural heritage as a medical system to be valued and reinvigorated in the face of imperial pretensions and biomedical domination (Alter, 1996). The Indian State (both colonial and postcolonial) was itself instrumental in propagating India medical systems of knowledge, particularly those with legible and readily identifiable histories (Alavi, 2005; Jeffery, 1979). However, in doing so it has also excluded other commonly practised forms of medicine (Arnold, 1993, p. 51), creating systems of regulation and, some would argue, sanitising traditional medicine from its unruly elements (Alavi, 2005; Arnold, 1993). The modern State, in India, has witnessed the relegation of many traditional practices to the margins (Cant & Sharma, 1999, p. 177), imposing controls and supervising its usage in unsanctioned spaces (Pinto, 2004). Moreover, there have been ongoing problems associated with a lack of regulatory control over biomedical practice, including a paucity of quality control measures and formalised training in many areas of India (Pinto, 2004). The State, in sum, has been instrumental in the shaping of what should be protected and what should be discouraged in terms of medical knowledge and practice, in the Indian context.

By drawing on these conceptual issues, we seek to explore 'pluralism' as seen in the everyday experiences of cancer clinicians in India. How, we ask in this study, is medical pluralism perceived in the everyday working lives of cancer clinicians, and how would they make sense of their patients' therapeutic decisions, and their engagement with TCAM?

Methods

We selected the three hospitals and one palliative care service that provide cancer and end-of-life services for Delhi and the surrounding areas. After ethics approval was secured from the lead author's university, we approached hospital management regarding

participation of the oncology/haematology consultants and nurses. Agreement was reached and clinicians in each hospital were informed about the study via senior management and asked if they were willing to take part in an interview. Data was collected during September and October 2008, and in total, 22 clinicians participated in a 30–60 min in-depth interview. We interviewed 16 medical specialists (medical oncologists, radiation oncologists, palliative care specialists, surgeons, haematological oncologists, paediatric haematologists) and 5 oncology nurses and one oncology clinical psychologist. We included a mix of ages, gender, seniority and involvement in research/academia to ensure heterogeneity in the sample. The interviews explored: perceptions of patient decision making and therapeutic trajectories; cultural/structural processes in and around TCAM and biomedicine usage; distinctions/similarities between biomedicine and TCAM; and, the broader implications of therapeutic diversity for their everyday clinical work.

The methodology for this project draws on the interpretive traditions within the social sciences, focusing on establishing an in-depth understanding of the practices, views and experiences of the respondents. This involved taking an in-depth exploratory approach to data collection, aimed at documenting the subjective and complex experiences of the respondents, rather than merely measuring such things as the level of patient usage of TCAM or risks/benefits of non-biomedical practices. The aim was to achieve a detailed understanding of the varying positions adhered to, and to locate these within an appreciation of broader underlying beliefs and/or agendas. The approach used was developmental, in that knowledge generated in the early interviews was challenged, compared with, and built upon by later interviews.

The actual process of analysis began during data collection. This provided an opportunity to establish initial themes and then to look for deviant or negative cases, complicating our initial observations and retaining the complexity of the data. We approached the analysis initially by systematically reading through each interview several times, writing notes, discussing ideas with one another, and noting emerging patterns within the data collected. Within this process, we continually sought to retain the complexity of the respondents' experiences, documenting atypical cases, conflicts, and contradictions within the data. Following this initial analysis, we looked back through these notes in to establish themes emerging across the interviews. Within this process, once we had identified a theme, we would search through the transcripts for other related comments, employing constant comparison to develop or complicate these themes further. This process meant that events that we initially viewed as unrelated could be grouped together as their interconnectedness became apparent. The final step involved revisiting the literature and seeking out conceptual tools that we could use to make sense of the patterns that had emerged from the data.

Methodologically it could be suggested that these biomedical clinicians put a negative 'spin' on, or tell atrocity stories in regards to, therapeutic options outside their profession (see Dingwall, 1977). From our position as qualitative researchers, we do not seek to validate or contest these clinicians' perspectives so as to establish a definitive 'truth'. We recognise their elite status (see Shore & Nugent, 2002) but also the importance of documenting their experiences and as such we present their accounts as situated interpretations of pluralism in Indian cancer care.

Results

Tradition and modernity in contemporary India

As a platform for exploring more specific issues, we asked the clinicians to reflect on the relationship between different healthcare practices in Indian culture. The idea here was to get a sense of these

clinicians' understandings of the positions of therapeutic modalities in their and their patients' everyday lives. A key theme that emerged was the 'everyday' nature of use of TCAM and its integral role in Indian sensibilities and the home environment:

Clinician 5: Because you are born [in India] with so many things in place, even the spices that you use for, in food for example...steadily I learned that each of them also has some kind of medicinal use...I mean, turmeric and cumin, yeah, that's what we've been hearing about [in the literature]... the traditional medicines are our way of life without our even knowing it... [consultant, medical oncologist]

Another participant:

Clinician 8: Alternative medicines are ingrained in our social and cultural system. Even, you see, at home, if you have some abdominal discomfort or headache, you don't go to a doctor, they'll say "try some home remedies". Even your elders within the family will give you some medicines, or they'll go, take you to the Homeopath or Ayurvedic, or some practitioner... [consultant, head and neck surgeon].

Another participant:

Clinician 10: Ayurvedic, I personally use it for jaundice...we take out the leaves of that plant, and we make it a paste, and you take it with milk, every morning for one week. After that I checked my bilirubin count...with jaundice, it is effective. [specialist oncology nurse]

For these clinicians 'being Indian' necessarily involved use of traditional practices, at least in the context of 'everyday' ailments. Traditional medicine comprised part of their habitus, deeply internalised through various structures of community membership. Not surprisingly, therefore, each of the clinicians interviewed had personally used TCAM for minor issues (e.g. colds or cuts and bruises) and the response "of course I use them" was typical. Yet, there was consistent reflection on being rather precariously placed between support for 'the traditional' versus the pre-eminence of modern science. This ambivalence seemed to centre on being implicated in 'community' structures as part of their everyday life, while concurrently serving as strong advocates for the validity of modern values and scientific rationality. A way of making sense of this disjunction seemed to be the placing of traditional medicine firmly within the domestic sphere – the home (cf. Das, 1999b). As one consultant stated, "we tell our cancer patients not to use them and then we go home and use them ourselves". These parallel lives, on the part of the clinicians, reflected a wider trend whereby structures and knowledge systems of the modern India co-exist, albeit with tensions. Yet, whilst traditional practices were broadly accepted as 'normal' and 'Indian', there was high value on scientific rationality (Bharadwaj, 2006), and these clinicians deployed such notions discursively as a means of ascribing and reinforcing their professional legitimacy.

Practices of distinction and distinction in practice: evidence, faith and the politics of care

Within the interviews we were interested in examining forms of self-representation and therapeutic delineation. Documenting such practices and strategies, from our perspective, would be an important part of situating participant accounts in the broader politics of professional and paradigmatic struggle. When asked about the character of biomedicine and TCAM, there were several key rhetorical practices used to articulate their features and, in effect, legitimacy:

Clinician 14: Even today, even in these [organised] traditional or these alternative [Ayurveda, homeopathy, Unani]...when traditional practitioners talk, they talk in superlatives. When I talk, I say [for example], the cure rate is seventy percent...The

traditional practitioners, he [sic] says, "don't worry, it will be all right. I'll give you [courage] and God willing, you will be all right, you know". He puts that word "God willing" that, because that gives [him] as easy way out... [consultant, paediatric haematologist, head of department]

Another participant:

Clinician 4: So, traditional medicine is more of compassion, probably, and less of medicine, clear cut medicine...it is born of faith, people do not have that much faith in the allopathy, because they know it is what it is. Like, what is God? I do not know God. I can't visualise what is God. So, I have faith in God, it is something that is nebulous. Similarly, traditional medicine is. [consultant, paediatric haematologist].

In distinguishing between TCAM and biomedical practice, scientific rationality and its various manifestations (global-defined efficacy, objectivity, quantification, and trial evidence) were articulated as central. Rhetorically, these clinicians positioned the relationship of TCAM and biomedicine within the modernity/tradition dichotomy, critiquing the mysticism and quasi-metaphysical referencing of the archetypal 'traditional healer', and espousing the importance of rationality and physical (rather than metaphysical) mastery. In their accounts, oppositions were repeatedly utilised rhetorically to denote legitimacy/illegitimacy, including modern/traditional and rational/superstitious. Those who practised traditional medicine were marked by mystification and even false consciousness; they were represented to us by the consultants as actors yet to achieve the degree of self-reflexivity that characterises modern social order (Beck, 1994). Yet, despite this binary conception of TCAM and biomedicine, there was an underlying ambivalence regarding the grassroots separation of 'rational' biomedical science and the 'metaphysical' referencing ascribed to traditional medicine. For example, while initially suggesting an incompatibility of TCAM and biomedicine, as the interviews continued these distinctions, including the rationality/mysticism dichotomy, were problematised and deconstructed, with important reflections around the incompleteness (and even fallacies) of claims to rationality and objectivity in the grassroots biomedical treatment of cancer patients in India:

Clinician 14: ...when it comes to religion and politics versus science, religion and politics will always win. I mean, we consultants... I have always been amazed, that the doctors [in this hospital] are so intense about their treatment, their way of treating, that it has become religion and politics, more or less. So whenever we [try to] form a single protocol, we cannot sit down and agree on a single protocol...So when it comes to religion and politics, whether allopathic or alternative, science will always lose. [consultant, paediatric haematologist, head of department].

Another participant:

Clinician 20: You know, in the end people get better God willing. We only help... We can only know certain things. Other things are not up to us. [consultant, medical oncologist]

As shown in the above excerpts and in the accounts of the other clinicians interviewed, as the discussion continued, bias, politics and the subjective, intuitive elements of biomedical work were consistently emphasised. While maintaining a theoretical distinction of rationality/accountability as delineating biomedical cancer care from TCAM, the influences of politics (whether departmental, organisational or societal) on biomedical cancer care were viewed as strong and delimiting, ultimately blurring the distinctions between 'us' and 'them'. Furthermore, despite the rational/metaphysical dichotomy evident initially in their accounts, their own perceived 'failings' (lacking certainty, consistency, technologies or

mastery) were often contextualised within a metaphysical realm with the use of phrases such as “God willing” or “it is up to the gods”. This is reminiscent of what Bharadwaj (2006) describes as a clinical theodicy in the context of uncertainty. While not as explicit as is the case for IVF (a technology that by its very nature problematises cultural understandings of birth/fate/karma), metaphysical referencing is used to ‘explain and contain’ treatment outcomes and structural limitations in the Indian cancer services (see Bharadwaj, 2006). Yet, despite this blurring of inter-professional boundaries and the explicit problematising of the objectivity/rationality of biomedicine, there was, as we shall see below, overwhelming concern regarding TCAM and its role in Indian cancer care.

Treatment trajectories and traditional practices

A key issue for each of the clinicians interviewed was what their patients were using before presenting to hospital. In discussions within the consultation, most of their patients indicated that they had used TCAM before presenting to hospital and this was a major concern for all of these clinicians. In a revealing quote, one oncologist stated “we are all palliative care physicians in India”, reflecting a despondency amongst all the interviewees regarding the time it takes their patients to get biomedical care. Use of TCAM was viewed as a critical factor in explaining why patients presented late to hospital. As we see in the data presented below, there emerged a complex interplay of socio-demographics, belief and access, each shaping access to care:

Clinician 14: Approximately 60,000 kids which have cancer are expected to be diagnosed every year in India...50,000 probably do not [get] to centre also where their diagnosis is properly made. Or they go to the traditional medicine. Out of this 10,000 who reach a centre, nearly fifty percent, [of that amount] fifty percent will drop out due to whatever the reason...only 5,000 will end up getting the state of the art treatment and somewhere around 3,000 would make it... So that means that we are losing out on 25,000 kids whom we could have saved every year. [consultant, paediatric haematologist, head of department]

Another participant:

Clinician 8: I would say that fifty percent of them [patients] would have already used alternative therapies...they want to try for two, three months, all those [alternative] methods of treatment. Then they come up at stage four disease, stage three disease. Then we say, “we cannot operate”, we cannot offer them curative treatment, it is going to [be] palliative, that is an unfortunate situation. [consultant, head and neck surgeon]

It was clear from all these clinicians’ accounts that use of TCAM was conceptualised as a major reason why patients did not present early, thus delegating Indian oncology specialists to operating as ‘palliative care’ specialists. There were persistent themes of disappointment, melancholy and expressions of impotence regarding the perceived failures of biomedicine in penetrating Indian communities to support effective patient care. Furthermore, the interviews revealed consistent anger at the so-called tendency of TCAM practitioners to treat in contexts ‘out of their depth’ and delay biomedical treatment. However, as the interviews continued, the picture emerged as far more complex than the so-called ‘lure of alternatives’ and ‘erroneous claims to efficacy’. Rather, complex socio-cultural understandings of cancer and structural inequalities emerged as intertwined in people’s engagement with TCAM. The initial blame ascribed to TCAM was transformed into discussion around the intersectionality of biography, disease type, social structures, and treatment trajectories.

Symptomatology and seeking help

It was evident in discussions with these clinicians that the character and symptomatic manifestations of particular types of cancer were critical in shaping patients’ therapeutic trajectories. It was not *just* about understandings of cancer more broadly, but the idiosyncrasies of certain forms of cancer that shaped pathways to care. Paradoxically, as seen below, symptoms could both force help seeking or complicate pathways in diagnosis as bodily responses were interpreted, ascribed meaning and revealed:

Clinician 7: In Delhi, generally, I can say that from the initial symptom, to [presentation] of disease...a time factor is something like six months to two to three years... Say, some lady has some lump [inside] she will try to take the local help [traditional healer] first. Somebody will say to her, oh no, it will heal automatically; you take this um... this local plant...Once...it’s a fungating mass and it’s bleeding, oozing pus, something like that, then only they are told that ok this is something that yes, cannot be controlled here. [consultant, medical oncologist]

Another participant:

Clinician 21: Those things [haematological cancers] are still very far off. They don’t even realise [they have cancer], and people die. Like for example, leukaemia. The only symptom is like, fever... so initially it is confused with fever and treated along the lines of fever only for several months, until the haemoglobin level drops to two or three, patient faints...non-solid tumours like leukaemia and other myeloma and other things, they don’t even understand what is it, even not the local physicians. [consultant, medical oncologist]

Another participant:

Clinician 20: If you talk about prostate cancer, most of the prostate cancer I see here, they, I have not seen, I’ve seen few only, taking alternative medicine.... Early prostate cancer, most of the time they do, they come straight away, they get, generally they are diagnosed here, or they have diagnosis by urologist or somebody who says PSA is high, so these are the patients they’ll end up with us straight away... [consultant, urologist]

The type of cancer and symptomatology emerged as critical in pathways to care and help seeking. In the context of fever, each consultant emphasised how cancer patients (particularly those with haematological malignancies) were generally treated for periods of time for various infectious diseases by traditional healers *and* local biomedical physicians before eventually dying or getting progressively worse and being sent to hospital. Internal solid tumours were particularly problematic given the observed tendency of individuals (particularly women, an issue described in more detail later in the paper) to conceal these until they got worse and thus present at an advanced stage of disease with poor outcomes. Breast cancers, in particular, were discussed as ‘able to be concealed’ for significant periods of time, whereas cancers of the mouth, for example, were ‘made public’ very quickly, even if they were not immediately understood as malignancies. Yet, the picture is even more complex; the character of particular diseases and how they act on the body, in terms of impact on help seeking and treatment trajectory (including use of TCAM), was in turn intertwined with class and gender.

Socioeconomics and the economies of care

While ascribing some blame on TCAM practitioners, these clinicians emphasised the centrality of ‘cost of care’ in shaping their patients’ therapeutic trajectories, emphasising the hugely expensive private sector and the costly public system. Furthermore, economics were articulated as interplaying with notions of the ‘hopelessness of

cancer' in shaping decisions regarding whether or not to pursue biomedical versus TCAM treatments:

Clinician 13: The costs are minimal when you compare it to the West, but for an average person living in India, the costs are quite high, I mean... If you have, for example, acute myeloid leukaemia, the cost would be somewhere to the tune of about five hundred thousand to six hundred thousand rupees... So, if you're earning about two, three thousand rupees a month, which is what an average labourer or somebody would be earning, that's a lot, and the hospital doesn't provide you anything. [consultant, paediatric haematologist]

Another participant:

Clinician 15: ...Like if it is ALL [Acute Lymphoblastic Leukaemia], and it's a paediatric patient, we definitely want them to be treated, so we have a lot of Angels [wealthy philanthropists], who will adopt these children, and provide therapy... But then the problem is if they relapse, the Angels are unlikely to support because they... [pauses] the cost will go up tremendously plus they want that feel-good factor of you know, having the child cured, so they would much prefer adopting a fresh new case rather than a relapsed case. [consultant, paediatric haematologist]

The co-contribution in public hospitals and the role of philanthropy in supporting care were highlighted as important but also highly inequitable practices. Children considered 'likely to survive' were supported by wealthy Indian philanthropists whereas those with a poor prognosis would receive no financial support from private sources. The idea of philanthropy and 'Angels' is particularly revealing in terms of the structure of contemporary India and processes of polarisation in the context of economic development. Hindu faith does not have angels; rather, it is a Western notion. In this context philanthropy too is a novel practice, effectively delineating the (new) wealthy upper-middle classes and their practice of conspicuous consumption. Here philanthropy is articulated as rational act, in that it will support a child's recovery, but it is *also* a purifying act, absolving one of guilt and sin (see Caplan, 1998). Yet, ironically, there is a clear inextricable link between charitable acts and the prospect of recovery. That is, the prospect of recovery is contingent upon early diagnosis and early diagnosis marred by structural inequalities (examined in more detail below). The very need for philanthropy is in turn linked to the State's inability to provide adequate health services and de-stigmatise cancer through public health initiatives.

The issue of cost came up in subsequent interviews as interplaying with the cultural stigmas in and around cancer, with the clinicians describing how perceptions of 'terminality' mediate use of biomedical treatment, rather than distinctly 'modern' beliefs or understandings of effectiveness:

Clinician 5: ...in India, [people think] cancer is equal to death. So, then all the assessments start from that point for many patients. It's a serious diagnosis, it affects my... [long pause] it's a question of my life and my death, now let me take stock of things... And then finances become a major, major issue, so if there is [traditional medicine] which take care of my pain, and it doesn't cost me much. I would rather go for that... [consultant, medical oncologist]

Another participant:

Clinician 7: [There is] stigma... lack of awareness is a major factor in our society, and generally people get information from each other, [by] word of mouth. So, suppose somebody having breast lump, if she queries from her friend, or family elder, elderly from the family, she is told, "this looks like cancer", and the end of [your] life. You can't do anything. So you have to just try some [traditional] medicine... that fear prevents them to go to the centre and get admitted here. [consultant, medical oncologist]

As shown in the above excerpts, a self-perpetuating process is recounted by these clinicians whereby perceptions of cancer as a death sentence promote a view of costly biomedical treatment as 'not worth it'. Friends and family members were represented as in some ways complicit in preventing individuals from accessing the domain of biomedical and rational knowledge. Of course, these accounts reflect a particular perspective – that of the clinician – and as such must also be viewed as involved in the subordination and exclusion of certain kinds of knowledge, practices and practitioners. Yet, their perspectives also shed light on potentially important socio-cultural processes in and around treatment selection and access. Specifically, treatment selection may be more than simply patients not understanding best treatment or supporting TCAM. Rather, it may be a decision informed by cultural stigmas and understandings of cancer and a broader sense of hopelessness around chances of success. This process of strategic selection of treatment, based on notions of cost, value and benefit, was viewed by these clinicians as further complicated by the gendered landscapes of Indian culture, and complex notions of human value.

Gender, social value and treatment trajectories

Indian society is considerably patriarchal in character and men retain a position of significant power and authority in the family and in wider society. As such, it is perhaps unsurprising that gender emerged in these clinicians' accounts as critical in shaping therapeutic trajectories. Specifically, non-presentation to hospital and drop-out (post-diagnosis) were viewed as inextricably tied to patriarchal dynamics and priority-setting based on notions of 'value':

Clinician 13: ...in India, generally, I would say the females would be using a lot more alternative medicine because they don't even come to the hospital, actually. I mean, we have a huge disparity in sexes for all the patients that we treat, for every disease. In Hodgkin's, it's something like twenty to one, in leukaemia, it's easily ten to one because, for a female, they would not even be bringing the patient to a tertiary care hospital. I mean, they would be lost somewhere along the way. Interviewer: Tell me why?

Clinician 13: Basically because, why would you spend so much money on a female child, or a female relative? I mean, see in India, you have a breadwinner. That breadwinner is the most important person, and everything is spent on maintaining the breadwinner's health because without him [sic], the whole family is going to suffer, but if a female dies, you can always have a second wife or you can have another daughter... [consultant, haematologist]

A consistent theme in the interviews was the value placed on males within the family structure and its relationship to whether the family could 'afford' treatment or not. Hospital data and anecdotal data were viewed as clearly indicating the reluctance of some Indian families to seek (or pay for) biomedical treatment for women who had cancer due to 'value to the family'. Being 'replaceable' also emerged as a hugely problematic discourse within the patriarchal depictions of decision making around cancer in India. These patriarchal structures were interwoven with what these consultants described as a 'reluctance' and 'shyness' on the part of Indian women to seek help or to even share symptoms or pain. The existence of patriarchal structures around 'personal value' and 'breadwinners' seemed closely tied to interpersonal dynamics in the family, at least, as seen through the accounts of these clinicians:

Clinician 20: In India, women they came late in for hospital, because they are shy, they hide their complaint and they [do]

not tell to their husband, to their family, until they feel they can't hold, they can't tolerate the thing... Even people, ladies from affluent class, they also come late. [consultant, urological/gynaecological surgeon]

Another participant:

Clinician 9: In India females are shy about talking about any, like, especially the breast cancers and the cervical cancers. Here, we see in advanced stages because females are not very comfortable talking about it. So generally until it's getting to something big, they will not even talk to their husbands about it. [consultant, radiation oncologist]

Another participant:

Clinician 7: There's sex-wise difference and delay in [presentation] and all those things... they [women] do not have that freedom to go and express themselves, they do not have access to the lady doctors in the community, in which they can go and talk to them. [consultant, medical oncologist]

As seen in the above excerpts, the interviews revealed major concerns regarding community and family decisions not to treat women based on financial constraint, and furthermore, the (related) perceived tendency of some Indian women to conceal their symptoms until they would be 'untreatable' from a biomedical perspective. The patriarchal structures of Indian society were viewed as complicit in the paucity of women accessing biomedical cancer care; the view of female family members as of less 'value' to the family was a common theme in the accounts of these clinicians. In certain cases, TCAM was perceived as being used for family members of a 'lower priority'. However, this notion of *social value* also crossed gender lines, impacting on older men:

Clinician 20: We have held [a prostate clinic] on many times, the response was good, but older patients would not come for biopsy and [treatment]. There are financial questions, you know, everything costs money so, if he has to pay, he not bother, and especially after 60, they have finished their liabilities, their social responsibilities... they then come in [later] with advanced disease... [consultant, urologist]

Another respondent:

Clinician 21: ...males they get treatment faster, because he is the bread earner for the family, so family is very concerned, so they quickly come to us... but children I feel, especially girl child, they are not that, not keen... I feel males, young males get very fast, middle aged men also get fast, but old age, not so much... [consultant, radiation oncologist].

The idea of social value and economic rationalism is not by any means specific to India. Many treatment protocols in Western healthcare contexts are based on assumption of value/contribution and so-called 'benefit to society'. However, the levels in inequity in usage of biomedicine recounted in these interviews and the linkages of structures in inequality to TCAM use are revealing and important. It is also important to emphasise that such socio-cultural processes are not just a concern for Indian women. While younger men may be viewed as 'benefiting' from quicker access to biomedical cancer care, the broader valuing of human life and health is highly differentiated between groups of Indian men. As such, these hierarchies of health should be viewed as impacting on men *and* women, albeit differentially depending on their class and age among other factors.

Discussion

Recently there has been an emphasis on embracing pluralism in international health initiatives, promoting a public health agenda that seeks to harness traditional practices in combination with biomedical development (Bodeker & Kronenberg, 2002; WHO, 2001,

2005b; see also Srinivasan, 1995). There is no doubt some merit to such policy trajectories, yet there is *also* a need to contextualise such policies with the (multiple) realities of grassroots experience in developing countries such as India (Connor, 2001). The results of this study reveal a complex and at times contradictory view of 'pluralism' in Indian cancer care. TCAM practices were often articulated as 'effective' and 'inherently Indian', as inescapable and rich elements of contemporary Indian culture and sensibilities. TCAM practices were viewed as forming an integral part of Indian medical lore (Sujatha, 2007), as part of an ontologically diverse mix of knowledge systems operating concurrently but not necessarily 'in harmony'. Rhetorically biomedicine and TCAM were consistently juxtaposed (i.e. rationality/superstition; modernity/tradition; objectivity/faith), yet these very distinctions between therapeutic practices and epistemologies were problematised in interview dialogue about everyday clinical experiences. Indeed, the assumptive bases to therapeutic delineation were deployed *and* deconstructed as these clinicians sought to make sense of the character and intersectionality of TCAM and biomedicine in contemporary India.

The key finding from this study was the embeddedness of patient disease and therapeutic trajectories in vast social inequalities and, indeed, the intermingling of pluralism and the politics of social value. Medical pluralism, while reflecting important richness in cultural knowledge and practice, emerged as inextricably linked to forms of social inequality and suffering. The use of Indian practices such as Ayurveda, Unani and Siddha, for example, reflects a complex combination of religion, identity and belief, but also severe economic constraint and restrictive notions of human value. In turn, patriarchal relations and the politics of ageing seemed strongly linked to engagement with TCAM, with women and older people viewed as less of a priority than younger or male members of their family. In turn contemporary economic conditions were seen as resulting in new forms of healthcare polarisation (and conspicuous philanthropy) that mediate and limit access to care depending on one's prognosis, age and other socio-demographic variables.

Given these results, we argue that presenting 'medical pluralism' as a desirable development trajectory creates an illusion of linearity and evades forms of structural constraint. Such illusions of linearity and agency/choice in plural contexts have previously been identified by others who also question pluralism, as deployed by some medical anthropologists (e.g. Connor, 2001; see also Cant & Sharma, 1999). These romantic visions of plural medical cultures conceal social-cultural cleavages, overlooking (or even denying) the politics of human value and the restrictions placed on certain groups.

As emphasised previously, it is vital that the 'hierarchies of health' evident in the accounts presented here be situated within an understanding of the role of the State. The modern Indian State has drawn on and utilised nostalgia and the 're-discovery' of tradition, whilst concurrently (and differentially) pursuing the values of modernity and progress. Indeed, notions of pluralism fit comfortably with this tradition/progress political trajectory, with nostalgia for tradition placed carefully beside the desire for progress in the pursuit of what is distinctly Indian. Yet, the State in postcolonial India has not achieved this balance in many areas of health service delivery. Rather, as shown in the results presented here, in grassroots contexts medical pluralism is often transformed into forms of marginalisation and polarisation (cf. Farmer, 1996). In this way, the deployment of pluralism may actually act to conceal forms of suffering and structural problems in and around healthcare delivery (Das, 1999b, 2003).

In light of these findings we perceive the need for a more nuanced conceptual understanding of medical pluralism, as seen and experienced in grassroots settings. Pluralism, it would seem, can be an

uncritical representation of complex processes of social exclusion (Das, 2003), indicative of a lack of access to services among marginalised populations (see Pinto, 2004). Given these findings we argue that a focus on the politics of care and the non-linearity of therapeutic engagement would contribute to a realigning of international health policy toward an acknowledgement of grassroots need as well as a focus on protecting traditional knowledge systems.

In presenting this critical analysis of pluralism as, at least in part, structurally mediated, and in some ways a reflection of the failings of the modern State, we are aware that we risk the reification of social structure as determinative. This brings with it the erroneous portrayal of the poor as victims of tradition, trapped in antiquated cultural structures of gender, community and class (cf. Alam, 1994). In other words, the poor are once again denied agency, as 'their' practices and choices are represented as determined by structural conditions. Indeed, by drawing on the accounts of these elites, we promulgate certain conceptions of the oppressive nature of custom and tradition; the inferior status and modest nature of Indian women, the economic calculations motivating the poor and so on. Yet, as social scientists we must problematise such representations of contemporary Indian society. In fact, there is ample scholarly literature to suggest that such a construction of Indian society is highly debatable (see, for example, John, 2008; Mines & Lamb, 2002) and, while examining this debate would carry us well beyond the scope of this paper, it must challenge us to think as to why such constructions are given, what they may achieve and what interests these may serve.

As sociologists we are aware of the importance of recognising diverse knowledge systems and the multiple ontologies of health, illness and the body. However, in this study, we find the structural impediments that constrain access to care (of any form) important to emphasise. Anthropological literature has been valuable in identifying and conceptualising diverse knowledge systems, cultures of practice and documenting the effects of marginalisation, where 'ordinary' people encounter regimes of power, including medical institutions. It is against this backdrop that we see the need to highlight the 'view from above', as it were, often missing from such accounts (Shore & Nugent, 2002). These clinicians reveal a complex and ambivalent set of perceptions and ideologies that not only reflect occupational identity, and the need to maintain and reproduce professional distinctions, but also concerns around power structures and their inability to instigate change even with the help of professional expertise and technical interventions. In saying this, in studying these professional elites, we seek to bring to bear a view that must necessarily be incorporated into a wider program of research documenting the perspectives of other stakeholders including carers, TCAM practitioners and, of course, patients themselves.

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References

- Alam, J. (1994). Tradition in India under interpretive stress. *Thesis Eleven*, 39, 19–38.
- Alavi, S. (2005). The Unani public sphere: Urdu medical texts and the Oudh Akhbar in 19th century India. *Indian Economic and Social History Review*, 42, 101–129.
- Alavi, S. (2008). Medical culture in transition: Mughal gentleman physician and the native doctor in early colonial India. *Modern Asian Studies*, 42, 853–897.
- Alter, J. (1996). Gandhi's body, Gandhi's truth: nonviolence and the biomoral imperative of public health. *Journal of Asian Studies*, 55, 301–322.
- Alter, J. (2000). *Gandhi's body: Sex, diet and the politics of nationalism*. Philadelphia: University of Pennsylvania Press.
- Alter, J. (2004). *Yoga in modern India: The body between science and philosophy*. New Jersey: Princeton University Press.

- Arnold, D. (1993). *Colonizing the body*. Delhi: Oxford University Press.
- Attewell, G. (2007). *Refiguring Unani Tibb: Plural healing in late colonial India*. New Delhi: Longman.
- Bala, P. (2007). *Medicine and medical policies in India*. Plymouth: Lexington Books.
- Beck, U. (1992). *Risk Society: Towards a New Modernity*. London: Sage.
- Beck, U. (1994). The reinvention of politics: towards a theory of reflexive modernization. In U. Beck, A. Giddens, & S. Lash (Eds.), *A reflexive modernization*. Cambridge: Polity Press.
- Benner, D. (2005). The medical ethics of professionalised Āyurveda. *Asian Medicine*, 1, 185–203.
- Bharadwaj, A. (2006). Sacred conceptions: clinical theodicies, uncertain science, and technologies of procreation in India. *Culture, Medicine and Psychiatry*, 30, 451–465.
- Bode, M. (2006). Taking traditional knowledge to the market. *Anthropology & Medicine*, 13, 225–236.
- Bodeker, G., & Kronenberg, F. (2002). A public health agenda for TCAM. *American Journal of Public Health*, 92, 1582–1591.
- Broom, A., & Tovey, P. (2007a). Therapeutic pluralism? Evidence, power and legitimacy in UK cancer services. *Sociology of Health and Illness*, 29, 551–569.
- Broom, A., & Tovey, P. (2007b). The dialectical tension between individuation and depersonalisation in cancer patients' mediation of complementary, alternative and biomedical cancer treatments. *Sociology*, 41, 1021–1039.
- Broom, A., & Tovey, P. (2008). *Therapeutic pluralism: Exploring the experiences of cancer patients and professionals*. London and New York: Routledge.
- Cant, S., & Sharma, U. (1999). *A new medical pluralism?* London and New York: Routledge.
- Caplan, L. (1998). Gifting and receiving: Anglo-Indian charity and its beneficiaries in Madras. *Contributions to Indian Sociology*, 32, 409–431.
- Connor, L. (2001). Healing powers in contemporary Asia. In L. H. Connor, & G. Samuel (Eds.), *Healing powers and modernity* (pp. 3–21). Westport: Bergin and Garvey.
- Das, V. (1999a). *Critical events: An anthropological perspective on contemporary India* (3rd ed.). New Delhi: Oxford University Press.
- Das, V. (1999b). Tradition, pluralism, identity: framing the issues. In V. Das (Ed.), *Tradition, pluralism, identity* (pp. 9–21). New Delhi: Sage.
- Das, V. (2003). *Technologies of the self. Poverty and health in an urban setting*. Sarai Reader.
- Dingwall, R. (1977). "Atrocity stories" and professional relationships. *Work and Occupations*, 4, 371–396.
- Farmer, P. (1996). On suffering and structural violence: a view from below. *Daedalus*, 25, 261–283.
- Frank, R., & Ecks, S. (2004). Towards an ethnography of Indian homeopathy. *Anthropology & Medicine*, 11, 307–326.
- Goldstein, M. (2004). The persistence and resurgence of medical pluralism. *Journal of Health Politics, Policy and Law*, 29, 925–945.
- Gupta, A. (1998). *Postcolonial developments: Agriculture in the making of modern India*. New Delhi: Oxford University Press.
- Hammer, J., Aiyar, Y., & Samji, S. (2007). Understanding government failure in public health services. *Economic and Political Weekly*, 42, 4049–4057.
- Hirschhorn, K., & Bourgeault, I. (2005). Conceptualizing mainstream health care providers' behaviours in relation to complementary and alternative medicine. *Social Science & Medicine*, 61, 157–170.
- Jeffery, R. (1979). Recognizing India's doctors: the institutionalization of medical dependency, 1918–39. *Modern Asian Studies*, 13, 301–326.
- John, M. (Ed.). (2008). *Women's studies in India: A reader*. New Delhi: Penguin.
- Khan, S. (2006). Systems of medicine and nationalist discourse in India. *Social Science & Medicine*, 62, 2786–2797.
- Khare, R. (1996). Dava, daktar and dua: anthropology of practiced medicine in India. *Social Science & Medicine*, 43, 837–848.
- Kishore, J., Ahmad, I., Kaur, R., & Mohanta, P. (2008). Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pacific Journal of Cancer Prevention*, 9, 155–158.
- Lupton, D., & Tulloch, J. (2002). Risk is part of your life: risk epistemologies among a group of Australians. *Sociology*, 36, 317–335.
- Mines, D., & Lamb, S. (Eds.). (2002). *Everyday life in South Asia*. Bloomington: Indiana University Press.
- Mizrachi, N., Shuval, J., & Gross, S. (2005). Boundary at work: alternative medicine in biomedical settings. *Sociology of Health and Illness*, 27, 20–43.
- Naraindas, H. (2006). Of spineless babies and folic acid: evidence and efficacy in biomedicine and Ayurvedic medicine. *Social Science & Medicine*, 62, 2658–2669.
- Nisula, T. (2006). In the presence of biomedicine: Ayurveda, medical integration and health seeking in Mysore, South India. *Anthropology & Medicine*, 13, 207–224.
- Pal, S. (2002). Use of alternative cancer medicines in India. *Lancet Oncology*, 3, 394–395.
- Pal, S., & Mittal, B. (2004a). Fight against cancer in countries with limited resources. *Asian Pacific Journal of Cancer Prevention*, 5, 328–333.
- Pal, S., & Mittal, B. (2004b). Improving cancer care in India. *Asian Pacific Journal of Cancer Prevention*, 5, 226–228.
- Pati, B., & Harrison, M. (2001). *Health, medicine, and empire: Perspectives on colonial India*. New Delhi: Orient Longman.
- Pinto, S. (2004). Development without institutions: ersatz medicine and the politics of everyday life in rural North India. *Cultural Anthropology*, 19, 337–363.

- Prasad, R. (2007). Homoeopathy booming in India. *Lancet*, 370, 1679–1680.
- Shore, C., & Nugent, S. (2002). *Elite cultures: Anthropological perspectives*. London: Routledge.
- Srinivasan, P. (1995). National health policy for traditional medicine in India. *World Health Forum*, 16, 190–193.
- Sujatha, V. (2007). Pluralism in Indian medicine. *Contributions to Indian Sociology*, 41, 169–202.
- Tovey, P., & Broom, A. (2007). Cancer patients' negotiation of therapeutic options in Pakistan. *Qualitative Health Research*, 17, 652–662.
- World Health Organization. (2001). *Traditional medicine strategy 2002–2005*. Geneva: Switzerland.
- World Health Organization. (2005a). *India*. Core Health Indicators. Geneva: Switzerland.
- World Health Organization. (2005b). *WHO global atlas of TCAM*. Kobe, Japan: WHO Centre for Health Development.