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# Delivering breast cancer care in urban India: Heterotopia, hospital ethnography and voluntarism

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## ABSTRACT

Despite substantial strides to improve cancer control in India, challenges to deliver oncology services persist. One major challenge is the provision and accessibility of adequate infrastructure. This paper offers ethnographic insight on the conceptual and material conditions that are currently shaping the delivery of oncology in Mumbai, focusing specifically on the way India's socio-economic context necessitates non-biomedical acts of voluntarism or 'seva' (selfless service). Developing the premise that hospitals are not identical clones of a biomedical model, detailed attention is paid to the way 'care' emerges through 'praxis of place' (Casey, 2003) within the cancer hospital as a multi-scalar 'heterotopic' (Street and Coleman, 2012) site. Such a perspective enables global/local tensions to come into view, together with the heterogeneous confluence of juxtaposing materialities, imaginations, social practices and values that both propels and constrains the everyday delivery of care. The paper reflects on the theoretical implications of hospital *seva* in Mumbai in light of social science studies of hospital ethnography and health activism and contributes important ethnographic insight into the current global health debates regarding effective implementation of cancer services in India.

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## 1. Introduction

Despite substantial strides to improve cancer control in India, challenges to deliver oncology services persist. Affordability of care and provision of adequate health personnel and infrastructure is significantly contributing to cancer mortality (NCCP, 2002; Lancet, 2014). The continuing challenge of the Indian state to provide sufficient cancer public health services and support to its citizens speaks to what Reubi et al. (in this issue) describe as the 'politics of care'. This paper is an initial attempt to unpack the politics of cancer care by offering a critical engagement with the conceptual, political and material conditions that are currently shaping the delivery of urban oncology services in India. The paper aims to achieve this by illuminating the specific intersection between the post-liberalisation decentralisation of public health services that has led to wide spread resource shortage in cancer care, and the increase in local non-governmental (NGO) activity around cancer over the past fifteen years.

The ethos of this paper is based on the premise that hospitals are not identical clones of a biomedical model, but rather are invested with socio-cultural meaning and reflect the setting in which they are embedded (Kearns, 1993; Berg and Mol, 1998; van der Geest and Finkler 2004). This is especially so in resource poor

settings where a standardized and regulated vision of biomedicine is frequently disrupted by resource shortage. Here 'care' emerges as precarious and fragile, and is often achieved through 'im-provised' (Livingston, 2012) channels such as domestic kin work (cf. Brown, 2012; Mulemi, 2010) and the 'inventiveness' of medical practitioners (Zaman, 2004). Thus rarely exclusively biomedical, hospitals are often rendered effective through shifting local/global socio-political, economic and ethical configurations or 'assemblages' (Collier and Ong, 2005; Street and Coleman, 2012). In a similar vein, this paper offers insight on the complex ways non-biomedical acts of voluntarism or 'seva' (selfless service) are imbricated in biomedical and bureaucratic regimes of hospital spatiality. To this aim, the cancer hospital is explored as a 'heterotopic' (Street and Coleman, 2012) site where global initiatives, national governance, materialities and local acts of empathy and care converge in the everyday delivery of oncology. Specific attention is paid to the diverse material, conceptual and spatial-temporal dimensions of 'care' that emerges through 'praxis of place' (Casey, 2003), and the way this both propels and constrains the everyday delivery of oncology services. By offering the perspective of charitable voluntary activities in the clinical setting, the paper extends social science research on hospital ethnography that highlights the constitutive role of non-biomedical care in resource poor hospital settings (Brown, 2012; Livingstone, 2012; Street and Coleman, 2012; Mulemi, 2010; Zaman, 2004). In doing so, the paper also brings important ethnographic insight to bear upon the

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current global health conversation surrounding the effective implementation of cancer care in India, and in resource poor settings more generally (e.g. [Lancet, 2014; 2005](#)).

## 2. The ethnographic setting and methods

The population of India is experiencing a shift in its disease burden and cancer is now an urgent public health problem ([Lancet; 2005; 2014; Pal and Mittal, 2004](#)). For example, the breast cancer burden among older women in Mumbai is predicted to increase by over two thirds by 2025 ([Dikshit et al., 2012](#)). As part of a World Health Organisation (WHO) initiative to improve global cancer control, India was one of the first countries in the global south to implement a National Cancer Control Program in order to document its increasing cancer burden ([NCCP, 2002](#)). Today, the NCCP is served by both rural and urban population-based cancer registries (PBCRs) and various hospital-based cancer registries, all of which generate data on India's cancer burden as part of the National Cancer Registry Program (NCRP) under the auspices of the Indian Council of Medical Research. As part of this agenda, the government introduced regional cancer hospitals that offer treatment and cancer detection services to surrounding cities, towns and villages.

Today however, effective cancer control in India is hindered by a number of factors. Most notably this revolves around a lack of both global and national resources, as well as the prevailing material conditions that underpin public-private health services in the country (cf. [Lancet, 2014, 2005](#))<sup>1</sup>. Despite India's economic growth and a burgeoning private health care sector, this has not yet translated into better public health services as India spends just 1.2% of GDP on public health resources. This has resulted in health care provisions that are often rife with inequity, inaccessibility, and a lack of qualified staff (cf. [Dreze and Sen, 2002](#)). In the context of oncology, the situation fares somewhat worse because the prevailing health infrastructure is not equipped to deliver the polyvalent and specialist services required to prevent, detect and treat different types of cancer. This includes essential equipment such as CT, PET, radiotherapy and mammography machines, as well as quality-trained staff. As cancer incidence rates have increased across the population, India now faces a huge problem of supply and demand for cancer care. For example, there are currently around 2000 medical and radiation oncologists in India – one per 5000 newly diagnosed cancer patients ([Lancet, 2014](#)). Moreover, only some aspects of cancer treatment can be provided free of charge in the public health sector. Even for the neediest, at least some aspects of specialist treatment such as radiotherapy and chemotherapy must be paid for with out of pocket funds. Thus many households are financially crippled by the medical costs of cancer care.

Access to cancer treatment is also exacerbated by the 'centre-periphery' divide of urban–rural health care, and a regional imbalance of cancer services that can vary dramatically between states (cf. also [Pal and Mittal, 2004](#)). There is limited, if not non-existent, cancer services in remote and rural areas. Although each state has an allocated government regional cancer centre in select urban cities, these are often far away and difficult to access. It also requires out of pocket costs for patients and any caregivers who

struggle to pay for travel across large distances and pay for food and board. The lack of facilities in a patient's immediate vicinity, especially in rural areas, often results in multiple referrals and delayed diagnoses. This is significantly contributing to a high rate of diagnoses of late stage cancers ([NCCP, 2002](#)), which not only substantially decreases the chance of a hopeful prognosis but also often requires more complex and costly treatment. The paucity of rural facilities also directly impacts urban public oncology services, many of which are also underserved. Urban regional cancer centres, whilst better equipped, act as referral points for large areas of the country and thus take a huge influx of out of town patients. As such, these hospitals are currently subject to long waiting lists and overcrowding.

The previous overview has broadly sketched some of the initial public health challenges surrounding cancer control in India. In what follows, I aim to flesh out the ethnographic reality of these challenges by drawing on data collected in the Mumbai Cancer Hospital<sup>2</sup> (henceforth MCH), a state cancer hospital in Mumbai. My involvement in the MCH was part of a wider qualitative project<sup>3</sup> examining grassroots breast cancer voluntarism with several indigenous cancer NGOs and patient groups in Mumbai, Delhi and Pune. Non-governmental mobilisation around cancer has increased dramatically in India over the past fifteen years, and is now a burgeoning field characterised by large multifaceted NGOs, charities, neighbourhood patient associations and support groups<sup>4</sup>. Some of these organisations focus on specific cancers such as breast cancer whereas other, often larger organisations cover the broad spectrum of cancers. Depending on their size and financial capacity, NGOs and charities offer differing levels of service aimed at providing social welfare and financial aid, together with the implementation of policy initiatives surrounding prevention, early detection and treatment. For example, in the absence of nationwide screening for breast cancer, and lack of a standardised information and education strategy, NGOs and patient groups organise early detection 'camps' across the city and in neighbouring towns and villages in order to provide sporadic asymptomatic community screening. This includes clinical examinations and educational efforts to raise awareness of the disease. On a daily basis, a major component of NGO activity involves the provision of outreach services to Mumbai's hospitals, which includes providing psychosocial support to patients and their caregivers (cf. [Macdonald, 2015](#)), as well as disseminating information about cancer and its treatments.

The material I present below draws on my research with female volunteers who participate across a range of patient groups and NGOs in Mumbai. These women are from predominantly Hindu middle-class socio-economic backgrounds. All of the women I discuss are previous breast cancer patients, many of whom received cancer treatment in the MCH. As part of my research on breast cancer voluntarism, I shadowed the activities of these women in both public and private hospitals, which included spending a considerable amount of time in the MCH. Here I observed interactions between patients, volunteers and health professionals,

<sup>2</sup> All names of institutions, organisations and individuals have been anonymised.

<sup>3</sup> Research was conducted between March 2009 until August 2010, and again in April 2012.

<sup>4</sup> At the time of fieldwork there was no international breast cancer activist presence in India. However, some local organisations do participate in international cancer conferences, such as those organised by the National Breast Cancer Coalition (NBCC) and the International Union Against Cancer (UICC). As a result of this, many organisations have adopted Euro-American breast cancer advocacy practices such as wearing a pink ribbon and dressing in a pink *sari* and/or *salwar kameez* at awareness events to signify their solidarity to breast cancer advocacy, as well as celebrating breast cancer awareness month in October and participating in 'walks for the cause'.

<sup>1</sup> My interlocutors frequently cited socio-cultural perceptions of cancer as a barrier to seeking diagnostic advice and /or treatment (cf. also [Broom and Doron, 2011](#)). Knowledge of cancer outside of the urban metros is minimal, and the fear that cancer is incurable has created immense silence around the disease (cf. also [Macdonald, 2015](#)). While this is not the specific focus of this paper, it is important to note that socio-cultural perceptions of cancer can impede the delivery of effective cancer control in India.

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