

Breast Cancer Survivorship in Urban India:
Self and Care in Voluntary Groups

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Thesis submitted for the degree of Doctor of Philosophy (PhD)

2013

Declaration

I, Alison Charlotte Macdonald confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

This thesis explores the lives of middle-class women who have had breast cancer and are charity volunteers for small associative patient groups in urban India. It is through their activities and experiences as ‘post-cancer volunteers’ that the thesis attends to the notion of breast cancer ‘survivorship’ in relation to emergent forms of solidarity, belonging and personhood. The thesis has three main areas of concern. The first explores the role of survivorship in generating a novel form of lay expertise that gives rise to emergent forms of grassroots patient activism within the interstices of different spheres of care in a distinct urban oncological health landscape. This is described in relation to novel forms of disease affiliation such as practices of therapeutic mediation, the creation of pragmatic and sentimental solidarities, and the reconfiguration of novel forms of gendered self-care. The activities of the voluntary groups are explored as a particular form of spiritual humanitarianism conceptualised as *sevā* (selfless service) and are discussed in relation to recent anthropological studies on biosocial patient mobilisation around biological affiliation and emergent forms of health citizenship. The second area attends to the post-cancer volunteers’ individual experiences of recovering from breast cancer as initiating the cultivation of certain practices of self-care and attempts to harness the self in a more singular mode of personhood. These experiences are considered in light of recent ethnographic research on contemporary forms of Hindu devotion and longstanding anthropological debates on Indian personhood, gender and the individual in anthropology more generally. Finally, the thesis explores these novel forms of personhood and patterns of philanthropic care at the intersection of particular visions of Indian modernity that are seen to unfold in complex ways in urban India today.

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Glossary of Acronyms

All India Cancer Trust.....	AICT
Women’s Cancer Association of India.....	WCAI
The Cancer Centre.....	CC
The Bombay Cancer Hospital.....	BCH
Government Hospital A.....	GHA

Acknowledgements

First and foremost I am grateful to all those women who shared their experiences with me and welcomed my participation in their lives at times of often considerable difficulty. My most sincere thanks to them. Special thanks are due to the women with whom I worked intimately within the groups. I am truly indebted to them for their patience, kindness and never-ending generosity. Thanks also to those who eased my experience in Mumbai and enabled practicalities of fieldwork in considerable ways: Mr Sapru, Shital and her family, Kumar, Akiv and Shilpa, Bharat and Lakshmi, Himanshu, Ashwini and Mrs Kumar to name but a few.

This research was funded by an Economic and Social Research Council (ESRC) scholarship for which I am most grateful. It was also made possible through various institutions in India and the UK. In India, I would like to thank the Tata Institute of Social Science in Mumbai for all their assistance, and I am of course indebted to all the organisations and institutions I worked with. At UCL I am indebted to my first supervisor, Dr. Sahra Gibbon for her steadfast guidance, support and continued enthusiasm for the project and also to my second supervisor, Dr. Rebecca Empson whose encouragement and feedback has been invaluable. I am also grateful to Dr. Mukulika Bannerjee who initially started this project with me, to Dr. Nanneke Redclift for her support in the initial writing up phase, and to Dr. Soumhya Venkatesan who shared her manuscripts with me. I also extend thanks to the administrative staff of the anthropology department for bureaucratic support during and after fieldwork, and particularly to Chris Hagsavva for endless computer assistance.

The process of writing up was greatly ameliorated through the support, enthusiasm and companionship of my peers at UCL. Particular thanks to Aaron Parkhurst, Antonia Walford, Beata Swivek, Catalina Tesar, Dimitra Kofti, Julia Sauma, Matan Shapiro and Tom McDonald. The thesis also benefited greatly from my participation in various departmental reading groups, including the Cosmology (CROC) reading group where I extend my gratitude in particular to Dr Martin Holbraad and Dr Allen Abramson for many invaluable conversations, as well as the Biosociality and South Asian reading groups where many of the ideas in this thesis were fruitfully discussed.

The process of writing up was made all the more bearable through the never-ending moral support, care and understanding from friends and family. Special thanks to Ashley Johnson, Clara Paul and Benjamin Goode, my life long companions without whom I would never have gotten through the entire process; to Alice Elliot for all the years of understanding, sisterhood and solidarity; to Adrienne Thadani for everything in India and beyond and to Nicola and Layla. Sincerest thanks also to my family for their continued support for all that I try to do: to Alex, Clare, Constance, Lydia, Sophie, John, and especially James and Charlotte for the many moral pep talks during the very last stages. Finally, I am truly indebted to my mother Janice for everything, and to my father Alan for introducing me to India. This thesis is dedicated to him.

INTRODUCTION

Breast cancer, self and care

Encountering breast cancer in urban India

This thesis maps the emergence of breast cancer charitable groups in urban India over the last fifteen years and focuses in particular on the lives of the middle-class women, who have recovered from breast cancer and participate in these groups as volunteers¹. It is through detailed description of their experiences as post-cancer² women and their activities as volunteers, that the thesis grapples to explore articulations of breast cancer ‘survivorship’ which are becoming intertwined with emergent forms of personhood, belonging and solidarity within the urban metropolis. By surveying the specific intersection of patient volunteer interaction, the thesis charts the ways in which this group of women, described throughout as ‘post-cancer volunteers’, contribute to an emergent arena of breast cancer activism, which is also becoming interlinked with the articulation and cultivation of certain kinds of subjectivities of the

¹My interlocutors refer to themselves as ‘volunteers’.

²The use of the term cancer ‘survivor’ has become increasingly politicised in some activist arenas, where it has been criticised for its implicit victimisation and ‘heavy-handed’ heroism (see for example, Stacey 1997), or it is rejected because it implies that breast cancer is curable (see Kaufert 1998: 307). In this sense, the term has become infused with particular Western connotations of what cancer is and means. Ethnographically I find myself in a dilemma over whether to use the term. Many of the post-cancer volunteers did refer to themselves as ‘survivors’ (using the English word when speaking Hindi) whereas others did not and actively dissociated from the notion of being a cancer survivor. Furthermore, given the particularity of the ‘Survivor’ figure in the western imagination, I have chosen, for reasons that I hope ultimately align most sympathetically with my interlocutors (and with the wider scope of the thesis as will become clear) to describe the women who have had breast cancer with the more neutral terminology of ‘post-cancer’.

volunteers in life post-cancer. ‘Survivorship’³ is therefore a key focus of the thesis, intended to capture analytically a specific space after illness, of being post-cancer, in order to mediate between and reflect upon certain aspects of individual recovery that are subsequently imbued in and generative of the practices and ethos of the voluntary groups.

Breast cancer is an emerging disease in India⁴ and so too is its associated patient activism. As an arena of inquiry, cancer more generally appears to have received little ethnographic attention in India (for important exceptions see Trawick 1991; Broom & Doron 2011). There is, however, a burgeoning body of anthropological studies on a range of issues related to cancer and, while these have focused predominantly on the Western context, this has recently shifted to include a non-Western focus (see for example, Hunt 1998; 2000; Gibbon 2009; Lorn-Wainwright 2010) and this thesis is intended as an initial contribution to this emerging arena of study.

While the thesis attends predominantly to the activities of the women involved in the voluntary groups, it also attempts to introduce indigenous conceptions of breast cancer and describe how women suffer with the disease in urban India. The experiences of breast cancer suffering that I encountered in a wider viewpoint, bring into view certain complexities related to the distinct ways that local groups and

³For lack of a better word, I use ‘survivorship’ in a specific analytical way to capture those aspects that pertain to the volunteers’ experience of disease, recovery and breast cancer charity.

⁴India is purported to be facing a double burden of emergent chronic non-communicable diseases alongside the persistence of infectious diseases, and cancer in particular has become one of the ten leading causes of death in India (see Reddy et al. 2005; NCCP 2002). According to data collected by the Indian Council of Medical Research (ICMR) and Population Based Cancer Registries nearly 800,000 cases of cancer were reported to be diagnosed in the year 2000 and of those 550,000 were reported to result in death. Breast cancer is emerging as the leading cancer in women, and is the commonest cancer among women in urban cities, and the second most common cancer in rural areas (see NCCP 2002; NCRP 2002).

individuals are beginning to mobilise around the disease. Non-governmental organisations (NGOs) are not advocating a cure for cancer, post-cancer volunteers are not influencing scientific research or state policy, and the wider public are not pinning pink ribbon⁵ badges in a celebration of solidarity against the disease. In India, as in other countries, cancer is an extremely feared disease and, given its association with death, it is a disease shrouded by silence and subject to stigmatisation. This is apparent in a notable absence of wider public images of cancer. Apart from the medical and charitable communities, there is very little by way of public discussion and acknowledgement of the disease, as well as minimal public health awareness campaigns.

For the patients themselves, living with breast cancer can be a shameful and frightening experience, necessitating strenuous acts of concealment and secrecy. The first part of the thesis, which does not focus exclusively on the volunteers, elaborates on this in more detail together with an exploration of indigenous notions of the disease and the way it necessitates certain kinds of practicalities for patients and their families. Situating this in relation to other studies that explore the cultural metaphorical elaborations of cancer as an inherently ‘disorderly’ and uncontrollable disease (Sontag 1991; Stacey 1997; Weiss 1997; McMullin & Weiner 2008), this part of the thesis draws upon Annemarie Mol’s (2002) notion of a ‘disease multiple’ to explore, from a different perspective, the ways in which breast cancer in urban India is ethnographically rendered chaotic.

⁵The use of the pink ribbon in breast cancer activism has become an internationally recognised symbol of breast cancer awareness. Pink ribbons, and the colour pink more generally, identify the wearer with the breast cancer cause and express moral support for women having suffered with the disease. It was adopted as the official symbol of National Breast Cancer Awareness Month in 1992.

At the same time, the silence of living with breast cancer is criss-crossed by the post-cancer volunteers' appeals for 'voice and visibility' (Kaufert 1998). This is in some sense emblematic of the breast cancer movement in the West. Here patient activism, especially in the US, grew out of the women's health movement and AIDS activism of the 1970's and 1980's. This started with a few individual women who, having developed their own oppositionary and public discourse around breast cancer, sought initially to remove the stigmatisation around cancer and reformulate the encounter between the patient and the medical system. Women sought to overturn the perceived 'disempowering' health policies around breast cancer, and contest the co-option of women's bodies by medicine and science. In this way, breast cancer activism became imbued with the nature of political protest to create a 'resistance' feminist-focused social movement (Kaufert 1998).

Part of this process involved transforming the public identity of the woman with breast cancer from "tragic victim to heroic survivor" (Klawiter 2004: 847). Within the emergent patient lobby the identity of being a woman with breast cancer was seen to change from passivity to action as women started to weave new identities for themselves, creating a new phenomenon of the breast cancer 'activist' (see Kaufert 1998). Some of these early activists reinscribed breast cancer as an inherently political concern by linking their illness to questions of injustice, racism, violence and sexism in order to highlight the systemic inequities of a capitalist society that had, in some sense, been "written on their bodies" in the form of breast cancer (Broom 2001: 265; see also Lorde 1980; Kaufert 1998; Klawiter 2000a). Since the early 1990's the disease has emerged with a heightened and even hyped visibility in these contexts, as the focus of the lobby has shifted significantly to advocate for scientific and medical research and the hope for a 'cure' (see Gibbon 2007).

In urban India, claims to ‘voice and visibility’ are realised in distinct ways that are as yet not translating into a wider social movement or lobby. However, modalities of reform and renewal are seen to operate through specific sets of collaborations and alignments between the volunteers, patients and medical professionals that arise out of the specific cartography of oncological care in India. Given the paucity of state oncological health care, the experience of breast cancer is frequently dominated by a demand for access and resources and therefore the volunteers’ activities are directed towards helping patients manage the multiple practicalities of receiving oncological treatment within the urban milieu and clinical setting. This has resulted in the emergence of networks of care that revolve predominantly around practical and pragmatic biomedical concerns. Here, the volunteers situate themselves at various intersections between patients, their families and the doctors, to emerge as ‘therapeutic mediators’ – facilitators or brokers of different kinds of information about breast cancer that is crucially derived from their own experiences of having suffered with the disease.

At the same time, the post-cancer volunteers attempt to try and overturn the fear of breast cancer and instil hope in patients. Part of the original mobilisation of these groups involved recognition of the need to introduce novel interventions of a more ‘patient’- focused care within the hospitals. Those early pioneers would go out onto the wards and share their experiences with other women, offering information on otherwise non-existent modalities of post-operative care and attesting to the possibility of living a ‘normal’ life, when it was otherwise considered that people could not survive. These activities have since evolved quite substantially and the thesis explores the nature of these changes with specific focus on the particular novelty of the patient ‘support group’.

The volunteers' mediatory activities are also positioned in relation to certain gendered practices. Doctors, NGO workers and post-cancer volunteers constantly speak about the neglectful health practices of Indian women, and even on my first day in the Bombay Cancer Hospital (BCH) the resident oncologist told me somewhat bluntly, "India is nothing like the West. It is very different structures. Women don't come [to the hospital]". On the one hand, public health imperatives demand vigilance and responsibility from women to engage in practices of prevention and early detection, while, on the other hand, I found that many women struggle to come to terms with their suffering because fears of being 'selfish' arise from their sudden inability to perform certain family duties and obligations. This impacts on the ways in which they manage the disease in their lives, for example by refusing treatment, and the thesis explores these dilemmas in more detail as they interface with the activities of the post-cancer volunteers, who appear to be reconfiguring gendered notions of self-sacrifice in innovative ways in relation to their own experience of suffering with the disease.

The thesis thus explores how the volunteers mediate an ongoing tension, articulated around different ways 'do and give' to self and to others within the family that appears to become more acute when suffering with breast cancer. Simultaneously this can be seen to intersect with wider public health discourses of awareness and prevention that call for individuals to take responsibility for their own health. However while the experiences and activities of the post-cancer volunteers appear to emerge in accordance with such appeals, the thesis attempts to describe how they are subject to complex negotiation and resignification as more established modes of being 'responsible', such as 'doing for the family', come to frame emergent forms of gendered well-being in life post-cancer, and be reinscribed in novel ways through the

work of the post-cancer volunteers. The volunteers therefore appear to be encouraging novel practices concerning ethical gendered self-care as a need to self-prioritise that contributes to particular visions of breast cancer survivorship as part of contemporary gendered modernities.

Articulations of self-prioritisation are also related to the volunteers' own experiences of recovering from breast cancer which was often described as a positive opportunity for change. The thesis explores the ways in which the volunteers describe themselves in life post-cancer as "better", "new" or "happier", and view breast cancer retrospectively with gratitude and actually attempt to engage in novel forms of self-cultivation that are related to changing notions of gendered forms of obligation, duty and responsibility within the family. The thesis attends to the ways these attempts to harness novel forms of gendered personhood require ascetically inspired practices involving the performance of all action as *sevā* (selfless service) and *nishkam karma* (selfless action performed with no attachment to the intention) in order to achieve soteriological benefits and liberate the *ātman* (soul).

In turn, these self-cultivations are seen to feed back into the very notion of activist practice itself as their voluntary activities are rendered through notions of charity, *sevā* (selfless service) and *dharma* (duty) and, therefore, perceived as a particular vision of political action that is concerned with the provision of the most basic humanitarian care. This also appears to set their activities apart from other women's social welfare groups in India as the voluntary breast cancer groups do not seem to

have emerged in dialogue with the explicitly feminist women's movement and, as such, perhaps speak to quite different aims⁶.

In this way, the post-cancer volunteers emerge as particular kinds of intermediary figures as their daily activities give rise to novel forms of social brokerage that involves the mediation, navigation, translation and negotiation of a confluence of different values, aspirations and imperatives that coalesce around breast cancer in urban India. In this sense, this thesis is tightly focused on a small, and in some sense, marginal but also emergent community of women, who navigate the continuing force and legacy of a liberalising post-colonial society from within which new and emergent forms of knowledge are beginning to unfold. They do so from the specific position of being 'post-cancer', whereby pain, suffering and death are at once criss-crossed by creative survival, transformation and hope that is seen to give rise to perhaps unexpected futures. From the perspective of the breast cancer community then, one encounters both anguish and possibility, suffering and becoming as part of the everyday work of being a post-cancer volunteer.

⁶In the initial stages of fieldwork, when I asked the post-cancer volunteers if their work was about feminism, I was told it had nothing to do with this, and instead it was described as a 'family problem'. While I readily acknowledge that there are fundamental differences between 'Western' and 'Indian' feminism (see for example Mohanty 1986; Chitnis 1988), the very fact that they seemed disinterested in mobilising themselves in alliance with feminist women's groups and imperatives led me to stop asking about it. For examples of how feminist women's groups have mobilised in India, and the way 'feminism' is operationalised within them see (Jayawardena 1986; Basu 1995; Ram 1998; Ray 1999).

This thesis explores the volunteers' charitable activities and experiences of recovering from breast cancer in relation to three theoretical concepts: care, self and modernity. In what follows I will elaborate and discuss each one in turn.

'Care'

The focus of the thesis on post-cancer volunteer charitable care is situated in relation to studies of biosocial health mobilisation and citizenship, as well as recent work on charitable donation and philanthropic practices in India. Starting with the former, the thesis speaks to a large body of recent medical anthropological research that attends to the emergence of patient health activism and forms of lay 'expertise' in relation to disease advocacy in a range of health contexts (Rapp 1999; Petryna 2002; Rose & Novas 2005; Biehl 2007; Gibbon 2007; Gibbon & Novas 2008; Nguyen 2010). These studies have revealed the ways in which biological identities are increasingly being reproduced at the interface between health activism, scientific knowledge and medicine, as disease advocacy organisations are seen to fuel collective action, and, in turn, shape the production of knowledge about biological conditions in ways that result in the formation of new sites of knowledge and power.

Such changes are intertwined with and manifested over a range of struggles for biological identification, affiliation and forms of 'biosocial' collectivisation; the thoroughly modern ruptures of science and medical innovation that are giving rise to a "new type of autoproduction... [where]...nature will be known and remade through technique and will finally become artificial, just as culture becomes natural" (Rabinow 1996: 99-102). The concept of biosociality originated from Paul Rabinow's

(1996) analysis of contemporary transformations in genetics, particularly the development of the Human Genome Initiative, a project that for Rabinow signalled the reshaping of society and life itself that, in response to the then dominant term ‘socio-biology’, sought to explain the biological or natural determinants of human behaviour and culture (see also Haraway 1991). Rabinow states: “the new genetics will cease to be a biological metaphor for modern society and will instead become a circulation network of identity terms...” (1996: 99). Nature is thus transformed into a site for human intervention, a thoroughly modern rupture that as a locus of ‘artificiality’ is an object produced by humans that calls into question long established ideas of what counts as ‘nature’ or ‘natural’. In this way Rabinow envisaged the likely formation of new groups, individual identities and practices that emerge as persons mobilise around “chromosome 17, locus 16,256, site 654,376” and have “medical specialists, laboratories, narratives, traditions and heavy panoply of pastoral keepers to help them experience, share, intervene and “understand” their fate” (ibid: 102).

The concept of biosociality has since gained widespread currency among social scientists in mapping and investigating the transformations in knowledge and identity brought about by new genetic knowledge as well as other emergent contexts of health and disease. This has given rise to studies that describe novel forms of lay expertise such as the ‘proxy’ or ‘anticipatory’ patients of the new genetic technologies (Rose & Novas 2005; Gibbon 2007; see also Gibbon & Novas 2008), as well as ‘moral pioneers’ (Rapp 1999), ‘biological citizenship’ (Petryna 2002; Rose & Novas 2005), ‘diseased citizens’ (Biehl 2007) or ‘therapeutic pioneers’ (Nguyen 2010), who, by campaigning for access to services and resources, are seen to create new objects of

social contestation and moral and ethical modes of entitlement based upon biological conditions.

In India specifically, while the emergence of biosocial formations and forms of biological citizenship has been explored, the potential for patients to create associative communities and influence public state institutions has been posited as minimal and / or perceived to operate in a different way (Das 2001; Das & Addlakha 2001; Bharadwaj 2008; Sunder Rajan 2008). This is in relation to conditions of structural insecurity, characteristic of the Indian biomedical landscape, that shape the struggle to access not only basic care but also more innovative technological interventions, and can in turn sustain entrenched structural inequalities and further compromise the subjectivities of individuals and their families in often unexpected and disempowering ways (see for example, Dreze & Sen 2002; Jeffery & Jeffery 2008; Pinto 2008; Bharadwaj 2008; Sunder Rajan 2008).

For example, in his ethnography of mill workers' submission to international clinical trials, Sunder Rajan (2008) states that there are different registers of subjectivity formed as consequent to strategic and tactical state and business rationalities and industrial 'biocapital'. Again these subjectivities are not based on a shared biological identification and do not form a locus of sociality. Although he claims that 'experimental' subjects are the very condition for the possibility for biosociality *elsewhere*, it is in fact impossible for such a figure to become a political subject in Rainbow's (1996) sense of having the capacity for political voice and forming socio-political linkages (see Sunder Rajan 2008: 179).

These processes are also often subject to social stigma (Das & Addlakha 2001; Bharadwaj 2008; Bharadwaj & Glasner 2009). In relation to the secrecy and stigma

surrounding biomedical IVF treatment and stem cell technologies, Aditya Bharadwaj has recently claimed that infertile couples are not “assembling around their failing biology with the view to actively carving out sociality. Their biological and social bodies are simply too frail, isolated and stigmatised to accomplish this” (2008: 109). Bharadwaj states that by remaining biosocially “inactive, inert or indifferent”, the biographical inscription around IVF treatment rarely produces an articulation of the ‘double discourse’ of acceptance and normalisation. While demands to resources and appeals to pain may be heard, given rife socio-economic inequality and the stigmatised bodies of the sick and health seeking, Bharadwaj concludes that biosocial formation is almost never ‘identity-forming’ either individually or collectively. Rather, survival strategies are focused on managing the consequences of identities that are “almost always ascribed as opposed to achieved or assumed” (Bharadwaj & Glasner 2009: 54) and that these circumstances “seldom produce powerful opportunities to harness or gain anything profitable from being biosocially active” (see Bharadwaj 2008: 101).

It has been pointed out that, as a concept, biosociality was never intended to ‘travel very far’ (Bharadwaj & Glasner 2009: 41). As such, recent studies from India have highlighted the concept as inherently contingent and therefore limited in its ethnographic reach and theoretical potential as a means to think through the biological and social complexities arising out of recent biomedical developments and experiences of health (Bharadwaj & Glasner 2009: 40-41; Sunder Rajan 2008; Das & Adlakha 2001). The concept may privilege the existence of “one among many other possible cultural biographies of human biology” (Bharadwaj & Glasner 2009: 40-41). Therefore biosociality is perceived not as a formulation requiring expansion to include the ‘excluded others’ (ibid: 41) but rather as a provocation through which its

very problematisation has given rise to conceptual re-workings such as ‘bioavailability’ and ‘biocrossing’ (Bharadwaj 2008; Bharadwaj & Glasner 2009), ‘experimental subjectivities’ (Sunder Rajan 2008) and ‘domestic citizenship’ (Das & Addlakha 2001) that attempt to capture the nature of the social and individual entanglements and alignments arising in contemporary biomedical contexts in India today. In particular it has been suggested that persons in India who seek to mobilise around disease, disability and health care in politically inclined ways, do not necessarily operate through the formation of associative groups that make purchase on the state as ‘liberal biosocial individuals’ (Das 2001), but rather by forging tactical alliances both within and outside of the domestic sphere as ‘connected body selves’ in relation to the state (Das & Addlakha 2001) and the everyday work of providing care (Bharadwaj 2003).

The thesis speaks to this body of work and follows in the footsteps of these authors in conceiving of biosociality as an initial provocation for ethnographic research. The volunteers are clearly participating in forms of patient associational groups and are coming together to advocate for breast cancer in particular ways that is seen to take shape through the associational medium of breast cancer survivorship. However, the activities of the volunteers are complex and speak to particular situated tensions and are underpinned by specific concerns that make their charity work distinct. Therefore, by exploring the core tenets of biosociality heuristically, and what I identify here as being related to questions of affiliation, belonging and solidarity, the thesis attempts to attend to the particular kinds of alignments and collaborations that are created and sustained by the volunteers as part of their everyday activities. This is a significant aspect of the thesis and is explored throughout in relation to the following set of emergent ethnographic issues.

The first is in relation to what I describe as constituting forms of ‘therapeutic mediation’- the tactical alliances created between volunteers, patients and medical professionals within the urban clinical setting. The second explores the saliency of ‘vision’ in the post-cancer volunteer activities and, in doing so, I draw upon the volunteer as analogous to the figure of a guru as a way to think through the different ways that disease affiliation is created between the post-cancer volunteers and patients. Building on this, the thesis then explores how these more fleeting bonds are concretised through participation in support groups where certain solidarities are cultivated and potential novel forms of belonging are pursued in relation to specifically gendered concerns and visions of well-being.

The next area of concern takes a slightly different tenor and turns to explore how the post-cancer volunteers are producing and reproducing novel modes of subjectivity as more established modes classification, such as ‘doing for the family’, are seen to inform or exist in tension with newer kinds of biological ‘identities’ (see Gibbon 2007; Gibbon & Novas 2008). In turn these are shaping the ways in which the post-cancer volunteers conceive of gendered subjectivities in life post-cancer. Finally the thesis maintains a focus on the practice of charity work as *sevā*. This resonates with recent research on charitable gift-giving and donation that explores the intersection of more modern models of social ‘utility’ and acts of giving or *dan* as means of acquiring spiritual reward (Bornstein 2012; Copeman 2009). Of particular relevance is Jacob Copeman’s (2009) study of blood donation in devotional religious sects, in which he suggests that acts of gift-giving as *sevā* are at once linked to giving to the wider humanity and the welfare of society, and are also specifically linked to self-realisation which is revealed to be intrinsic to the value of ‘utility’. In this way, utility has been assigned a pious aspect, as the logic of “making social” seems to indicate

that “only through adding to ‘in need’ society can self-orientated spiritual aims be satisfied”, while a privileging of ‘self-love’ emerges as having epiphenomenal benefits for the overall welfare of society (2009: 55). As such, the work of donating blood is rendered as ‘biospiritual’ and is refracted through guru-amended modernities of devotionals sects that promote the medical practice. In a similar vein, being a volunteer is conceived of by these volunteers from within their own conceptions of a wider Hindu cosmology, where individual survival is ultimately perceived to be united with the well-being and potential survival of others through acts of *sevā* (selfless service) or *dharma* (duty), so that, by serving humanity, one is serving god, which, as the thesis sets out to illustrate, is also epiphenomenally serving the self by having soteriological benefits and spiritual aims. This thus circumscribes their charity work from within a specific set of ontological principles (see also Bharadwaj 2008⁷) and the thesis ultimately attempts to revisit Rabinow’s original paradigm of biosociality through these emergent insights.

The overall focus on charitable care giving in the thesis is therefore not only intended to speak to a wide body of research on patient activism trans-nationally, and contemporary forms of philanthropy and charity in urban India, but is also positioned in conversation with a much broader arena of anthropological work on women’s experiences of health and their associated practices (for example see Ginsburg & Rapp 1995; Lock & Kaufert 1998). The thesis also aims to contribute to the rich body of work on women’s health and gender politics in India, which has previously focused mainly on rural reproduction and the politics of childbirth (Jeffery et al.

⁷With regard to his research on reproductive technologies, Bharadwaj has pointed out that in the Indian context science and religion forge a symbiotic relationship that the concept of biosociality fails to capture (2008: 110-111).

1989; Jeffery & Jeffery 1996; Ram 1998b; Van Hollen 2007; Pinto 2008a; 2008b). This thesis brings another dimension to these studies through its focus on breast cancer and speaks to recent studies on specifically urban middle-class gendered personhoods (Caplan 1985; Donner 2003; 2008; Thapan 2009).

'Self'

The concept of self is considered through two interrelated areas. The first speaks to the predominance of the family that is foregrounded throughout the thesis in relation to various aspects of experiencing breast cancer that I encountered. The family emerged as inextricable from many women's experiences of suffering and recovery from breast cancer. Patients were embedded in a wider nexus of domesticity as families struggled to conceal breast cancer and sought to 'contain' the illness in order to preserve and protect kin networks from social panic, judgment and pity in the wider community. The prominence of the family also pertains to the different ways women experienced suffering and recovering from breast cancer. Frequently women's suffering was spoken of as the disruption and suspension of attachments of *sevābhāv* (service of love and care), duty and interfamilial transaction. Likewise getting better was often allocated within the family and described through constant appeals to family support (whether this was present or not), and cultivating relations of obligation, duty and 'doing for others' emerge as key modalities through which gendered well-being was often sought and fulfilled. As such recovery from breast cancer involves a reanimation of familial connectivity as certain acts, such as the operation, taking medication or just having the will to live, are operationalised through modes of sacrifice, as 'doing for the family'. At the same time, suffering and recovery from breast cancer brings to light a certain ambiguity towards particularly

gendered sacrificial practices in family life that result in changing relations with the gendered self.

The ubiquity of the family I encountered in urban India resonates with many studies that have pointed to the prominence of the family in India more generally and with the ways in which it continues to be reproduced at the core of India's culture, especially regarding the middle-classes (see Mankekar 1999; Donner 2008; Thapan 2009; see also Cohen 1998; Lamb 2000; Donner 2003; 2008; Trawick 2003; Uberoi 2003). It has been suggested that where the Indian nation once formed the site of the loss and recovery of self (see for example, Nandy 1983), the family now emerges as the location for the cultivation of post-colonial middle-class selves (Cohen 1998; Donner 2008). Studies have often pointed to the prominence of enduring 'joint family' values and the hierarchical intergenerational and gendered structures that constitute the quotidian domestic sphere in which persons are embedded (see Uberoi 2003; Trawick 2003; Donner 2008; Thapan 2009), as well as suggested that family relations emerge as shared; constituted through the flows of obligation, 'substance' and reciprocal transactions of *sevā* as kin become mutual parts of each other (see Daniel 1984; Cohen 1998; Busby 1997; 2000; Lamb 2000).

This is reflective of a more general conjecture within the anthropology of South Asia where personhood is considered to be relational, primarily and reflexively structured through its relations to others and not in terms of an autonomous and interiorised individuality (Dumont 1970; Marriot 1976; Marriot & Inden 1977). In particular Louis Dumont (1970) stated that 'true' individualism did not exist in caste bound hierarchical society, except in the figure of the renouncer whom he considered to be an 'outwardly' individual that exists outside of society. Likewise, Marriot (1976) has suggested from an ethnosociological perspective that Indian persons are constituted

relationally as fluid, porous and transactional ‘dividuals’, constantly engaged in affective flows of the exchange of ‘substance code’ and are thus not bounded autonomous individuals (see also Marriot 1976; Daniel 1984).

This premise has since been substantially readdressed in varying ethnographic elaborations in the Indian context. For example, Mines (1994) has suggested that in south India individuality often takes the form of assuming responsibility for others as distinct from the Western ontology of achieving autonomy from others. Therefore, while persons may recognise individuality in specific ways and contexts, they do not value ‘individualism’. Shifting the terrain from questions of definitive ‘persons’, Pandian (2010) has explored how the ethical subject is constituted through a Deleuzian process of ‘interiorisation’ whereby external moralising ‘forces’, such as those residual of the colonial encounter or the use of Hindu devotional poetry, become folded into an internal horizon of ethical subjectivity as relations with the outside are transformed into relations with the inside in order to cultivate an interior topography of selfhood. Furthermore, Khare (1984) has eloquently demonstrated that in a Chamar community in North India, the Indic spiritual soul (*ātman*), as opposed to the ‘person’, forms the critical analytical unit of individuality.

Feminist ethnographies in particular have presented a strong challenge to the premise of Indian personhood as primarily relationally derived, arguing that lack of individuality implies a lack of agency, which thus denies the possibility for subjectivity while also projecting women as a radically disempowered ‘other’ (see Jeffery & Jeffery 1996; Raheja & Gold 1994). This body of work has sought to overturn stereotypical portrayals of passive ‘Third World’ women as veiled figures “acting out graceful pantomimes of submission and debasement” having been gifted in marriage and “unquestionably internalized their socio-cultural subordinated status”

(Gold 1994:33). Accordingly, as per feminist imperatives, these authors have focused on the inter-relation of structure and agency, foregrounding the dynamics of power in which women are multifariously situated, exploring the tensions and ambiguities that exist across a range of social contexts in women's everyday lives. To this effect, anthropologists have eloquently demonstrated how women strategically carve out spaces of agency from within hegemonic social structures that condition but ultimately do not completely determine women's lives (see Donner 2008; Lamb 2000; Jeffery & Jeffery 1996; Thapan 2009; Raheja & Gold 1994; Das 1988).

More recently it has been suggested that motherhood forms the site for the cultivation of modern post-colonial selves (Donner 2008). Focusing on the constellation of socio-political and economic processes in which persons are located in her rich ethnography of mothering practices, class and family, Henrike Donner describes how social change and globalisation are transforming the more 'traditional' site of motherhood into a nexus for the modern self-crafting of neoliberal selves. Globalisation, indexed in her ethnography by consumption and food practices, is reconfiguring motherhood within the constraints of a rigid family setting, by creating a particular space for agency as women are invested with a certain kind of choice. This choice is related to the practice of 'new' vegetarianism within the family, as young mothers are deciding to become vegetarian in an act of "conscious self-cultivation" that signifies the "new selves" of young mothers who "use the ideology of the single child family and the cultural repertoire of maternal devotion, including fasting on behalf of others and ascetic vegetarianism, to make a stand and create a space where their individuality has to be recognised by their affines" (2008: 176). Donner argues that such assertions are in keeping with the emergent climate of neoliberalism that has led to an increased significance of individualism and personal

choice and thereby forms a gendered form of adjustment to new realities in post-liberalisation India.

In light of my ethnography where familial relations were foregrounded and given the temporal nature of changing modes by which to conceive of the gendered self in times of suffering and rupture, the thesis is less concerned with trying to define static, pre-given notions of ‘self’ or ‘personhood’ that in turn can be distinguished against other definitive ‘selves’, both within my field site and elsewhere. This has particular saliency, taking into consideration the fact that the thesis is positioned at the interface of patient-volunteer interaction and thereby attempts to incorporate the points at which different visions of gendered wellbeing meet and articulate. Therefore the thesis attempts to attend to the ways in which gendered conceptions of specific relations of self are disrupted, mobilised and reconceptualised in the experience of suffering with and recovering from breast cancer. While I follow others and consider gender to be a processual, partial and shifting terrain that is pragmatically performed, subverted and crafted in response to specific contemporary socio-cultural expectations (see Butler 1990; Jeffery & Jeffery 1996; Thapan 2009; Donner 2008), the main focus of the thesis is to explore how different aspects of being a woman relate to certain key ethnographic issues such as ‘sacrifice’, ‘responsibility’, ‘duty’, and ‘prioritisation’ that take different, shifting forms in the experience of breast cancer⁸.

As a way to try to capture these relations as I encountered them in the field, I draw upon Lawrence Cohen’s (1998) evocative notion of the ‘familial body’. Here Cohen

⁸In researching and writing this thesis I have often contemplated what Marilyn Strathern (1988) has termed the ‘awkward relationship’ between feminism and anthropology. While I see this thesis as a feminist contribution I also stay close to the worlds of my interlocutors, regardless of how this impacts upon ‘Western’ feminist sensibilities.

re-reads the notion of the relational or dividual ‘Indian’ self as the ‘familial body’. ‘Familialism’, in this sense, is not a static quality of Indian ‘culture’ or an Indian ‘self’, but rather forms a site of anxiety and conflict of “the simultaneous manoeuvres of loss and recovery in the construction of personhood and community within the space of an urban India modernity” (1998: 105). The ‘familial body’ is a pivotal nexus of relations constituted by the transaction and exchange of material substance and affection, including modes of *sevā* between intergenerational family members. Describing the way aging and Alzheimer’s disease is experienced in urban India, Cohen shows how the breakdown of a set of relations, those of intergenerational care and obligation, reveals the welfare of the old body as a reflection of the welfare of family relations; it signifies relations elsewhere. He states, “the breakdown of signification occurs simultaneously as a crisis in an individual body and in its family. The two are indivisible, the same thing” (ibid: 177).

In a similar vein, the thesis attends to the different ways relations are constituted, contested and negotiated within the familial body as different experiences of living with breast cancer come to the fore. Thus as the thesis unfolds, the familial body comes in and out of view in relation to the different ethnographic issues that the thesis seeks to describe. This also enables a focus on temporality, a key feature of specifically the post-cancer volunteers’ experiences of recovering from breast cancer as entailing processes of change and self-evaluation. It is a medical anthropological axiom that illness is experienced as processual and transformative and can entail a reorganisation of identity, through which the sick person tries to find coherence and meaning in the illness experience⁹ (Kleinman 1988; Mattingly & Garro 2000). I do

⁹These studies often explore this process of ‘meaning making’ through the construction or performance of narrative that is considered to be a fundamental human way of giving

not dwell on the fact that the post-cancer volunteers are having transformative experiences *per se*. Rather, the thesis focuses on the ways in which the post-cancer volunteers ‘co-make’ with events (Humphrey 2008) of rupture, illness and trauma that, related to gendered dilemmas in the family, appear to produce a distinctly novel relation of self-prioritisation. The thesis thus attends to the experiences and practices of the post-cancer volunteers through the invocation of breast cancer as an ‘event’, a temporal rupture that brings new things into focus, be this a novel facet of a person or new modes of action that reconfigure older forms to create a unique set of possibilities (see Humphrey 2008; Das 1995). Drawing in particular from Caroline Humphrey’s (2008) exegesis of the event in relation to the formation of singular subjects¹⁰, the thesis explores how suffering and recovery brings about the “sudden focusing or crystallization of certain multiplicities inherent to human life and thus creates subjects” (2008: 359). More specifically, the thesis pays particular attention to the way this ‘singularity’ is harnessed in relation to post-cancer gendered personhoods. As such, the thesis speaks to other studies from South and Inner Asia that have explored the ways in which people in varying social contexts attempt to harness a more singular mode of subjectivity (Pedersen 2012; Empson 2011;

meaning to experience and serves to mediate between an inner world of thought and feeling and an outer world of observable actions and states of affairs (Mattingly & Garro 2000). Illness thus becomes assimilated into a story in which the illness is given a form and structure as the often disparate and potentially chaotic conditions of suffering and disruption are gathered together in a process of meaning-making that can counter feelings of dissolution, provide a way to come to terms with the experience and thereby concretise suffering (Kleinman 1988; Mattingly & Garro 2000; see also Young 1995; Kilshaw 2009). In this way, attending to an illness narrative is to attend to the illness experience itself (Kleinman 1988; Frank 1995).

¹⁰In this paper Humphrey advocates a return to the ‘individual’ in anthropology and theories capable of conceptualising singular analytical subjects: individual actors who are constituted as subjects in particular circumstances and ‘fix’ at certain times on the ‘who am I’. Humphrey draws upon the work of the philosopher Alain Badiou who claims that subjects are persons who recognise the ‘truth’ of a great historical event, and in turn develops the notion of the ‘decision event’. This, she suggests, is situation of innovation or improvisation when there is a break with the past, and “singular personalities burst into the field of vision” so that the multiple strands of personhood achieve unity and singularity (2008: 357).

Humphrey 2008), and in particular relation to religious conversion and participation in contemporary Hindu devotional sects (see Venkatesan nd; Desai 2010)¹¹. The thesis thus attempts to explore the way post-cancer women harness novel forms of gendered personhood through idiosyncratic modes of selfless action as *nishkam karma* in search of soteriological benefits that has Hindu self-enlightenment at its core.

While this particular approach may risk being perceived as fixating on “folk” concepts and symbolic and structuring elements that create “stable categories of ‘culture’ which tend to overstate the representation of social relations and take idealized norms as the equivalent of experience” (Donner 2009: 39-40), the thesis is attempting to attend to those particular and emergent forms of gendered self-becoming in a way that does not render them ultimately subject or residual to wider processes of global change¹². At the same time, it attempts to keep a handle on the complex and dynamic engagements that arise out of the particular experiences of suffering with breast cancer, as they intersect with changing notions of health responsibilities in middle-class urban India and the increasing saliency of novel

¹¹Morten Axel Pedersen (2012) has recently discussed the ‘reinvention’ of the individual in anthropology (see also Humphrey 2008) and claimed that anthropology needs theories capable of capturing the multiple forms of human becoming that are increasingly being encountered in the field today. He discusses this in relation to experiences of the converted Christian individual in urban Mongolia where he attempts to consider a relational concept of the individual as he states: “what must ‘the relation’ be in order to be an individual?” (2012: 62). In the ensuing discussion he suggests that it is fruitful to conceive of the process of conversion as “a unique relational transformation, or...introversion, resulting into qualitatively new kinds of entities, concepts and forms” whereby what we call the “individual is in fact a relational cosmos that has imploded into itself and given birth to a new kind of relation, and a new concept of the individual in the process: the ‘self-relational’ person” (2012: 63) or “auto-relationality”. While the thesis is not concerned with religious conversion, or the notion of ‘auto-relationality’ *per se*, it does however find the underlying tenet a useful way to begin to approach the post-cancer volunteers articulations of personhood post-cancer.

¹²For a discussion of how ‘meta narratives’ of modernity and global assumptions within anthropology can frame ethnographic research see Englund & Leach (2000).

health care initiatives in cancer public health discourses. It thereby explores the post-cancer volunteer's experiences as 'intersubjective dynamic interaction'; both social enactment and particular domains of affect and agency (Biehl et al. 2007). It is hoped that such a focus will provide the opportunity for subjects "to think through their circumstances and to feel through their contradictions" and open a space to conceive of the possibilities that persons may envision for others and for themselves (see Biehl et al. 2007: 14).

'Modernity'

The final, overarching theme of the thesis relates to questions of modernity in relation to suffering and survivorship. While there is a wealth of scholarly debate on the question and location of 'modernity' in contemporary post colonial India (see for example Guha 1983; Gupta 2000; Chakrobarty 2002), the thesis approaches this question ethnographically by exploring how ideas and practices related specifically to social change are increasingly becoming intertwined with perceptions of cancer aetiology and activist practice within the voluntary groups. Conceptualisations and practices around breast cancer in urban India appear to feed into wider social narratives about the 'ills' of modernity that are seen to be impacting on the health of the Indian post-colonial nation (see Alter 2000; Nichter 2001; Ecks 2004) as well the stability of the family (see Cohen 1998; Donner 2008). Gandhi first conceived of modernity as colonisation at the site of the body, rendering people sick through the creation of a consumer body and the enslavement of Indians to increasing industry as rendering bodies unhealthy. His fight against modern allopathic medicine and his preoccupation with a patient praxis of decolonising bodies through control of ones cravings for food, sex and commodities, was an act of resistance to urban-industrial

civilisation (Alter 2000). Somatic signs of modernity are also discernable through complaints of indigestion that emerged as a central trope for a defective modernisation that is inextricably linked to lack of self-control and self-care engendered by modern modes of dependency (Nichter 2001; Ecks 2004). Such novel modes of dependency also ramify at the level of the Indian joint family whereby intergenerational *sevā* has been replaced by the self-interest of a younger generation whose wayward behaviour, together with the lure of the West, is resulting in a lack of care that is making elderly parents mad and sick (Cohen 1998).

In the anthropological literature cancer is often associated with certain kinds of modernist conditions and practices that are connected with wider processes of globalisation¹³. It has been described as a “disease of capitalism”, a carcinogenic manifestation caused by changing agricultural and environmental practices that are directly linked with the necessary “civilisation” of modernity (Karakasidou 2008), or else as a pathology of the post modern body in late capitalism whereby the cancerous body, “surrounded by and containing rapid, flexible change” is reflective of and underpinned by “globalization” and late capitalist changing socio-economic structures (Weiss 1997: 469). This takes on particular saliency in the context of postcoloniality where, for example, among Native American Indians, cancer was previously conceived of as the “white man’s disease” because of its diagnostic and treatment procedures, which contrasted with indigenous health practices (Weiner 2008: 113). In this context, Native Indians describe cancer causation with reference to ‘neocolonial’ practices that have made individuals sick through the disempowerment of the political, social, environmental, and ideological systems of their communities

¹³The World Health Organisation (2005) asserts that, in non-western countries especially, socio-economic and cultural change due to globalisation, industrialisation and urbanisation, as well as increased population ageing, are driving chronic disease population risks.

(Weiner 2008). In a similar vein, Margret Trawick (1992) has stated that cancer is widely used as a ‘metaphor’ for the activities of western governments and western owned companies in non-western settings. She interprets her interlocutor’s discourse around social change and ‘cancerous’ capitalistic enterprise in India, whereby the “pure cells beating the drums of war drive out polluting foreign substances”, as constituting a compelling critique of the postcolonial condition.

It is tempting to see the increase in breast cancer as an explosion of the impact of globalisation at the site of the body, the multiplication itself a nefarious parody of post-colonial capitalist enterprise. I frequently encountered notions of breast cancer in Bombay linked to social change and flux. In a private medical clinic, whilst I was accompanying a volunteer on her rounds, I had a conversation with a family while their mother was undergoing chemotherapy. We were sitting together and discussing the possible causes of breast cancer, prompted by the husband’s queries as he pointed specifically to changes happening in urban cities, especially where children are moving away and the family is more dispersed. Together he and his son marvelled at the difference between life in the city and life in the village where they explained that family stay together more, which in turn prompted questions about cancer incidence in the villages. The volunteer explained that there was less breast cancer in the villages than in the city and they nodded as if this was what they had expected to hear. “There are two Indias” the husband said, and then added, “but of course it should be one!” The son then pointed out that urbanisation in the last twenty years has had good effects, especially in computers and IT, but this also has side effects, and he pointed to his mother lying on the bed with the IV drip attached to her arm.

It was an evocative image that stuck in my mind as I persistently heard that ‘things are changing’ – be this values, bodies, selves, mindsets, medicines, therapies or

families. Often, cancer was at the apex of change, seeming to demand an immediacy of social transition and reform, as well as slicing through the familiar and knowable of everyday life within the family. Among health professionals, cancer, like diabetes and heart disease, is considered to be a ‘lifestyle’ related disease and is purported to be connected to changing patterns of life, such as physical inactivity, smoking tobacco, chewing *paan*¹⁴, eating ‘junk’ foods or cooking with an abundance of *ghee*¹⁵, drinking alcohol and taking a non-vegetarian diet. For breast cancer specifically, these lifestyle choices are also particularly related to urban women’s reproductive life cycles and the ‘emancipation’ of women, through which education and the pursuit of careers are delaying the age of marriage, the age of first childbirth and the length of breastfeeding (all of which are considered protective against breast cancer).

While these risk factors were alluded to by health professionals, they by no means represent a clear cut picture of the nature of cancer aetiology in India. The patterns and trends of the Indian cancer profile (which itself is multi-dimensional and specifically differentiated given the size and diversity of the country) are only beginning to emerge¹⁶ (Mittra et al. 2010: 982-3). Certainly the West is prominent here, for not only is cancer defined as a disease entity by Western biomedicine and its aetiology described in Western biomedical terms, but there is also little mention of the causes and mechanisms of cancer in the Indian medical tradition (see Trawick

¹⁴*Paan* is a form of chewing tobacco.

¹⁵Clarified butter used in Indian cooking.

¹⁶For example, there is an earlier age of onset of breast cancer in Indian women, showing more premenopausal breast cancers, as well as a higher incidence of the more aggressive HER 2+ type. This thereby opens up the potential for the presence of other risk factors influencing common cancers in India (see Mittra et al. 2010). A large-scale collaborative project is also currently being undertaken between 12 oncology centres in India and the Indox Cancer Research Network at Oxford University, UK (see <http://www.indox.org.uk/research/epidemiology/casecontrol>) to examine the role of various lifestyle factors in relation to common cancers in the Indian population.

1992). There are, however, complex negotiations underway as an epistemological struggle to establish authoritative parochial knowledge concerning India's cancer burden and the appropriate modalities needed to control it are emerging. Due to a dire lack of local public health policy and initiatives, NGOs such as the All India Cancer Trust (AICT) frequently adopt, adapt and reconfigure western cancer guidelines and statistical information in order to attend to and provide interventions that are congruent with the Indian context. This is in some sense redolent of the post-colonial struggle, part of which took place through the establishment of biomedicine and science as the Indian nation sought to become both 'modern' but also distinct (see Prakash 1999; see also Arnold 1993). From this perspective, as India seeks to define itself in relation to parochial knowledge of cancer and oncology on its own terms, it does so caught within the looming presence of the West. Yet at the same time, it is through this ambiguous opposition that Indian contingency is wrestled with and expressed, as the West would appear to be both the problem and the solution to India's rising cancer burden (see also Cohen 1998).

In this way, cancer is conceptualised as part of wider anxieties concerning Indian modernity and social change that involves the West but, as the thesis sets out to describe, is not necessarily seen to be directly derivative from it. The biomedical discourse that speaks to lifestyles and patterns of 'global' social change glides into other concerns for ambivalent temporalities, wherein livelihoods are conceptualised as compromised by the state of society '*ājkal*' (nowadays) that, tending towards moral disintegration and cosmological restlessness, is resulting in increased potential for suffering. The thesis sets out to begin to convey some of the tensions and ethnographic complexities that exist around breast cancer as a 'modern' condition in

specific relation to experiences of suffering, survivorship, self-care and patient activism that, in turn, would suggest they are irreducible to westernisation.

One important aspect of this is the notion of cancer survivorship itself, which is entrenched in particular ways in the Western popular imagination. The figure of the cancer patient, once associated with death, hopelessness and victimisation, has been transformed through a biomedical and public culture focus on 'survival' whereby cancer patients are encouraged to confront cancer through a 'discourse of hope', and, as a challenge or battle that can be beaten with a 'fighting spirit', to recover as victors or heroes (DelVecchio Good et al. 1990; Stacey 1997). This has given rise to particular meta-narratives of the struggle to survive cancer in biomedicine, 'self-health' cultures and the 'alternative' therapy movement, where survivorship is presented as a story of 'triumph over tragedy' and illness emerges as an individually heroic enterprise in which the patient, having plummeted to the depths of despair, recovers and in doing so re-evaluates the meaning of life and emerges as a new, better and 'true-er' person (Stacey 1997).

These narratives are suggested to contribute to an emerging cancer 'culture' in the West, aspects of which have been criticised for its 'hegemonic and homogenising' narrative that can construct quite narrowly defined subjects and visions of survivorship (Stacey 1997; Stoller 2008). It is suggested that this is inimical to recovery because those who do not render their illness in these terms are consequently silenced or marginalised (see Lorde 1980; Stacey 1997). In turn, this has been linked to an emergent and established form of enterprise culture and pervasive emphasis on individual responsibility for health in the UK and the US (see Del Vecchio et al. 1990; Balshem 1991; King 2001), that has been espoused by state withdrawal of welfare and a relocation of concerns towards the individual (Stacey

1997; Broom 2001; Wilkinson 2001). The preoccupation of ‘self-health’ cultures also ironically feeds into these novel patterns of health consumerism by promoting novel therapies that emphasise the very same notions of individual responsibility and control (Stacey 1997). In this way, it has been suggested that predominant aspects of cancer survivorship within biomedical and self-help cultures promote a “hyper individualism” and are ascribed a kind of omnipotent power whereby the individual is the supreme authority and agent of fate (Stacey 1997: 211). Citing Giddens (1991), Jackie Stacey suggests this epitomises the condition of modernity that involves self-conscious auto-production by which self-identity becomes reflexively organised and persons can self-objectify. Thus “fantasies of omnipotence, of masculine invincibility and individual effect” (ibid: 21) are said to predominate in some biomedical and self-health visions of survivorship in the Western context.

It is important to note that the heroic rendition of the cancer ‘survivor’ is just one of many possibilities of conceiving and experiencing recovery from the disease and that there are very few studies of any kind of cancer ‘culture(s)’, Western or otherwise. While the diversity and complexity of the sociality that surrounds cancer suffering and recovery, as well as what it means to live in remission, has been touched upon in various ways and in relation to different topics such as breast cancer activism (Kaufert 1998; Klawiter 2000a; 2004), self-help and support groups (Matthews et al. 1994; Matthews 2000; Stoller 2008), identity politics (Hunt 2000), and through more autobiographical studies (Lorde 1980; Stacey 1997; Broom 2001; Stoller 2004), this area still requires further research. Nevertheless, it is interesting to note that, as the thesis unfolds, breast cancer survivorship in the specific sphere of middle-class charitable care in urban India also speaks to heroic stories of the cancer survivor and, significantly, claims to a transformed and renewed self. This certainly chimes with

predominant notions of Western survivorship and therefore at first glance there might be assumed equivocation (see Viveiros de Castro 2004¹⁷). While the thesis is not dedicated to explicating a comparative project, given this initial resonance, it does endeavour to continue to attend to the way such ‘global assemblages’¹⁸ (Collier & Ong 2005) articulate and in turn, give way to reveal particular sets of concerns that are established in distinct ways through the activities and experiences of the post-cancer volunteers and communities of breast cancer care.

Mapping the field

Within the last thirty years the oncological health care landscape has seen an increase in cancer NGOs, charities and patient association groups. The backdrop to the thesis is the city of Bombay (also referred to as Mumbai), the capital of the state of Maharashtra. At the time of my fieldwork (from March 2009 until August 2010) I was aware of eight charitable organisations and non-government organisations (NGOs) working for cancer and, of these, four worked specifically for breast cancer. These groups consider themselves to fill in, as and where they can, the absences that state services should be providing. This includes funding for cancer medication, providing patient information and support during hospitalisation, conducting cancer

¹⁷The notion of equivocation is used by Viveiros de Castro (2004) to capture the way in which the nature of comparison is used in anthropology. He states that while the informant and the anthropologist may be engaged in directly comparable intellectual operations, direct comparability does not necessarily signify immediate translatability just as ontological continuity does not imply epistemological transparency. While he develops this concept in relation to Amerindian perspectivalism, the underlining tenet speaks to the project of anthropology more generally.

¹⁸Rather than examine changes associated with globalisation in terms of broad structural transformations of secular change *per se*, Collier and Ong seek to explore how global forms are articulated in specific situations or “territorialised” in global assemblages as sites for the formation and reformation of what they term “anthropological problems”; the domains in which the forms and values of individual and collective existence are problematised, or at stake in the sense that they are subject to technological, political, and ethical reflection...” (2005: 4).

awareness programmes and screening detection ‘camps’. I was told that simply not enough is being done because the government has other competing health ‘priorities’ to deal with and therefore cancer control is marginalised. At the time of my fieldwork, there was no international cancer activist presence in India¹⁹, although many of the organisations participate in various international cancer forums and conferences such as the National Breast Cancer Coalition (NBCC) and the International Union Against Cancer (UICC). However, as far as I am aware, there is no source of organised international funding.

Despite scientific advances and a burgeoning private health care sector that has expanded due to neoliberal reform and continues to profit vastly from international medical ‘tourism’ (see Sengupta & Nundy 2005; see also Bharadwaj & Glasner 2009), the implementation of structural adjustment programmes in the 1990’s has resulted in a decrease in public health investment in the country over the last ten years (see NHP 2002). This has resulted in health care provisions that in some cases continue to be rife with inequity, inaccessibility, lack of resources, and qualified staff (see NHP 2002; see also Dreze & Sen 2002). Furthermore, in the past, private clinical health providers have focused more on developing advanced health care facilities for the urban ‘elite’, who were falling prey to non-communicable diseases and could afford to purchase health care, and it has been suggested that this has prevented public sector resources from flowing into chronic disease prevention and control (see Reddy et al. 2005). Much of the basic infrastructure of government health care in the city, while it fares better than the rural areas, has many of its own problems. For

¹⁹Assumed to be the exclusive preserve of richer nations as ‘diseases of affluence’ and ‘lifestyle’ related causes, cancer and other non-communicable diseases such as diabetes and heart disease have been marginalised in the global health agenda, having hitherto been the ‘neglected epidemic’ of international development (see Horton 2005; Geneau et al. 2005).

example, despite the proximity of many of the poorer urban inhabitants to health care facilities their access is severely restricted. This is due to them being “crowding out” because of the inadequacy of urban public health delivery system (see NUHM 2010). Ineffective outreach and weak referral systems limit access, as does a lack of information and assistance at the secondary and tertiary hospitals, which makes the urban hospital an unfamiliar environment. With limited economic resources, poorer inhabitants are also restricted from accessing the private health care sector²⁰.

In terms of cancer control, although, as part of the World Health Organisation initiative, India was one of the first countries to create a National Cancer Control Programme²¹ (NCCP) in 1975-76, however today the delivery and provision of state oncology services is widely disparate and many institutions are ill-equipped to deal with the provision of polyvalent and specialist oncological services. This is reflected most urgently in the lack of any nationwide organised early detection initiatives in the country as 75-80% of patients present for diagnosis at an advanced and incurable stage of the disease (NCRP 2002; NCCP 2002; see also Pal & Mittal 2004; Lamberts Okonkwo et al. 2008).

²⁰Up until quite recently urban health has been marginalised in policy planning at the expense of the enormity of aid needed in rural areas. The Indian government did intend to launch the National Urban Health Mission, a sister programme to the National Rural Health Mission. This plan aims to resolve some of the issues raised above, by strengthening the extant primary health care centres, introducing community level outreach schemes, and including community participation. A large proportion of this mission focuses on community health risk pooling and health insurance in order to start protecting the poor from out-of-pocket expenditure (see NUHM 2010). However, while it was proposed that the NUHM would be implemented in the latter half of the 11th Five Year Plan, it was announced in the press in 2010 that the project would be postponed (see ‘*Urban health mission shelved for now*’ Times of India, 12th February 2010)

²¹This was initiated by the Indian Council of Medical Research and six cancer registries, five urban and one rural, were organised to form a National Cancer Registry Programme to document India’s increasing cancer burden. The NCCP has since been through various reformulations and there are now 19 Regional cancer research and treatment centres across the country (see NCCP 2002).

Much of the charitable work and activism around cancer is therefore related to the specific socio-economic context in which individuals are attempting to access and retain oncological care. There are different forms and arenas for this. There are two predominant large scale NGOs in the country, one of which is the All India Cancer Trust (AICT). This is a multi-faceted aid-dispensing agency focusing on patient care, awareness, screening, diagnostics, fundraising, public health policy, intervention and advocacy. These organisations rely on donations, most of which come from Indian sources, and well established connections with the rich philanthropies of an urban elite who attend celebrity dinners, galas and fashion shows, as well as through the often anonymous donations of a few regular well-wishers who give a substantial amount of money each month (anything from 50,000 INR to 2 lakh²²).

Alongside these larger organisations, there are smaller volunteer based groups and associations that work exclusively for breast cancer patients and are led by post-cancer women. These groups are the current focus of the thesis, and in this way the thesis is not dedicated to elaborating a study of the ‘development’ of cancer in India or even of NGOs *per se*, but rather is concerned with the nature of survivorship that emerges from the work of post-cancer volunteers who have mobilised themselves in distinct ways. To this aim, the thesis draws directly upon my participant observation with three groups; The Women’s Cancer Association of India (WCAI), the Cancer Centre (CC), a breast cancer rehabilitation clinic, and *Saheli* (meaning, specifically, female friendship), a self-proclaimed support group. Breast cancer patients and / or their oncologists initiated these groups during the late 1990’s and early 2000’s. The Cancer Centre (CC) and the Women’s Cancer Association of India (WCAI) are

²² One lakh is equivalent to one hundred thousand rupees (£1,129).

charities that primarily seek to provide post-operative emotional support, information and the prosthesis, and the WCAI in particular funds a small amount of free medication. These groups operate on a much smaller scale than other cancer NGOs as their outreach is local, and their funding capabilities extremely limited. These organisations are wholly dependent upon word of mouth, either through their members and volunteers, who tell their friends and family, or via the patients themselves.

The women who organise these groups and engage in the delivery of care are from wide ranging middle-class and upper caste backgrounds. Many, but not all, are English speaking, having attended English medium schools, and also speak Hindi and Marathi. A few have pursued graduate and post-graduate studies, and some have undertaken employment as teachers, bank clerks, nurses and doctors, but the majority are housewives. There is a minimal focus on caste in the thesis. This is partly in response to the fact that my interlocutors did not focus on it; gendered issues were much more important to them and pervaded aspects of their voluntary work. It has also been recently pointed out that, while caste has not become insignificant in shaping identities and interactions, it is not the “encompassing” determinant of behaviour (see for example, Appadurai 1986), and other social categories such as class and gender are equally important to how Indian women specifically experience social interaction and personhood, and this is especially so in the urban cities (Caplan 1985; Dickey 2000; Donner 2008). Furthermore, the axis of ‘difference’ in the thesis is breast cancer itself, and this is explored in particular relation to wider questions of gender and class that emerged ethnographically. This is not to say that caste is insignificant in relation to cancer or for the women I worked with. Indeed I sometimes found that caste concerns were often voiced in subtler ways and frequently

through the idiom of socio-economic class. Therefore where salient, I point to the presence of caste, but the specific relationship between caste and breast cancer is currently beyond the focus of the thesis.

Socio-economic class, however, emerges as significant. Being a middle-class activity, class inevitably frames the nature of the volunteers' activities, values and experiences of survivorship and the kind of practices that they advocate. As such, the voluntary breast cancer groups have emerged in a similar way to other women's groups (see Caplan 1985) and the women's health movement in India more generally. The entry of Indian women into the discourse on Indian's women's health is shaped by colonialism and class and initial women's groups were organised by middle-class women who established nongovernmental voluntary associations dedicated primarily to family planning and reproductive health (see Ram 1998a; Ray 1999). The voluntary breast cancer groups therefore should be conceived of as part of a wider legacy of middle-class reform concerning social welfare and women's health in India. Class is also reflected in the kind of gendered concerns that the post-cancer volunteers articulate and indeed their very attempts to harness the self in particular ways in life post-cancer. Therefore, while the thesis is not intended as an exposition of class *per se*, it forms a significant backdrop to this specific exegesis of a particular group of women.

Methodology and Ethics

This project started to take shape during my MRes, when I conducted a pilot study on breast cancer in Delhi, India. This initial work formed the foundation of inquiry for my PhD, and through it I began to explore questions of gender, personhood and 'spirituality' as they relate to breast cancer and local variants of 'activism'. During

my time in Delhi, and having travelled to Bombay for a large breast cancer awareness event, I learned that Bombay has many more cancer NGOs. It was for this reason that I decided to conduct my doctoral fieldwork in Bombay, although I made subsequent trips back to Delhi to follow up previous fieldwork connections.

I spent my first two months of fieldwork familiarising myself with the charitable 'scene' in Bombay and the thesis draws predominantly upon my work with three of the organisations there, although my association and participation with many other organisations also inform it. My first port of contact was with the WCAI and it was via this organisation I managed to gain access to the Bombay Cancer Hospital and attend the breast cancer post-operative classes. I also tried to make contact with other NGOs and charities. This I did manage to do, mainly through word of mouth as people would keep telling me the names of women that I *had* to meet, and in turn they were affiliated to different groups. I also attended any event in the city related to breast cancer, and cancer more generally. After a few months, when I was becoming a 'regular' at several different group events, I decided to devote myself to three organisations: the WCAI, the Cancer Centre and the All India Cancer Trust.

At the Cancer Centre, I was able to witness direct interactions between patients and volunteers (which were often conducted in English, Hindi or a combination of the two), and spend a considerable amount of time with the volunteers, while volunteering at AICT enabled me to train on their onco-volunteer programme, spend considerable time in the office (and mainly with the patient care department), help in various areas of the charity's work, such as attending awareness lectures and screening camps, co-organise conferences, attend fundraising events, and, from October 2009 to June 2010, run the support group. It was through my work and contacts with AICT that I became an 'accredited' and *bona fide* volunteer within the

charity and medical community, and this in turn opened many doors through which I met patients and post-cancer women. Towards the very end of my fieldwork, I came to know about the group I name *Saheli*. This group of women is located in a city outside Bombay and is different to other organisations because they are not a charity or NGO, but a self-proclaimed breast cancer support group. I made several trips to stay with them where I attended the ‘official’ support group meetings and participated in their everyday activities. The women I met here became extremely dear friends and welcomed me into their fold without hesitation, and they figure prominently in the thesis.

Even though I was heavily involved with AICT, the organisation itself was not my main focus; I do not foreground its activities nor place it as a central focus in the thesis. Instead, the thesis is primarily concerned with the numerous smaller groups, organised and run by post-cancer women and volunteers. AICT was in a sense a ‘gate keeper’ *par excellence* through which I could engage in many different kinds of interactions. These interactions have made their way into the thesis in various forms, but do so independently from association with AICT as an organisation. AICT have a political investment in their reputation as an organisation, and I am concerned to distinguish my work and approach as an independent researcher from their activities, especially in those moments in the thesis where ideas between us might clash. I am extremely indebted to this organisation for their hospitality, friendship and welcome into the AICT ‘family’. Therefore, I have an interest in minimising any criticism towards them and I have ensured, to the best of my ability, that the organisation and its workers have anonymity, as well as clearly demarcating all groups, persons and ideas presented throughout the thesis that are associated with them.

My methodological approach was wholly determined by the nature of the field. Not only was I researching breast cancer, but I was interested in the “urbane”; a specific way of life to be found in the cities that deals with the urban landscape (see also Donner 2008: 3) and specifically the urban cartography of health care. As such I position myself alongside other studies that have noted a ‘traditionalist bias’ towards rural field sites, which is especially true for South Asia (see Dickey 2000; Donner 2008). In conducting urban research I found the field was dynamic and shifting as I spread myself over different spheres within the city setting: the home, the hospital, the clinic and the NGOs, that also at times moved beyond the city to the ‘camp’, for example, as I followed the activities of my interlocutors (see also Copeman 2009). In this way, this thesis is as much about breast cancer, as it is about the political nature of the urban space through which my interlocutors are seen to move and interact.

In this way I draw on my interaction and participation with many different groups, activities and events. I also interviewed all the founders and volunteers of the charities with whom I made contact, and spoke with as many volunteers, patients and post-cancer women and their families as possible. I would often gather stories in the hospital waiting rooms, although some were more snatched than others depending on the time, place and suitability of the conversation at hand. I was often accompanied to government hospital A by Laxmi, an employed researcher with AICT, who helped me approach women and also aided the translation process where Hindi conversation was particularly complex or where women only spoke Marathi.

I also slowly assembled a group of women whom I would describe as my main interlocutors, and it is with these women that I spent most of my time. It is their lives, stories and experiences of breast cancer and being a post-cancer volunteer that immediately inform this thesis. I formally interviewed these women using a semi-

structured interview guide and a digital voice recorder but, more often than not, I learned about their experiences by participating in their lives, by spending time cooking, eating, running household errands, shopping, and chatting with them in their homes on lazy hot afternoons lying on their beds under the cool of the fan.

My relationship with these various groups and women were naturally perceived in varying ways. On the one hand, being a young, female student far away from home made me analogous to the women's children, many of whom were my own age. Being treated as a *betā* or daughter had its advantages, for I was brought into the family fold. Through this bond, I also found that women opened up to me in quite remarkable ways. Some opened up fairly quickly and spoke candidly about their lives, whereas others were less forthcoming, and it took a long time before they were able to share with me. With those I knew less well, I was frequently treated with suspicion (*why aren't you studying women in your own country? What is it exactly that you want to know?*), or else I was thought to be a doctor, which often made me feel very uncomfortable. However, more often than not, I found that women, although hesitant at first, were happy to speak with me. While my association with NGOs aided access and enabled me to observe the post-cancer volunteers, it inevitably placed me, with some patients, in the position of being treated as a 'mam', with all the power and respect that that word implies. I therefore often tried to foster particular relationships with women and their families independently and away from the NGOs.

It has been difficult to incorporate the plurality and contradictions of all these different voices and actors within this thesis. While I have focused on the post-cancer volunteers, their work and their specific rendering of survivorship, I readily recognise that this is just one privileged position of the experience of breast cancer. At the same time, since my research was positioned somewhat uniquely at various intersections of

cancer care, be this patient and volunteer, patient and doctor, volunteer to volunteer, patient and family, the juxtapositions or ‘critical nodes’ of fieldwork (see Cohen 1998), such as where the post-cancer volunteers experiences and interactions resound and ‘bump’ with those of other post-cancer women and patients, have brought to light many significant aspects that would not have been captured, if I had focused exclusively on the post-cancer volunteers. In this way this thesis is not only about them; it includes stories and experiences from a range of voices, as well as my own observations and impressions, although I readily acknowledge that men take a backstage role in the thesis.

Following the ASA ethical guidelines I tried to ensure the terms of my research were clear to all those I worked with in the different organisations and among the various women I interviewed and spent considerable time with. Given the sensitive nature of the thesis subject and the fact that I focus in detail on individual women’s lives, I have tried to assure anonymity by using pseudonyms and omitting personal details from ethnographic descriptions. I have also changed the names of all organisations and hospitals in order to protect, to the best of my ability, their privacy.

Chapter Outline

The first chapter explores the way in which breast cancer is indigenously conceptualised in urban India. It traces the various practical movements of patients and their families as they attempt to access oncological care. This forms a prologue and descriptive backdrop to the rest of the thesis that turns to explore the activities of the post-cancer volunteers. The second chapter describes the emergence of the voluntary groups, and the ways in which the post-cancer volunteers are beginning to mobilise around the practical aspects of the disease through the fundamental notions

of *sevā* and charity. Here I discuss the notion of ‘therapeutic mediation’ as the work of the volunteers emerges as first and foremost related to pragmatic concerns. Chapter three explores in greater detail the way in which relations of ‘affiliation’ between patients and post-cancer volunteers are reckoned with, and focuses in particular on a tension between sharing as ‘talking’ in the support groups, and sharing through the work of vision. The chapter then goes on to examine how ‘belonging’ is crafted and cultivated through participation in a ‘support group’. Chapter four turns explicitly to the issue of gender and appeals to ‘self-prioritisation’ by the post-cancer volunteers. Here the dilemmas of self-sacrifice are explored as they unfold in both patients’ and post-cancer women’s experiences of having suffered with, and survived breast cancer. In turn it describes how gendered notions of self-sacrifice are being reconfigured within the groups to produce novel visions of ethical self-care. In the fifth chapter, the thesis turns to explore in greater depth the post-cancer volunteers’ subjective experiences of recovering from breast cancer, and hones in on three individual women’s lives to examine the struggle to harness the self in particular ways that leads to a final reflection on the nature of biosocial patient mobilisation in India.

CHAPTER 1

Breast cancer as movement in urban India

This chapter is first and foremost descriptive. It sets out to introduce the multi-faceted complexities I encountered around breast cancer in Bombay and initially introduce indigenous concepts of breast cancer as a disease. This involves an exploration of the ways in which breast cancer is associated with death that, in turn, gives rise to extreme fear of the disease. Health professionals and post-cancer volunteers in Bombay speak ubiquitously about the ‘stigma’ and ‘taboo’ of cancer and persons describe themselves as ‘hiding’ from society. Therefore, I was told nobody wants to talk about cancer in India. In the opening part of the chapter, I explore the relationship between death, fear and breast cancer in more detail by attending to the ways that living with breast cancer necessitates strategic acts of concealment and ‘containment’ of the illness within the family. The ‘familial body’ emerges as particularly significant here, not only in the way breast cancer is conceptualised as something that transmits and spreads between persons, but also the ways in which the stigma of breast cancer as ‘living death’ appears to be confronted from within the domestic sphere in the face of wider community fear, panic and pity.

In second part of the chapter, the focus shifts to explore the kind of practical issues engendered by breast cancer, since suffering with the disease requires particular geographical and physical movements that have significant ramifications for patients and their families. Health policy literature frequently highlights the structural conditions and, in particular, the centre-periphery divide of the Indian urban/rural

landscape as shaping and mediating the delivery of, and access to, cancer care (see Broom & Doron 2011). I found that many of the patients, who were seeking care in the large state hospitals in cities such as Bombay, have travelled from surrounding rural areas due to a paucity of adequate oncological facilities. The delivery and provision of state oncology services is widely disparate, and many institutions are ill-equipped to deal with the provision of polyvalent and specialist oncological services. Availability and affordability of treatment can vary dramatically both between and within states, with the poorer states emerging as grossly underserved. In rural areas especially, there is often little access to any cancer diagnostic and curative facilities and, while cities fare much better, municipal tertiary institutions are still often subject to severe overcrowding, long waiting lists and, in some cases, lack of technological facilities (see NCCP 2002; Pal & Mittal 2004). This heavily impinges upon the ways in which patients and their families' access oncological treatment. The chapter expands on this by exploring in detail the nature of the oncological clinical engagement and, in particular, pays attention to ways in which suffering is articulated as a concern for the stability of the 'familial body'.

More specifically, other studies of cancer have noted that the disease is frequently conceptualised through pervasive cultural metaphors (Sontag 1991). Cancer is widely understood as a disease of uncontrolled cell growth and, in biomedical and Western cultural imagination, cancer is often described as a disease of disorderly cells or cells "gone mad" (McMullin & Weiner 2008a: 11). This is considered to be particularly 'chaotic' because the disease conjures up issues of uncontrollability within one's own body and violates otherwise sacred boundaries of self / other (see Sontag 1991; Weiss 1997; Stacey 1997; McMullin & Weiner 2008b). In particular, it has been suggested that metaphors of transformation and pollution constitute cancer in a symbolic space,

where it is often metamorphosed “beyond culture” (Weiss 1997: 457). Certain Western popular and biomedical metaphors combine to take on the authority of medical science, and thus represent cancer as a universal symbolic concept which, in this way, can presumably “cross national and geographical boundaries, transgress social demarcations, and disrupt the inner boundaries of the human body thus transgressing, or obliterating even, culture” (Weiss 1997: 471).

Certainly in Bombay, there are concerns for breast cancer as a disease of transgression, flow and pollution that speak to overarching, biomedically defined conceptions of the disease as chaotic. However, rather than focus on the cultural elaborations of overarching, indigenous metaphors of cancer in India and elsewhere, the chapter attempts to capture the uncontrollability of breast cancer by attending to the ways in which the disease appears to create and necessitate certain kinds of ‘movement’. This focus on movement is related to the different ways in which I encountered breast cancer as motile; something that ‘moves’ and spreads between persons; a disease that propels patients into a space of existential liminality as ‘living death’ and, in turn, pulls the ‘familial body’ apart through the practical and physical movements to the city, and within the city itself. Then I explore how this gives rise to suffering, expressed as both a ‘stretching’ of relations within the ‘familial body’ as well as a kind of stasis, as women are immobilised in the city away from the home for prolonged periods of time.

The chapter draws liberally on the concept of the ‘disease multiple’ in Mol’s (2002) ethnography of ontology in medical practice. Here Mol explores the ways in which diseases are ‘done’ in medical practice as medicine attunes to, interacts with and in doing so thus enacts its objects of concern and treatment. Mol explores how atherosclerosis does not exist outside of perceptions as a concrete object to be

perceived according to different contexts, but rather she suggests that its very existence depends upon enactments, between different contexts and different people, such as the interactions between the patient and the doctor, as well as the medical technologies that allow the disease to be ‘confirmed’ or ‘denied’. Her focus on practice thus shifts attention away from the interpretations and meanings that people may assign to their disease, and instead she attends to the ways bodies, objects and events have been lived through as “events-in-practice”²³. While ontological medical practice itself is not the focus of the current chapter, the notion that a disease can be enacted over various fields and therefore ‘spread’ is a particularly efficacious viewpoint from which to begin to explore and capture the ethnographic movements of breast cancer patients and their families in Bombay.

Part One: Conceptualising breast cancer

1.1 Fear and ‘living death’

In Bombay I encountered an incessant and debilitating fear of cancer. Cancer is considered to be a new, mysterious and dangerous disease because undoubtedly cancer *jīvan leta hai* (it will take life). What, why, and how cancer happens is perplexing and terrifying, and stories of hearsay circulate whereby what can never be fully seen is imagined and made manifest through metonymic signs of ‘death’, such as coughing up blood, becoming emaciated, looking pale, withered and withdrawing from society by not meeting people. As I tried to uncover what the ‘stigma’ around

²³Mol suggests that something quite different emerges here. She states “if practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead objects come into being-and disappear-with the practices in which they are manipulated” And since the object of manipulation tends to differ from one practice to another, “reality multiplies”. Thus “the body, the patient, the disease, the doctor, the technician, the technology: all of these are more than one” (2002:5).

breast cancer meant²⁴, I was told first and foremost that just hearing the name cancer conjures fear (*cancer ke nām se dar lagta hai*). More specifically, I found women consistently spoke about their fear of cancer in relation to problems of contagion, transmission and *maut* (death). Cancer is considered to be ‘spreading’ (*phail raha hai*), ‘catching’ or contagious (see also Karakasidou 2008; Weiner 2008), primarily possessing the ability to pass through and move between persons. Women don’t necessarily know how this could happen, just that it can happen through different modes of contiguity during illness. For example, many Indian women and their families believe that it can spread from a patient to her child through breast milk, or else through the contact of maternal blood to her foetus. It can also transfer through sexual intercourse and the sharing of food and utensils. Occasionally, transmission was also spoken about as specifically hereditary but this did not necessarily replace concerns with breast cancer as being able to ‘spread’ but rather fed into the main underlying anxiety concerning the principle of movement and transmission between members of the family. What is clear is that, if somebody in the family has cancer, it can move.

Breast cancer is also frequently considered to be a *pāp* (sin; wrong doing) and / or a punishment (*sajā*) from *bhagwān* (god) for inadvertent moral transgressions that might have been committed in this life or previous ones. In this way, it is also conceived of as part of a woman’s *nasīb*, that is her luck or fate, and was therefore sometimes said to be *likhā huā* (written). Sometimes this seemed to provide a means

²⁴It has been noted that terms like ‘stigma’ used by both our interlocutors and social scientists more generally have become blanket explanations that can gloss over deeper social complexities (see for example Staples 2007). Taking heed of this, the chapter attempts to begin to explore the notions and practices that underpin public health descriptions of breast cancer as stigmatised.

of relative stoic acceptance. I was told that not only does everything happen for a reason, but that ultimately “*bhagwān joh karēgā achā karēgā*” (what god does is for the best). Questions concerning causality were frequently articulated in these terms, and rarely sought solely in biomedical factors. Many women are aware of the biomedically defined risk factors for breast cancer, such as late marriage, delayed child birth, minimal breast feeding, ageing and obesity, and while some related to them in lesser or larger degrees in their own personal situations, most appeared to be indifferent to them or else further perplexed because they did not find any resonance with their own lives.

More frequently however, I encountered the possibility that breast cancer causality is linked to problems of stress and ‘tension’. In the South Asian medical context, the body is considered to be composed of fluids, essences or humours and elements that ebb and flow in a constant process of dynamic interaction and, as such, can slip out of health in any number of ways and for many reasons that emerge as linked to “idiosyncratically unique ecologies” (Alter 1999: 46; see also Marriot 1976; Daniel 1984). In this way I found tension described many different distressing situations, and particularly those that pertained to restless (*adhīrtā*) or imbalanced states of being. I often encountered this explanation from women who described prolonged difficulties, such as attempts to manage economic scarcity that caused them to have *chintā* (worry) about the welfare of their families that in turn led them to ‘take tension’ (tension ho rahā hai)²⁵. Concern for sick children or domestic discord were also given as other tension-inducing causes. These distressing situations were also

²⁵Lawrence Cohen has also noted that ‘tension’ is perceived differently from *chintā* (worry; anxiety) and is associated with weakness, and particularly mental weakness, as part of wider perceptions of notions of ageing as revolving around ontological states of balance and adjustment.

sometimes connected to wider anxieties about social change, which was linked to the current temporal epoch *kaliyug*. As the last of four cycles of time in Hindu cosmology, *kaliyug* is the age of vice, a morally turbulent time of spiritual degeneration, dissent, turmoil, doubt and delusion, when people migrate abroad, crimes increase and there is general animosity between persons. The invocation of *kaliyug* has been noted to encode and explain many of the dilemmas of everyday life in India as they pertain to the (most often) negative aspects of modernity, including contexts of illness and health (see Copeman 2009; Cohen 1998; also Pinney 1999).

In a similar way, *kaliyug* was described to me as a *kharāb* (bad) time that was emphasised as a time of inherent imbalance. Not only has this resulted in widespread natural calamities in the world, such as the Tsunamis of 2009, the rise in terrorism in India and abroad, as well as the rise in crime and corruption, but it also affects the way persons act. Problems of tension and increased suffering were sometimes perceived to be borne out of a wider malaise with social change, by which people are becoming more restless and agitated due to the increase in desires or the feeling of *asaktī*, of attachment or involvement with the material world. Living in such a world, and sometimes under conditions of stress and strain due to family discord for example, creates more tension in the mind, which in turn impacts the body leading to the emergence of novel diseases such as breast cancer²⁶ (see also chapter 3).

²⁶Some women also discussed the notion of tension in relation to the proportion of ‘*gunas*’. This recalls *Sāṃkhya* theory (one of six schools of thought in Hindu philosophy) that states that the universe is made up of two principles, the universal soul (*purusa*) and the realm of matter or substance (*prakṛiti*) which is itself constituted by three *gunas* or qualities: *sattva* (lightness, truth), *rajas* (force, action, vitality) and *tamas* (inaction, darkness, lethargy). These properties are animated when the principle of *purusa* is combined with *prakṛiti*. The *gunas* interact in different ways and with varying levels of degrees in each person uniquely and, in turn, this can impact upon the nature of a person and accordingly their actions. Some women explained that in *kaliyug* there is more chance for these *gunas* to be unbalanced and many

At the same time breast cancer is also associated with death, not only by patients themselves, but also by the wider family and community. Patients often described themselves as being spoken of as *becharī* (a pitied, hopeless fellow) and health professionals and volunteers frequently explained to me that this is because the cancer patient is treated in society as if they are ‘already dead’. Survival is considered impossible. From patients and their families I learned that suffering with breast cancer induces mandates of mourning such as taking to your bed, withdrawing from society and having to endure the fleets of family members that come to ‘view’ you.

While there was immense fear around the nature of cancer as a disease, it was also often said that people do not die of cancer (*log cancer se nahin marte*), they die of the fear of cancer (*cancer ke dar se marte hain*). While hoards of relatives would often visit the patient, I was also told how people would stay away and deliberately not visit. Like a spell or the evil eye, the word ‘cancer’ itself is also considered dangerous (see also Weiner 2008; Balshem 1991; Trawick 1992). ‘Saying’ or ‘seeing’ cancer is considered to be thoroughly inauspicious. Speaking of or dwelling upon the idea of cancer too much can bring the disease into being, and accordingly patients are encouraged by their families to not speak or think about cancer. Very often the word ‘cancer’²⁷ is not used and is instead replaced by the much softer sounding *gārnth* (lump), cyst, or more simply *chāti taklīf* (breast / chest problem) and *cīz* (thing). Sometimes volunteers were discouraged or berated even for speaking about cancer in their friends or relatives homes because it is considered to bring bad luck into the house. I also frequently experienced difficult or uncomfortable situations where I

more people have a higher disposition of the *tamas* quality which gives rise to more acts of selfishness, greed and jealousy.

²⁷I did not come across an indigenous name for cancer in the Hindi language.

could not speak of cancer. On one of my very first days in the field, I moved into my little rented paying guest accommodation and the mother of my landlady took me aside and, knowing about my research, suggested that I did not mention “too much of this cancer thing” to her daughter, who had a few years earlier lost her husband to the disease.

The fear that surrounds cancer is perhaps comparable to the feeling of *payam* (fear) that Trawick (1990) discusses, whereby this kind of fear is expressed in relation to revulsion and is the ‘feeling’ that goes with pollution. It is also the feeling evoked by death and, to survive in the face of it, one must “put some kind of fence around it or oneself” (1990: 190). In a similar way, the association of breast cancer with sin and shame brings together certain cultural anxieties concerning impure, polluting or liminal states of being, for example it is considered that people die from sin that manifests in emaciation, illness and decay, and death itself is conceived of as one of the most polluting or impure conditions (Parry 1994; Barrett 2008). As a ‘living death’, breast cancer seems to propel patients and their families into a state of existential liminality that is feared to the point of avoidance of all associated things, persons and ideas, and emerges as something that must be contained. This gives rise to strategic acts of concealment within the community and the family in order to obfuscate social judgement and thereby enable everyday sociality, in whichever ways it is desired, to ensue. This includes withdrawing from social activities within the communities or even abandoning communities all together; keeping medical files in the hospital so no one might see them; requesting NGO branded vans, if they were making a home visit, to park in another road from the patient’s home; wearing the breast prosthesis to hide bodily deformity; wearing a wig to hide hair loss from chemotherapy or else informing neighbours and family members that this is the result

of religious pilgrimage to the south Indian temple Tirupati Baiaji that is known in particular for sacrificial devotions of hair.

1.2 Protecting and preserving the familial body

The familial body is particularly significant here, emerging as the site at which the experience of living with breast cancer must be managed, concealed, protected and contained. In confronting the opprobrium of stigma of living as ‘death’, breast cancer is experienced from within the sphere of domesticity and becomes pitted against wider kinship and community as the disease emerges interpersonally as ‘off’ the body and conceived of as a problem of “connected body-selves” situated within a network of social and kin relations (see Das & Addlakha 2001: 512; Das 2001; see also Cohen 1998²⁸). Patients spoke about the incessant and invasive questioning from *log* (people) or *sub log* (everyone). Well-meaning relatives, friends and neighbours appeared in patients’ narratives as faceless, nameless voices, questioning and inquiring: “How many days are left for you? What will happen to your children? *Arrāy!* (hey) Where did they cut you?” Although these concerns are usually directed towards the well-being of the patient, they are also often experienced as ‘lethal’ as the suggestions, counter suggestions, excessive voices of anxiety, hyperbolic sympathy and fear within the community and kin networks insert into the “space of the imaginary when the hold over the real was seen to slip” (see Das 2003: 100²⁹).

²⁸Cohen (1998) has noted in relation to Alzheimer’s disease that the angry and confused voice of the old person is heard as an index of the moral coherence of his or her family. To speak of her voice is to thus address the state of her family and therefore he concludes that the old body is not stigmatized as “itself” but as the body of the family.

²⁹Veena Das (2003) has noted a similar point in relation to the way health care is sought and experienced by women within kin and neighbourhood communities in urban Delhi.

Madhuree, a sixty-year-old widow, who had come to Bombay for treatment, expressed this concern. She was diagnosed with breast cancer when she was living in her village and thought that the illness was rooted in a wider genealogy of family disease – as she explained, it was in the *parivār* (family). Her mother died of a uterine problem (Madhuree did not know if it was cancer or not), and her two sisters also had gynaecological problems. She recalled the horror of the “*kālā kālā khūn*” (black blood) coming from inside her sister and how she had not known what to do. The fact that “*sub log*” (everyone) was suffering made her think that these illnesses were a punishment from “*bhagwān*” (god). Madhuree explained that, after her diagnosis with breast cancer, life in the village had been especially difficult because everyone said she would not be saved. Having fled the village to come to Bombay for treatment, where one of her son’s lived, she was offered the possibility of anonymity that made her life a little easier.

In not too dissimilar a way, Isha also left her home in Bihar where she and her husband experienced excessive fear around a *gārnth* (lump) that she had found in her breast. After enduring several misdiagnoses (one allopathic, another Ayurvedic), and at the point where the lump had burst through her skin, they sought treatment in another allopathic clinic where she was told she had cancer. Their family and the wider community were concerned that this was a *pāp* (sin), and Isha decided she wanted to leave quickly because the evaluations of the nature of her illness were coming from everywhere and this was made worse by the fact that people were saying that, now that she had breast cancer this meant that life will cease.

Therefore, the experience of breast cancer as kind of ‘living death’ engenders liminality within the wider domestic sphere and kin networks in the community and

this, in turn, can necessitate the movement away from the proximity of kin relations to the anonymity of the city. Such strategies also included families operating under ‘veils of silence’ (see Das 1995)³⁰ in order to make cancer manageable in everyday life. This often involved concealing the fact of the disease, often even from the patient herself, as families fear that, if they tell a breast cancer patient that she is suffering with the disease, she will just die of shock or fright³¹. Geetu, who decided along with her father to not tell their mother she was suffering with breast cancer, explained this as follows: “Cancer is such a strong thing, not everyone can take it. Therefore you don’t tell. You can’t know how she will react”. She continued, “We were scared because you know in the last stages she might spit blood and everyone knows that this is cancer, so then what would we do? Even at her death, she still didn’t know and she died peacefully at home without ever knowing why she was actually dying”. It also emerged as imperative to conceal the disease from wider members of the family, and often parents-in-law especially, if the couple were young and were yet to have children, as breast cancer is perceived as a direct threat to their potential fertility, which itself is cause for great concern as raising a family is not only expected by family elders, but is also deeply desired by couples themselves³² (see also Bharadwaj 2002).

³⁰Veena Das (1995) describes how in the aftermath of horrific rapes that took place during partition, families managed the consequential breaches of norms by covering them with “veils of silence”; imposed collective censorship so that these women could be absorbed within the normal structures of family and marriage, allowing a “practical kinship” to ensue and in turn render the offspring of sexual violence ‘invisible’.

³¹For the most part I found doctors are complicit with this. It has been noted elsewhere that truth disclosure in India is not mandatory because doctors are extremely worried about the emotional and depressive reactions from a patient to a truthful disease disclosure and so they revert to telling family members (see also Broom & Doron 2011).

³²Recent work on infertility and adoption in India has described how the secrecy of treatment and the minimal consideration of adoption as a viable option for infertile couples is considered to feed into wider concerns with obfuscating the ‘public and visible’ violation of a cultural ideal of child bearing (Bharadwaj 2003).

Furthermore, concealing the disease from the wider community is deemed particularly necessary if women suffering with breast cancer have unmarried daughters. Many families are anxious that, if the mother has breast cancer, then other people will think that the daughter is in some sense ‘spoiled’ and therefore unmarriageable. Given that most marriages are still arranged in India, and also still within the restriction of preference to caste group and ethnic community³³, the onus is very much on finding a good match for a daughter. The revelation of cancer within the family therefore not only makes the daughters themselves seem more susceptible to cancer, but also potentially threatens the respectability and honour of the family by bringing shame on them because no one will want to marry their daughters³⁴. At the same time, it continues to suggest that suffering with breast cancer arouses concern for interpersonal transgression and the bodies of others within the family.

While families engaged in attempts to contain the inherent motility of breast cancer and thereby protect the boundaries of the familial body, the way that breast cancer also necessitates movements from within and away from the domestic sphere gives rise to suffering articulated as a fear for sudden ‘stasis’ of the familial body. In this way, the family emerged as the pivotal locus of gendered well-being as getting better was so often directed towards protecting the family unity and sphere of domesticity. So often women’s articulation of their concerns while they suffered with breast

³³I heard about the importance of caste frequently in relation to arranging marriages where, for example, families tended to look within their own communities for suitors with backgrounds that match their own, and in some cases preferred a potential suitor who did not come from a ‘mixed’ or intercaste background. Or else they themselves were subject to scrutiny in a situation where having had a ‘mixed’ caste marriage, their daughter was not considered to be as “pure” and therefore less desirable.

³⁴This is also potentially redolent of the ways middle-class women in particular have become enveloped by specific roles that require them to take responsibility for producing and maintaining the symbolic indicators of family status, emerging as metonymic for the moral welfare of the family (see also Dickey 2000; Donner 2006; Das 1995).

cancer were inextricable from their obligations and structures of care, and heard as a concern for the disorder of attachments and relationships within the family³⁵. The family was always in some sense near; patients are accompanied by relatives to the hospital, where they would stay with the patient and sleep on roll mat beds laid down by the side of the hospital bed. When I commented on this to one of the volunteers, she compared it to the West and said "...see in the USA you see all these greeting cards by the bed and bouquets but not a single human soul. You may have the greeting cards but we have the human touch".

However, women often spoke about their own suffering as, to a greater or lesser degree, disrupting their attachments within the family and thus suspending the flows of obligation, responsibility and care that often lay elsewhere. Women spoke often about the impact of being abruptly wrenched away from the comfort of their daily routines and their inability to perform fundamental acts of care within the home. Darshana, for example, was feeling "tension" because she was away from the village and there was nobody there to do her housework, to care for the family, and she

³⁵This is potentially reflective of the fact that the family in India continues to be highlighted as site for the self-cultivation, and for women especially, this takes place within the site of motherhood (see Donner 2008; Thapan 2009; Lamb 2000). I discuss the gendered dimensions of this in more detail in chapter 4, but, to put it in more general terms here, Lawrence Cohen (1998) eloquently describes how the *pāgal* (madness) of old women and men in urban Varanasi is couched in terms of the "bad family" of modernity that is constituted by the decline of the joint family structure and values. What is significant in this shift is not so much the change in the institution of the family, but rather the set of relations in which the reciprocity of the gift relationship, of *sevā* (service), has been weakened and replaced by modern pursuits of self-interest, thus making the elderly mad and sick. Other studies of suffering in India also emphasise this relational aspect. James Staples (2003; 2007) illustrates how bodily difference of a community of leprosy sufferers in south India serves to create a community of the afflicted as a collective, intersubjective 'body' formed of many deformed bodies within which awareness of individuated parts dissolves. Furthermore, ideals of mental health are prescriptive of a person's behaviour in relation to others, especially the family and community (see Kakar 1982), and the experience of emotion itself is posited as fundamentally relational, as "heart felt, embodied, semiotically mediated and morally and ideologically charged sentiments that relate as much, if not more, to interpersonal concerns as to the psychological functioning of an individual" (Desjarlais & Wilce 2003: 1181).

articulated a sense of urgency to get back as soon as possible. Her son added that he kept telling her not to worry, that she should take rest and relax (*ārām karnā*) because he had instructed his older brother to get married quickly so that there would be a daughter-in-law to take care of the house and the family duties while his mother was away.

Nina, a mother of two who worked as a clerk in a state bank, also spoke about her separation from her children as particularly distressing. She impressed this upon me when, having navigated me through her diagnosis, the fear of the operation, the pain of chemotherapy and unbearable anxiety she felt in telling her children, she stopped and highlighted a specific moment during her chemotherapy. The doctor had ordered her out of the house to stay with her sister to reduce her risk of infection because her young daughter was ill with chicken pox. As she recalled this memory, Nina started to cry. “I had to leave for me. For me!” she said. This was a complete inversion of her normal life, and Nina couldn’t fathom not being able to care for her poorly child. “India ladies are very attached to their children”, she told me, “but I had to leave! Even though my daughter was so ill with this thing. Why?”

At the same as women spoke of suffering as a concern for attachments, thinking “good” or “positively” (*achhā sochna*) and being “strong” (*śakti*) were also often contingent upon the wider welfare of the family, and were articulated as a concern for wanting to make everyone happy and for being able to resume normal roles in family life. Heena, a post-cancer housewife and mother of two sons, expressed this when she explained, “If we haven’t got this”, and she paused and touched her hand to her forehead, “because my children are in front of my eyes, for them I have to live”. When I asked her about her treatment, she explained that she did whatever the doctor told her, for the only thing she wanted to be given was “five years only” so that she

could “settle” (marry off) her sons. As she recalled the pain of the invasive medical procedures and the fear of the constant onslaughts of injections and medication, she spoke of settling her children as the goal that enabled her to endure, and she told me that this wasn’t because she was a “brave woman”; it was just because her children were “in front of her eyes” that she managed to come out of it. Like many other women, she framed survival as necessary for the well-being of her children and husband, pointing to the latency of her own body as the cohesive nexus for the cultivation of intimate relations.

1.3 Movement, stasis and containment

It has been suggested that the inherent ambiguity and ‘horror’ of cancer derives from its ability to operate across boundaries and as a transgressor of self and other (see for example Sontag 1991; Stacey 1997; McMullin & Weiner 2008). Jackie Stacey, discussing the nature of cultural conceptions of cancer in the West draws on Kristeva’s (1982) notion of abjection to explore the taboos of cancer as a specific fear for bodily boundaries. She suggests that this fear surrounds the fact that cancer constitutes the natural process of regeneration turning in on itself so that cancer not only “promises death, but it promises death by means of life...by reproducing life, it reproduces death” (see Stacey 1997: 80). She suggests that it is by “death infecting life” that cancer echoes the horror of abjection which is the fundamental transgression of self / other boundaries. As neither subject nor object, cancer transgresses bodily boundaries that are otherwise perceived of as fixed, safe and secure, and therefore threatens what is taken to be impenetrable and sacred by constantly “reminding us of the impossibility of fixing permanent or immutable boundaries between self and other” (Stacey 1999: 76).

In India, the violation of the transgression of breast cancer appears to be located not only in the movement within one's own boundaries, but the potential intersubjective movement between the boundaries of self and others. This is not only redolent of more familiar modes of substance exchange ubiquitous of Indian social interaction, whereby persons are said to engage with, and connect to, other persons through flows of 'biomoral' substance that they exchange with each other via everyday interpersonal contact (see Marriot 1976; Daniel 1984), but also the way in which the potential overspill and spreading of cancerous movement is an interpersonal concern for the bodies of others, experienced like other forms of stigma as 'off' the body within a wider network of kin relations (see Das & Addlakha 2001). At the same time, the experience of breast cancer as a kind of 'living death' engenders a social liminality that recalls other contexts of pollution, impurity and inauspiciousness. This can propel the movement of patients away from the domestic sphere, or else be conceived to violate the boundaries of the family in ways that require vigilant containment and concealment of the disease, both within and outside of the familial body as embedded in the wider community. Thus on the one hand, breast cancer brings the family together with more intensity in order to contain or preserve it, yet, on the other, women articulate the suffering and pain of living with breast cancer as immobilising the cultivation of relations within the family. In turn, this gives rise to the chaos and uncontrollability of cancer through its very state of paralysis. In the second part of the chapter, I continue to explore the ways in which breast cancer engenders certain kinds of movement by paying attention to the geographical and physical movements from the village or town to the city, and movements within the city itself, that give rise to another dimension of suffering as inherently practical. This

offers another perspective from which to perceive breast cancer in urban India as ethnographically chaotic and uncontrollable.

Part Two: Practicalities and patient pathways

As I learned about the ways women would come to the charities for support, volunteers frequently informed me, sometimes quite matter of factly, that “poorer patients do not want emotional support, they only want money³⁶”. “Emotional support means different things to different people”, explained a senior cancer NGO activist. She continued, “For the poor, who can’t even afford to pay to get to the hospital, talking about the disease is immaterial”. Certainly in my own conversations with patients, the distress of breast cancer was spoken about in the same breath as the everyday hardships of life and poverty within the struggle to make do whilst simultaneously negotiating a confusing, partial and nebulous health care landscape. While this was not the only way women spoke about breast cancer, I frequently heard the emotional devastation caused by the illness in the very materiality of managing breast cancer; in the appeals of “*kyā karu?*”; “*What to do?*”

I spent a week volunteering in the cancer detection tent of a medical and surgical camp in a rural area in the north-western part of India. This camp is run once a year by a charitable trust that offers free medical consultation and surgery to inhabitants of neighbouring villages. I was working with an oncologist who was screening women for suspicious breast lumps by clinical breast examination. On one of the afternoons,

³⁶Nguyen (2010) has documented a similar situation in West Africa where the introduction of confessional technologies collided with local economy of ideas and practices of the self whereby talking would not solve problems that lay elsewhere, in the difficulties of their material circumstances and the social relations around them.

she discovered a lump in a woman's breast and, knowing that the camp did not provide these kind of facilities and that none of the surrounding medical establishments would be equipped in this way, she explained to her that she needed to have a mammogram at the regional cancer hospital, which was unfortunately many hundreds of kilometres away in the main city. The woman replied that she had no money to get to the city, let alone pay for the necessary test. The doctor was frustrated, and tried to persuade her she needed to go because, as she put it, "*yeh bohat galat hai*" (something is very wrong) but the woman persisted "*mere paas paisā nahi hai*" (I have no money).

This brief anecdote barely scratches the surface of a much wider problem of accessing and retaining oncological care in India. Despite the sustained and significant growth of many urban areas in India, the availability and quality of oncological care is still disproportional. Health policy literature on cancer in India points to the structural conditions and in particular the centre-periphery divide as shaping and mediating the delivery of, and access to, cancer care (see Pal & Mittal 2004; Broom & Doron 2011). The rural areas have minimal, if any, oncology facilities and trained oncologists and therefore rural patients are frequently sent to the larger cities, such as Bombay, for treatment. Urban metros like Bombay have a wide range of medical establishments and, although there are a fair amount of government tertiary health care centres, many of these are ill equipped for oncological care because they lack diagnostics facilities and technologies such as CT, PET and radiotherapy machines, as well as qualified trained staff, and are subject to very long waiting lists and overcrowding. There is also a plethora of private care institutions and, although private treatment is expensive, it is often preferred because it is

considered to be more efficient and offer a better quality of service³⁷. Therefore many families choose, or in some cases have no other option, to sell vital assets, such as inherited property, land or jewellery, and take out short-term high interest loans to access the necessary cancer care. In addition to this, patients engage in extensive ‘doctor shopping’ as they try to find the best and cheapest deal. Indeed the nature of the health market is such that people fear monetary manipulation by either bogus or greedy doctors, who indulge in ‘fee splitting’ with referring diagnostic centres, or at worst nefarious medical practice. One hears stories of aunties or friends who unknowingly paid for unnecessary diagnostic tests or were asked to pay 1000 rupees just for a repeat prescription. This has generated a health culture in which reputation and family recommendation are key aspects in obtaining health care, but also one that now operates much like a market system (Dreze & Sen 2002:202) in which care, diagnoses and drugs are treated like any other commodity, which for many are often unattainable (see also Jeffery & Jeffery 2008³⁸).

Arguably, Bombay has become a hub of cancer care, with the Bombay Cancer Hospital (BCH) as its incubus. I was told again and again by patients that were sent there from all over India; “Everybody said come to Bombay. They know in Bombay”. The BCH is a regional cancer specialist institute that is part government and part privately funded. It has varying levels of service to offer, from the heavily

³⁷India ranks among the top 20 countries in private spending with 82% of health care coming from ‘out of pocket’ or personal funds. Private health providers comprise 82% of outpatient visits and 58% of inpatient expenditure, as compared to just 5-10% of total patient care after independence (see Sengupta & Nundy 2005).

³⁸Jeffery & Jeffery (2008) document a similar issue concerning the legitimacy of the health care market wherein choosing between private and public care becomes especially problematic given the “ambiguous, partial and contested” rural health landscape founded on the fickleness of the logic of ‘neoliberal’ health market and a ‘discrimination of money’ whereby persons are expected to be autonomous ‘consumer citizens’.

subsidised general wards to the semi-private, private and 'deluxe' wards at the top of the building. The hospital is, however, mainly utilised by middle and lower class families, as the subsidised private wards are an attractive option, costing about a third of what it would cost elsewhere privately. The hospital also caters for the poorest of India's society, taking a large proportion of patients from surrounding rural areas. As a result, the BCH sees some 50,000-60,000 patients walk through its doors each year, and in the breast wing three consultants manage over 3000 patients a year.

1.4 Coming to the city

Coming to the city is both the start and the end points of long journeys. Bombay is a sprawling metropolis, every nook and cranny filled to the brim, expanding and pulsating with traffic, people and noise, and it can be a disorientating and alienating experience. Many of the women I met had come with a son, uncle or husband (depending on who was the main breadwinner in the family, and who could leave their work station), having left the rest of the family behind. It is not the case that patients will be gone for a few weeks. Often they remain in Bombay for months on end. Sometimes the whole family uproots and children are taken out of school and brought to the city. The financial burden of this uprootedness is devastating, as relocating requires shelter, food and travel expenses, and if a family member is unable to work, then livelihoods become incredibly precarious.

Most patients, whether from outside Bombay or not, will start their treatment in the BCH and can, if lucky, receive the majority of treatment there. However given the waiting lists and the vast number of patients, many will inevitably have to seek services in other institutions across the city (public and private). Thus patients and their families have to suddenly negotiate multiple medical spaces with a myriad of

tests, technologies and bureaucratic hurdles. Furthermore cancer treatment is a very costly disease to manage, as it requires a wide range of diagnostic tests and biomedical procedures. The expense is exacerbated by the cost of second line cancer drugs, used in chemotherapy for example, which are extremely expensive.

I spent time in government hospital A (from hereon GHA), listening to women's stories and hearing about pathways in which practicalities were paramount. In this hospital, patients do not pay for their consultation or their surgery, but they do pay for other treatment and medication. Radiotherapy is charged at 400 rupees (£4.50) for the very poor, and 1500 (£17) for the more 'affording' patients. There are varying prices for chemotherapy, and the hospital tries wherever possible to give reduced prices, for example, one cycle free every three months. A young and ambitious doctor oversees the running of the oncology wing that consists of a surgical theatre, ward, radiotherapy lab and chemotherapy day care. On my first visit he took me on a tour of the oncology wing. Starting in his office, the consulting room, he showed me his filing system for patient files, neatly tucked away in freestanding metal cabinets. "To give this place some kind of order", he said jovially. He then showed me the radiotherapy machine, an intimidating bulk of machinery that stood in the middle of the room. Plaster of paris moulds of body parts constructed in various sizes and shapes were abandoned on some shelving in the corner. The doctor explained it only costs 50 rupees to make these types of casts so it is the most economically viable option for their patients. The machine is an outdated cobalt model that, unlike the latest 'linear' models, runs on gamma rays that are constantly emitted in only one shape so it 'hits' a wider than necessary area in the body. However, the newer linear model can make a grid so that the technician can copy the tumour size and shape, thereby making the procedure much more precise and limiting unnecessary cell

damage. He had been campaigning for this newer model for months by writing a letter each week to the Ministry of Health in Delhi, until one fine day they called him up and invited him for a meeting. Now this new machine, with the latest linear technology would be arriving in the next 8-10 months, something of which he was very proud.

The rest of the wing comprises the patient waiting room which is fairly large, with wooden benches running down the middle and concrete ones lining the walls at the side. The paint is peeling in a mix of white and yellow and a tap in the corner drips into a metal plug dug roughly into the ground. A few posters are stuck up on the wall, one of which is from AICT. The main consulting room is large with high ceilings. A desk and a few plastic chairs are placed in the middle and two windows, shutters pulled back, are open but covered by painted metal bars. The sister intermittently calls out of the window, her voice reverberating into the yard outside, as she summons patients waiting under the cool shade of the trees. The room has an adjacent examination cubicle, simply furnished with an examination bed, curtain and utensil trolley. The walls, though painted a cheery blue, are crumbling and damp, and medical posters pinned to the wall peel at the corners. On a Friday morning, a slanted, hand written sign in red ink reads ‘O.P.D’ and is taped onto the open door.

On the recognition of a *gārnth* (lump) or pain that inhibits work, many of the women that I spoke with, who were receiving treatment in government hospitals in Bombay, had sought medical assistance. Some had initially gone to see either a private allopathic doctor, or a local healer, such as an Ayurvedic or homeopathic doctor, in their hometown or village. In many cases their complaints – the *gārnth*, dizziness, chest pain and general fatigue – were misdiagnosed. Sometimes patients would ‘shop around’ and try different kinds, or a combination of doctors, before they eventually

ended up in a cancer specialist hospital. All of these different consultations would in turn levy costs, including any medication that may also be prescribed. By the time a patient receives the correct treatment a year or more may well have passed³⁹.

Darshana is 45. She was married at the age of twenty and has three children. Her father and brother are the earning members of the family in a village in rural Maharashtra. Initially, she told her son that she was experiencing pain in her chest, weakness and tingling in her fingers so she was finding it hard to do her housework. Her local doctor in the village told her it was nothing (*kuch nahī*), but when she started experiencing fever, she went to see a doctor outside of the village. During a physical examination, this doctor discovered the lumps and told her “*tumharā operation karnā padēgā*” (you need an operation). This doctor had performed some kind of procedure (she did not know the name) which she had mistaken as the actual operation itself. Therefore she was not concerned at that time because she thought she was well again and could return to the village. However, that doctor also did some tests (of which she did not know the names) and told her that she needed to go to Bombay. It was not until she reached Bombay, and was admitted to BCH, that she realised the enormity of the situation and that she had breast cancer. She was operated in the BCH and started to have the ‘*barā light*’ (radiotherapy) at GHA. She is currently in her 6th cycle of chemotherapy at government hospital A.

Her son opened her bulging medical file. The pages mapped journeys of attempted, failed or successful care. Paper edges, folded and creased, traced journeys back and forth across the city and beyond, the imprints of previous tests, medicines, stapled

³⁹Time is essential in cancer detection because the stage at which a person is diagnosed can make all the difference to a hopeful prognosis.

medical bills and the hurried scrawls, in different coloured inks, of the different attending practitioners. The medical file is in some sense ‘affectively loaded’, capable of carrying, containing, or inciting affective energies when transacted or put to use in specific webs of social relations⁴⁰ (see Navaro-Yashin 2007: 81). In this way, receipts of diagnostic tests spoke of how much money had already been spent; the village income certificate displayed lack and struggle and the consequent anxiety. However, the bulging file also embodied hope and possibility, as the possession of a cost certificate provides the means of procuring charity and subsidised state treatment. Darshana is having 16 cycles in total: 4 costing 6500 rupees (£73) per cycle and 14 costing 4000 rupees (£45). Her total costs for treatment so far are 67,500 rupees. Their annual family income, as written on their village income certificate, is 24,000 rupees. Her son explains that GHA can only give a free chemotherapy cycle every three months so they are trying to seek financial aid from other trusts.

Pushpa lives with her husband’s brother and his family in Dharavi, Bombay’s largest slum resettlement. He is a locksmith and she a housewife looking after their four children, the oldest of whom is thirteen and the youngest six. Her husband has not been working recently because he has been accompanying his wife to hospital. He engages in a long and anxious dialogue about his concern over his wife’s treatment and hospital choice. Pushpa had pain in her arm and leg so they went to a private doctor who gave her medicine and said the pain would go away but the “*davā*” (medicine) did nothing (*kuch nahī huā*). After some time, she was then later admitted

⁴⁰The sociality around the medical file that I encountered resonates with Navaro-Yashin’s (2007) work on documentary practices among Turkish-Cypriots where describes how the struggle with administrative bureaucracy, in the form of letters and documents, has affective and phantasmatic qualities.

to a government hospital for the treatment of tuberculosis and this is when they found the lump in her breast, just by chance, and performed a mastectomy. However, now they are confused because there appear to be more lumps. Opening the medical file the husband continues to explain that the doctors are unsure what to do because the lump is positioned between the veins. He explains that he overheard the doctor telling the family in front of him in the queue that they must go to a private hospital. He thinks private hospitals are better, but “*pasiā nahī hai*” (there is no money). “*Kyā karu?*” (What to do?)

The experience and concerns of this couple are a common one: attempted and/or misdiagnosis, reattempts at diagnosis and more tests, referral to the BCH for diagnosis/pathology, referral to Government hospital A for mastectomy, referral back to private clinics for more pathology tests, then re-referral to government hospital A for radiotherapy, all the while back and forth from home to hospital. With the husband out of work, money has temporarily stopped coming in and he has taken a loan of 40,000 rupees (£453) to pay for treatment, food and travel, and they keep asking, “What to do?”

The confusion of patients is also exacerbated by the nature of the medical encounter itself. In GHA, Doctor P., a pro bono surgical oncologist, is in charge of the OPD on a Friday morning. However there were some Fridays when he failed to arrive, having been caught up with his own private practice in an upmarket hospital. I would know if he was there or not, because his slick black car would be parked outside the oncology wing. When working, Dr P. sits on a stool in the middle of the room surrounded by junior doctors. Patients and their relatives queue out of the door into the corridor outside. He has to work fast. Doctor P holds up x-rays, scans and charts, making quick decisions. He engages in minimal conversation with the patient, often using

complicated medical jargon without explanation, speaking in English to his juniors who rush in and out, writing on charts and looking suitably busy. He says, “She is metastatic. Both were removed and she is young”. Then turning to the patient he asked her, “*Tumhare kitnē bachche hain?* (How many children do you have?). The woman replies none. He nods and closing her file says, “*theek hogā*” (it will be ok) and moves on to the next patient.

I discussed the nature of the consultation with Dr P. He cared for his patients, and certainly felt the lack of government support in the rudimentary surroundings in which he worked on those Friday mornings. He explained to me that, when working in such difficulties, what could he do *but* treat as many patients as possible within the little time and resources that he had. In the face of such paucity and suffering, at least the patient was getting something (even if that ‘something’ was compromised, partial or haphazard) because surely something was better than nothing at all. He said, “See, patients are not interested in the complexity of the treatment plan. They just want to be comfortable with the cost. These are poorer than poor patients who come here”.

In this way, patients treated in GHA are pointed in the right direction for charitable trusts, and recommended to reliable and affordable private practitioners; indeed a whole stack of business cards are ordered neatly in a small plastic pot on the doctors desk. However, this does not make the situation any less confusing or overwhelming. There is a similar situation at the Bombay Cancer Hospital (BCH). The BCH is a unique hospital and was often spoken about ambivalently, with both awe and apathy, by patients and volunteers alike. Everyone had told me that I wouldn’t know anything about cancer in India until I visited the BCH.

1.5 Moving and waiting

As you enter the main entrance and turn towards the breast OPD, you join swarms of people, becoming engulfed by the crowds moving in and out of the hospital. The smell of sweet but slightly acrid clinical disinfectant hangs in the air. Queues of people seem to be waiting everywhere. That is the first thing that hits you: the amount of people, waiting, moving, or jostling nervously whilst clutching plastic bags containing medical files. Patients sit with relatives outside the front entrance on the steps; others perch inside on the floor, in packed corridors; some have children who wear green surgical masks covering their faces, whilst others wait next to suitcases piled on top of each other, their *dabba*⁴¹ nestled carefully on the top. Family members sleep on roll matt beds, opened out and laid down by the side of the hospital bed. On my first visit with Anupama, a long-standing post-cancer volunteer, I waited awkwardly outside the private category breast OPD on the ground floor. She had gone into the doctor's office to collect the key so that we could pick up the bags that we needed for the post-operative class. As I stood amongst the crowd, I watched as the doctor went behind a curtain, one of four lined in a row. Three minutes later he re-appeared, a quick scroll on the chart and it was handed back to the relatives who were guided outside into the throngs of people, bristling eagerly at the door.

When a patient is first referred to the BCH they must have their correct documentation. This includes a ration card that proves Indian citizenship and details their economic and family status and proof of income. I was told by AICT's patient care department that it was not unheard of for a family member to be sent back home,

⁴¹Metal food containers.

however far that may be, to collect the ration card as treatment will be refused without one. Once documentation has been completed it is referred to the resident social worker who then categorises them according to a rigorous criteria which will determine the level of care they receive. For those with little income, they will be classed as “general” category and pay nominal hospital service charges, depending on whether they are outpatient or inpatients, but are exempt from paying professional or consultation charges. They also have to pay 150 rupees (just over £2) per day for the hospital bed. The other category is “No Charge” and these patients are exempt from nearly all charges, excluding CT scans, X rays and certain molecular pathology tests. This comes with its limitations though, as these patients are not given a choice of doctor and, depending on the urgency of their case, will be placed on a waiting list for treatment. The doctors do as many free or minimal fee paying patients as and when they can. This can take anything up to six months in some cases, but can require patients to come to the hospital everyday to see if their name will be called, or if there has been a cancellation.

In the BCH things and people move quickly and slowly simultaneously. Flurries of action are interspersed with expanses of stillness and waiting. People are incapacitated by not knowing what is going on, hearing unclear directives from the doctor “*yeh karo, woh karo*” (do this, do that), as seemingly endless cycles of bureaucratic and biomedical hurdles whirl around them and have to be constantly overcome. I accompanied Leelabai, a breast cancer patient that I had befriended through my work with AICT, to one of her appointments at the BCH. She was in her early eighties and described herself as “*akeli*” (alone) because she was a widow and had no children. She was classed in the general category in the BCH. Leelabai’s appointment was scheduled for 2pm. We arrived at the gates to the hospital and

walked in towards the general breast services OPD, where she had to hand in her file so that it could be processed in time for her appointment. The whole department was filled with people, sitting on the chairs or on the floor, their eyes fixed on the crowds. Some were sleeping, others listless and blinking lethargically in the heat of the room. Due to the hive of activity and sheer volume of people, the whirring fans did little more than swirl hot heavy air throughout the room. Leelabai tried to hand her file in at the desk but was quickly admonished by a man at the front of a makeshift queue who told her “*line mē jāo*” (get in line). Tempers were frayed and everyone jostled anxiously behind each other, craning their necks to see what was happening behind the desk. One of the assistants at the desk, who I noticed was particularly cantankerous, snapped remarks at patients whilst hammering at the keys on her computer keyboard. As we leaned against the wall, the security guard came by, blowing his whistle and motioning with his arms that people should keep the corridors clear. Everyone re-shuffled back a reluctant inch or so. Another man tried to push in the front of the queue and the self-imposed line controller at the front explained, once again, that there was a line. We waited thirty minutes before the file was eventually taken by one of the nurses behind the desk and Leelabai and I managed to squeeze ourselves onto one seat.

We sat with everyone else, staring at the number board. The patient number bleeper sounded monotonously every time a new number flashed up, three ascending beeps that were repeated twice each time. We spent two and a half hours sitting and watching that board. Leelabai nudged me and laughed, “*dekho dekho*” (look, watch) she widened her eyes, gently making fun of the two of us looking at the number panel so intently. We settled into the wait and occasionally shifted in our one shared seat and argued over giving each other as much space as possible. Finally, when I started

to become concerned that we had missed our number, it flashed up. Leelabai jumped up, grabbing her plastic bag and my arm and we went through the door behind the desk and stood outside joint consultation room 21. A patient came out, pushing the door open, and we went in. The room was small and four doctors were inside, three sitting and one standing behind the desk. To the left was an examination table and a curtain. Two other patients were standing inside and Leelabai and I shuffled around behind the chair, as she handed her file to the doctor. We waited, shuffling forwards and sideways as patients came in and left. One woman came and sat on the examination table, and was examined as people came in and out of the room. I suddenly realised she could be seen by the crowds outside every time the door opened, and quickly pulled the curtain across.

The doctor who dealt with Leelabai had a very gentle nature. She asked her some questions about the pain and then took her behind the curtain for examination. The consultation lasted no more than ten minutes. Leelabai told the doctor she had been having pain around her heart and chest area, tenderness in her back as well as headaches and she wasn't eating properly either. I waited for her to come back out and the doctor told her she needed to have a bone scan. She would have to take an appointment for this scan from outside, at the desk with the irritable receptionist. Leelabai didn't ask any questions, just took her file and we moved outside. Again, we had to wait while her file was processed which was made worse by the fact that the computer had temporarily broken. After another twenty minutes, the file was processed and returned with yet another, new piece of paper requesting a scan. Leelabai slipped it safely in her file, and placed it back in her carrier bag and we made our way down the stairs out of the building and towards the bus stop.

On another occasion, I met Sujata, along with her husband and daughter, during the post-operative class on a Friday morning. We arranged to meet in their hotel in Dadar the next day. Although they had taken private care in BCH, they still emphasised how much time they spent waiting outside the office of Dr X, the Head of Oncology, queuing amongst anxious others, sometimes for hours and hours on end. Sujata's husband rushed around, getting forms signed, waiting to hand in one piece of paper only to be told it was the wrong one, or that it needed to go to different place. Once admitted, the chaos and confusion continued as, during the operation, Sujata's husband was suddenly phoned and told to go and buy more surgical dressings during the surgery from the pharmacy. This was confusing and disorienting; he remembered thinking, "What was she doing? Just lying there while they waited for medicines?"

Her daughter said she even started to keep a record of what her mother ate and when, how much water she drank and when she took her tablets because the nurses appeared incompetent to them. The element of improvisation in a space of presumed certainty was startling. It was only when they spoke about meeting with their doctor that their faces calmed. Sujata's husband commented: "I remember him saying, minimum invasion for maximum result. 100%" He repeated it twice, the simplicity of the dichotomy "minimum for maximum" set against the chaos of queues, documents, panic and disorganisation seemed to be a like a mantra for him now as he spoke the words steadily and assuredly. The family had put all their faith in Dr X's ability to treat Sujata successfully and, as they spoke about him now in the calm after being discharged, relief washed over their faces at the memory.

In the whirl of bureaucratic and medical practicalities, the BCH not only emerges as a place of chaos and confusion, not least because it houses suffering and death, but it also offers miracles because 'doctor is god'. Because of this, the BCH has a strange

spiritual quality to it, a veneer of hope, for to have reached BCH means that something ‘good’ or ‘proper’ or ‘certain’ might happen. As the last stop in long journeys, from village doctors, to state regional centres, biomedicine was often perceived here as the only hope of a cure, and patients readily relinquished themselves to the hands of their doctors, going through the motions of treatment as best they could with the belief that doctor and god would not leave them “like this”. Indeed in the modern world of the medical clinic, of sonograms, injections, lasers, pills, doctor *is* god (see also Bharadwaj 2006; 2008; Broom & Doron 2011) and is invested with the power to save lives in situations where otherwise there is little hope. I learnt very quickly that doctors were treated with deference, utmost respect and, in some cases, awe as it was explained to me that faith in god or faith in the doctor is the same thing⁴².

This section has sought to outline the kind of inherently practical movements that are engendered by suffering with breast cancer. This is apparent from the ways women have to travel suddenly from the village to the city, engage in short bursts of anxious movement that in turn become juxtaposed against a much longer malaise of immobility: waiting for results, waiting in line, waiting to go home, waiting to know if one can be well again. As a disease, breast cancer could also be conceived of as

⁴²This includes the volunteers who were reluctant to speak badly of doctors, many of whom had been treated by the same doctors as their fellow patients. Those with more critical eyes sometimes commented with me privately about the high status awarded to doctors. For example that because ‘so and so doctor’ had introduced chemotherapy to India he was “up there” or else because Indian oncologists can now do lumpectomies they think they are “heroes”. At the same time I was told that in the BCH all patients want to be operated on by Doctor X, the extremely revered Head of Oncology. Due to the overwhelming number of patients, this would never be possible. However, even if Doctor X was not performing the surgery, he would still go and speak to the patient who had asked to ‘see’ him before they went under anaesthesia, in order to reassure them that he would be performing the surgery.

sprawled and splayed between persons and things, not only within the hospital, but further afield as patients are pulled from here and there, back and forth, wrenched from the family for long periods of time. In this way, the ‘familial body’ is not only constantly stretched throughout the hospital, as Sujata’s case makes clear, where her disease not only involved her, but also her daughter who administered her medicines, her husband who signed the forms and Dr X. who made the incisions, but the disease is also experienced from the city and beyond, as families are constantly in a state of stasis, paralysed by absences and suspension of fundamental acts of care as women repeatedly asked of their own fate, *mere bachchon ka kyā hoga?* (What will happen to my children?)

1.6 A disease multiple

This chapter has attempted to present a broad and initial picture of the ways breast cancer is conceptualised, experienced and managed. Firstly, breast cancer is conceptualised as a kind of ‘living death’ that appears to be connected to polluting or inauspicious states and thereby emerges as an inherently liminal and feared condition. The ways in which patients are propelled into states of liminality necessitates strategic acts of concealment and containment from within the domestic sphere that is embedded in and, simultaneously, becomes pitted against the wider community. At the same time, the chapter has attended in more detail to the ways in which breast cancer necessitates multifarious movements. These movements through which the disease is ‘spread’ emerge as physical, geographical, existential or practical as families must move from the village to the city and engage in a multitude of tasks within the city to access care. Also, the way in which women articulate the pain and suffering of breast cancer, as a concern for the disorder of attachments, can also be

conceptualised as arising out of the stretching and stasis of the familial body that is at once both moved and immobilised through their actions in managing the disease.

As poignantly discussed by Susan Sontag (1991), cancer as a disease has become imbued with an ‘excess of meaning’ that is frequently described through varying cultural metaphors of inherent uncontrollability and the inchoate. In Bombay, breast cancer also appears as something chaotic, difficult to control and of ambiguous perplexity. But rather than capture this through a focus on ‘Indian’ metaphorical elaborations of cancer, this chapter has sought initially to describe the ways breast cancer appears to engender certain kinds of movement within and beyond the urban setting. What emerges here is a sense of the inchoate of breast cancer as inextricability tied to different kinds of motility; not only in its very composition of cells multiply again and again, moving and spreading within the body but also clearly splayed, outside of it, something that moves and spreads between and through people within the family as it is intricately and perplexedly coordinated over many spaces, places and people. This requires specific strategies of concealment within the domestic sphere in order to contain cancers inherent motility, as well as to protect and preserve the body of the family. This movement of breast cancer also manifests as persons rush to depart from the domestic sphere, or attempt to access and retain the right kind of care that is simultaneously juxtaposed with the waiting, immobilisation and paralysis of the familial body as quotidian flows of obligation and care are suspended in the longevity and uncertainty of treatment in the city.

CHAPTER 2

Pragmatic partnerships and therapeutic mediators

Within the last thirty years the oncological health care landscape has seen an increase in cancer NGOs and patient association groups or charities. Many of these groups were started by individual breast cancer patients, who emerge as pioneers of a grassroots activism that has evolved into varying associations, charities and ‘drop in’ clinics, and in turn initially resulted in some significant changes to the health care system in relation to post-operative breast cancer care. Today however, their work is first and foremost in direct response to the partial, nebulous and inherently motile urban oncological landscape, and, in what follows, I describe the forms of these organisations, some of which emerge, operating as diffuse ‘networks of care’ that are woven by volunteers as they extend support to breast cancer patients and their families throughout the city.

More specifically, the chapter focuses on the role of the volunteers, and particularly the post-cancer volunteers and the ways in which they have begun to mobilise themselves around breast cancer and create particular forms and patterns of care. The post-cancer volunteers emerge as intermediary brokers in webs of sociality between the patients, their families and the doctors within the urban medical milieu. As therapeutic mediators, the volunteers disseminate vital information about all aspects of cancer in ways that can be seen to ‘fill in’ the gaps of a state system that is grossly overwhelmed by the rising cancer load in the country. As seen previously, cities such as Bombay become a hub for oncological treatment because of a paucity of facilities elsewhere in the country. This presents a huge pressure on the state institutions that are subject to overcrowding, long waiting lists and often a general sense of confusion

and pandemonium as patients struggle to overcome numerous administrative hurdles. In this way, a predominant aspect of the voluntary groups' activities involve sending volunteers on outreach missions to both state and private hospitals in order to deliver patient information and post-operative care that pertains most immediately to the practicalities of managing breast cancer.

Having previously described the nature of the cancer care landscape populated by patients, their families, volunteers, NGOs, associative groups, a myriad of medical establishments and clinics (both municipal and private), this chapter seeks to explore the kind of collaborations or strategic alignments that are emerging out of economic instability and uneven state health care provision. In doing so, it draws on other studies that have explored the kind of relations that are formed by patient turned activists in response to state absence and scarcity of resources. For example, Joao Biehl (2007) has eloquently explored the ways in which AIDS activism in Brazil has emerged out of a micro-politics of 'patienthood' that gave patients the possibility of surviving economically by becoming 'diseased citizens', which in turn made it possible for patients to become welfare recipients and generated newer kinds of politicized sociability (2007:120-121). In a similar vein, Vin Kim Nguyen (2010) has recently suggested that a 'therapeutic citizenship' emerges where there is a lack of access to drugs and the absence of large-scale stable state institutions. With regard to the HIV/ AIDS activist movement in West Africa, he states that, by both submitting to clinical trials, and later by being able to speak openly and 'tell a good story', by delivering charismatic testimonials, patients turned activists or 'therapeutic pioneers' could capitalise on social networks and become advocates for the supply of drugs from abroad. This has developed into a system of triage that in turn is dependent upon the ability of others to become advocates for further procurement of medication.

Studies that have explored the possibilities for patient mobilisation and associational community politics in India are positioned somewhat differently. These studies have revealed the limitations faced by patients and their families to mobilise collectively around health and illness, pointing a lack of political capacity and pervasive structures of stigma that surround issues such as infertility, adoption and disability (Das 2001; Das & Addlakha 2001; Bharadwaj 2003; Bharadwaj 2008; Sunder Rajan 2008; Bharadwaj & Glasner 2009). In particular, it has been suggested that, rather than potential biosocial mobilisation taking place at the intersection of associational community with state (because of a lack of both economic and political purchase), various alignments exist from within a ‘politics of domesticity’ whereby the family is pitted against wider kin and community but still uses strategic resources of the state to enable better health outcomes (Das 2001; Das & Addlakha 2001).

By describing the grassroots activities of the post-cancer volunteers and the kinds of pragmatic relations and collaborations they form not only with patients, but also with doctors and their own families in creating and delivering networks of care, I aim to bring another dimension to the question of potential for patient biosocial mobilisation in India. At the same time, I describe the story of one post-cancer volunteer in particular, in order to reflect upon the figure of the volunteer as a certain kind of person: a local healer, a great *mātāji* (revered mother figure), whose liminality and ambiguity, due to having been a breast cancer patient, is generative of a kind of lay expertise that in turn establishes ‘survivorship’ as a pivotal medium of activist practice. At the same time, this chapter attends to the post-cancer volunteers’ conceptualisations of their charity work as *sevā* (selfless service) and situates their activities within a specific sphere of activist practice as a kind of divine

humanitarianism that is ultimately concerned with service to humanity so that one can also serve god.

2.1 The emergence of voluntary groups

Rajeswari had found the lump in her breast. She felt it for seven or eight days, letting her finger roll over it, but then it disappeared. A month or so later, she noticed it had come back and this time it felt a little bigger. Rajeswari mentioned it to her sister who said they should show it to a doctor. Her sister had had minor surgery with a female doctor and recommended Rajeswari to go and see her. After examining her, the doctor started to panic: “*ārray!* Cancer!” and informed Rajeswari that she needed to have a radical mastectomy right away. When Rajeswari’s sister heard the news, she had started to cry. “My sister is going to die!” she exclaimed. But Rajeswari, who explained to me that she was ‘a little different than most’, quietly dressed herself and told her sister to stop crying. “I am not dead”, she had said. “When I am dead, then you can cry.” That afternoon Rajeswari spoke with her son. Her son recalled that an old family friend was a senior doctor at the BCH and therefore Rajeswari should go to there for a second opinion. However Rajeswari refused. She said, “She wants to cut, so he will also want to cut. What is the point?”

On the third day after the initial consultation, Rajeswari underwent a mastectomy. She recalled the disorientation of the biomedical process, how she didn’t know what was happening with all the drips, tests, food restrictions and prescriptions. Even after her operation, when the tissue was sent for pathological testing at BCH, Rajeswari still didn’t know the extent of the malignancy and was confused by the technical language. When the report came back from the BCH, it stated that the cancer was stage one and therefore there was no need to remove the full breast. Frustrated with his mother,

Rajeswari's son scolded her for not having gone to BCH in the first place where she would have received the correct kind of care. But Rajeswari explained she could never have gone to the BCH, to the doctor who was an old family friend because she was feeling shy. The prospect of exposing herself to him was totally out of the question. Rajeswari realises her mistake today. It was this traumatic experience that formed the impetus for Rajeswari to start an association for 'mastectomees'; a group that was one of the first of its kind in India that sought to provide assistance to women who had lost a breast to cancer but had survived.

Rajeswari founded the Women's Cancer Association of India (WCAI) in 1998. Like other groups in the city, including the Cancer Centre (CC), Rajeswari sought to mobilise around the experience of a rudimentary provision of care and patient-centred information, which was perceived as inadequate. This was especially so with regard to knowledge about how one should live after breast cancer: what to do 'if you survived'. Many of the early pioneers of the breast cancer groups recalled that, when they were diagnosed, there were no volunteers, no information booklets, no outreach programmes, no patient rehabilitation clinics nor even the breast prosthesis. Therefore the activities of these early trailblazers were paramount in changing the ways in which post-operative breast cancer care was delivered in some hospitals.

Post-operative breast cancer care often started out from collaborative efforts between individual patients and oncologists, who in some sense legitimised their efforts and granted them access to patients. This was the case with the WCAI, whereby Rajeswari sought allegiance with a physical therapist in the BCH who, like her, was concerned about the lack of post-operative care for patients. However, in those initial stages, the presence of volunteers was in some cases perceived by other medical professionals as an unnecessary interference in medical matters, and in these instances it represented a

challenge for those early pioneers, who had to fight to get access to certain hospitals. Rajeswari described how she had struggled with a doctor in order to be allowed to enter the wards and speak with women in a municipal hospital, where the doctor criticised her for trying to introduce what were deemed to be inappropriate “American ways” of talking into the Indian health care system. She recalled her words at that time, “[I said]... don’t you take American medicines? Why are you taking American medicines? Take Indian medicines! So after that they kept quiet”.

Highlighting the issue further, she recounted one of the first women she had ever helped. A woman was refusing to speak to the nurses on the ward of a municipal hospital in south Bombay, and was lying hidden under her bed sheet. Rajeswari had asked her “*Amma, kyā huā?*” (What happened?), and when she remained rigidly silent, Rajeswari proceeded to explain that she too had undergone this surgery, that she had recovered and therefore maybe she could offer her some help. The woman responded to Rajeswari and explained that she felt naked because the nurses had forced her to remove her green glass bangles, signifiers of her marital status, for the operation, and now they were lost. The next day, when Rajeswari returned to the hospital, she brought with her a cardboard box of new green bangles for this woman. Something so simple, Rajeswari repeatedly pointed out to me, with an impact so great was precisely the reason she wanted to help others.

The Cancer Centre also emerged through collaboration between a breast cancer patient and her oncologist. Anjali, like Rajeswari, was concerned with a lack of information for those who were recovering from breast cancer, and she recalled feeling extremely low, questioning how she would ever “go out into the world” again. However, through conversations with her doctor at the private hospital where she had been treated, they decided to start a ‘drop-in clinic’ for patients at her home. He

would recommend patients visit her, and accordingly she would provide post-operative information and care. However, few patients actually visited, and so it was decided that she should relocate to the hospital itself, utilising a room in a small annexe at the side of the hospital, next to the patient waiting area. From here on, the clinic grew to become the Cancer Centre (CC), operating differently to other NGOs and groups because it had 'in house' facilities and stocks and provides the breast prosthesis as well as patient information leaflets. The clinic runs twice a week in the morning for breast cancer patients. Two volunteers attend it, and usually three to six patients visit during that time. Anjali has built up a stronghold of volunteers over the years, many of whom were previous patients who had also decided to join the group.

2.2 New beginnings

At the time of my fieldwork, Rajeswari claimed the WCAI had over one hundred members, but about ten of those were actually active working members. Some of these members were previous patients, and others, describing themselves as "socially conscious housewives" were not. As the association evolved, Rajeswari also initiated what is now a highly regarded volunteer training programme in collaboration with the BCH. It is conducted once a year in October to coincide with breast cancer awareness month, and Rajeswari uses this opportunity to try and recruit new members and volunteers.

During this time, when the WCAI and other groups such as the CC were gaining momentum, a few more post-cancer women decided to join the organisation. They included Anupama and Prema who became dedicated volunteers in the BCH. Anupama had already started to help other patients, while she herself was undergoing treatment, by just striking up conversations in the waiting area or helping patients fill

out their medical file. Gradually Anupama made friends with the reception people and file administration people, becoming a familiar face to them so that they would be forthcoming in helping her. Patients soon approached her because they had seen her around in the hospital before, speaking with others, and she became a figure known by patients and nurses alike as somebody who knew about the BCH and cancer. During this time, she met Prema. After striking up a conversation in the radiotherapy patient waiting room in the BCH, where Prema was receiving treatment, and while Anupama, having just finished her own, was accompanying a patient, they became friends. Their friendship eventually led to a partnership that resulted in a significant change to post-operative patient care in the BCH.

Anupama and Prema could not put into words the kind of bittersweet awe with which they regarded meeting each other in the BCH, a meeting they regarded as destiny. They had decided to join the WCAI together at the same time in 2006, having finished the training workshop. Soon after, they both participated in the 3rd Asia Pacific Reach to Recovery⁴³ International conference that was held in Bombay. This conference was one of the first of its kind to be held in India and was entitled '*Jagruti*' (The Awakening). It was here that Prema spoke for the first time, openly and publically, about her experience with breast cancer, delivering a short testimonial entitled 'My Journey'. Anupama also spoke at the conference, participating in a panel on post-operative care where she shared her lay knowledge of managing lymphedema. Speaking openly about breast cancer was considered to be extremely difficult, and also courageous. Even though many of the post-cancer volunteers were

⁴³This conference is part of a wider project designed by the International Union Against Cancer (UICC) to promote worldwide volunteer breast cancer support and awareness programmes. Held every other year, the conference has previously been organised in Malaysia in 2002, and Singapore in 2004.

determined in their attempt to overturn the fear of cancer and support other women, this did not necessarily mean that they were completely free of these fears themselves. For example, one post-cancer volunteer explained that, while her husband and children knew about her breast cancer, her wider family still did not know. I asked her if they were aware of her voluntary work, and she said they were, but they thought it was a simple matter of contributing to social service and were not aware of her personal connection to the disease. This woman explained that she could never tell her parents-in-law for fear they would react badly or panic.

It was also at the conference that Anupama and Prema participated in a workshop where they were introduced to the Patient Information Kit (PIK) bag. This was brought to the conference by a volunteer from a breast cancer organisation in South Africa and contained various items to give to women undergoing treatment. Prema and Anupama thought this could be particularly useful for patients in BCH, where women are treated and discharged within a matter of days, and thus decided to adapt the PIK bag for the 'Indian scenario'. After the conference, Prema went to the market and bought the cloth; a thick cotton that was durable and bright pink so that it matched the colour of the breast cancer ribbon. She then stitched the bag, replicating the one she had seen in the conference, and filled it with small keepsakes: a small pot of coconut oil, talcum powder, a headscarf and a packet of mints, and the WCAI patient information leaflets in four different languages (Hindi, Marathi, Urdu and English). Anupama and Prema then approached senior doctors at the BCH and suggested the PIK bag become part of the mainstream delivery of care for breast cancer patients. They suggested the volunteers could take them on their ward rounds and hand them out to patients, especially those on the general ward who would be discharged very quickly. The idea was agreed to, and Anupama applied for funding

through her husband's company which had a Corporate Social Responsibility (CSR) foundation and would fund socially-minded causes. The company approved the project, and it was decided the money would be sent to the WCAI as it had to be channelled through a registered charity. Anupama would be in charge of organising the bags each week and Rajeswari would in turn organise the volunteers. The bags have been implemented in the BCH since 2007, however after a year or so, Anupama suggested that, in order to save time and maximise their work, rather than visiting the wards and speaking with patients individually, they could now bring the women together in a group, and hold a small seminar type class where the volunteer could instruct the patients on post-operative care and the patients could ask questions. This signalled a significant change in the work of the volunteers, and the way that post-operative care was delivered within the hospital.

These initial groups also tried to change practices around the breast prosthesis. In those early years, the only prosthesis available was the Western silicone one, which had to be imported from abroad and cost 25-35,000 rupees (between £287-£400). At such an extortionate price, women like Rajeswari and Lata were instructed by their doctors to stuff some cotton gauze into their sari blouse or bra instead. In these formative years, Rajeswari, among others, had been extremely active in trying to lower the price of the silicone breast prosthesis to an affordable rate, and at the same time she made her own contact with a tailor, asking him to stitch a cotton equivalent of the breast prosthesis, which is now described as the "Indian" prosthesis, and is sold for a fraction of the price at around 250-450 rupees (£2.50-£4.00). When I was in the field, the availability of this prosthesis had grown substantially. Many groups and private hospitals now provide the silicone prosthesis and it costs between 3-7000 rupees. While this is fairly affordable for those in the upper-middle classes, it is still

far too costly for a vast majority of women who are instead advised to use the Indian cotton one. These are now manufactured by different charities, including AICT, and are filled with small beads to provide the necessary weight to ensure balance. Specially made cotton bras, with a tailored pocket for the prosthesis to fit into, are also provided.

2.3 Charity as sevā

As discussed so far, the breast cancer voluntary groups in Bombay were fundamental in beginning to bring breast cancer into the public domain, by acknowledging themselves as previous sufferers in ways that had not been heard before, and this included participation in emergent forums for the display and sharing of survivorship experiences. Furthermore, mobilising around the disease also brought with it changes to the delivery and provisions of the oncological health care system. Many volunteers were, and still are, critical of wider state health care structures, which have not overcome problems such as over crowding, the inaccessibility of medicines, the lack of rural facilities and haphazard delivery of care. While this is frustrating, there is also a sense of understanding that tends more towards reform by working with doctors and the medical establishment to put in place structures that would ameliorate the biomedical experience in small, but hopefully significant ways⁴⁴. Even if the state were to listen seriously to the plight of so many cancer patients, especially when, as I was so often told, the government has other more pressing health concerns to deal with, the actual potential to induce change is considered to be extremely challenging.

⁴⁴This is also apparent in the Western breast cancer movement, where affiliation to different groups espouses difference in opinion not only of the notion of being an ‘activist’ (see Blackstone 2004) but also some groups were geared more towards complicit reform by working with the medical establishment, for example the Susan G Komen Foundation (see Kaufert 1998; Klawiter 2000a).

For example, pharmaceutical drug cost is a substantial and urgent problem blocking many patients' access to treatment and, especially, the chemotherapy and second-line drugs used in cases of reoccurrence. However the scale and reach of taking up a battle against pharmaceutical drug prices is considered to be beyond the remit of the post-cancer volunteers and small voluntary groups that I worked with, who do not envisage themselves as having any kind of purchase here⁴⁵.

However, the Reach to Recovery conference was consistently pointed out to me as an example of an attempt to reach state attention. Rajeswari and other group founders wrote collectively to Sonia Gandhi, inviting her to attend and to 'get the message across to the government' as Rajeswari put it, and, although Mrs Gandhi wrote an opening declaration for the conference programme, she didn't attend and nothing else came out of it. Kavita, a founder of a women's health NGO that had branched out to focus on breast cancer care, explained to me how she and Rajeswari, who had co-organised the conference, perceived this. She said, "It's not like we can really go there and knock at their doors because we don't have that kind of a thing. We don't have the kind of funds for travel or the people... we are housewives and working in our own areas and we are running this organisation. Always there day to day, whoever needs

⁴⁵To this end however, The All India Cancer Trust (AICT) have launched an ongoing advocacy campaign, the 'Affordable Drug Initiative' that entails an online petition demanding pharmaceutical companies reduce the rate of cancer drugs and an open letter to the health minister outlining the plight of cancer patients' struggle to obtain drugs, which they consider to be a basic 'humanitarian' right. AICT were also involved in a law case against the drug company Novartis for the patent of the drug Glivec, whereby Novartis were requesting exclusive manufacturing rights for the patent of the molecule thereby preventing the production of cheaper generic forms. Novartis was selling Glivec for 125,000 rupees (£1,409), whereas generics could be sold for anything between 5000-10,000 rupees (£56-112). The case went to court and AICT won. Over the years AICT has also worked to establish itself as a reliable aid-dispensing agency. It has various 'tie ups' with local pharmacies that offer them drugs at a reduced rate or in a 'buy one get one free' deal. This along with substantial donations enables them to fund government-registered patients with up to 2500 rupees every month for up to three years.

us and we respond”. Furthermore, Lata, a longstanding post-cancer volunteer who was associated with AICT but worked alone, remarked somewhat cynically that it wouldn’t be until one of the government minister’s wives got breast cancer that they would see some kind of change.

While many of the voluntary groups and volunteers conceive of themselves as having limited political capacity to make purchase on the state, this does not necessarily dominate their perception of their grassroots work. Many of the post-cancer volunteers do not conceive of their work as activism and do not refer to themselves as ‘activists’ in the sense that they lobby for patient rights at the state level. Rather, as charity volunteers, they consider themselves to be engaged in acts of *sevā* (selfless service) and conceive of their activities as a specific form of ‘political’ action that sets out to provide the most basic humanitarian duty. I was always reminded of the nature of this by an old, worn poster, which depicted a scene of patient counselling from the 1970’s and was stuck to the wall in the AICT patient care department. Below the picture there was a caption which read: I dreamt and slept that life was joy, I awoke and found that life is duty. Behold! Duty is life! This sentiment was echoed by many post-cancer women who often spoken about their voluntary activities as both *sevā* and / or *dharma*. *Sevā* is a polyvalent term that has claims to virtue in different contexts and settings, whether this is a child doing *sevā* for their aging parents (Cohen 1998) or devotees doing *sevā* for a guru or deity (see for example Warriar 2005). *Dharma* also has manifold meanings, and in Hindu tradition is often described as social or religious law. It was described more vividly by my interlocutors as something one has to do, like fire that is meant to burn or like a scorpion that stings; it is doing what it has been born to do. Therefore *dharma* was often spoken about as a kind of duty. Padma, a post-cancer volunteer, explained that it was her *dharma* to do *sevā* and

serve others through her work with the group *Saheli*. She compared this to the ultimate form of *sevābhāṅ* (service of selfless love) of Mother Teresa who, she said, did “*sevābhāṅ* for all”. Lata, also conceived of her voluntary work as *sevā*, and repeatedly told me that one should just try and be a “good human being” and do the work of service and sacrifice. Furthermore, Rajeswari explained that her work was founded on the recognition that each of us has come from the “same source”. She exemplified this with the simplicity of the *namaskār*, the traditional Hindu greeting meaning “I bow to the goodness or divinity in you”. As she clasped her hands to her lowered head, I was reminded not only of the volunteers’ humility, but their belief in the nature of humankind as ultimately divine.

The post-cancer women also explained that they had decided to become volunteers because they wanted to “give something back” to *bhagwān* (god) to express their gratitude for having survived breast cancer. For many this could only be achieved by ‘doing something’ for others and was spoken about as a natural or inevitable progression after their recovery. Their gratefulness to god was often inseparable from a desire to help other patients, as the volunteers would position themselves next to those who were much less fortunate, and therefore whose suffering was deemed to be a great deal more. Considering themselves to be “lucky” in this sense, they constantly reminded me of the scenes of suffering in hospitals like the BCH and the fact that ultimately we can “all go down the same path”. Many of the volunteers often described their trips to the BCH as a kind of pilgrimage during their own treatment. Seeing the suffering of others was somehow extremely important. It *had* to be seen. Again and again volunteers and patients alike would remark that “you forget all your suffering in front of them” as they recalled the scenes at the BCH.

Both Prema and Anupama said that the only way in which they could express gratitude to god for having survived breast cancer was by ‘doing’ something for other cancer patients. Prema explained that not being a “temple going kind of person” she did not want to go and do *puja* (ritual prayer) there so, instead, she decided to become a volunteer. Likewise, Anupama having struggled through two episodes of breast cancer was just grateful to god for having given her this “much life” already and therefore, rather than “go and listen to some guru” or “sit at the temple for hours and hours”, she considered there to be no other option after recovery than acting in the service of others. The two were inextricably linked as she told me, “By god’s grace I am blessed to serve my fellow patients. I could sit at home or I could help...what would I rather do?” In this way, being an individual survivor is perceived as being united with the well-being and potential survival of others through acts of *sevā* or *dharma* that in serving humanity one is ultimately serving god⁴⁶.

2.4 Therapeutic mediators

Having established the ways in which volunteers conceive of their charitable activities as encompassing practices of *sevā* that are deemed to have political purchase in different ways, this section now turns to discuss in more detail the actual activities of the volunteers. Many of the NGOs and smaller charities send their volunteers on outreach missions to various private and municipal hospitals within the city. Here they either sit at specific designated help desks, visit radiotherapy and out-

⁴⁶This resonates with recent studies on novel philanthropic practices and charitable donation as *dan* (the Indian ‘gift’) (see Bornstein 2012; Copeman 2009). For example, one of Copeman’s interlocutors who lost her son in a car accident and for whom three people had donated blood in an attempt to save him, said that, rather than go to the temple and “cry crocodile tears”, she felt she was actually doing something by donating blood, which in turn could save somebody else’s child (see Copeman 2009: 73).

patient department waiting rooms or go on rounds of the hospital wards where they hand out patient literature offering all kinds of information related to the disease. Although Rajeswari sometimes described the WCAI as a support group, this was not in the sense that it involved regular meetings between patients and group sharing (see chapter 3), but more that the organisation was constituted by a network of ‘associated’ women who went out to the hospitals to offer information and advice, and to distribute free medication (mainly Tamoxifen) and packets of protein powder⁴⁷. For many years, Rajeswari herself went to the hospitals, liaised with patients and conducted small awareness camps in and around Bombay in housing societies, women’s groups, hospitals, and schools. However, when I arrived in the field, her ailing health was preventing her from working and she had taken more of a backstage managerial role.

In the hospitals, the volunteers meet patients in often fleeting one-time associations, which quite simply involve reading prescriptions or scanning appointment slips in order to translate, clarify, direct and navigate. Some volunteers sit at specific information desks. One of these, in one hospital, is located in the basement, next to the pharmacy. It is noisy and busy as people queue for medication and move in and out of the main waiting area. Patients come over to the desk amongst the commotion to ask where counter 39 is, or to have something that is written in their files, be it English words, sets of numbers, icons or letters, explained to them. Most of the time they ask and leave hurriedly, but sometimes they sit a little while longer, explaining their financial anxieties, briefly telling their stories of coming from afar, of not

⁴⁷This is given to women living in poverty in order to bolster their health and energy levels during chemotherapy.

knowing, of going here, running there, and all the while the volunteer flips the pages of the file and tries to reassure.

The volunteers also visit the general ward, going from bed to bed, motioning to their volunteer card and offering information and pamphlets. Sometimes they try to answer questions related to a specific concern. One morning on the general ward with Lata, the father of a breast cancer patient was particularly worried and sought reassurance about the fact that his daughter, a young mother of three, had recently been diagnosed with a *gārnth* (lump) and he thought that it could spread. Listing his grandchildren's ages as eleven, five and just five months, he asked Lata about breast feeding because his daughter had been nursing her baby while infected with this "thing". He motioned awkwardly with his hands, moving them back and forth in front of him. Lata explained that no, the lump could not spread in this way through *dūdh* (milk). But the father persisted, asking about transmission from blood (*khūn*) to blood, again concerned that the child who was only 5 months old may have been infected in vitro. This time Lata explained that cancer was not an 'infectious disease' and it could not spread between persons, and the father seemed satisfied, at least for the time being. I also found that, when I accompanied Laxmi, another volunteer on her visits to the government hospital A, we would spend considerable time talking with patients, giving out information, flipping through medical files, scribbling down the phone number of the AICT patient care department and answering a myriad of questions from patients. Once, Laxmi even drew a diagram of the female reproductive system to show a patient the location of the ovaries and cervix so that she could see exactly what part of her body had recently been operated on.

In the BCH, Anupama and Prema, along with other WCAI volunteers, delivered the post-operative classes. The classes were rarely a forum for in-depth discussion of patient concerns. Rather the point of the class was to give out as much information about post-operative care as possible. Patients were often timid, and there were not usually more than four or five questions asked per class and frequently these came from a relative; sometimes there were no questions at all. On average, there would be between eight to twelve women, each with a relative, at the class, but sometimes there were more than twelve which made the room very cramped, and relatives would have to sit on the cubicle beds, or stand behind the chair of their respective patient. The women would come straight from the wards. Most wore their hospital pyjama suits, blue for the general ward and white for the private wards. Some covered their heads and chests with a colourful *dupatta* and carried their drainage box in a plastic bag. Very often the women that participated in the class were in pain and distressed. Sometimes they were dizzy and had to lie down on the examination beds. Others vomited into paper bags. Even so, they would muddle through the classes as best they could, since they are now considered to be an essential part of post-operative treatment.

Anupama and Prema would often open the class by reassuring the patients, “*āp theek ho jāyenge agar āp mein ladne ki himmat hai*” (you will be OK if you have fighting spirit), or else “*sub se pahle, abhi āp theek haiñ, aur normal life lead kar sakte haiñ*” (Firstly, you are fine now and you can lead a normal life). Anupama would pick up one of the pink PIK bags and showing it to the class say, “*hamāre breast cancer kā rang pink hai*” (our breast cancer colour is pink), and would go on to demonstrate that the drainage box, which would be attached to the arm for the next 10 days, should from now on go inside the pink bag so that the women can move about easily when

they leave the hospital. Basic information about post-operative care would then be given and during this time patients or their relatives would ask questions regarding different aspects of treatment. What is chemotherapy? What causes cancer? Is it catching? Is there a cure (*ilāj*)? Does hair (*bāl*) come back? Why are there so many injections? What food can she eat? When can I do work in the *ghar* (house)? Sometimes the questions were more indicative of a deeper anxiety, as women would ask what *pāp* was there in their life, or how to tell *riṣtedār* (relatives) when they eventually went back home. The post-cancer volunteers would try and answer to the best of their ability, explaining that chemotherapy was another part of the cure; that they must tell relatives about cancer because it was important to spread awareness or “give back” (*vāpas do*) information to the community about the disease. But the volunteers were also keen to warn patients not to let friends and family intrude too much with their “*dekho! dekho! Kaisā haĩ? Kaisā haĩ*” (show, show, how is it? how is it?). They were also keen to emphasise that cancer is neither a punishment nor a *pāp* but rather, as Prema would so often say, it was an opportunity from god to now live life in a better way (see chapters 4 and 5).

At the same time as going out to the hospitals, many of the individual activities of the post-cancer volunteers, like Anupama, Lata and Prema, go above and beyond what is prescribed by the organisation or what other volunteers do. Sometimes this just involved talking on the phone and navigating women through the practical process of being in hospital, right from what clothes one would need to wear – a loose fitting *kurti*⁴⁸ that is easy to take on and off – to what happens after surgery to prepare them for the pain and disorientation. They also gave out their mobile numbers to patients,

⁴⁸This is a long cotton top.

and therefore sometimes maintained relationships over longer stretches of time. Patients, who had left Bombay to return home, would still come back for check-ups, and would frequently meet up with the post-cancer volunteer that they had met the first time round, in order to share their progress and continue to cross reference information and take advice. Sometimes the volunteers also made home visits or invited patients to their own homes. Occasionally whilst I was at Anupama's home, a family would turn up at her house, coming in just to sit and discuss treatment plans and take solace in a willing, listening ear.

As it was so often explained to me by volunteers and patients alike, because doctors do not have time to give patients detailed consultations, and patients also find they are inhibited from putting questions and vocalising their concerns to doctors, the volunteers' activities deal with a vast medical 'overflow' and in doing so emerge as facilitators or medical 'brokers' to provide a bridge or link between doctors and patients. Partly because of the way the medical burden is shared collectively within the family that leads to aspects of the disease being concealed, or partly because the patient and their family might not be able to read or access the information contained in it (and how to find out and who to ask is sometimes far from a simple, straightforward process), patients are not always fully clear of their medical plans and treatment trajectories, and this renders the role of the volunteers as therapeutic mediators all the more salient. In this way, the volunteers consider themselves to be contributing to a patchwork of care, and, in the case of the post-cancer volunteers specifically, who have, of course, been through the clinical experience themselves, they have intricate, unique and invaluable knowledge related to all aspects of breast cancer; they know how, where and when one should 'move'.

This is not however without ambiguity. I often felt this in relation to the way patient prognoses were handled by the volunteers. The volunteers do not necessarily know if a patient knows the stage of their cancer or their prognosis, either because the doctor has not shared it with them, or the family has decided to conceal it from the patient. Therefore, while volunteers would be happy to look at a scan slip punched into the file in order to simply direct a patient to a certain place, and were always willing to answer any questions about practical issues or to re-iterate what the doctor had already written, they were extremely reluctant, and many had a definite policy, to not comment on things such as prognosis or questions relating to the treatment plan. Certain things were thus noted but never spoken. The volunteers were terrified of revealing a prognosis out of turn. Frequently, this kind of situation happened; while one volunteer might be busy helping a patient try on a prosthesis behind the curtain, another volunteer would flip through the medical file to take down the patient's details for their records. As she did this, she might slide the file towards me and silently try to get my attention, by tapping on the page with the tip of her pen. I would look down and perhaps read "stage IV", written in black ink. Without glancing at her, I would nod my head and the volunteer would pull the file back towards her and continue writing. Meanwhile, there was a flurry of activity behind the curtain as the first volunteer, her voice upbeat and assured, would explain to the woman how to tuck the prosthesis into her bra. Such silent exchanges were common and heavy with the gravitas of fatal sickness, since the woman, who appeared from behind the curtain, her face patted affectionately by the volunteer to a chorus of gasps, "*oooohh acchi lagti ho*" (you look nice; good; lovely), was unlikely to become well again. These situations, therefore, involved the delicate balancing act of carefully managing one's own speech, second-guessing who knew what (and thus how much could be

revealed), and usually meant that, more often than not, the volunteers would plough on with stoic optimism. Furthermore, the volunteers never wanted to interfere with the doctor's work, and always made this clear to patients who asked for explanations of their treatment. While the volunteers would look at the file and could see that the patient was prescribed, for example, six cycles of chemotherapy, if the patient asked questions like "Why do I need this" or "what is this?", they would reiterate the prescribed treatment and then go on to explain in a more general way what chemotherapy would entail. If the volunteer were asked whether chemotherapy were necessary, or even why there were six cycles and not four like other patients, then the volunteer would always revert to "doctor's orders" and explain that '*BCH sub se acchā hospital hai, bohat achche doctors haiñ*' (the BCH is the best hospital, the doctors are very good) in order to ease any concerns and encourage the patient to ask their doctor these questions.

At the same time, however, pragmatic alignments were also created outside of the hospitals. This was the case with Vaishali. She was born in rural Maharashtra and inherited her mother's skills, as a *dai* (midwife), of massaging and bathing newborn babies. She was married at the age of eight and had four children. Her first son and daughter were born in the village but her next two children were born after she had moved to Bombay. She described her husband as never doing any work, having got into the habit of drinking alcohol and roaming around with his friends. Therefore for many years, Vaishali was the main breadwinner and, when they first arrived in Bombay, she would go from house to house, morning and evening, working in the kitchens of middle-class neighbourhoods. However, she soon started to bathe and massage new born babies for mothers. She lived in Navi Bombay and would make the long journey everyday to the women's houses in the centre of the city. This was how

she met Kavita, a longstanding volunteer working with a small women's health NGO that had a specific focus on breast cancer.

Vaishali had felt some pain in her right breast so she went to see a local allopathic doctor in her neighbourhood. This doctor told her she could not deal with the problem and sent Vaishali to another doctor. This doctor then told her she had a lump and would have to have it taken out. A lumpectomy was performed in the doctor's small, private clinic and, after a few days rest, the nurses re-banded her dressing, removed her drainage box and allowed her to go home. Vaishali left thinking that her procedure was completed, that the *gārnth* was removed and that she was now well and fine.

A few weeks later Vaishali wanted to show Kavita her medical file, because she knew she worked in medical matters, and wanted to double check that all was well. Yet when Vaishali went back to the doctor to retrieve her medical files, the doctor informed her that she did not have her reports and, in fact, Vaishali's daughter-in-law had already come and collected them. At home, Vaishali asked her daughter-in-law to show her the files but she refused, reassuring her that she need not worry, and remonstrating with her for wanting to see the because they told her everything is fine. Her husband and son also repeated the same thing, that everything was normal and she did not need to see the files. It was only when she got upset and angry, insisting that she wanted to show the file to Kavita, that her family relented and gave it to her. When I asked Vaishali why her family had kept her files hidden, she said she did not know, that maybe, since an operation had been performed and the lump had been removed, there was nothing else wrong with her and they were concerned for her well-being, not wanting her to worry.

When Kavita saw the reports, she could see that Vaishali's case was much more complicated. The lump that was removed was in fact malignant and had spread to the lymph nodes. Kavita sat down with Vaishali and told her calmly that she was not well and she needed to go back to hospital. Although I asked what had actually happened in the first procedure, neither Vaishali nor Kavita seemed to know and in fact the actual procedure itself did not seem important to them. They were more interested in the second round of treatment that she received at BCH. Using her influence in the BCH as a volunteer, Kavita managed to get Vaishali to be seen a little sooner on the surgery waiting list, and, while she acknowledged that this was unfair practice, she explained to me "when it is your own people you have to do it". Vaishali waited six weeks, until finally one morning she got the call early in the morning that her surgery would happen that very day.

In this instance, various alignments were brought to the fore as Vaishali tried to manage her illness. The management of disease continues to be seen as embedded in the family. But, while her family were acting out of concern to protect Vaishali by hiding the medical file, their actions were in fact misplaced. At the same time, the failure of the doctor to inform Vaishali of her disease meant that she had to seek information elsewhere. It was her association with Kavita, separate from her family and the sphere of the hospital, that fortuitously enabled her to eventually access the right kind of care. It is thus within the interstices of a partial care system, both private and public, and limits of protective care of the family, that the figure of the volunteer begins to emerge with particular saliency in the urban setting.

2.5 Anupama: mātājī of the BCH

For some of the post-cancer volunteers, being a volunteer had surpassed the quotidian requirements set out by many cancer charitable organisations and had in fact become a way of life. This was the case with Anupama, who was perhaps more unique than others for she most often worked alone and started her social work when she herself was still a patient. For Anupama, what started out as reading files for patients in the waiting rooms evolved and propelled her into becoming one of the individual pioneers of breast cancer care in Bombay. It is through her story that I want to begin to consider the post-volunteers as a certain kind of people and survivorship as especially significant as a medium for associative care. Anupama was born and brought up in a midsize town in the state of Maharashtra. She was the youngest of three brothers and five sisters. She had previously lost one of her sisters to breast cancer six months before she also was diagnosed with the disease. Anupama grew up in an orthodox Hindu Brahmin family, and was restricted in her freedom from an early age. She was never allowed to be away from home for long periods of time, nor allowed, like other girls of her age, to go out with friends until she was much older. She attended an English medium school but, because her family did not value education for their daughters as highly as their sons, Anupama had to fight with her family to allow her to attend college. She was not allowed to stay away from home, so she attended the local university where she soon realised how important education was in her life and thus continued to fight to educate herself, against the wishes of her family and successfully completed her undergraduate and postgraduate studies. Anupama in particular was able to do this because the youngest child she still had

time before her marriage would be arranged as her other siblings were yet to finalise their nuptials. In her final year of education she received a proposal of marriage from a suitable boy, and her marriage was arranged imminently. After her marriage, she moved to her in-laws house in Calcutta until finally her husband was transferred to the States for work.

Both Anupama's children were born in America. Anupama never worked; she was, and still is, a housewife. Although her husband was supportive of her going out to work, pointing out that she had worked so hard for her education that she should use it, Anupama felt that, as a mother, she had now invested her life in her children, which later in life, she told me, would "pay off dividends". After 12 years, Anupama wanted to move back to India, the nostalgic sense of belonging there had become overwhelming. They relocated back to Bombay and a few years later her sister was diagnosed with breast cancer. Then, six months later, on the last day of her sister's chemotherapy, Anupama was also diagnosed with breast cancer. They were both fine for a year and a half, until her sister had a relapse and died a year later. Anupama herself also had a recurrence in 2001. When I met her in 2010 she told me she was living well in remission.

Unlike others who concealed and denied the fact of their illness, Anupama had no problem with people knowing she had breast cancer. On the first afternoon that I met her, as we sat eating lunch from her *dabba* she exclaimed, with her arms stretched out in front of her, "I tell the world I am a breast cancer survivor!" Indeed, Anupama's experience of suffering with and surviving breast cancer, as well as the trauma of losing her sister to the disease, had transformed her entire life. She considered herself blessed, not only because of her own survival, but because she was in a position whereby she could now serve her fellow patients. Her social work, as she described it,

was what she was meant to do. While she had trained with the WCAI and had been instrumental in implementing the PIK bags, her connection to the WCAI was otherwise minimal. Anupama enjoyed working alone. Much of her work is opportunistic and through word of mouth, receiving phone calls and responding at anytime or just meeting patients in the corridor of the BCH, handing out 100 rupee notes for medication or taking patients under her wing.

Anupama has also, through her own experience, become an expert in the management of lymphedema⁴⁹. Anupama suffered with this after her first operation in 1998. Once the swelling arises, it is very difficult to try and reduce it and, unchecked, it can expand to huge proportions. She discovered a bandaging technique that, over time, completely reduced the swelling in her arms, so had thus developed her own expertise which she then tried to teach to the physiotherapists at the BCH. She devised a novel bandaging pack that she had managed to get into the pharmacies, which was sold at an affordable rate of 320 rupees. Anupama explained to me that the nature of the medical system in India was such that it did not prioritise ‘lateral’ health issues such as this, and many doctors were only interested in the dominant modalities of treatment: radiotherapy, chemotherapy and surgery. However, as she pointed out, the after effects of such treatments were just as important, but she felt that there was no adequate support system or rehabilitation for women with regard to breast prostheses, wigs and lymphedema prevention and management. She said, “After all the treatment is over, what happens next? No one knows! So that is when people like us come in”. Anupama had no medical training and she relied on her own experiential knowledge to aid other women through their struggles. She often reminded me of this, proud of

⁴⁹Lymphedema is a condition of swelling that can occur after the removal of lymph nodes during surgery.

the world, albeit small, that she had single-handedly built up around her. “I am an NGO all on my own!” she said.

Even though she conducted the post-operative class once a week, Anupama also attended the lymphedema clinic three times a week in the BCH. She was also connected independently to another NGO, and had befriended the physiotherapist there. Frequently, Anupama would meet patients in the corridor of the BCH and take them to this NGO, a short walk away from the hospital, where she could use their space to treat patients in the lull of the hot, quiet afternoons. During these sessions, she would sit calmly with the patient, not only teaching them how to manage their lymphedema through self massage techniques, but also answering any questions they may have had, and trying to impress upon them the importance of keeping time for themselves and taking rest during this traumatic time. In cases where the patient might be financially impoverished, she also often paid for the lymphedema pack herself.

Dr X fully endorsed Anupama’s work. For the last five years she had been teaching the lymphedema exercises in his private office, and it was only in the last six months that she had actually made the shift to working in the occupational therapy department. It had taken her five years to persuade the physiotherapists that her technique worked. Dr X and Anupama had also constructed a lymphedema management scheme that Anupama would take to hospitals all over India, as well as locally in Bombay, giving demonstrations to volunteers at other NGOs. She had in some sense embarked on a personal crusade, not only to improve the delivery of care to patients, but also to disseminate the value of ‘quality of life’, a concept she considered to be non-existent in India, especially among women. Having grown up in a restrictive family setting, Anupama was particularly attuned to the specific gender

dynamics of her society and made it a focal feature of her work not only to give women practical aid in their recovery from breast cancer, but also to advocate for their own self care within the family (see chapter 4). She had imbued lymphedema management with the concept of caring for the self, and used this practice to illustrate to women how and why they should take time out from their domestic duties to care for themselves.

Anupama's presence amongst the medical faculty was not without its problems. The physiotherapists did not believe that Anupama, untrained in medical practice, had anything constructive to offer them and were at times reluctant to work with her. Her interaction with the physiotherapists was a constant source of tension that had to be deftly navigated. She explained to me how she had gathered all her courage to go and speak with Dr J, the Head of the Occupational Therapy Department, to suggest the implementation of her novel bandaging techniques. Having befriended her, Dr J helped her make the changes to the running of the clinic. Although this was a victory for Anupama, she still experienced resistance from the physiotherapists in their daily activities. This upset her, and she commented about her liminality often with me, saying things such as: "What is the threat? Can I take away their white coat?" She was also angered by the way some of the staff sometimes engaged with the patients, speaking briskly and with impatience. "They are not very sensitive", she said. "They turn patients away who arrive 20 minutes late for the clinic!" This irked her because these women, who most likely lived far away from the hospital, had to make another journey back to the hospital another day, which could mean another night's stay in a hostel, another long bus ride, more money spent and thus the likelihood that they would not attempt to come back.

Thus there was an underlying ambiguity to Anupama's presence within the hospital. Her experiential authority was both novel and liminal, and at times she struggled to reconcile overarching biomedical authority with her own survivorship that was driving her daily activities as a volunteer with patients. This tension became particularly apparent one afternoon when, having enjoyed a lunch with the physiotherapists after the post-operative class (which was something we occasionally did), Anupama and I prepared to leave. As I stood holding a big plastic bag containing PIK bags I became aware of Anupama chatting with the one of the physiotherapists and suddenly she started speaking about her own experience of breast cancer – an outburst that stunned everyone into an awkward silence. I stood looking at my feet, shifting the rather heavy bag quietly from one hand to another while Anupama spoke. She recalled how she was diagnosed just six months after her sister, how she then lost her sister and was herself re-diagnosed with another lump. All this happened while she was mother not only of two children (her own), but now five, having taken on the responsibility of her sister's children as well. In this moment, we were all reminded of where Anupama had come from and what she had been through. When she finished speaking, she apologised if she had spoken 'out of turn' and said her goodbyes. We walked out of the room into the hot, humid mass of crowds outside.

Anupama lived for her social work and cared deeply for patients to whom she devoted most of her time, spending the majority of the week at the BCH. She had turned her trauma into a virtue, channelling her pain and sorrow into an experiential knowledge that she now shared with others, reinventing herself as a kind of local healer. Indeed, Anupama had a certain status in the BCH. She had developed the inspective gaze of a doctor, gently turning heavy and painful arms to evaluate the

extent of lymphedema swelling. She was self-assured in the way she worked and spoke confidently, with the assurance of somebody with certain knowledge. She was in some sense more than a volunteer. The way patients approached her, with deference and respect, clasping their hands to their heads, their gratefulness that she would never acknowledge, and her tireless devotion to the cause made her a kind of great *mātāji* (revered mother). This was more than apparent in the way Sujata and her family (see chapter 1) described their interaction with Anupama, who, they told me, had helped them when they were lost in the OPD queue, informed them about the post-operative classes and explained things “so nicely” to them. In this way if doctor is god, then the volunteers are his ‘boon’. Anupama was addressed as “mam” in the same way as the senior doctors and treated with similar deference and respect. Doctor J, would often take over and demonstrate the lymphedema exercises from those (non-cancer) volunteers who delivered the post-operative classes, thereby somehow marginalising the volunteers to the periphery of the class. However she never did this with Anupama, to whom she accorded a great deal of respect, which Anupama received with an embarrassed pride.

2.6 Pioneering breast cancer survivorship

This chapter has set out to describe the emergence of some of the first breast cancer patient associations and charities in Bombay. Initial claims to solidarity around the disease emerged from a few pioneering patients who recognised the dire lack of resources, and difficulties faced by patients attempting to access treatment in a partial and uneven health care landscape in which they themselves had received care. In turn this has led to the formation of particular collaborations between patients and their doctors that resulted in the growth of small associative groups who try in whatever

ways possible to advocate the disease, and in doing so have introduced novel forms of care within the hospitals such as the introduction of the PIK bags in the BCH, the 'Indian' prosthesis and implementation of the post-operative class in the BCH.

However, the volunteers' quotidian participation in groups such as the WCAI emphasises less the notion of being associated with, or belonging to a group and community, and more the basic provision of care to patients. This is borne out of their own personal experiences of suffering, and from within their wider conceptions of charity work as kind of divine humanitarianism as they strive to 'do' something for others as part of their own gratitude and humility of having survived. They thus perceive their own survival as united with the well-being and potential survival of others through acts of *sevā* (selfless service), that in serving humanity one is ultimately serving god.

This is seen to occur through diffuse networks of care that are being created and sustained individually by post-cancer women within the urban clinical setting. Indeed, the individual figure of the post-cancer volunteer emerges as a particularly pivotal feature of grassroots activism within the oncological care landscape. While women such as Lata, Prema and Anupama are associated with an organisation, they work alone within the hospitals and draw upon their own experiences of having suffered, even if this is just having received treatment in the same institution or being familiar with the protocols of the medical file, in order to extend care to women and their families. They do this by engaging in pragmatic partnerships and relations, some fleeting, others more concrete, that are based on a solidarity of knowing where, when and how to 'move' through the sprawling motile oncological milieu. This involves acting as 'therapeutic mediators', conveying grassroots medical knowledge, navigating and guiding patients through the networks of hospitals, clinics and

bureaucracies that speaks to the urgency or immediacy of the need for clarification and reassurance. This is taken even further by Anupama, who has creatively seized upon the inherent liminality and ambiguity of having survived breast cancer, as being “betwixt and between” (Turner 1967: 97), in order to carve out a niche for herself within the biomedical clinical setting. While suffering with breast cancer can be constrained by the unspeakable and subject to concealment and containment within the domestic sphere and community (and in this sense Anupama is exceptional because she was certainly more vocal about her illness), it also emerges as a generative resource through which to mobilise novel forms of care in the particular sphere of the biomedical clinic.

Breast cancer ‘survivorship’ thus appears as a pivotal medium around which the volunteers are initially mobilising. It is generative of a kind of lay expertise that in its most immediacy speaks to a pragmatic solidarity that is created and sustained through the formation of strategic collaborations between individual volunteers, doctors, patients and their families. The work of managing breast cancer in urban India therefore emerges as diffused and shared between various actors over which the disease is spread as volunteers emerge as therapeutic mediators, facilitating forms of medical ‘brokerage’ positioned within and between a ‘politics of domesticity’ (Das 2001; Das & Addlakha 2001) and is played out within a fragmentary biomedical setting. In the context of accessing and retaining cancer care, this can be seen to include the pragmatic partnerships engaged in by patients and volunteers, however fleeting or concrete these may turn out to be.

CHAPTER 3

Affiliation and sentimental solidarities

A large proportion of the voluntary groups activities revolve around the provision of practical care and establishing pragmatic alignments within the context of nebulous care pathways, complex treatment plans and scarcity of state resources. In this chapter, the focus shifts from the practical nature of the individual post-volunteer's work, to examine in more detail the complexities around patient and the post-cancer volunteer participation in the voluntary groups and the charitable oncological scene more generally in order to attend to the way associations, and potential novel patterns of sociality are being created and sustained by and between patients, volunteers and post-cancer women around breast cancer suffering and survivorship. As we have seen, the post-cancer volunteers work in specific ways within the hospitals, but, if we shift the focus away from their grassroots activities, the charitable scene emerges as more ambivalent in the urban setting. Patients and their families do not appear to seek out support (*madad*) from the *bāhar* (the outside). This is considered novel and sometimes unnecessary, given the claims of family support (*parivār ki madad*) and family as the bastion of care giving. In turn this appears to impact the ways in which patients choose to engage with the interventions of the voluntary groups.

This chapter focuses in particular on the complexities surrounding the ways in which patients participate in voluntary groups, and more specifically on the novel intervention of the patient support group. The support group is a particular form of patient support that derives from the West; it works to create a space for intimate group sharing, which, it is hoped, will create bonds of solidarity and ameliorate the patient's experience of suffering and aid recovery (see for example Klawiter 2000b;

see also Matthews et al. 1994; Matthews 2000). While many of the volunteers and charitable groups are keen to implement such a group, the success has been fairly limited. Charting the tensions that surround attempts to implement and participate in such groups, this chapter brings another dimension of the post-cancer volunteers' mediatory role to bear on this specific issue by focusing on the ways in which appeals to the post-cancer volunteers' own survivorship now transcend the practical element of their mediation, in order to work to instil hope and courage in the patients they meet. Where patient participation in groups with a view to harness solidarity is negated, and talking about cancer emerges as especially difficult, the chapter explores how the volunteers mediate the silence and fear of cancer, and initially attempt to engage with disease affiliation through the medium of sight. Here revelations of being a breast cancer survivor are mobilised in particular ways and at specific times and emerge as an initial mode of communion through which to inspire hope and offer patients the possibility that 'normal' life can be resumed.

However, even though many patients are not seeking out forms of belonging and solidarity through participation in patient groups, the second part of the chapter turns to explore a specific case study of a successful breast cancer support group *Saheli* in order to further describe the kind of bonds that are forming among the post-cancer volunteers specifically. This group was conceived of, and implemented by, an enthusiastic doctor, who having worked in the UK, saw the model of the support group there and brought the idea back with him when he returned to work in India. He had approached one of his recent patients, Minu (the now president of *Saheli*) and asked her if she would help him start something and she was the first person to enrol her name. The chapter explores how the group has evolved, focusing in particular on the relationships between the core members. Here gendered predicaments concerning

‘tension’ and stress within everyday domestic life, that in itself has specific implications for the ways breast cancer causality is perceived, are given expression within the group and in turn give rise to stronger bonds of solidarity that are created through relations based on a form of biomedical kinship (see Nguyen 2010). The chapter discusses the potential opportunities for emergent forms of belonging and sociality to be created through the novel space of the breast cancer support group and further build upon the notion of breast cancer survivorship as a multidimensional associational medium through which the post-cancer volunteers are establishing relations of affiliation and bonds of group solidarity.

Part One: Novel forms of care

3.1 Support from the ‘bāhar’

One of the most recent introductions to urban oncologic care provision in India within the last ten years is the ‘volunteer’. While the voluntary groups have been, and still are, instrumental in delivering all kinds of care and information to patients, many patients do not actively seek support from volunteers, or what was often referred to as support or help from the ‘outside’ (*bāhar*). This is exemplified by the practice of palliative care, for example, which is considered to be at a bare minimum in India. With the ‘dying space’ traditionally in the home (see Cohen 1998) placing patients in care homes or hospitalising them for palliation is not a common practice. A nurse, who was training to be a palliative counsellor at the hospital associated with the Cancer Centre (CC), would come into the clinic a few times and in our conversations she explained to me the difficulties surrounding palliation. “People are very reserved,” she said. “We Indians are set in our ways. Don’t take to asking outside support, you know, just the family you can call on for help”. I asked her about the novelty of

‘counselling’ more generally and she agreed saying, “[they] don’t know about it and if they do, they don’t like it, they don’t trust... people poking their noses in, selling them medicines. Family support is there. Counselling is a new concept” The volunteers also often said that people do not seek out this kind of help because it is considered a stigma to go to “*those people*”; the social workers or psychologists working in the hospitals, and that ‘psychiatric illness’ is not recognised as a ‘real’ problem (see also Kakar 1982). “No one wants to admit to getting help,” explained a senior member of the AICT team, “it’s not like in the US where people say ‘I wear Gucci, Armani, I’m so stressed, stressed and I have therapy three times a week!’ People here don’t tell anyone. You are just *pāgal* (mad)!”

Furthermore, through my conversations with patients and post-cancer women independently of my work with the volunteers, I continued to learn that talking about breast cancer was particularly difficult. Many patients and post-cancer women told me that they did not want to seek out or meet (*milnā*) other survivors. To speak about the disease is to *yād karnā* (remember), which keeps a *zakhm* (wound) open. As Leelabai so often told me, “*Cancer ke bāre mẽ bāt karne se mere dil mẽ dard hotā hai*” (to speak about cancer brings pain in my heart). At the same time, the fear and marginality of experiencing the disease as ‘living death’ also contributes, as we have seen (see chapter 1 & 2), to the immense silence and concealment around the disease, that is not only directed out towards the wider community, but is also experienced within the domestic sphere itself where some patients are not told they are suffering with the disease, or women strategically try to conceal their suffering from the gaze of parents-in-laws and family elders.

These complexities over the ways in which breast cancer can be spoken and shared within, and outside of the familial body, are seen to clash sometimes when brought

into the sphere of the hospital and the activities of the volunteers. While many patients were receptive to volunteers out on the wards and in the hospitals, they were, as we have already seen, often primarily interested in gathering practical or medical information. This is further complicated by the fact that many patients are not told that they are suffering with breast cancer and I was told that some volunteers in the past, unwittingly and accidentally, had revealed a diagnosis of cancer to patients on the wards, even by just mentioning the word ‘cancer’. This is considered to be extremely problematic and stories circulated amongst the volunteers about patients who had found out this way, with one incident even reported in the press where a patient committed suicide by jumping from the window of his hospital room, after hearing the nature of his disease from a volunteer. Therefore some, mainly private, hospitals have since refused the presence of volunteers, or at least only allow one organisation, or even only one volunteer (such is the case with Lata), to visit their establishment.

Accordingly, volunteers are now trained to ask the patient, before any exchange of information can take place, why they are in hospital or to simply say: “*kyā huā?*” (what happen?). It was common to hear patients on the ward of BCH say that they were suffering with other illnesses such as tuberculosis. If the patient’s answer was cancer, the volunteer could go ahead and speak openly with them. However if they did not mention the word cancer, then the volunteer could not use this word either. So volunteers were trained to be led by the patient’s choice of words for their condition, for example *gārnth* (lump), but had to be careful not to reveal too much while providing as much information as strategically as possible. This often meant that a volunteer would instead stand a little to the side of the hospital bed and give information and any leaflets she had to the family members present.

At the same time, the support of the family was consistently appealed to as managing sickness and health as a collective unit of care taking (see also Broom & Doron 2011). *Parivār ki madad* (support from the family) negates a need for support from outside (*bāhar*) and I was often told that breast cancer is a “family problem”. Furthermore, people spoke constantly with pride about the “Indian family” which was highlighted by one particularly buoyant doctor whilst addressing a group of breast cancer patients when she said, “*Indian family world famous hai!*” (The Indian family is world famous). Indeed, many conversations in the field were spent comparing the differences in “family support here” and “there” (usually meaning America and the UK, or sometimes the ‘West’ more generally). I was always being asked, in a rhetorical form that often came across as more of a statement awaiting confirmation, rather than a question: “How is it over there? There is less family over there *nah?*” I always found myself struggling to answer these kind of questions, for when I found myself pitted between “the West” and “India”, I knew what answer was expected, but I also felt as though I had somehow to defend a ‘Western’ lack of family values (that I did not necessarily agree with). I often encountered surprise when I tried to give examples from my own personal background of Westerners being “family” orientated. Frequently, I was pushed to explain further, for my interlocutors, who considered themselves to be fairly well-informed on life in the West, would say things such as: “But children are out of house? So young, they are gone!”

Often my own ambiguous situation was used as an example of Western difference in family values. For my interlocutors, the fact that I was even in India, far from home, at such a young age and of an unmarried status was quite astonishing. At the same time however, my appeals to Western family values were perceived as representative of the fact that I appeared to be very at home with “Indian” ways, that I might settle

there with an Indian husband, and was therefore considered to be in some ways different from other foreigners. However, even though there was constant emphasis on the notion and value of the family, this is not to necessarily suggest that the domestic sphere is always an idealised space of benevolence and protection. As will become clear below, and throughout the thesis, where family breakdown occurs or relations don't perhaps work as they should, participation in support groups becomes more appealing in specific ways.

3.2 Participating in support groups

Even though family support was claimed to be axiomatic (and even in those instances where it was not given it still emerges as salient through its very absence), many of the charitable organisations were interested in implementing breast cancer support groups. In the West, although breast cancer support groups differ in their form, and are turned to by women for various reasons and at different stages of living with breast cancer, they have become a prolific feature of health care systems in the UK and America (see Klawiter 2000b). Here the support group emerged as a common space created for patients to come together and facilitate the exchange of multiple kinds of knowledge and experience of the disease. In doing so, these groups have “shattered institutionalised barriers” that separated women from each other and in turn replaced these with “new relationships, emotional support, social connections, flows of information...a sense of ‘groupness’, solidarity and new sensitivities” (Klawiter 2000b: 310; see also Matthews et al. 1994; Matthews 2000; 2008).

In India however, health professionals and volunteers consider the support group to be an extremely novel intervention in the Indian health care system. Many of the doctors in some of the private hospitals, with whom I discussed this considered the concept to

be “ahead of its time” in India, and likewise many volunteers shared with me their stories of failed attempts, explaining that no one considered participating in the group as a priority. There were however a few groups operating whilst I was in the field. These were mainly attached to private hospitals and of those that I attended, I found that they were often set up like a small seminar that opened with one or two patient testimonials, and then the delivery of a lecture, given by an oncologist or specialist speaker who would present on certain issues, such as yoga or meditation with a question and answer session at the end. That being said, many of the post-cancer volunteers were interested in the idea of a support group and more ‘internationally’ informed styles for supporting breast cancer patients and I was frequently asked to divulge information about the way that cancer volunteers operate in the UK. Many of these women had participated in the South Asian Pacific Reach2Recovery conference in 2006, and others had also travelled abroad for breast cancer forums and coalitions such as the National Breast Cancer Coalition (NBCC). They enjoyed these expeditions abroad and valued the learning experiences, but sometimes such international conferences were spoken about with some sense of puzzlement. This was not because the volunteers did not enjoy them or learn new material, but because they realised, for example, that the virtues of the Reach2Recovery’s basic principle that survivors are better equipped to support other patients, was something they already knew.

Therefore, while many of my interlocutors appreciated the sentiment behind the idea of a unification of breast cancer suffering and activism, and indeed, while some were more eager ‘to learn from the West’ than others, many of the advocacy and policy issues raised in these ‘global’ forums were perceived to be incongruent with the Indian context and the specificities of Indian breast cancer patients (see also Klawiter

2000b)⁵⁰. Instead, what was often emphasised to me about these events was the cultural differences between themselves and Western women (whom they considered to be very ‘outspoken’, but at the same time were amazed by the level of advocacy that was being achieved), and recalled most frequently the quality of the food, the joy of meeting so many different women and the striking fact that there were *so many* breast cancer survivors in the West; this was something they were not used to seeing in India.

For many years, Sarojini had also wanted to start a patient support group as part of AICT patient care activities, which she envisaged differently as something like ‘Alcoholics Anonymous’, a small intimate group of (mainly middle-class) women who meet in a non-clinical setting to support each other through a sharing of experience. In the past, when Sarojini had tried to organise this no patients had turned up, apart from a few who were seeking financial aid. However, seeing in me the eagerness of a fresh-faced anthropologist she offered me the task of trying to organise one, and said that since I wanted to meet more patients and learn about women’s experiences, this would be a good place to start.

We planned the first meeting in October 2009, to coincide with Breast Cancer Awareness Month. Before that first meeting, I was nervous that no one would come. However, our first meeting was one of the most successful. The group was composed of myself, Sarojini, another AICT employee, Anupama, Lata and three post-cancer women; two of these Lata had met on her hospital rounds, both of whom were now

⁵⁰Klawiter has made a similar observation about the ‘globalising’ breast cancer assembly. She states that these international gatherings, “despite the participation of activists, experts and allies from around the world, are clearly the projects of local, specifically North American, contexts and conditions...in other words [they] are the projects and projections of very specific and privileged sites of activism” (2000b: 328)

finished with hospital treatment, and the other, who had seen the advert I had put in the newspaper, had phoned me up to enquire about participation. Finally, there was the sister of a breast cancer patient who had just completed treatment but did not want to attend herself. These women became fairly regular members, however it remained incredibly difficult to recruit more. We printed flyers and left them in hospital waiting rooms; I gave them to the volunteers at the CC to hand out and included them in patient packs that were sent out with the AICT volunteers, but rarely did anyone new come along or call to enquire.

The other difficulty was the format of the group. Although the meetings generated a good deal of discussion, and while the members were fairly regular in attendance, no one was interested in taking the group on and making it a patient-driven entity. Given the stilted nature of discussion in the group and the general lack of interest, in subsequent meetings I organised speakers to come and discuss certain topics that the members had expressed interested in: diet, lymphedema, managing hair loss, and yoga. In fact, the yoga teacher became a regular member and led the last few groups that I had organised with great success. However, ultimately, the group was perhaps only half successful. Sarojini used to tease me in front of the other volunteers, saying how sweetly I would sit and wait with my *chāy* (tea) and snacks, but no one would ever come. The employees of AICT and other volunteers were sympathetic too, but even they would tell me that they would not go to a support group. “I find better support at home”, said one of them, while another commented, “Over here, social networking is better: friends and family. It’s not uncaring over here”. With “here” being juxtaposed to what they imagined to be over ‘there’ in my own country, they played off India’s more tightly-woven and enriched social fabric against the very need for a support group itself, which simultaneously just confirmed the disparate nature of

‘Western’ families. Although the volunteers at the CC supported my attempts, there was still the question, highlighted in more awkward moments, that I was *not* a survivor so therefore how could I organise the group in the first place. Questioning the validity of my own status as a non-survivor provided a reason for the group’s apparent failure whilst also reconfirming the perceived significance of the role of ‘survivors’ in post-cancer care.

Thus while the group brought women together, it never really managed to become what Sarojini had envisaged⁵¹. She would ask me again and again why it was not working, why women were not coming forward, and she was slightly bemused that the ‘Westerner’ could not even make it work. In turn, I had extremely mixed feelings towards Sarojini’s insistence on implementing it. Sarojini considered the failure of the support group to be because women were not making themselves a priority (see chapter 4). Although Sarojini’s intentions were in the right place, at the same time, through my participation with other voluntary groups, it was clear that patients and post-cancer women were participating in certain forms of groups, but doing so in different ways and under specific circumstances.

3.3 *‘Seeing’ survivors*

The significance of ‘seeing’ survivors was attested to by many post-cancer volunteers, patients and family members. I witnessed this time and time again, as I sat in patient waiting rooms hearing patients exclaim how lovely the volunteer looked, or else

⁵¹After my departure from the field I learned that the group disintegrated. Although the yoga teacher had initially tried to keep the momentum going, it seemed everyone lost interest. On subsequent returns to Bombay however I learnt that AICT had launched another group, but this time it was in a private hospital and ran much like other groups, as a kind of social seminar and forum for question and answer with a resident oncologist.

watching a post-cancer volunteer run her hands through her long, thick, black hair as patients sat astonished that she had once been a cancer patient. I observed it in the post-operative classes where Anupama and Prema would often open the class by telling the women: “*maĩ survivor hũ*” (I am a survivor), or else they would be ‘shown’ by Dr J who would tell the group that this is what they would also look like after recovery. The most frequent questions asked by patients were concerned with how many years the volunteer had “completed” after treatment.

The significance of ‘seeing’ was reiterated and emphasised continually by the post-cancer volunteers in *Saheli*, for example, who often made home visits (because patients did not want to go out) and they would ‘show’ themselves to the family so that they could see that their wife or mother would soon become like them. About this Padma said, “They have to just see us, see how we do our normal routine” and this has formed the motto of the group; that once they have visited the patient, she would have the reassurance of knowing “I will become in such a state that she has become”. It is often a family member who comes to see the post-cancer volunteer, coming to see if she looks “normal” and sometimes, instead of the patient herself, the husband might attend *Saheli’s* group meeting. Minu expanded on this: “There was one patient, our friend, her husband used to come for so many meetings because he was worried about his wife’s survival but he used to get that positive feeling, like ha! So many ladies have survived, now my wife will also survive...!”

I was often struck by the frequency with which the post-cancer volunteers relied on the work of vision and revelation in their interaction with patients. One Tuesday morning, I was sitting in my usual spot on a low stool next to the examination bed in the small and cramped room of the CC; one of three rooms in a small annex at the side of the hospital near the waiting area. Today Jyoti is the attending volunteer. A patient

knocks on the door. Jyoti calls to come in, and a woman enters the room and she sits down in front of the small desk, opposite Jyoti. She is alone and appears very nervous, hesitant and shy. She takes out her medical report from her plastic shopping bag and hands it to Jyoti, and asks her if she could explain the report. She has just had a mastectomy and has been told by the doctor she needs chemotherapy and radiotherapy but she does not know what this entails. Jyoti opens the file, looks down briefly, and starts to explain what chemotherapy is. The woman looks particularly anxious and seems distracted, and Jyoti stops mid sentence and asks her in English: “Why are you looking very tense?” Jyoti reaches out to rub the woman’s hand affectionately and the woman starts to cry. Jyoti tutts gently and says “Nothing is going to happen to you *nah?*” And then continues: “I am a survivor from five years back. Look at me! Do you think I had the same surgery? No!” she exclaims. “We are the lucky ones”. The woman looks completely surprised and shocked. Jyoti continues to explain why both of them are lucky, because compared to those who had treatment fourteen or fifteen years ago when medicine “wasn’t so advanced”, now there are “so many newer drugs”. “Be positive, it will come from within you” says Jyoti, “Nothing is going to happen, be positive” and asks the woman if she is working. She nods and says she is a lecturer in commerce and business studies. Jyoti smiles enthusiastically, encouraging the woman to open up, which she does, a little, and the conversation continues as Jyoti advises her how to manage telling people at work about the illness, perhaps to wear a wig so, in public, people cannot tell.

On another occasion, again sitting in the CC, a woman and her husband have just been brought in. The woman had been crying on the ward so one of the volunteers had brought her down to talk with more ladies in the CC. Rani, the attending volunteer, takes her hand. “Don’t worry” she says, “pain is there but this is temporary. Don’t

worry. You have this trauma but *theek hoge* (it will be ok)”. She starts to tell her about the prosthesis. “This will make you feel better” she says, as she takes out the prototype prosthesis from the box and lays it in front of her. The woman is clearly distraught and tries to speak, saying something about stitches and the pain on her chest. Her husband interrupts and starts to speak but Rani cuts him off, saying firmly “Please, this is a problem of female psychology. You are not supposed to understand”. Not looking at the husband, but focussing on the crying woman she says, “It is her day today. What ever she feels” and strokes her hand. The conversation continues, and then Jyoti opens the door and comes in. Rani looks up and says to the patient, “Look *she* is a survivor!” The woman looks at Jyoti astonished. Jyoti, accustomed to such bold and spontaneous introductions, smiles and says, “I am five years completed. I am normal”.

The husband, who looks quite bewildered by the whole situation, comments that “This woman is looking very smart” and Rani turning her attention back to the woman says, “See, don’t worry”. The woman who has still said nothing, smiles. The awkward ambiance dissipates slightly and a more relaxed flow of conversation ensues as Rani starts to talk her through the post-operative exercises and puts cancer leaflets in her medical file. She gives her the helpline numbers, and tells her, “We are your extended family now. Call us anytime”. While this has been going on, her husband has been on the mobile phone with their daughter, and the woman asks Rani if she will speak with her because she is also crying. Rani takes the phone and says, “Why are you crying when your mother is here laughing nah? She looks fine, she has a little pain but she is fine”. The husband thanks Rani as he holds his hand out for the mobile phone. As he finishes the call, the woman and Rani hug after she gets up to leave. Jyoti opens the

door for them, and Rani walks them out of the small compound. When she comes back into the room she comments, “He is a very good supporter” and winks.

Both vision and ‘survivorship’ thus take on particular meaning here. When I asked the post-cancer volunteers to describe the importance of seeing, they did so using the word ‘*nazar*’, (meaning ‘stare’, but they translated it as the ‘manner’ or way at which you look at things that also involves the exchange of ‘feelings’ [see also Eck 1985; Pinto 2008⁵²]). This speaks to the ubiquity of the significance of sight in Hindu culture that is aptly captured by Diana Ecks when she claims, “whenever Hindus affirm the meaning of life, death and suffering, they affirm with their eyes wide open” (1985: 11). The overarching metaphor for visual practice and culture in anthropological studies of India has traditionally been through the concept of *darśan*; the act of ‘seeing and being seen’ that constitutes the moment of religiosity between the devotee and the divine (see Babb 1981; Eck 1985; Pinney 2004). This central act of Hindu worship consists of beholding the image in which the deity is present. This visual apprehension is charged with religious meaning from which the devotee ‘takes’ or ‘receives’ *darśan* from the deity or *sādhu* (priest), just as Arjuna was given eyes so that he could ‘see’ Lord Krishna in the Bhagavad Gita (Eck 1985). I also learnt that Hindus could ‘see’ the divine in anything and everything, and that they engaged in cultural practices underscored by mandates to ‘see’- be this the new bride, the deity, the guest, the dying person or the sick. It has been claimed that the act of seeing therefore goes beyond mere visual representation or objectification of a subject, to emerge as a ‘corporeal’ engagement (Pinney 2004).

⁵²Sarah Pinto (2008) engages in a particularly interesting discussion of the way in which notions of nefarious *nazar* and complexities of visibility and vision play a key role in the management of pregnancy in rural India.

These initial interactions and exchanges between the post-cancer volunteers and patients recall the giving and receiving of auspicious *darśan* as I was consistently told that such interactional modes of ‘seeing’ and emotional exchange conferred a greater impact on a patient’s will to live than any amount of ‘talking’. The volunteers often commented that such revelations are like miracles. “She just has to sit there”, Rani said. “It’s a miracle working for them [the patient] mentally”. Thus the moment of revelation, of ‘seeing’ the ‘survivor’, impacts and surprises through the instantaneous juxtaposition of death with life and an ambiguous crystallization of exceptionalism and normality. In turn this constitutes a moment of communion and affiliation wherein ‘I am like you’ or ‘you can be like her’ is realised in a very immediate way and turns on the evocation of *darśan* as the divine knowledge of life itself.

It could therefore be suggested that the post-cancer volunteer emerges as a role model analogous to a guru⁵³ figure. This is not to suggest that the post-cancer volunteers consider themselves to be gurus, or that other people necessarily refer to them in this way; it is most certainly not intended to romanticise nor mystify them and thus render their work any less ‘politically’ informed and inscribed. But rather if cultural forms consist “of the way people draw analogies between different domains of their worlds” (Strathern 1992: 47), it is suggested as a fruitful starting point from which to begin to think through and capture a particularly significant aspect of the volunteers’ work in

⁵³Guru is a category of religious leadership in Hinduism and is explicitly connected to a teaching tradition involving philosophical instruction. Gurus have usually rendered their social and civic identity as dead, which is achieved through the performance of their own death rite as symbolic of cremation, and in turn have orientated themselves to experiencing divine unity. Gurus are continuously experiencing the ‘real’ or higher consciousness known as Brahman, which is a pure and unmediated reality. In doing so a guru inspires others, initiates aspiring devotees and gives spiritual instruction to others for the advancement of personal self-realisation and evolution as a human being. In a more ‘popular’ sense however, the title of guru can be bestowed on anyone with capacity for instruction; the guru is ‘the path’, a dispeller of darkness who is able to point out the way (see Pechilis 2004a: 26; see also Babb 1986; Khandelwal 2004; Pechilis 2004; Warriar 2005).

relation to the ways they mobilise around disease affiliation. Given the nature of the landscape of cancer care as rushed and inducing panic, and given that patients may only, if ever, seek out *madad* from the *bāhar* the one time, these revelations of survivorship take on a particular significance. Patients attending the CC, and patients who are visited at home by volunteers, as well as those patients who meet volunteers out in the hospitals, are not necessarily seeking to affiliate with other survivors, and, more often than not, when they do come to the groups what they are seeking out is practical guidance and information. Even once patients leave the clinic or the hospital, most do not have further contact with the groups or the volunteers, and if for example, volunteers see patients out in the market or in the street they pretend they don't know them, as more often than not, the volunteers must respect the modes of concealment and 'veils of silence' through which patients and their families operate in daily life.

Therefore, this would seem to suggest that many patients are not seeking any notion of collective identity or group affiliation, whether this is through participation in support groups or otherwise (see also Nguyen 2010)⁵⁴. Furthermore, given that a sister of a breast cancer patient was a frequent member of the AICT group would further seem to suggest that persons as 'connected body-selves' (Das & Addlakha 2001) can 'stand in' for one another; as does the fact that survivors just need to be 'seen' by any member of the family in order for them, as inclusive of the patient, to know that

⁵⁴Nguyen (2010) has also noted in the context of HIV AIDS triage in West Africa that western assumptions that solidarity based upon a shared biomedical condition could result from self-disclosure through 'confessional technologies' were lost in translation. He describes how 'talking' was a social adhesive that did not, at first stick in a setting where kinship framed the terms of solidarity and persons feared ostracization from family and community for speaking publically about their HIV status.

recovery is possible. It is here that the work of mobilising around disease affiliation emerges as salient for it is within the interstices of the familial body that the post-cancer volunteers can offer patients, who experience breast cancer as the despair of living as ‘death’, the possibility of returning to ‘normal’ life. It would seem that this inheres through the more individualised visual interaction and exchange with the post-cancer volunteer as analogous to a guru-devotee relationship as the practice of ‘seeing’ survivors, as auspicious *darśan*, emerges as a significant mode of communion that inspires and instils hope in patients and their families, and in turn points to the ways by which the post-cancer volunteers begin to mobilise around disease affiliation in relation to breast cancer survivorship.

At the same time however, through my participation with the support group *Saheli* I came to learn that much stronger bonds are also forming specifically between the post-cancer volunteers. These bonds are being complexly woven together in relation to particular gendered predicaments and are intertwined with specific concerns around breast cancer aetiology. It is to these issues that I now turn to explore in more detail in part two.

Part Two: Saheli breast cancer support group

3.4 The work of sharing

In *Saheli*'s first meeting Minu (now the president of the group) recalled that a new message was conveyed to the patients. Whereas previously doctors would tell patients, including herself to forget their illness once treatment was over, that it was gone, that “nothing is there now and you are a ‘normal’ woman”, today, they were being told actively to remember it because it was better to live with their illness and take care of themselves rather than to neglect it. Minu remembered this distinctly and

told me that in addition to this, just sitting in that room and seeing other ladies like her, was one of the best things about that meeting. Hearing the variety of stories that were in some cases of more hardship and pain than Minu considered she had in her own situation, made her realise that she was in some sense more fortunate than others. “This is how we came to know that sharing helps to cope with illness”, she told me.

After that initial meeting, Minu found it increasingly difficult to recruit members for the group, and in 2002, with dwindling success at their meetings every month, Minu started visiting women at home and in the hospitals where patients and their families were more willing to talk and find out information about cancer. About this she said, “No one wants to hear or listen to that word cancer...[they say] what is the use of listening all the time? And you know it’s a little ‘closed’ society”. However, being a ‘survivor’ started to take on specific meaning as a means to enable ‘care’ and ‘hope’ for others, both between patients and the volunteers, and between the members of *Saheli* themselves.

Saheli have been active now for ten years. Over the years, the group has developed a stronghold of ‘core’ members lead by Minu and Padma, and then around four or five other ‘core’ members as well, since there are up to fifteen women that attend the group meetings each month, what Minu described as a ‘floating population’. It is not the case that new members replace older ones; it is more that this core nexus of women bring patients into their fold and keep them there until they are ready to leave, after which time they may or may not maintain association with the group.

The core members of the group have an extremely strong collective identity, described by Minu as ‘comrades in distress’ and expanded on by Padma, the group secretary, who told me simply, “...we had gone through all these pains and we

wanted to share the pain”. Likewise Sharanpal explained that at 48 she was ‘using medicine’, but at 52 she was ‘with the group’. The core members describe the group as a *parivār* (family) with one member even saying that while she can survive without eating, she cannot survive without ‘*Saheli* family’. The core members frequently spoke of female solidarity as “*bahut zarūrī hai*” (extremely important; necessary) and I witnessed this in moments of intimate friendship between women or whilst women moved expertly around each other’s kitchens as they prepared food – as Padma was keen to point out, they were all “comfortable” in each others homes.

The patients and post-cancer women in the group were extremely emphatic about the role of the core members. Acting as role models, women attested to the virtues of coming and seeing the joviality and vitality of the post-cancer members. Alka, a longstanding member of the group, had a recurrence of breast cancer a couple of years ago, six years after her initial diagnosis. Not only did she attest to the significance of seeing the other members who came to visit her in hospital after her first diagnosis, but her daughter also marvelled at the way the group had helped her mother. She told me that she remembers the first time her mother was diagnosed with breast cancer and all the relatives and friends came to the house to see her mother to tell her that she would be ok. However this was nothing compared to when the *Saheli* ladies came. She recalled how they were dressed “so nicely”; “looking normal, more than normal” she enthused. “After this she knew she could come out of it and become like them” she said. She then compared this to her mother’s relapse, when she considered her mother to be much more confident because of her participation in the group. About this she said, “She would put on compact [make up] and come out and meet friends”.

Alka elaborated on this herself during a group meeting. She explained how she felt hopeless and helpless, particularly highlighting that ‘society’ focuses on everything

the patient can- not do, while in the group they would always tell her what she could do. “*Oh my god cancer! Oh my god!*” exclaimed Alka as she described how others reacted to her illness, and she juxtaposed this with the group who had helped her to focus on herself in such a way that gave her strength and *himmat* (courage). Gesturing to the different women in the group, she explained how the different members had told her what they did to help them feel better, whether this was listen to music, draw, paint, or read books. For Alka what was most important for her recovery was being able to do things for her family. She said: “...that makes me, as well as my family, happy and I forget what are the wrong sides of this cancer... I hear all good things so I think all good things!... even though I couldn’t do many more things for my family, I could do at least one cup of tea which is very helpful for me and my family to keep my family happy. The first day I will only do a cup of tea. Second I will do a little bit, only rice. So with that I can get my confidence and I can look after my family very well; do the proper thing that I want to do for them all.” After she finished speaking, the group, who had perhaps heard this triumphant story many times before, started clapping and nodding in appreciation.

Clearly participation in the support group presents a novel space where patients can discuss cancer in a mild and calm atmosphere, and in doing so gain support through shared biomedical solidarity as women are learning from each other based on the direct experience of having suffered with the disease. At the same time, the group had also created a discursive space for the discussion and deliberation of wider gender predicaments that are perceived to play out in the lives of the core members in different ways, but connects them all through their entwinement with breast cancer. This is with specific reference to the ways breast cancer is conceived of as arising out of conditions of ‘mental tension’ particularly in relation to marital and familial

discord. Certainly not all the women considered breast cancer aetiology in this way, but it was something that was alluded to frequently and in turn contributed to a particular shared sentimentality among women in the group. In the following section I turn to explore the nature of this in some detail.

3.5 Gender and 'tension'

The concept of 'tension' was used to describe a range of contexts, problems and troubles that relate to 'restlessness' (*adhīrtā*) imbalance and stress. 'Tension' can arise from just stepping outside of your house: the crowds of people, the volumes of traffic, the noise, pollution and dirt. People are out to cheat you; you have to be very careful with your money. Tailors do not stitch on time; maids arrive to work late. At such a time when there are more and more material goods, desire increases. Where before one was happy to have earned 500 rupees, now if one is earning five lakh one is still not happy. People want and need more and more. The craving or feeling of *asakti*, of 'attachment' is everywhere. If someone has a two wheeler (a motorbike) they are not contented. They see others with a car and then decide they too must have a car. Therefore people work more, to earn more money, to buy more things, but this creates *chintā* (anxiety) that in turn leads to tension, specifically 'mental' tension and sadness which inevitably leads to suffering and *bīmāri* (illness).

Inside the house too there is the possibility of tension. Family food is made fresh every day, prepared in the morning for breakfast and lunch, so one has so much food to cook, followed by duties of housework. The demands of managing a household that women so often described, can be usefully thought of here as a female version of the

*grhasthya*⁵⁵ (the householder), whereby women's bodies constitute a cohesive nexus that cultivates and sustains intimate relations in the family. This involves the responsibility of ensuring the rightful passage and 'settling' of children as they move to adulthood: overseeing their education, ensuring study is completed and grades are achieved, feeding, caring and supporting ones husband, marrying off one's daughter into a good family, caring for aging parents-in-law, "doing" so much and keeping obligations to extended family members to name but a few. There may also be economic insecurity, with competing priorities within the family for resources and so the welfare of the family demands perennial surveillance. Furthermore, now that women are educated and working, this is also said to create tension as women must try to balance family life with that of life *bāhar* (outside).

For many of the post-cancer volunteers a particular source of stress is that of absent children and the simultaneous virtue and anguish of having children who lived away from home were often alluded to. As the volunteers would sit together engaging in general chitchat, much time was spent gossiping, assessing whether children had married into good families and lamenting the degeneration of family values and the wayward path of the young. Sometimes conversations turned to changes, especially for young girls who have nothing to do unlike themselves, who in their time and 'tradition' had so many responsibilities in the house. Such comments would elicit sighs, tuts and murmurs of "*what to do? What to do?*" Often these conversations turned to expressing concerns for those children who had managed to make the leap and study away from home, either in another Indian city or abroad. Whilst waiting for patients to arrive in the breast cancer clinic, a volunteer might bring out snacks – veg

⁵⁵This is the third stage of 4 traditional Hindu *asramas* (life cycles).

pizza and *pakora* – mentioning in passing with pride, that this one is the favourite of an absent *betā* (child). At the same time however, the absence of a child was conceived of as causing ambiguity concerning familial obligations and parents’ expectations of children in old age (see also Cohen 1998).

When I asked how it was possible for *bīmāri* (sickness / illness) to result from mental tension, my interlocutors (and not just those in *Saheli* but other volunteers and some doctors too) consistently pointed to an axiomatic non-dualism of mind and body. As introduced in chapter one, the body is considered to be composed of fluids, essences or humours that flow in a constant process of dynamic interaction (see Alter 1999). Therefore negative or positive thoughts (conscious or unconscious) contained in the mind will inevitably impact on the body. I was told that if one has a restless mind this will create ‘negative energies’ which in turn damages the body through ‘chemical’ changes that result in *bīmāri*. A *zakhm* (wound) will not heal as quickly if one is thinking negatively and medicine will not react with the body in a positive way. Conversely, positive thinking has an ameliorative affect on the body. Positive and negative energies or ‘waves’ can also be ‘thrown out’ by people and affect others by making them feel happy and good, or cause persons to become restless, sick and sad. States of restlessness are however considered to be more acute in the world today given that it is *kaliyug* and therefore delusions and ‘modern’ preoccupations with desires and attachments to material goods and gains leads to selfish action (*sakam karma*) and the consequent break down of systems of morality.

For example, Padma told me one morning that she had read in the newspaper the day before of a woman who gave birth to a baby but threw it away in a dustbin. She told me she could not sleep all night just thinking of that baby. “Nobody has *shanti* (peace) in the mind” she said. I asked for clarification about this and she told me it is because

people are 'restless'. I asked for an example of an everyday situation where one's mind can become restless like this, and Padma explained: "If by chance we get two rupees extra from the *sabzīwalla* (vegetable seller) we become restless because with god in our heart we know we have not done good and until we return those two rupees to him the next day, we won't have peace". It is from within this wider conceptualisation of temporal conditions of modernity and social change that 'tension' is being articulated as linked to breast cancer causality in specific ways by the post-cancer volunteers, who not only share in each other's pain of suffering with breast cancer, but also in domestic discontinuities that are perceived to create this very suffering in their lives in the first place.

3.6 Sentimental solidarities

Although some of the members of *Saheli* spoke fairly openly about their personal situations of domestic discontent, speaking 'badly' of the family was not something that was discussed easily in the 'official' monthly group meetings, and, throughout my fieldwork, I suspected many women did not want to speak negatively of family members, especially husbands. Sharanpal, one of *Saheli's* longstanding members, explained that it is difficult to coax women into sharing openly because they do not want to speak of these more 'shameful' matters in public. At one group meeting whilst we sat discussing the role of family support in recovering from breast cancer, and towards the end of many testimonies of "*pūra*" (complete / full) *parivār ki madad* (family support), Padma interjected and suggested to the group that they should also speak if they did not receive their family support. Whether this was the case or not, no one offered this information and the group remained silent. When I asked Padma and Sharanpal about this later, they said that women will not speak badly of the family in

the group. “They are ashamed to say it” said Sharanpal. “Maybe one on one they would”, she added and after a moment’s thought said, “I don’t know if this is good or bad”.

Outside of the group meetings, I collected many stories from different members of the group about their experience of breast cancer. These stories focused particularly on familial discord. One afternoon Padma and I were invited to lunch with some of the other members of *Saheli*. We arrived at Preeti’s house, and as we sat in the hall eating snacks she explained that her breast cancer was due to fifteen years of living under tension in the house of her *sas* (mother-in-law). During this time she was not allowed to see her own maternal family, had to work all day in the house and her financial spending was strictly controlled. Preeti explained that “nothing” (*kuch nahi*) was in her “hand” (*hath*) and it made her become “*pāgla*” (crazy). She could not argue nor could she say anything about this to her husband because it upset him. Speaking about her unhappiness and sense of personhood she said “*meri shādī ke bād ek dum se kam ho gayā*” (after marriage I literally became ‘much less’; narrower) and she drew her hands together as if cupping rice. Soon after her mother-in-law died, Preeti was diagnosed with breast cancer. She attributes this to living under so much tension. “*Impact tha*” (there was an impact) she said and raised both her eyebrows at me. The whirl of the pressure cooker started to whistle and as she got up to attend to it, Padma turned to me and asked me, “You must have noticed all these ladies saying this problem of tension *nah?*”

On another evening, Dulari a more recent member of the group, came to visit Padma, and we sat in the hall while she shared her experience of breast cancer. Dulari was diagnosed five years ago. She said she had neglected the *gārnth* (lump) she found because her son had his 12th standard exams, to which Padma, staring knowingly at

me interjected, “Typical Indian woman”. Dulari continued to explain how she had dizzy spells and had headaches on one side of her head only, and it was when this became unbearable that she decided to go and see her family doctor. At the time of her diagnosis, Dulari was also undergoing a divorce. She said she had no support from her mother-in-law and told me how ashamed she had felt at having to go to that house begging for money to pay for her medication. During this time, and indeed in the years leading up to it, she said she was under immense mental ‘tension’ and stress that was kept ‘*andar andar*’ (inside), which she demonstrated with her hands, pushing them down in front of her body. This is what she believes caused her breast cancer, living under such conditions for so many years when she could not speak out as she had to protect her sons. Again Padma interrupted and explained that marriage for Dulari was like a ‘punishment’ because her husband had abused her. However, she said more gently, this marital breakdown is her *prarabdha karma* (destiny; the ‘ready’ to experience karmas in this current life) to which Dulari agreed and explained that this has given rise to her *nasīb* (luck; fate) of suffering with breast cancer.

Dulari described Padma as like her ‘mother’, sometimes saying in fonder moments that she even went beyond the duty of a mother in the way she had supported Dulari throughout her recent struggles. Dulari said this was her only source of *sukoon* (relief) and since her recovery a few years ago she had become a committed member of the group. *Saheli* thus offers a forum for the discursive deliberation of gendered predicaments that are perhaps unable to be spoken of elsewhere (including the clinic where I was told some doctors are sceptical about the link between tension and cancer). By doing this, it appears to enable the cultivation of new relationships based upon a shared biological condition and thereby gives rise to intimate ties and

‘sentimental kin structures’ (Sharp 2006)⁵⁶ between different women who participate in the group as they become ‘like mothers’ to each other in their pursuits of well-being, however variously conceived, and creates a kind of sentimental solidarity. At the same time however some core members of the group, such as Padma, appear to have particularly strong ties to *Saheli* and as such the experience of breast cancer seems to be becoming more intricately woven into her own sense of personhood as she cultivates these new relations as part of a renewed and enduring sense of sociality.

3.7 *Belonging*

Padma was frequently the key pivot in fostering relationships with patients in the group. Notably many of the stories I heard were often co-authored by her, as she had been the patient’s guide during their illness. Padma appeared to be particularly attached to the group, perhaps more so than others, and had taken on her role there as secretary as a kind of crusade. When I went to visit *Saheli*, I would stay with Padma. She is a Maharashtrian Hindu, from a middle-class Brahmin background. Her family is originally from Bombay and she is the youngest of three sisters and a brother. After her marriage, she moved to a neighbouring town and her only child was born there soon after. Padma has a diploma in teaching and, before her husband’s death ten years ago, she gave tutorials to schoolchildren from her home. Otherwise she has been a

⁵⁶Lesley Sharp (2006) offers biosentimentality as an adaptation of ‘biosociality’ to describe the intimate ties between former strangers in the context of organ donation. According to Sharp, what emerges here is a strong sense of ‘sameness’ and emotion that turns on the uniqueness of the ability of organ transfer to transcend normative forms of human coupling where the notion of sameness is at once about shared human fragments and about sentimental kinship structures. This biosentimentality is particularly powerful, states Sharp, for those who desire communication to help quell the horrors of individual suffering.

housewife for most of her life. Padma was diagnosed with breast cancer in 1994 when she was forty years old. She also felt lumps in her breast, but like Dulari, because her son was in the 12th standard and about to take his exams, she ignored them for nine months. Even though they were painful, she suffered and waited until it was unbearable, and then she went to her doctor. Padma did not join *Saheli* until after the death of her husband in 2003 and has devoted herself to the group ever since, having aided hundreds of women through their treatment for breast cancer.

Padma's life course up until the time when I met her in 2010 had been turbulent. She described her life as marred by calamities. After the birth of her son, she had two miscarriages and was unable to conceive another child that she so desperately wanted. Her relationship with her husband had not been a happy one, and this deteriorated during her treatment for cancer. "I did not get my family support", she told me. "I can tell this to you now he [her husband] is no more". Although her husband had driven her to her appointments, waited while she took chemotherapy and paid for her medication as per his correct duties, it was subtler things that upset Padma. For example, she explained that he had been a heavy smoker, and during her treatment she had asked him to stop smoking, or at least not smoke near her because of her cancer. However, he replied indignantly, "*Joh Hogā dekha jaēgā* (we'll see what happens)". Her turbulent relationship with her husband was also exacerbated by extended periods of financial insecurity in the family, which she felt added to the stress and tension. She explained to me that 'no one' can live under such conditions for so long and therefore this caused chemical changes in her body and the emergence of breast cancer.

After she recovered from breast cancer she described her life as miserable. She felt panicked and thought about committing suicide. Relations with her husband did not

improve. She never divulged too much of the nature of these problems, just that she did not have the courage to defend herself, or say no. She described herself as being in a state of depression, which was then exacerbated after the sudden death of her husband from a heart attack. From this time onwards she has lived alone, although her son and daughter-in-law stayed with her for a few years until they took up work posts in another city. In this way Padma describes herself as '*akeli*' (alone). At this time, she had no idea how she would manage, and when I asked her about it, she still spoke about her self sufficiency with surprise and attributed it to her own will power, which at times she spoke about with pride. For example, not depending on her son in those years was an achievement in one sense as she told me "I am *akeli*; I can do by myself". Sometimes I heard her joke about living by her own 'law' in her house and this was often with the other members of the group who would lament the fact that they did not live under their own law, not with husbands, children and parents-in-law to take of. She also often pointed out to me when I stayed with her, that she did not have a helping hand (maid). I asked her if this was a good or a bad thing, and she said it was bad in one way because people would think that she was "below dignity" but then again it was all right because she did not think this, and considered it to be exemplary of her state of, albeit ambiguously, living alone.

It was only after joining *Saheli* that she started to gain confidence yet she continues to feel the ramifications of *akelīpan* (loneliness). Her work with *Saheli* however goes beyond that of many of the other members to become a way of life and is what Padma intends to do until the end of her life, which she has pinpointed as ending in five years' time. At near sixty she considers herself "ready to go" and told me often that she was waiting for "him" [god] to take her "up". As part of her activities with *Saheli*, Padma records the name and phone number of each woman who has ever passed

through her home in a worn notebook that she keeps by the phone. Each month she phones twenty-five women from the list categorically to see how they are. She frequently told me with pride that all patients love her and that if she is unable to attend a meeting then they will not come. She explained that many women who come to her for support for breast cancer, also share with her a ‘great many things’. She pointed to her rotund stomach, and holding it with one hand told me that it has become ‘swollen’ from taking in all the sorrow and pains of so many ladies. She laughed, and said she was like a ‘sad clown’: there to make others smile. At the same time however, Padma was proud of the many relations she had cultivated with women, and told me that the ladies referred to her as the ‘mother’ of the group and Minu as the ‘father’, given their respective tendencies as *bāvānik* (emotional; sentimental) and ‘practical’, thinking all the time. Minu agreed with this, and speaking of Padma’s pivotal role in the group, explained that patients ‘stick’ to Padma in ways that differ from other core members of the group.

This is reflected in their different styles of support where Minu and other strong minded members like Sharanpal tell women they have to stand on their own two feet during treatment, whereas Padma is more ‘coaxing’ with them and she lets them be dependent on her because she thinks this is what they need. Although Minu and Padma have their differences, which they acknowledged openly and jovially with each other, they were united in their belief that volunteers make patients feel more ‘comfortable’ by accompanying women to their hospital appointments, for example, in order to help the patient remember what questions to ask, or else they stay with them in hospital overnight after the operation. Padma would also call patients home to stay with her, which she told me was also to do the “brainwash”. While she said this in a joking manner, it is fair to say that the core members do feel as though they have

to work really hard to get women to care for themselves, and to take time out from family duties during their treatment for breast cancer, or else to persuade women that they can actually recover from cancer, and it is often away from the hysteria of the family that such support can take place. In this way, there is a proud acknowledgment of the work they do and Padma joked that patients would tell their husbands to stay home and instead call the volunteer for support at the hospital because it was said, in moments of gentle mischievousness, that wives do not ‘need’ their husbands anymore.

Padma grapples with the changes that have happened in her life and the feeling of *akelīpan* (loneliness) from which I think she seeks respite through her attachment to other post-cancer women, and thus through which she now comes to define much of her own personhood as the ‘mother’ of *Saheli* or a ‘*mātā*’ volunteer. In this way breast cancer ‘survivorship’ begins to emerge as an extremely important pivot around which much of Padma’s life revolves, as she told me, “breast cancer has given me so many things which otherwise were not possible in my life as a housewife”, the enduring ties and rich relationships she has formed as part of her work with *Saheli*.

3.8 Affiliation and survivorship

Recent studies have explored how patient mobilisation and forms of lay activism around novel biological conditions is giving rise to certain kinds of ‘biological’ identities and / or leading to the formation of variants of biosocial associational communities that in turn confront and contest state legislature, enact certain modes of citizenship and influence scientific research (Rabinow 1996; Petryna 2002; Rose & Novas 2005; Gibbon 2007; Gibbon & Novas 2008; Biehl 2007; Nguyen 2010). In relation to the voluntary groups in Bombay however, it would seem that many of the patients are not mobilising around the disease and likewise not seeking out forms of

belonging based upon breast cancer. The way in which breast cancer is seen to be experienced as a form of 'living death' makes dissociation from the disease through strategic acts of containment and concealment imperative (see also Bharadwaj 2008; Bharadwaj & Glasner 2009). In turn, this can sometimes make it incredibly difficult for many women even to share their disease within the domestic sphere and, as we have seen, subjects them to strategic manoeuvres of containment and concealment within the 'familial body'. At the same time however, by focusing on the interactions between patients and post-cancer volunteers, be them fleeting or otherwise, survivorship is operationalised by the post-cancer volunteers in moments of revelation and visual exchange as means to shock, awe and inspire. The post-cancer volunteer emerges here as a guru-like figure that turns on the invocation of 'seeing' as an act of *darśan* by which survivorship embodies the possibility for normal life within a paucity of hope. Where many patients are not seeking any notion of collective identity or group affiliation, be this in a support group or by joining groups such as the WCAI or the CC, the work of sharing and disease solidarity might be inherited through the more individualised and personalised visual interaction and exchange with the post-cancer volunteer.

At the same time however, in the specific sphere of the *Saheli* support group, there is a much stronger mobilisation of collectively shared identity as the group has opened up an available space to start to challenge, and thereby reconfigure structures of patient isolation, silence and invisibility (see also Klawiter 2000b). Even though much of what *Saheli* offers is based on association with breast cancer as a disease, and indeed emphasising the exceptionalism of surviving, they are simultaneously constantly working to move beyond it through appeals to their own 'normality'. On one of my last visits with *Saheli*, Minu had organised a small party for one of the

members whose son was getting married later that year. Sitting on the floor of her living room, having eaten south Indian snacks, singing songs and putting jasmine flowers in our hair, Sharanpal suddenly turned to me and pointing to the women surrounding her, said “You would never think we are the cancer patients?”

While shared disease affiliation is fundamental here these bonds appear to be created and intertwined with much wider constellations of gendered predicaments and familial discord that are perceived to criss-cross the lives of the core group members. Not only is this crucially given expression in the group, but it results in solidarities that are based on the formation of a biomedical kinship and relate to the sentimentality of suffering and everyday domestic politics than appeals to citizen claims or entitlements. This would also suggest a strong sense of belonging, especially for women such as Padma, and I attempt to build upon this further in chapter 5 by exploring the ways in which attachment to the relations espoused by the group become significant in her assessments of her own personal situation and cultivation of self in life post-cancer at the intersection of other post-cancer volunteers’ attempts to harness the self in particular ways.

CHAPTER 4

Reconfiguring gender and prioritising the self

This chapter addresses the role of gender in breast cancer charitable care and explores how gendered predicaments that arise out of suffering with breast cancer are being realigned and intertwined with more novel forms of health ‘responsibility’ and patterns of gendered ‘self-care’⁵⁷. More specifically it attempts to describe the ways in which the post-cancer volunteers are reconfiguring gendered notions of self-sacrifice and in turn, are circulating these novel notions as particular visions of what breast cancer survivorship could entail in relation to gendered wellbeing in life post-cancer.

Claims to the ‘neglectful’ Indian woman are a ubiquitous feature of public health discourses and practices of cancer detection, prevention and control, and it is frequently asserted that women are not making their health a priority and are putting themselves last in all matters relating to health through acts of familial and maternal self-sacrifice. While this is a predominant discourse within many of the cancer charities and medical communities, it is also one held by the post-cancer volunteers themselves, since many of them had the experience that suffering with breast cancer, like other women, instigated certain gendered predicaments. Here more established

⁵⁷Following others who explore modes of subject formation (for example see Mahmood 2005; Ecks 2004) I draw upon Michael Foucault’s notion of ‘care of the self’ and ethical subject formation as a way to capture the practices, techniques, and discourses through which a subject is given potential to transform herself in order to achieve a particular state of being, happiness or truth. Foucault states that concern with the self, and care of the self are required for the right conduct and proper practice of freedom that is not ascribed, but rather is brought about through active self-creation through practices of the self (see Foucault 1986; 1997).

forms of familial duty and obligation emerge in tension with the imperative to ‘do for the self’ in a more ‘singular’ way that at first glance appears ‘selfish’. In an attempt to capture something of this complexity, the chapter attends to the different ways patients, post-cancer women and the volunteers conceive of suffering as initiating certain dilemmas related to acts of self-sacrifice and responsibility in the family. The chapter hones in on the activities of the post-cancer volunteers in their interaction with patients to explore how such predicaments are negotiated, elaborated and reconfigured in particular ways. The discussion below speaks to various other arenas of anthropological inquiry that attend to the nature of women’s health, gendered politics and the biomedical encounter in India. These studies have provided rich accounts of women’s conceptualisations of their own health practices as they relate to wider kin relations and socio-economic structures that are often seen to impinge upon these experiences in various ways. At the same time, they also often call into question the authorising agents and biomedically defined interventions and increasingly institutionalised practices, by unearthing the multiple and complexly intertwined attitudes and motivations behind appeals to ‘good’ health (see Jeffery et al. 1989; Jeffery & Jeffery 1996; Ram 1998; Donner 2003; Van Hollen 2007; Pinto 2008a; 2008b).

In a similar vein, this chapter sets out to explore the nature of gendered predicaments that surround women’s experiences of health and wellbeing in the context of breast cancer, however the focus is less on the dynamics between biomedical intervention and policy ‘at the top’ with patient experience seen ‘from below’, and instead on questions of breast cancer suffering, health and well-being from the position of the post-cancer volunteers who continue to emerge as intermediaries, acting as medical brokers that navigate, translate and negotiate the confluence of different values,

aspirations and imperatives that coalesce around breast cancer in Bombay. More specifically, it attends to the way their own experience of suffering appears to give rise to the revelation of certain aspects of the self that have previously not been considered or deemed insignificant. In this way it explores the nature of breast cancer as an event that brings into light new sets of possibilities for ethical subject formation and self-care (see Humphrey 2008), and thus shows another, important dimension of the mediatory activities of the post-cancer volunteers and their associated groups.

From this perspective, the ethnography I discuss below also resonates with studies that have described the ‘feminisation’ of breast cancer activism and associated medical practice (Kaufert 1998; Hallowell 1999; Klawiter 2000a; Kolker 2004; Gibbon 2006; 2007; Kampriani 2009). Here gender and sexuality has become intimately bound up with wider social and cultural transformations, as breast cancer activists expressed a powerful articulation of rights and ‘resistance’ by demanding a reformulation of ‘disempowering’ health policy and contestations over the control of women’s bodies, which led to changes in the way oncology was practised⁵⁸. It also simultaneously raised questions of personal empowerment as being a ‘survivor’ was re-inscribed to form an empowering foundation for a new self (Lorde 1980; see also Kaufert 1998: 293). At the same time however, the breast cancer movement in the West also draws upon sometimes contradictory frames relating to gender equality, gender identity, sexuality and the family (Kolker 2004). Concerns about female nurturance and motherhood, which predominate in some ‘cultures of action’ that emphasise different ways breast cancer can be “enacted, enunciated, emoted and

⁵⁸This included changes to breast cancer treatment by advocating for a shift from radical mastectomy to breast conservation therapy and making women more inclusive as informed decision makers in their treatment plans (see Kaufert 1998).

embodied” related to varying ‘gender styles’ (see Klawiter 2000a: 64-67), are also reinforced through more ‘heteronormative’ ideologies such as ‘caring for others’ that are placed at the forefront of campaigning messages (Blackstone 2004; Saywell et al. 2000). In relation to health awareness, and specifically breast cancer genetic risk, it has been suggested that a ‘paradox’ of ‘awareness and care’ (Gibbon 2006) exists in tension between being an ‘anticipatory patient’ and ‘selves in relation’ (see Hallowell 1999). Here women attending the genetics clinic display a discourse of rights and morality of health awareness that powerfully informs their rationale for needing to go, while at the same time this is intertwined with a gendering of responsibility to inform others and manage risk as obligation towards them. In turn this leads to slippage or paradox between socially configured gendered rights as caring for oneself, and naturally perceived female desire to take care of and ensure the well-being of related others (see Hallowell 1999; Gibbon 2006).

The gendered predicaments of the Western breast cancer movement clearly resonate at times with the kind of issues that are emerging around breast cancer activism in Bombay. However the ways of becoming ‘visible’ in Bombay are subject to certain situated dynamics and tensions wherein claims to act towards the self in a novel way signal the emergence of a distinctive relationship or articulation of mode of subjectivity for the first time. Therefore, some of the voluntary groups in Bombay grapple with what are perceived to be stark discontinuities between ‘self-awareness’ and ‘care’ in relation to oncological practices that promote preventative health care and early detection where certain visions of ‘self awareness’ must be taught from the outset. Questions pertaining to public health and education in awareness are often conceived of as a particularly murky terrain of health politics (see for example Ram 1998; Pinto 2008a; 2008b). This chapter attempts to explore the ambiguity and

tensions that occupy this particular intersection of breast cancer suffering and charitable care, by touching upon the ways that gendered practices are being configured by the post-cancer volunteers at the interface with wider public health oncological discourses of health awareness and prevention that call for individuals to take responsibility for their own health. At the same time, while the experiences and activities of the post-cancer volunteers appear to emerge in accordance with such appeals, they also appear to be subject to complex negotiation and resignification, as more established modes of being 'responsible' are reinscribed in novel visions of self-care and gendered personhoods in distinct ways.

4.1 Neglectful bodies

In urban India, claims upon the self-sacrificial nature of women are ubiquitous and have become entangled with public health discourses and practices of cancer detection, prevention and control. In public health discourse among health professionals, this is conceived of as a problem of female 'neglect'. "They don't come", Sarojini told me. "And what we are finding is, it is more the educated ones who are not coming forward". I heard this so many times from frustrated doctors, nurses and NGO professionals in relation to different modalities of cancer management. For example, as I sat chatting with a doctor from the AICT cancer detection team, she told me about a recent breast cancer screening camp she had attended in Rajasthan. Speaking of the women she had met there, she said, "[that] trip was an eye opener. Women with lumps the size of tennis balls and don't even seem bothered". She had asked one woman why she had not sought medical attention for weeping welts on her breast sooner, and the woman had replied that she had been busy with her daughter's childbirth. While this doctor was perhaps more apathetic

than others, this allusion of hers to neglectful practices of women has in some sense become canonical.

In the public health discourses, these difficulties or health ‘behaviours’ are connected to the intertwining of various issues such as pervasive conservative ‘cultural’ factors, a persistence of patriarchal values in Indian society and also socio-economic structures, all of which together or in varying combinations, are perceived to impinge upon women’s health. This is sometimes framed as a problem of ‘male preference’ or gender bias within the family because the male is usually the breadwinner and the head of household and therefore his health care remains a priority, especially if economic resources are scarce. A social worker at the BCH commented on this with me when she recalled how during her twenty-seven years of service she had noticed this gender bias whereby, while treatment was ensured for male members of the family, once families came to understand the scale of cancer treatment, the female patients would just ‘disappear’.

At the same time however, public health discourses around breast cancer prevention and early detection call attention to the inadequacies of women as not attending to their health through appeals to gender and as an orientation of the woman herself. Among the health professionals I knew, there is certainly a sense of understanding towards these gendered practices. For example, while it frustrated Sarojini that women don’t come to have regular breast and smear tests, she readily acknowledged that eating after your husband is, in her own words, “like brownie points”, as she remarked to me that she had seen her mother do it. Likewise members of *Saheli* frequently lamented their failed awareness programmes with me, and joked with each other that, when they held ‘special’ events with a free lunch and prominent speakers, all the women would come dressed in their saris as if for a marriage ceremony, but

when it was a normal programme for teaching breast self examination for example, the room was always empty. Often they targeted schools and noted that frequently it was the men who came up to them afterwards thanking them for making them aware, saying they would take this message home to their wives, mothers and sisters. Another prominent breast cancer advocate explained that even after giving out free tickets for mammograms at the BCH during an awareness drive, not one single woman decided to take advantage of that offer and come.

I often accompanied different groups on their expeditions to give breast cancer awareness lectures all over the city. One afternoon in particular, I was accompanying two volunteers to Mulund in the suburbs of the city to give an awareness talk to women in a neighbourhood that was hosted by a branch of the Rotary Club of India. We arrived late afternoon to an empty hall with 100 red plastic chairs lined up in rows. Twenty minutes after the start time no ladies had arrived. One of the volunteers' tutted and explained it was because it was the day of *Karva Chauth*: a particular festival when wives worship the moon, perform *puja* and fast for the safety and longevity of their husbands. "That is why no one is coming" she said. Another twenty minutes later, after the Rotary club administrator had presumably done some running around behind the scenes, he ushered in a group of eight ladies who walked sheepishly into the hall.

In my interviews with patients and post-cancer women of all socio-economic backgrounds, nowhere did I find women who were not concerned about their own health, or illness and disease. The women I met in the government hospitals, for example, who had come to Bombay from the surrounding rural areas, contrary to what some professionals believed within the NGO circles, did in fact seek medical attention after discovering a lump, and they did so (perhaps controversially for some)

at the point where they could no longer work because pain persisted, they felt dizzy, weak and tired. However part of the reason they ended up receiving treatment in the city, perhaps a year or so after they first felt unwell, is because women such as Darshana (discussed in chapter 1) are not being correctly diagnosed at the local or even regional level. The rate at which I was told that misdiagnoses occurred, which prompted the hard struggle to access correct oncological treatment, was startling. However the situation is clearly more complex than this as while structural factors might impinge upon purported modes of ‘access’ and ‘availability’, and certainly economic factors certainly shape the way medical decisions will be made and the degree to which appeals to claims will be heard within the wider collective of the family, the issue also revolves around a tension in the way ‘health’ is conceived of in the first place. Frequently women spoke about their own health needs as the needs of others, whether there was money to realise those needs or not. I met women taking treatment in government hospitals, for example, whose family welfare was directly dependent on their ability to work (and indeed in some cases they were the earning members of the family), and they were eager to return home and resume their role there. Securing one’s own health here is important insofar as it exists to ensure the health of others. A similar principle underlines the health seeking behaviour of middle-class patients and volunteers. Here economic constraint was a less critical factor but still important nonetheless (see below). Also anxieties were clearly articulated as concerning conventions of modesty and complexes of visibility that give rise to shame and also fear. Feeling ‘shy’, as Rajeswari’s diagnosis story revealed (see chapter 3), also results in extreme discomfort in speaking about the breast, and reticence to show oneself to a doctor, especially if he is male.

In addition to this, it is also sometimes the case that obtaining medical attention for oneself was reached through the work of caring for others. Prema for example, could not tell me why she delayed going to a doctor after she had initially felt that small lump. She had felt something like a small boil above her left breast quite high up near the collarbone. It wasn't painful but she could feel it when she rolled her fingers over it and gradually it got a little bigger. She decided to mention it to her travel companion, a doctor with whom she used to sit on the train in the morning to work, and she suggested that Prema go and have it checked out with her family doctor. But nervous and seemingly in such good health otherwise, she did not do anything about it. Then heavy monsoon rains caused her daughter to develop blisters where her shoe straps rubbed against her feet as she waded through mucky water and these had become infected. Prema insisted she see a doctor, and to encourage her to go, Prema told her that she also wanted to show herself to the doctor, therefore they should go together, and she would then just mention the lump in passing. Recalling her actions, Prema told me she should have gone earlier because she had no idea it could be something as grave as cancer, but at no point did she believe she was neglecting herself. While she readily acknowledged that many women are not prioritised within Indian families, or even under-value themselves, she did not think this applied to her own situation. "I do for my family because I want to" she had told me.

The perceived self-sacrificial nature of women has certainly impacted the nature of care delivery by the patient groups. In the municipal hospitals, the volunteers from the WCAI give out free packets of Tamoxifen; however Rajeswari soon realised that women were taking this free medication and selling it to earn extra money for the family. Therefore WCAI started a policy whereby, in order to get their next packet of pills, women had to bring back their punched out empty pill packets. This she

explained was because a woman never thinks of herself. She said “first the child, then husband, therefore no medication! ...Fighting for survival women will always sacrifice her needs for the child and husband, even if he is beating and drinking”. At the same time, this perception of women also appears to be framing public health discourses on healthy citizenship whereby health professionals perceive education and awareness as key modalities to educate women of all socio-economic class about preventative health care practices, and as such they are encouraged to take ‘control’ of and care for their bodies by practising vigilance and engaging in novel bodily techniques such as breast self examination (BSE). This is part of a wider initiative undertaken by state preventative oncology departments that along with NGOs (many of whom practice independently of state institutions and conduct their own awareness programmes) seek to change the “mindset” of Indians with regard to cancer as a disease, which includes its stigma and fear, but also renew health practices more generally, by disseminating novel preventative health care practices that encourage persons to act in accordance with notions of health ‘risk’ and modify ‘faulty’ lifestyle behaviours.

‘Awareness’ therefore emerges as a central construct in the framing of the healthy Indian citizen and as such speaks to other public health campaigns in India, particularly those related to maternal and child health where ‘awareness’ and more specifically ‘non compliance’ are viewed ambiguously as something achieved or, in the case of the latter, overturned through educating women to ‘desire’ and ‘demand’. In turn this transforms persons into certain ‘moral’ subjects from within certain regimes of knowledge and power that can serve to reinforce embedded cultural

stereotypes rather than ameliorate women's health⁵⁹ (see Ram 1998b; Pinto 2008a; 2008b). The context of breast cancer, while it is notably different from maternal and child health, and the underlying 'morality' of health awareness that I encountered here in relation to gender is perhaps less rigid and more sympathetic, given the emotive nature of cancer as disease, than that which has been encountered elsewhere in India (see for example Pinto 2008a: 172-3). The problem of teaching breast cancer awareness still speaks to certain stereotypes of the "uneducated" and "educated" woman, for while it is considered that the 'uneducated' woman does not 'know any better' the 'educated' woman certainly *should* know better⁶⁰. The latter view is however something the post-cancer volunteers openly discuss in relation to their own experiences of breast cancer, and as will become apparent it is linked to a particular set of concerns towards not only their health practices but also wider conceptualisations of gendered personhoods and wellbeing within the family (see also chapters 3 and 5). For example, many of the members of *Saheli* told me that they delayed seeking medical attention after the discovery of a lump in their breast. Various reasons were offered for this, from having relatives to stay to a marriage in the family, or they had to attend to children's studies for important school exams and therefore a view of '*bād me bād me bād me*' (later) was adopted. Now, however, they try to encourage other women like themselves to come forward sooner. About this issue Minu, the President of *Saheli* said, "Unless someone is pushing her – her

⁵⁹For example, in rural India complex reluctances to see the doctor, bound up as they are with certain kinds of 'visibilities' regarding modesty, shame and fear, are often perceived as signs of ignorance or 'blind belief' because they fail to measure up to particular visions of medical knowledge (see Pinto 2008:172-3; Ram 1998b).

⁶⁰I say this with regard to the specific context of the city where urban women's health, and more specifically middle-class urban women's health, speaks to a completely different set of issues and is located within different kinds of health structures than the specific predicaments faced by women in rural areas. The interaction between rural women and oncology public health campaigns is something that requires further research.

husband, her mother – she will refuse to go. On her own she won't go. Like that only". I asked her if that is because of the fear of cancer that everyone speaks of and she replied, "Acchā scared but more the son and the husband. She is looking for her family and not for me". Therefore in life post-cancer such delaying practices are conceived of regretfully and are given as a reason why women should no longer neglect their own health and should prioritise the self in certain ways. This appears to signal the novel reconfiguration of gender in relation to biological conditions and appears to be becoming entangled with a more contemporary 'regime of the self' (Rose and Novas 2005). But rather than have an 'individualising' imperative (Rose & Novas 2005: 445), the kind of relations implicated in suffering and healing from breast cancer in Bombay reveal a potentially different set of concerns.

4.2 Dilemmas of self-sacrifice

As we have seen elsewhere in the thesis, the 'familial body' is the pivotal axis of many middle-class women's lives. Women described themselves proudly as 'keepers' of the house and as fundamentally 'attached' to children through emotional bonds of *sevābhāv* (service of love and care). The cultivation of family relations, particularly through acts of obligation and ties of 'attachment' were foregrounded in accounts of gendered livelihoods and thus notions and cultivating relations of obligation, duty and sacrifice can be perceived as key modalities through which gendered well-being is often sought and fulfilled⁶¹ (see also Donner 2008; Van Hollen 2007; Thapan 2009;

⁶¹These authors have described the various ways through which such notions and practices remain pertinent for Indian women today. For example, Celia Van Hollen (2007) describing the choices that HIV+ women in South India make regarding pregnancy and abortion of potentially infected children finds that the strong cultural imperative to be a mother influenced above all else women's choices not to abort their foetus but rather risk the birth of an infected child. This is articulated as a need not primarily for herself, but for her husband and his family. Furthermore Henrike Donner's (2008) ethnography of social change and mothering in urban

1997; Lamb 2000; Jeffery & Jeffery 1996). The emphasis on self-sacrifice is also resonant with older Hindu ideologies such as *pativrata* (taking a vow of devotion to a husband) dictated in the laws of *Manu* where motherhood is propounded as “compulsion without option” and a ‘good’ woman is one who “pleases her husband and gives birth to male children” (see Battaccharji 1990: 51). This is considered to be particularly salient for middle-class notions of femininity in India today as remnants of a post-colonial legacy that shaped gender in distinctive ways⁶² have produced particular visions of what a virtuous yet ‘modern’ Indian woman should aspire to achieve (see Sangari & Vaid 1990; Sunder Rajan 1993; Thapan 2009).

In my interviews and conversations with patients and post-cancer women, I learned about the ways in which suffering with breast cancer completely disrupted the flows of obligation and care within the family. While these experiences were described in myriad ways that were specific to each woman’s particular circumstances, they did point to a particular gendered moral predicament that revolves around differently elaborated versions of the tension between wanting ‘do’ for others such as the

Calcutta, finds that, although modernisation and globalisation have shifted and transformed mothering practices, women’s education, marriages and professional careers are still “arranged and represented in relation to the female role of a mother” that revolves around food and providing for the family and continues to be positively valued where mothers sacrifice their own needs in favour of children. In this way it has widely noted that a woman’s personhood is made and remade over critical junctures throughout her life through her ties to significant others at birth, marriage, childbirth and also widowhood (see Jeffery & Jeffery 1996; Lamb 2000).

⁶²Post-colonial nationalist discourses are perceived to have recast womanhood as a metonym for Indian ‘tradition’ whereby womanhood became the custodian of India’s spiritual essence through her association with the domestic sphere, family and spirituality that was seen to be in jeopardy from Westernism and the colonial legacy (Chatterjee 1993). In this way it has been claimed that the ‘vedic superwoman’, the “chaste virgin, pure and faithful wife, the all giving mother” (McMillin 2002:20) became responsible for birthing and raising the citizens of the modern nation (see also Sangari & Vaid 1990; Sakar 2001)

husband and children and having suddenly to 'do' for the self. Time and time again, women foregrounded these tensions in their descriptions as a primary source of their distress (see also chapter 1) and / or impetus for recovery. Sometimes this was apparent through different acts intended to protect and restore the familial body: active self-denial in order to maintain family security by not speaking openly of the pain within the family, refusal to lie down and take rest, keeping children or parents-in-law in ignorance about the disease and even refusing treatment.

This was the case with Sonali. At first she did not want treatment. She thought that cancer patients did not survive and that the treatment was painful. Also, the doctor had told her she would not live for more than three years and she felt it was an injustice and unfair for her husband to live with an incomplete woman. Therefore she thought it was better that she should die and then her husband could get re-married. She recalled her thoughts at the time, that, "One has to die one day. We come to this world, we leave this world. There is no point in living and dying so I just thought peace". Sonali considered that her diagnosis of breast cancer would disrupt her familial relations in such a way that her own death would protect her husband and thus save the family from having to live with her shame. Her family tried to force her to take treatment, telling her for their sake she must do it, and her husband had told her it was the duty of every 'human' to try and live 'until the last breath' and he did not want to live with the regret that, had she taken treatment, she would have survived.

The consequent appeals to live 'for the family' weighed on Sonali's mind, but she was not reconciled to them until one night she had a vision of the Lord Hanuman⁶³.

⁶³Hanuman is a Hindu deity.

She was surprised because she hardly went to the temple, rarely performed *puja* (ritual prayers) and just had a “lucky life”. However, when she was diagnosed she thought it was punishment from god for the sin of precisely not performing *puja*. So she started to pray, but not so that she would live. Rather she prayed for peace. Then in her vision, Lord Hanuman stood with her for three hours, consoling her and telling her that she would live and she should have faith in him for she would not die. From that day onward, she had thoughts in her mind that she would not die. She had come to understand that this was her share of sorrow and therefore she must accept it because god had never given her any difficulty in her life otherwise. Sonali’s will to live was thus not only contingent upon the well-being of others, but her ability to accept and act upon this contingency was enabled by a spiritual vision and revelation of her own religiosity. The actual deliberation between life and death was played out through intimate others and became the very edifice through which she had to try to live. In retrospect, she said. “I have a loving family so it was very difficult to die...”

At the same time however, women also articulated surprise and gratitude to find reversals in the flow of care whilst they were ill. Women recounted happily how *chāy* (tea) was suddenly being made for them and cooling buttermilk brought to them prepared specially by daughters-in-laws to quell nausea and the ‘heat’ of chemotherapy. Prema remarked exactly this to me when she explained that now, when she looked back to the time of her treatment, she actually enjoyed suddenly being the centre of attention because she had her family fawning on her and her husband asking her what she needed. But she described this as strange because normally she said, in “Indian families nobody is asking her ‘*kyā chāhie?*’ (What do you want; need). Very often these acts of care served as additional confirmation of the ties of familial reciprocity and intimate connectivity through which women then

spoke of their own strength and will to survive, as they reiterated how much they wanted to do for their families in life post-cancer, to make everyone happy and to work even harder so that they could provide more for their children.

While I frequently heard about the significance of family support in this way, I also was told about circumstances when support was not given. Stories were often told amongst the volunteers of friends, aunties and cousins who did not receive what they considered to be satisfactory family support, or of women who were abandoned by their families, left at the doors of the Bombay Cancer Hospital to fend for themselves. I also knew women who had particularly difficult relations within their joint families during breast cancer, and one who went through a divorce at the same time as her treatment. One post-cancer woman, Vasha, explained to me that her husband's family abandoned her after her husband's death. Her husband died when their daughter was two years old and her parents-in-law told her that they could no longer look after her and she had to leave the house. They also took her only vital assets – her wedding jewellery – and said they could not give her any money or land because since Vasha did not have a son, there would be no way of returning this back to them later in life through expected forms of familial *sevā*. When Vasha was later diagnosed with cancer the presumed transactions of care and financial security that she would have been entitled to were instead painfully absent and she struggled through her treatment with aid from various charitable trusts.

In other circumstances, the family was certainly present, but it was often the case that competing priorities within the joint family for the distribution and purchase of financial resources made some women feel devalued. Divya, a housewife who had just finished her treatment for breast cancer, explained to me that, during her treatment, her needs were devalued within the wider family as competing priorities

and louder claims to resources from her mother-in-law and brother-in-law were outweighing her own. Divya had heard from a friend that wheat grass juice would aid her health during her treatment from chemotherapy and therefore she asked her mother-in-law if she could have it in the house. Then her mother-in-law started to plant the wheat grass because she thought everyone in the house should have it, which included Divya's father-in-law, brother-in-law and his wife. However over some time, there was not enough to go around and Divya was beginning to miss out and felt hurt that the care had not been taken to ensure she had her juice because she was the one that was suffering with a disease. She described this feeling as a kind of 'mental torture' by her mother-in-law as her expectations of being cared for in a certain way, which centred on reciprocity and transactions of resources within the family, that were themselves supposed to be constituted out of love and compassion, were not met. Further to this, Divya felt she could not express her hurt about the situation, as even within her "own family" (her husband and two daughters) as Divya described it, she found that her angry, emotional voice was misconstrued as a demanding and selfish voice, which was heard by her husband as criticism of him and his care towards her.

In these situations, where these presumed transactions of familial care had gone awry and women felt they did not receive family support in the way they might have hoped for, it was through the reiteration of such unexpected absences that the significance of familial connectivity was continually affirmed. For even while the middle-class family emerges as a site of both fulfilment as well as disenchantment, what is clear in many women's accounts (of which few spoke so candidly as Divya) is that the healing of breast cancer also occurs in some sense at the level of the familial body; healing puts the family back together again however difficult that may be. At the

same however, other striking appeals of recovery are also heard about the need to prioritise the self in a way that was previously not considered or deemed insignificant. This is mainly from the post-cancer volunteers (but by no means only⁶⁴) as they often spoke about this in lesser or larger degrees in relation to their own lives. In what follows I explore how similar dilemmas of self-sacrifice are not only at the fore of suffering and healing, but also appear to reveal certain latencies that result in reconfiguration of gendered subjectivities.

4.3 Recovery and self-priority

Deepti, a post-cancer volunteer, was diagnosed with breast cancer in 1986 at the young age of 34 when she lived in a joint family of twenty. As she was the wife of the eldest son, she felt the responsibility of the entire household fell upon her. When she became sick, she felt she could not manage this responsibility; she felt guilty and nervous about the ramifications of this within the family. However at the same time, she realised that, although she was suddenly not able to act in her customary way, while this was difficult and traumatic, the family did not fall apart. In fact her parents had supported her very well, her husband too, with whom she said she had a good relationship, as well as with her children, who although they were “so small” handled her illness relatively well. By becoming ill, a space had shifted wherein flows of familial obligation were channelled back towards her.

In Deepti’s narrative of her experience however, always doing for others was now framed as a criticism of the fact that she thought Indian women were taken for

⁶⁴I spoke with many women, of varying backgrounds, who told me about the need to look after their health post-cancer in different ways, of whom Divya is one. However I restrict my discussion to the post-cancer volunteers because my research was predominantly focused on their experiences and how this in turn relates to forms of breast cancer activism.

granted and she explained that as daughter-in-law, wife and mother, “people don’t think they are separate and don’t give priority to themselves”. Paradoxically, because of suffering with breast cancer, certain latencies had been revealed, for once Deepti had started to recover she realised that she could do certain things for herself and this was distinct from doing something “forced” on her by others. This new perception of herself was described through a language of priority, responsibility and obligation; these were very same qualities that underpin and constitute the other kinds of relationships that made up her sense of personhood, and she now spoke about them in relation to her own health as something that she needed to care for, by taking rest or eating good fruits and vegetables, practicing yoga and meditation, alongside the wider project of caring for her family. Deepti emphasised this point in particular as she explained that giving priority to the self is important so that you can help others. Otherwise she said, “What is the use of you?”

Jyoti also experienced suffering with breast cancer as a particular tension related to relations of obligation. She did not live in a joint household but frequently had her parent-in-laws and relatives staying with her for extended periods of time whenever they needed help and support from her. Speaking about her life before cancer she told me quite clearly that her health had not been a priority for her. She described to me how she took charge for everybody’s health in the family, whether they lived in her house or not, and pointed out that this was normal for many Indian women. Jyoti’s fear of having cancer and the possibility of dying that it presented was experienced as a concern for her family. She said she felt guilty for having fallen sick with such a terrible illness and that she would potentially leave her family, not having settled her children. She grappled especially with how her illness was impacting on her family, anxieties which manifested in a contradiction in which she was suddenly required to

self-prioritise and be cared for. The ensuing tension was problematic and she recalled an example from her experience of chemotherapy. It was during her 5th cycle, which was particularly bad because she had a fever and was vomiting violently. The nurses had told her she would have to stay in the hospital over night because she was too ill to go home. Her husband was sitting outside waiting for her and she had said to the nurse that she wanted to go home and refused to stay in the hospital. The nurses insisted that they had strict instructions from the doctor but Jyoti persisted, and instead asked to speak with the doctor because she wanted to go home. Eventually they relented and she was allowed to leave. Commenting about this in retrospect, she said that she did not want to be away from her son any longer nor did she want her husband to be sitting up all night so it was just better for everyone if she was at home.

However once she entered into remission, she started to feel that she should focus on caring for herself more. She described breast cancer retrospectively and paradoxically as a 'respite' from her life because it gave her the opportunity to change things in herself, even if this was just changing her responses by saying 'no' and thinking of herself in a singular way some of the time. For example, she would no longer wait up for the family so they could eat together. She said, "If I was hungry I would eat". Or if she liked something, she would no longer save the best portion for her husband or children, but would cut herself a share, she would include herself. Likewise if she felt tired, she would not exhaust herself by waiting up for her husband to come home from work.

At the same time however, while she recognised the importance of acknowledging her own singularity within her familial ties and attachments, she was not divorced from her wider responsibilities and obligations. As she explained, when it came to her daughter she still had to do everything for her and this relationship could never be

subordinated to her own, new relationship to herself as prioritised. This was not least because caring for herself in this way was considered to be 'selfish'. The concern with selfishness is widely spoken about by many of the post-cancer volunteers who describe it as being too aware of oneself, being someone who appears to be always 'looking' at themselves and these qualities are not considered to be virtuous. Sometimes they spoke of these qualities as American, for example, when they saw people on the television that 'talk' about themselves and their emotions all the time. Jyoti even commented to me once that she had read in the newspaper that, 'to be healthy you have to be selfish' and she thought this was true because to be healthy, one has to have a certain 'mental frame' of looking at oneself the whole time.

Arguably, the experience of the longevity of the illness and prolonged treatment results in complex conditions whereby not being able to care, or fulfil quotidian obligations and duties creates certain anxieties and fears in women. However in the process of recovery, this experience also appears to have revealed a latency concerning notions of responsibility and duty. For if breast cancer is experienced by women as a potential 'separation' from the familial body, as a moral push and pull or tussle of trying to maintain flows of obligation and responsibility within the family whilst ill, for some this tension actually revealed the possibility that, as Deepti claims, women can be 'separate' and that the family will still in some sense remain 'whole'. In life post-cancer this possibility leads to women feeling as though they can cut fruit for the children and include a share for themselves; not just eat family leftovers; wear a Punjabi suit and not a sari; say no to unnecessary shopping trips with extended family members; take a rest or just ask for help without feeling guilty (see also

Donner 2008⁶⁵). ‘Doing’ and ‘giving’ for others therefore now includes the work of attending to relation to the self as one of many other relations at hand, and cultivating this in a separate but still relationally encompassed way; for it is ultimately conceived of as for the well-being of intimate familial others. Thus while breast cancer appears to engender the need to ‘self-prioritise’, this is reconfigured so that ‘doing for others’ becomes doing for the self in order *to* do for others.

4.4 Circulating self-care

The voluntary groups devote a lot of attention to trying to raise awareness about breast cancer signs and symptoms and encouraging preventative health practices which have also amalgamated into particular visions of survivorship. Firstly, recovery from breast cancer is considered to be a positive opportunity or possibility for change and this is becoming synonymous with appeals to self-prioritise. This is given expression in novel practices of ‘self-care’; the practices that in life before breast cancer were crucially not considered important or even recognised. Interestingly, this was often spoken about in terms of Indian women being able to now ‘see’ themselves. There is a general idea within the voluntary groups that women have suffered with breast cancer precisely because they have *not* taken care of their own health in the past, for example by not eating properly, by taking tension on behalf of others or by being stoic and suppressing their emotions (see chapter 3). Now however, survival from breast cancer is conceptualised as a positive possibility for women to attempt to single out or cultivate the self with priority that in turn enables them ultimately to become better wives and mothers. As Maitreyi, a post-cancer

⁶⁵Donner has also noted that where women’s roles revolve around food and providing for her family and they might be ‘constrained’ within the home through expectations to wear a sari or not eat meat for example, it is not surprising that the way in which they decide to affect change is by allowing oneself to eat first (2008: 181).

volunteer with *Saheli* put it, “If you are a survivor then you can look after your family for better things. You don’t forget you are the cancer patient, obviously you haven’t taken care of your health which is why the cancer reached you, but now also you have to realise you have to take care of yourself, that is much more important now. So many neglected their own health!” Speaking about different scenarios that women find themselves in on a daily basis she continued, “She has to do many things in the house but her health should be top priority so if you feel tired and today there is a function, don’t do much work. Keep your health in mind; top priority so that if you survive you can do anything! If you don’t survive what is the use?”

Many of the activities of the post-cancer volunteers are therefore directed towards encouraging women to reconceptualise relations of obligation, given particular tensions concerning self-sacrificial practices that emerge through the experience of breast cancer. This was something Lata, a long-standing post-cancer volunteer, also felt extremely passionate about. While she acknowledged the difficulty women face in overcoming an illness that is experienced as death itself, she was also attentive to the fact that such anxieties also concerned, as she put it, “Indian women taking everything less”. She told me that women would ‘*humesha degi*’ (always will give) or *tyāg karnā* (sacrifice; dedicate) for the family. But, she pointed out, “What about ‘*degi*’ for me?” Having spent years listening to patients agonise over familial obligations and refuse medical care, as well as trying to practice exactly what she herself preached (see chapter 5), Lata had developed a particular perspective concerning gendered predicaments that arise from the trauma of suffering with breast cancer.

I spoke about this issue with Lata frequently, especially the issue of selfishness. Lata would tell me the same story again and again of the woman whom she had met many

years earlier who had accused Lata of trying to make her 'selfish'. This woman had brought her child out of school to travel to Bombay with her while she was undergoing her treatment. The woman was worrying for the child so much that Lata had told her that perhaps it would have been better to keep the child in school and come to Bombay without her so she could focus on taking treatment and getting better, whilst her child would perhaps be better off staying in school and being with relatives there. Lata recalled how the woman was astonished at this suggestion and had said that Lata was suggesting she become *svārthī* (selfish). However Lata had pointed out that this was not selfish. It was in fact the exact opposite, because she needed to be in Bombay to get better, and that by focusing on herself in this way she would recover and be there for many years with her daughter, who simultaneously, would do better in school because she had been kept in education during the months of treatment which minimised the disruption to her. She then gave her another example of how to act upon this. Lata told her that that one might want to do things for the self, to relax and take care, but these things should be done in such a way that they incorporated others. The example she gave was painting. If a mother paints, the child will also paint and therefore this activity, while it is initially for the mother, will also benefit the child, so ultimately the act, while it might appear self-centred and even selfish, is relationally derived. It is duty.

These kinds of obligatory anxieties were also voiced in the post-operative classes at the BCH where, one morning in particular, Prema spent some time talking to a patient who had undergone a mastectomy the day before. Prema was suggesting she stay in Bombay for just a couple more days to recover before going back to her village because her body needed rest. However this woman was determined to leave that day, she had, in fact, already changed out of the mandatory hospital pyjamas into her sari.

She said her husband had broken his hip some days earlier and now had a problem with his kidneys so she wanted to go. Afterwards I asked Prema if she thought she would stay, but Prema shrugged her shoulders and explained that of course it would be better for her to stay and rest so that she could be more use when she returned home, but she wanted to go now, so what to do?

There were also situations where a woman might refuse to take chemotherapy because of the expense and cost to the family. Lata described this to me one morning after her rounds in a private hospital ward. She had been called in to see a woman who did not want to take chemotherapy because she wanted to save the money for her young daughter's education. This choice was being made against the wishes of her family members who, along with the doctor and Lata, were trying to reason with her and explain that by taking the medication and spending the money she was in actual fact "doing it for her family". As Lata explained to me later, she had told this woman that she must "spend for yourself so you have to be there to help them, guide them to be independent so that they can make ten lakhs themselves".

The volunteers who worked in the CC were also keen exponents of 'self care', and as they guided women through the practicalities of managing the ramifications of cancer in their lives, they would also try and ease women's fears and offer them ways in which to accept their situations or make choices that would be satisfactory to them and their families. Often they used light humour whilst also being careful to make a special comment about family support, of husbands who were caring and understanding, and of sons and daughters who had accompanied their mother to appointments, complimenting the woman on the attentiveness of her children.

One Tuesday morning at the cancer rehabilitation clinic, a middle-class woman, who was starting chemotherapy, had come along to the clinic to purchase a prosthesis that the doctor had mentioned to her. She came in the room alone, having left her son waiting outside while she tried the prosthesis. She was in good spirits and spoke at length with the volunteers. While a volunteer jotted down her details and filled in the necessary paperwork on her medical file, the woman started to explain that she was worried that, after chemotherapy, she wouldn't be able to do her daily cooking, prepare the evening meal which she liked to do and that her family was accustomed to. Her husband was a fussy eater, she explained. She and the volunteer bemoaned the role of being a wife, of having to make the perfect tasty meal for their husbands, "Good for them but bad for us", joked the woman. They both laughed and then, in a more serious tone, the volunteer told her to get one of the family members to help her cook because she should stay away from these chores during chemotherapy as she might feel unwell or the heat from the cooking fire would be uncomfortable on her scars. Instead, the volunteer suggested she write a cookery book and did something of interest to her but then finished by pointing to the closed door and said "But look at your support" indicating her son waiting for her and sitting outside, "That's the jewel in your crown".

Clearly the volunteer's encouragement that this patient write a cookery book, take rest and relax, goes some way to validate and therefore relieve her anxiety about what this woman perceived to be an ambiguous alteration of responsibilities brought about by the onset of illness. Yet this encouragement and validation is circumscribed within the wider framework of having 'good' family support as, although it was readily acknowledged that everyday family life was subject to various contestations, disputes

and often skewed relations of power, the sanctity of the family was ultimately reinforced and preserved.

On another occasion, Jyoti was sitting with a patient. It was a particularly busy day and there was a lot of commotion in room 19. The nurse was opening and closing cupboard doors, pulling out plastic bags and taking note of stock, while the volunteers next door kept running back and forth for different pieces of paper and different size prostheses. All this while a woman sat with her husband. Jyoti was asking her about family life. The woman explained that they lived in a joint family of eight and she was a housewife. Then she asks Jyoti what the symptoms of breast cancer were. Jyoti responded, “Why now you ask this question?” and the woman explained that she was worried that the cancer was going to return. Jyoti said she must do breast self-examination and went on to explain the procedure using her hand on herself, demonstrating the movement, “*Dekho, thorā-sā padding karo*” (look, do a little padding). The woman seemed satisfied by the demonstration, but still looked dejected and worried so Jyoti tried again to abate her fears. “I also have a problem like you”, she said and continued, “you have to be positive, you have to live, you have two small kids. Pray to God for strength to fight”. She went on to explain that it was not so good to be home all these days, just sitting there and thinking. “Don’t think all the time on these things”, said Jyoti trying to reassure her and asked if there was a computer at home. “Yes”, the husband replied, “but she does not know how to use it.” Jyoti clapped her hands, “You will show her how to use it. It is not good for her to be in the house with all these things in her mind”.

In the previous excerpts the volunteers were trying to encourage women to take care of themselves as they tried to recover from breast cancer, and did so through the suggestion of ‘acting’ upon the self via the recognition of this self as still sacrificial to

those intimate familial others. The volunteers gave out this kind of advice frequently, as they encouraged women to engage in activities for the sake of the wider prerogative of cultivating self as familial care. This included going for walks, practising yoga or meditation, spending time reading, singing, listening, or playing music. However I also noticed that practices around the breast prosthesis, by both patients and post-cancer volunteers, spoke to the reconfiguration of gendered sacrificial practices in particularly interesting ways.

4.5 The breast prosthesis

The loss of the breast seemed to be something that must be hidden. This was sometimes connected to the fact that cancer necessitated a fine balance of concealment and containment of the disease, both inside and out of the family home in order to obfuscate social judgement and avoid ostracization (see chapter 1), but also spoke to cultural mandates of modesty and shame for the breast is not something easily spoken about⁶⁶. Feeling ‘shy’, as Rajeswari’s diagnosis story demonstrated (see chapter 2), results in extreme discomfort in speaking about the breast, and reticence to show oneself to a doctor, especially if they are male. Furthermore women would say that they did not look at their bodies, never stood naked in front of a mirror as one might see in the “foreign” movies. Sometimes women explained that it was particularly difficult to speak about this topic openly in the family, especially if there were sons in the house. Even in the intimate spaces of the CC and the AICT support group, there was often an awkward atmosphere when mastectomy was spoken about;

⁶⁶It is noted more generally that Hindu femininity and the female body are constructed and experienced through complex oscillations of norms of purity and pollution that play out in women’s lives within the kin group. For example, menstruation is often surrounded by silence and taboo, and women’s ‘sexualised’ bodies are experienced as a source of shame (see Das 1988; Thapan 2009).

the conversations were stilted and women quiet even after sons and husbands had been sent out of the room. However, there was in some sense no time for being awkward here, as women were ushered behind the curtain and instructed to “*ūpar karo*” (lift up) their *kurti* or open their sari blouse, and the volunteers would giggle with each other about the discomfort of husbands who looked the other way while the volunteers spread out the mastectomy bras on the table.

That being said, even in more private conversations with patients and post-cancer women, I encountered what seemed to be a slight indifference towards mastectomy, as the breast was frequently objectified, described as an ‘organ’ that simply fulfilled a function. Having finished nursing babies many years previously, many women told me that they did not ‘need’ it anymore, questioned its ‘use’ and said they were happy to live without it. More often than not, I found this was expressed most strongly in relation to the fact of survival itself; the loss of a breast was deemed inconsequential when life itself was at stake. Or else the loss of the breast as an organ was compared to other amputated limbs which were much more difficult to live without. Frequently, I was told about moments where women saw a person without a leg or an arm in the BCH, after which there was a realisation that actually this was a much worse situation and they subsequently positioned themselves as ‘lucky’. During AICT’s first support group meeting, a post-cancer woman who had a bilateral mastectomy explained to the group that she did not wear prostheses. She said, “The only thing I thought was thank god it is in the breast. It is a part that I can live without”. However this did not mean that women did not discuss the breast as related to a loss of femininity, as one woman explained to me during an interview: “*Main ek aurat ki khubsurati khone ke baad adhoora mahsoos karti hun*” (I feel incomplete with the ‘woman’s beauty’ gone).

This ambiguity around the female body in relation to mastectomy is also brought to light through practices around reconstruction. Throughout my time in the field, I only met one woman who had chosen to have a reconstruction, and she had to struggle with her family to allow her to go through with it. It is considered to be a very novel practice, not only among patients, but also the doctors, especially the older and more conventional ones who, according to the volunteers, are not really recommending it. In my interviews and conversations with volunteers, patients and post-cancer women the message was very clear; women do not perceive this as necessary and have no desire to undergo another surgery. Furthermore, the operation is very expensive so it is only available to middle to upper class women, and even they do not consider it as something worth spending such a vast amount of money on.

Most women opt to wear the breast prosthesis instead (see also chapter 3). Among the post-cancer volunteers the prosthesis is considered to be essential for patient 'rehabilitation'. Rajeswari explained to me her frustrations over the price of the prosthesis because she thought they should be provided free of charge, but because the government considered them to be 'cosmetic', women had to pay for them. About this she said, "It is also for rehabilitation, the weight issue and important for women to get back into society. They should have concessions. Just as you want a leg you want a breast! Get back into society as a normal human being".

All the volunteers therefore encouraged the use of the breast prosthesis, and they did so for particular reasons. It was often frowned upon if women did not wear the prosthesis and they did all they could to ensure women managed to use something, giving them discounts wherever possible (which were often from their own pockets), teaching them how to stitch their own bras to accommodate the prosthesis and avoid spending the extra 150 rupees on a pocketed bra or even providing them with a

second hand prosthesis. In this way, although the prosthesis was considered uncomfortable and an encumbrance to the women, whom I heard complaining that it moved, itched or sweated in the heat, the post-cancer volunteers looked upon it for the most part positively because they considered it part of rehabilitating patients back into ‘society’. Rather than eclipsing some aspect of feminine identity or negating subjectivity⁶⁷ (see Lorde 1980; Kaufert 1998), the prosthesis worked in part actively to enable it. I explore this further below as I attempt to trace the complexities of visibility in relation to bodies and disease, but also in relation to ‘seeing’ selves and self-prioritisation in particular ways within the voluntary groups.

In Anupama and Prema’s classes at the BCH, often the first thing they would tell women is that now it was time for women to “*Driving seat kijīe*” (be in the driving seat). Standing in front of a group of women and their husbands one morning, Anupama explained that first women should look after themselves because they will always ‘give for their families’ (*aurat apne parivar ke liye humesha degi*). She went on to say that there was nothing wrong with this but ‘*āpne body par dhyān do*’ (attention should be given to your own body) so that in turn, women could ultimately take care of the family. Again she would explain that they should rest between household chores, and even joked with husbands about the need for a division of labour, instructing women to ‘*ek roti kam bannāo*’ (literally ‘make one less bread’). She would also always emphasise the use of the prosthesis. During a post-operative

⁶⁷Rather than become eclipsed by the identity of a breast cancer patient by wearing the prosthesis, Audrey Lorde chose not to wear it as an act of defiance and resistance. She claimed that, “prosthesis offers the empty comfort of “nobody will know the difference”. But it is that very difference which I wish to affirm...women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness. By accepting the mask of prosthesis, one-breasted women proclaim ourselves as insufficient, dependent upon pretence. We reinforce our own isolation...from each other, as well as the false complacency of society which would rather not face the results of its own insanities” (Lorde 1980: 62).

class at the BCH, a woman put up her hand and explained that her daughter was getting married soon and she was worried and unsure about what to do, because on such an auspicious occasion with relatives and friends, she would not be looking ‘good’ (*acchā*). Anupama, understanding that this was in reference to the mastectomy, started to explain about the availability of the breast prosthesis. She opened up a box and took out the silicone implant to show the women. After explaining how women could use the breast prosthesis, she emphasised, “It’s not about someone seeing you, it’s about your body!” She went on to explain the issue of having equal body weight and that more than anything the prosthesis is a physical necessity for the body to be ‘equal’ and have balance (*dono side equal honē ke lie aur balance karna parēgā*). The medicalisation of prosthesis is important, and was often alluded to because it is perceived by the volunteers as a way to validate the use of the prosthesis. By couching the necessity of the prosthesis in more medicinal terms, Anupama reinforced the message that women needed to be engaging in practices of self-care, of which the prosthesis was but one important part.

Just as this woman had asked in the class about wearing the prosthesis for a wedding ceremony, so many other patients frequently came to the CC to ask for a prosthesis with their concern placed squarely on the need to look ‘good’ to the ‘outside’ in order to preserve and protect kinship ties in the ‘inside’. In this way, the prosthesis emerged as particularly salient in strategically hiding bodily deformity and thereby effacing a surgical procedure that would otherwise induce questioning and in turn a declaration of having suffered with breast cancer. At the same time however volunteers were also aware of the importance of looking ‘normal’ to ensure that nobody in the community or within the household would notice a difference in women’s bodies. This was especially significant where women have not informed members of their family that

they are suffering with breast cancer, for as we have seen, this is part of the work of managing and containing the disease. Therefore while the prosthesis was described as something necessary for individual health, looking 'good' was also often located in a wider nexus of negating the view of others. It is unquestioned that women need to wear something in order to step outside the house. One morning, when after fitting a patient for a prosthesis, the volunteer asked the woman if she was having any tension. The woman said she was worried about going back home to her town because she had not told her family about her breast cancer; only her husband knew. Her father-in-law died of cancer and therefore she was worried to tell, especially her mother-in-law who, she feared, would become very agitated. She had told her children she had jaundice to explain why she had been away for two months but now she had to go back. She wanted to tell them but did not know how whether they would be able to withstand the shock. The volunteer interrupted at this point and said, 'You must tell or they just hear it elsewhere'. The woman nodded and said the problem back home was that no one knew anything so everyone would think she was dying and how would this impact on her children? She emphasised that she was less afraid of 'everyone' and more concerned for the welfare of her family, especially her mother-in-law. The volunteer responded by saying that when she told her children she must not cry. "You must look positive, find positivity in your inner self and this will come through and they will see that". The woman agreed and said that this was why it was so important that she went back "looking so good". She repeated it again, and the volunteer, a survivor herself, as she parcelled up the bra and cotton prosthesis, told her that "we want to give you strength", and smiling at her complimented her that now she was 'looking very nice' she need not worry anymore.

Here, the woman's anxiety about revealing breast cancer to family continues to illustrate how the need to look 'good' to the outside is instantiated by wearing the prosthesis that also enables the preservation and protection of kinship ties in the familial 'inside'. In these instances the prosthesis is therefore mobilised as a means of 'staging for others' to ensure the well-being of a self that is embedded within the flows and transactions of the 'familial body'. For frequently it seemed that 'being seen' often took precedence over seeing oneself. The emphasis on looking 'good' as being 'normal' was mobilised in the volunteers' discourse of the necessity of the prosthesis and was often appealed to through demonstrations of their own achievements of successful concealment. Sometimes post-cancer volunteers asked women to guess which one had 'gone' and when the patient could not tell, everyone in the room would praise the role of the prosthesis in achieving or reinstating 'normal' corporeality. Sometimes the patient might even have asked hesitantly if they could see or feel the volunteer's chest in order to believe that these women really were previous cancer patients like themselves.

At the same time, the prosthesis was also operationalised as a means of teasing out a space for the very acknowledgment of a more singular mode of subjectivity that could be acted upon, even though this mode of self-care was usually circumscribed within a wider project of self-prioritisation as caring for others and protecting the welfare of the family. While patients were keen to wear the breast prosthesis, sometimes women were reluctant to buy it once hearing the price; a reflex that was consistently explained by the volunteers as reluctance to spend on one's self. Like Anupama, the volunteers in the CC would also try and persuade women to buy and use a prosthesis, if not the silicone one, then at least the much more affordable Indian cotton one. Using a different strategy from Anupama, Jyoti would often compare the prosthesis to

jewellery. Women would come into the clinic, often shy and awkward, and the volunteers would brashly pull out the prototype prostheses from their boxes, handling them expertly, showing how they fit into the special bras, all the while explaining that this is “*bohat zarūrī hai*” (very important/ necessary), and always pointing to the silicone one to emphasise that this one is the better design and therefore makes women feel more confident. During one such session, when the patient had disappeared behind the curtain to fit the prosthesis, Jyoti turned to me and explained that the prosthesis is “like jewellery for them” and therefore something important to be worn on a daily basis. The comparison to jewellery connects the prosthesis to ideas of beautification and femininity. Jewellery has particular significance for Indian women, the necklace of black and gold (the *mangalsutra*), as well as green glass bangles and vermilion dusted in the middle parting of the hair, are all worn as signifiers of marital status, and the comparison constituted another innovative way through which the volunteers encouraged women to conceive of their own health and bodies as something distinct and important. Even when women would come in and ask for the silicone prosthesis and after trying it on and deciding it looked good, they would often not buy it after taking the price into consideration. Sometimes, women would explain that they would come back for it, but the volunteers, well-used to the fact that women rarely did, often pushed further and spoke from their own experience of how the silicone one sat better, did not move and stayed straight. Or else they suggested saving some money, keeping 500 rupees (roughly £7) aside a month so that in 6 months there would be enough money available to buy one.

4.6 Survivorship and the reconfiguration of gender

This chapter has attempted to describe the initial practices of the post-cancer volunteers as they mobilise around novel configurations of gendered notions of self-sacrifice. In doing so they appeal to the recognition and enactment of a novel singular relation of self-prioritisation that, previously considered unimportant, is deemed to be an essential addition to gendered livelihoods in life post-cancer. Perceiving of breast cancer in this way emerges from many of the post-cancer volunteers' own experiences of suffering with the disease whereby being ill disrupts the flows of familial attachments and manifests as a kind of 'separation' or 'stretching' of relations within the familial body (see also chapter one). While this is painful and distressing, for some women this can also reveal certain latencies in life post-cancer concerning relations of obligations and the nature of familial transaction. In turn, breast cancer is experienced as an event through which one can 'see' the self in a refracted sense, as a certain kind of subject in a new light, or even for the first time. Therefore, rather than focus on the fear and pain of breast cancer, the post-cancer volunteers are instead encouraging the virtues of reconceptualising suffering as a positive opportunity to harness more singular forms of well-being through novel practices of self-care.

This would also seem to suggest a 'feminisation' of breast cancer in urban India wherein notions and practices of gender are being realigned in novel and / or competing ways as self-care is deemed necessary whilst also simultaneously conceived of as selfish. The negation of certain aspects related to suffering with breast cancer, such as refusing treatment, worrying for others, or not wearing the

prosthesis, is considered to be part of the work of interfamilial modes of ‘biomoral’ self-sacrifice⁶⁸ (see Cohen 2001) and enacted for the sake of securing the livelihood of others. This is however becoming reconfigured so that those very same livelihoods are sustained through the addition of another mode of obligation: one that flows towards a more ‘singular’ modality of self that at the same time remains embedded in the flows and attachments of the family.

This raises important questions about the nature of changing attitudes and practices towards health citizenship and notions of gendered responsibility in urban India today. It would seem that public health discourses around oncology, prevention and treatment are moving towards the renewal of health practices in ways that promote the autonomy of a more ‘individualised’ responsibility to care and take control of one’s health. These are clearly becoming intimately intertwined with notions of breast cancer survivorship in distinct ways as recovery from breast cancer by the post-cancer volunteers reveal certain latencies concerning gendered livelihoods within the family that in turn is giving rise to the reconfiguration of gendered notions of self-sacrifice. Recovering from breast cancer can reveal the possibility to cultivate the self as embedded in flows and transactions of the family but also through another more singular relation of priority or duty to the self.

While this might seem congruent with novel appeals to changing notions of health responsibilities, this chapter has sought to explore the ways this appears to emerge

⁶⁸This resonates with Lawrence Cohen’s (2001) discussion of the ways in which kidney transplantation and donation within the family has become a means of reanimating conventional kinship structures and dependencies in order to sustain the family unit. Surgical transplantation is seen to revive the faltering bonds within the middle-class family by re-establishing the familial order of ‘giving’ that has been eroded by selfish, Western modernity.

through complex engagements between the different aspirations and imperatives that exist within the cancer communities in Bombay, and as such are leading to the reconfiguration of established practices and principles concerning health, personhood, the body and modes of interfamilial obligation in novel ways. This speaks to other studies that find gendered predicaments concerning practices of self-cultivation arise in conjunction with older forms of 'identification' as the family remains at the heart of middle-class modernities (Donner 2008; Van Hollen 2007; Thapan 2009). At the same time however, as this chapter has tried to show, this is still subject to pragmatic negotiation by women who grapple with the enactment of different modalities of responsibility within certain frames of possibility that are made available to them.

This chapter has thus sought to describe another dimension of the post-cancer volunteers' mobilisation around their biological condition in specific relation to survivorship where novel patterns of self-care and 'regimes of self' (Rose & Novas 2005) that are being circulated to other patients suffering with the disease as particular visions of gendered modernities. This continues to reveal the post-cancer volunteers as intermediaries as they mediate the powerful intersection where the biomedical clinic and its wider framework of public health imperatives that demand vigilance and responsibility meet with the patients themselves who grapple with particular dilemmas of suffering and fears of being 'selfish' as they attempt to live with and manage the disease in their lives. In this context in particular they appear to work as 'exemplars'; those persons who enable a discursive space for the deliberation of morality and ideals where individuality may be explored and the sense of self's moral being enhanced (Humphrey 2007:43).

The post-cancer volunteers in Bombay thus appear to offer a vision of breast cancer survivorship as a possibility to harness a particular kind of agency; a way of doing for

the self that emerges here as a novel relation of singularity that can be harnessed as one of many relationships already at hand, and like those very relations, is underpinned by principles of obligation, sacrifice and duty. As will become apparent (see chapter 5), the actual ways in which the post-cancer volunteers set about actively cultivating and acting upon such changes in their lives, while remaining welded to principles and practices of self-sacrifice, shift to focus on particular pragmatically defined quests for Hindu self-enlightenment that in turn raise important questions about the nature of breast cancer survivorship as a novel mode for potential identification and belonging among the post-cancer volunteers.

CHAPTER 5

Harnessing the self

*For those whose ignorance of the self has been destroyed by knowledge,
Their knowledge is like the sun,
Flooding the highest reality with light.*

Bhagavad Gita (chapter 5:16)

Within the voluntary groups, breast cancer survivorship is becoming ‘feminised’ in a broad sense as specifically gendered notions of self-sacrifice are being reconfigured so that other women might act towards themselves with a sense of duty and priority that in turn enables them to cultivate their many other relationships in the proper and desired way. Therefore recovery from breast cancer is articulated as an opportunity for positive change via the promotion of novel forms of self-care through which to cultivate gendered personhoods in a mode of singularity that is related to changing notions of self-sacrifice within the family (see chapter 4). In this chapter, the focus shifts away from the intersection of post-cancer volunteers with patients to explore in further detail the post-cancer volunteers’ individual experiences of recovering from breast cancer and living in remission. Many of these women speak about themselves in life post-cancer as ‘better’, ‘transformed’, ‘new’ or ‘happier’, and view breast cancer retrospectively with gratitude and a degree of surprising serenity. This chapter sets out to explore this further by attending to the post-cancer volunteers’ attempts, and in some cases their struggle, to harness the self through a more singular mode of subjectivity as part of a wider renewal of gendered livelihoods in life post-cancer.

The chapter continues to invoke the notion of breast cancer as an ‘event’ whereby suffering and survival can be seen to create a break with the past and re-jig earlier bodies of knowledge so that, emerging in a particular light, they reveal novel ways by which to conceive of the self as a more singular ‘subject’ (see Humphrey 2008). The acknowledgement of the pain and suffering of breast cancer, and also the way this is, in some cases, linked to the profound disappointment at the failure for everyday relations within the family to perhaps work as they should, appears to compel the simultaneous need to reanimate the purpose of one’s life and pursue self-knowledge through a process of disengagement that is markedly different to life before breast cancer. These self-cultivations still turn on the fundamentality of selflessness and notions of self-sacrifice as modalities through which to ‘see’ the self and do for others (see chapter 4). However, in the specific instances I will describe below, it appears that these cultivations are harnessed through the separation or detachment from relationships in order to attempt to establish a more singular mode of subjectivity or agency (see also Pederson 2012; Venkatesan nd; Empson 2011; Desai 2010). Rather than being focused on cultivating the self as embedded in many relationships, the post-cancer volunteers now appear to be concerned only with harnessing one: a relationship to *bhagwān* (god) and the *ātman* (soul).

In trying to capture the ways in which breast cancer recovery instigates particular processes of self-realisation in a singular mode, the chapter draws from recent studies of Hindu devotional sects in India (Venkatesan nd; Desai 2010). Soumyha Venkatesan (nd) has recently described how persons who consider themselves as Sivanadiyar (slaves of Siva) in Tamilnadu, voluntarily submit their lives to Siva in acts of loving devotion in order to realise the full capacity of the *ātman* and achieve liberation from the cycle of birth and rebirth. Becoming Sivanadiyar requires the

reconceptualisation of notions of obligation and changing the nature of relations with themselves. This is achieved by becoming ‘inwardly focused’ by harnessing attachment to Siva by devoting themselves and all things to Siva, but this also requires cultivating ‘engaged detachment’ from everything else in their lives as other relations become epiphenomenal. Venkatesan thus states that this leads to “intensive work on aspects of the self – cultivating some, such as deep contemplative understanding, and controlling others, such as mind and the ego” (nd:14).

In a similar vein, Amit Desai has explored how persons who have been victims of mysterious malignant attacks or suffering, join a religious sect whereby ‘participating in god’ requires a process of transformation that involves ruptures in relationships and re-evaluations of the notion of responsibility. Acceptance into the sect entails learning new forms of management, where one is no longer dependent on others but suffering is seen as one’s own failure to keep promises made to *bhagwān* (god). This entails transforming the nature of responsibility into one relationship with god and cultivating their agency through this proper relationship with god alone, and denying access to other forms of sociality. Desai therefore suggests that it is through ‘participation in god’ that “we might witness forms of agency, harnessed in a particular fashion in different forms of Hindu devotion” (2010: 315).

In what follows, the notion of cultivating ‘proper’ relations through the qualification of one’s actions, and separating oneself from relations as a particular articulation of subjectivity in specific contexts, emerges as especially salient in the post-cancer volunteers attempt to harness a more singular mode of selfhood. Even though what my interlocutors describe might seem reminiscent of conversion, these women are not ‘converting’ in any formal sense to religious sects nor are they becoming *sannyāsin* (a renouncer). In fact many of them do not consider themselves to be overtly ‘religious’.

The majority of these women maintain a deeply contemplative but non-ceremonial version of Hinduism. Very few attend the temple regularly, however many attend regular classes to listen to the spiritual discourses of the Bhagavad Gita⁶⁹, particularly those of the teachings of Swami Parthasarathy⁷⁰, and many appreciate various ‘neo-spiritual’ thinkers from Deepak Chopra to the much more established gurus such as Swami Vivekananda, Krishnamurti and Buddha. I found they would pick and choose which parts of Hindu philosophy they subscribed to, and how they interpreted them⁷¹. However, what is perhaps most significant is the fact that, while they recognised and worshipped various deities, they frequently emphasised the fact that ultimately ‘*bhagwān ek hai*’ (god is one). Therefore women frequently spoke about god in a more personalised form as *bhagwān* or as Ishvara (‘Lord’), the form that god takes when one tries to reach Brahman in this world through the mind. Indeed what emerges as significant in these women’s lives is not so much an organised religious practice by which to worship *bhagwān*, but the cultivation of novel ascetically inspired practices of ethical self-care that are directed towards liberating the *ātman* (soul; absolute self) from the cycles of birth and re-birth.

⁶⁹Meaning ‘song of the Lord’, the *Gita* is part of the great Sanskrit epic, the Mahabharata. It has variegated meanings and manifold interpretations, but essentially it is an example of how one should perform dutiful action and negotiate karmic morality and offers a way in which one can escape the bonds of karmic action, by acting without regard for the consequences by offering the fruits of all action as sacrifice to Lord Krishna who is revealed to be omnipotent. The story is dramatised through the protagonist Arjuna and his dialogue with Lord Krishna that takes place on the battlefield, as two armies, the Pandavas and the Kauravas, prepare for war.

⁷⁰Swami Parthasarathy is a contemporary exponent of Vedanta and its practical application in life with a particular focus on the principle of service and selfless giving. Vedanta, meaning ‘end of knowledge’ is associated with the Upanishads, a collection of philosophical texts that revolve around the interrelation of *Brahman* and *ātman*.

⁷¹This heterogeneity that I encountered is potentially reflective of the fact that Hinduism consists of a ‘family of features’ such as primacy of the Vedas, belief in karma, re-birth, destiny and worship of certain deities that are differentially shared by people who identify themselves as Hindu and therefore are to some extent subject to personal contingency given one’s life trajectory (see Barret 2008: 11; Sen 1961).

What is particularly striking about these cultivations is that their virtues are often spoken of in relation to specifically gendered predicaments that arise out of, or become more acute through, suffering with breast cancer. As previously discussed, many post-cancer women consider breast cancer to be caused by ‘tension’ resulting from anxiety-ridden conditions of marital discord or family unrest (see chapter 3). In life post-cancer, some of the volunteers are innovatively attempting to address such conditions in their own lives, and in doing so offer alternative visions of self-care to each other as ways to manage everyday relations within the family and enable women to act upon a relation of self-prioritisation. I learned that, on a more general day-to-day interaction with patients, the post-cancer volunteers are not necessarily advocating these visions of self-care. As Lata informed me, she only told women how she tried to cultivate such changes, if she thought they were ‘ready to listen’. This was not because of some sense of moral superiority; rather I think this came from a sense of respect that, as I was told, ‘each one is different’ and therefore reflects a wider philosophy whereby persons follow whichever path is ‘true’ for them.

This chapter thus attempts to give a description of the nature of these cultivations through the experiences of three post-cancer women: Prema, Lata and Padma. Not only did I find their articulations of self-cultivation particularly fascinating, as I came to learn about the symbiotic nature of suffering and well-being, but they also reveal yet another significant layer of the complex and multifaceted forms of breast cancer survivorship in India. In what follows, the post-cancer volunteers’ attempts to cultivate the self manifest in varied and sometimes painful struggles to manage relations and transactions of obligation and duty expected within the ‘familial body’, but in doing so, particular forms of gendered personhood are seen to be harnessed through the cultivation of ‘proper’ relations that are grounded in notions of duty, *sevā*

and *nishkam karma* (selfless action with no attachment to the fruits of the action). Finally, the concluding part of the chapter explores the way in which ‘self’ and ‘care’, that emerge as inextricably tied together through certain kinds of action, has further implications concerning the notion of biosociality in the relation to the activist practices of the post-cancer volunteers.

5.1 Breast cancer as ‘boon’

Many of the post-cancer volunteers conceive of suffering with breast cancer as a ‘jolt’, ‘boon’ or ‘gift’ from god and thereby consider the illness as a kind of teacher or ‘guru’ from which they must now learn and evolve. This is how Prema conceived of her experience with breast cancer. Prema was born in Uttar Pradesh where she spent her childhood until she moved to Delhi to pursue her post-graduation studies. She was married in 1982 when she was 25, after which she moved to Bombay where she had her first, and only child, nine months later. While her child grew up, she was a housewife, after which she decided to take a job as a clerk in the bank where her husband worked. She was 52 when I met her in March 2009. We would spend time together, sitting on the floor in her bedroom, the only room with an AC fan that she would switch on in the hot afternoons, and we would look through her bookshelf while she instructed me on which books I should read and readily encouraged me to borrow anything I pleased. Prema thoroughly enjoyed reading Hindu scriptures and the work of modern day gurus such as Deepak Chopra. While she did not go to ‘listen’ to these discourses, she was always avidly reading, and occasionally enjoyed watching various ‘guru’ channels on the television be these Hindu swamis or Christian preachers on the ‘god’ channel. Prema did not go to temple and she did not perform household *puja* save for the incense sticks that she burned each morning for a

moment of quiet reflection. Her parents had not engaged in religious ritual either, and likewise Prema and her husband did not raise their daughter to practice religion in this way. In the past eight years since Prema was diagnosed she has made some changes to her life. She has stopped working as the clerk in the bank and has dedicated herself to volunteering for cancer patients.

Although Prema considered the possibility that breast cancer could be a punishment from God for a *pāp* or sin, or karmic retribution from a previous life, she reasoned with this notion by explaining that because one could not remember what one did in a past life, and that she had only knowingly acted well in this life, there was therefore, no point taking tension on something we could never know. She said, “I believe whatever god does is good for us in some way. I may or may not be able to see it but god has a plan and whatever comes my way I must accept it... to that extent when I got cancer I didn’t think I had been punished by god... I don’t think god is like that. But there is such a thing, here is a path, a destiny, something will happen, something that has to happen will happen... This is my karma, my evolution... it will go on happening. Something I do has some consequence but I don’t like to look at the consequences as god’s punishment....” Prema thus believed one should accept one’s fate and disentangled herself from the moral underpinnings of cancer as *pāp* (sin) and instead perceived her disease with gratitude.

This gratitude was partly to *bhagwān* for having given her the disease and not her husband or child, and she explained she would not have been able to cope if it had been her child or husband. She told me “I can live with my own thing, okay, *challo* it’s me. I don’t think I could bear to see my husband or child suffering. So... if it had to be somebody, it’s ok”. At the same time this gratitude was directed to the way her life was before breast cancer where she considered life had been chaotic and hurried,

everything happening '*jaldī se jaldī se*' (quickly). She did not like working in the bank and considered everything to have been flowing on the 'surface'. Suffering with breast cancer was therefore less about doing something wrong, more about learning how to live correctly within a divine plan. She considered that god had given her eight years after that initial jolt in order to give her time to make amends. In this time, she had come to realise that it was not the occurrence of suffering itself that was important, the event of cancer as 'good' or 'bad', but rather how she 'took' it. While god gave her breast cancer for a reason, he also afforded her the choice to accept it 'happily' or not accept it at all and 'go down'. She told me repeatedly that she chose to accept everything that destiny threw at her because it was her due and god's work was always for the best (even if at the time we could not realise this). In this sense god's timing was always perfect.

It is in this way that Prema considered her survival from breast cancer as an event of self-awakening from which a different sense of self emerged. She now considered herself to be a better person and that the experience enabled her to do things for herself such as give more time to herself, stop working and care for her family more. In order to do these things, she was trying to now harness a novel sense of selfhood by focusing on a relationship to the *ātman* (the absolute self). In Hindu ontology there are different scales of existence; the body, mind, intellect and finally the *ātman* (soul), which is a state of bliss that has achieved wholeness or oneness with *brahman* as 'pure consciousness'. All persons have a soul (*ātman*), but it is trapped in the 'visible' world muddled and marred by constant activity and confusion of worldly attachment and illusion (*maya*) as it continues to pass through cycles of rebirth (*samsara*). In this way persons come into the world bound by their actions, that owing to their ignorance gives rise to the conceit of 'I-ness' - the ego or mind- as persons consider themselves

to be the 'doer' and become attached to objects and actions which in turn gives rise to desires (good and bad). The *ātman* passes through successive cycles of rebirth with each subsequent existence determined by the consequences of previous actions (*karma*). The aim is to break free of these cycles to realise pure consciousness. This is very much in keeping with the Brahmanic Upanishadic philosophy whose main message is the identity of the *ātman* with *brahman* (pure consciousness) and realising *moksha* (liberation). Realising this non-dualistic nature of reality can be achieved through different paths, one of which is through *karma yog*: disciplined selfless action that requires renunciation of all worldly attachments (usually undertaken in the last stage of life). Here persons try to remove themselves from any transactional action by engaging only in selfless deeds that have no desire (good or bad) attached to the *phul* (fruits) of their actions and thereby attempt to attain soteriological benefits and eventually break free of karmic cycles.

When Prema spoke of changes she had made to her life, she emphasised the way she was trying to detach from the 'material' world from which she would not take anything with her into her next life. The spiritual rewards of such cultivations she told me were thus not for 'one' life, but rather for life as a whole continuum as it evolves through the cycles of birth and re-birth. She considered evolution necessary and part of her duty as a 'human' was to try to change her natural state, to work from 'spirit' as she sought self-enlightenment. In order to do this, Prema had to separate, distance and detach herself from her relations to others by performing giving without expecting to be gratified. This included giving to 'humanity' as she put it, through acts of *sevā* such as her work as a volunteer. Yet crucially Prema must remain engaged in those very attachments, such as being a wife and mother, not least because she considered it her *dharma* (duty) but also this was what she wanted to do. She said

“You can enjoy life but it’s about being good and not doing it for the rewards. That is attachment. I do good things because I love people and I want to make them happy, not because I am thinking what can I get if I do this and this...?” She gave me the example of how much she did for her family regardless of whether she wanted them to be grateful and tell her that she was such a good wife and mother.

Although Prema said she acted for them out of love and devotion and not for the fruits or the rewards, she still worried for her family – her daughter, husband and mother-in-law whose wellbeing she considered to be her own. For example, she said, if her daughter was ever so slightly late coming back from work, she had a feeling in her stomach of nausea and disquiet. Thus the contradiction between different ways of being ‘attached’ were somewhat difficult to separate out in her search for equanimity and it appeared that she was trying to harness herself through a mode of ‘engaged detachment’ (see Venkatesan nd), whereby in orientating herself to one relationship to the *ātman* she continued to remain engaged in all her other relations but tried to do so by fashioning herself as in some sense ‘detached’ from the fruits of her actions.

While Prema readily recognised that to be fully ‘detached’, a person must have no desire whatsoever (whether it is good or bad, including the desire not to desire itself), she considered this extremely difficult to achieve, commenting that, in such circumstances, a person would be a real “*karma yogī*” (master of selfless action). About this she said, “Whatever mind I have I can’t comprehend everything. The conscious mind cannot comprehend everything. Some things are beyond my understanding but I must accept this and believe”. Ultimately for Prema, it came down to the fact that she was trying to be as good a person as possible by acting selflessly and she trusted that *bhagwān* would take care of her.

5.2 *Changing from the 'inside'*

Lata's family was originally from Kerala. She had one sister, and together they were married to two brothers and moved to Bombay after the marriage. Like Prema, she was not brought up to engage in religious ceremony. "I never saw my mother light a *diā*", she told me. However that did not mean that her family was not spiritually minded and to illustrate this she told me the story from her childhood about a man with no lower limbs who used to sit at the door of a temple near her parents house. He could not walk but would just sit there everyday holding a sword. However, on the Keralian New Year, he would jump up from his resting place with his sword held high in his hand. Her father used to marvel at this act every year and he pointed out to Lata that this was how one knew that there was some higher power guiding the universe. Such spiritualism took on a particular meaning after she had suffered with breast cancer. Lata considered her survival to have instigated a transformation in her personhood: what she described as a change from the 'old' Lata to the 'new'. Specifically, she had pinpointed the start of this change to ten years after her diagnosis, when she saw an advert in the local newspaper for Bhagavad Gita classes and decided to go. About this she told me, "Things fall into your hands when you are ready for them".

Suffering and recovering from breast cancer was in Lata's destiny; she had to suffer in order to learn and make necessary changes in her life. Lata told me that, in her life before breast cancer, her perception of the world had been 'blocked' by worldly illusion: the attachments and desires that she described as the "wants", the "me" and the "my". Specifically this is related to the kind of person she used to be: submissive, quiet, timid, and shy, suppressing 'wants' for the sake of others and feeling turmoil

because of unfulfilled familial transactions and expectations, of always doing for others, but finding these transactions were in fact only one way. According to Lata, the problem with living with such emotions and thoughts in the mind is that it created imbalance. The mind was the main perpetrator in marring her ability to see the world as free from illusion. She told me, “The mind is like a drunkard monkey being bitten by a scorpion and chased by a snake”. The mind wandered. It got stuck in the past and hankered after the future. It was in a general state of disarray and, if left unchecked, such delusions would lead to suffering. This is very much in keeping with wider Hindu philosophy whereby all the suffering of humans is conceived to result from ignorance of the ultimate reality as an unqualified unity of *brahman*. As Lata explained to me, all action sprung from the mind because it was the motivation and desire imbued in acts that determined the nature of that act. Therefore by acting mindlessly, one was engaging in a world of illusionary attachments, whether this was good or bad, and this would inevitably bring forth suffering. Indeed, it was this marring of perception that could bring about breast cancer in the first place.

Like Prema, and many others, the imperative for Lata, post-cancer, was on the need for growth and spiritual evolution. It was for this reason that I so often heard Lata tell patients, at awareness forums or in private conversations, that they must ‘change what was in their hands’, which Lata considered to be the internal attitude and orientation towards the inner self or (*ātman*). According to Lata, breast cancer patients frequently remained trapped in a negative or restless frame of mind, deriving not only from fear and pain, but also from their refusal to articulate, express or care for themselves. She expanded on this during a lecture she gave on the management of cancer at a private hospital in the suburbs of Bombay. “Your beliefs can help you to heal if you view your illness as a teacher, as a gift from which you learn something, an indicator for

change and as an opportunity to learn to deal with difficulties”, she informed the small group. “Beliefs are your biology” she stated, and went on to explain that thoughts in the mind could change “chemistry” and impact the body in negative or positive ways. “Therefore by just changing your attitude you can bring about changes in the body,” she continued. She highlighted this as something particular for the “ladies” who, she claimed, say they did not have time to do anything for themselves, or they did not want to be selfish. She finished the lecture by stating, “Make cancer the ‘Turning Point’ in your life and not a sign of it ending. Cancer is NOT cancel. Save your life and not the life that others have imposed on you. This disease gives you a jolt and so you can start living after this”. She ended with the sentence, “*Main apne aap ko change kar sakti hun*” (I am able to change myself).

It is exactly these kind of changes that Lata had made in her own life. When she spoke about her life since recovering from breast cancer all those years ago, she emphasised feeling a sense of self worth, and coming to learn that “I myself is also important”. Lata explained that one must ‘do for the self’ because that was itself a kind of duty. To exist one must act for the very physicality of the body required by nature. In her own words she said to me, “How will you ever become a grade one citizen if you don’t do the self in some way?” Lata explained that all action should be part of the work of duty based on the tenet of *karma yog*: disciplined action that has no desire attached to it for the rewards or fruits. This is the core message of the Gita. Therefore Lata said she was attempting to evolve from a position of ‘selfishness’ to ‘unselfishness’ and eventually to realise ‘selflessness’ that would be directed towards the larger soteriological goal of liberating the *ātman*. This would be no easy feat and she explained that one could not just decide to become ‘selfless’ but rather by trying to cultivate a ‘higher’ desire such as ‘doing for others’ one was simultaneously

attempting to lessen a 'lower' desire such as acting out of greed or selfishness. This she tried to achieve through the mode of 'engaged detachment' whereby she tried to perform all action as *nishkam karma* (selfless action without regard for the fruits), thereby qualifying the degree of 'attachment' imbued in her actions towards others so that she no longer expected to gain anything in return for such interaction. This aim enabled her to act towards others without 'taking tension' or feeling disappointed due to unfulfilled expectations, and also to act towards herself by taking time to practice yoga, and express herself; not in the form of anger or aggression but simply "to express" because, as she described it, it was "good to give priority to the self as part of finding what is right in your own person," and fostering that was part of one's ultimate duty towards god. This also included her charity work. She frequently reiterated to me that we must 'do work of service and sacrifice' and thus her work as volunteer fed into her attempts to harness a particular kind of agency in life post-cancer. According to her interpretation of the Bhagavad Gita, selfless duty was the only proper action, which she impressed upon me when she explained that the book started with the word "my" and ended with the word "duty".

What was also striking about Lata's self-cultivation was she appeared to attempt innovatively to reconcile particularly gendered concerns with the skewed relations of reciprocity, transaction and care that could cut across everyday life within the family, by reconceptualising the very nature of her own position within such connections in the first place. Lata elaborated on this through her interactions with patients where she often encountered women, who like herself, sometimes articulated ambiguity with familial relations of reciprocity and obligation. One prominent example of this was during one of AICT's monthly breast cancer support group meetings. The group was discussing familial relations and the problem of stress. One group member, Neelima,

was recalling a distressing memory during her treatment when she felt she did not receive enough support from her husband. Neelima had told me separately that her husband was a workaholic and was always away at the family farm. So during her six months of chemotherapy she went to live with her mother because, otherwise, she had no support. She told me that she had spent her life in the kitchen doing for everyone else, for the husband's 'wants', buying what her daughter liked but never what she liked. She explained that, when she was being wheeled into the operation theatre for her mastectomy, she was taken in 'alone' and this upset her. Neelima was highlighting the lack of the love and care that she expected to come from her family, as part of the transactions and obligations from within which the familial body is sustained. At this point, Lata interrupted and started to explain how Neelima could try and deal with such disappointment. She said "As wives we must do something for the husband" but this must be an "unselfish act" because otherwise we get hurt when nothing is given in return. We get hurt when we are expecting "something to come to me and we attach ourselves – 'my' husband", she emphasised. She went on to explain that what needed to change was the "inside".

What Lata was suggesting was that, rather than conceive of self-fulfilment as embedded in transactional flows of doing and giving within the family, well-being should instead be harnessed by cultivating the self through acts of *nishkam karma* in a mode of 'engaged detachment'. For while women could not change their duty because as 'wives and mothers' this was their *dharma* or rightful attachment in this world, then, as Lata so forcefully claimed, it was the 'inside', the internal attitude, where change must take place. This involved detaching oneself from the fruits of actions by fostering the right attitude in which one 'does' and 'gives', as per her specific obligations and duty to her family, without expecting to be gratified by them.

Acting with desire or ‘wants’ from ‘my’ husband was therefore now perceived as ‘selfish’ because one was expecting to gain something from such an interaction; one was, in other words, too ‘attached’. While Lata did not further expand on the nature of the principles underlying her suggestion⁷², it was representative of her own attempts to harness herself in a more singular mode through a re-orientation towards the ‘inner’ self in order to foster not many, but only one foundational connection with the *ātman*.

Lata was not the only post-cancer volunteer who espoused the virtues of harnessing the self in this way. The members of *Saheli* also frequently spoke about detachment as a key principle by which to cultivate the self in life post-cancer. In some ways they were more emphatic about this cultivation as related to questions of women’s health and wellbeing that had become inextricably tied to breast cancer survivorship. As already stated, there was a general notion among the post-cancer volunteers that women were being diagnosed with breast cancer precisely because they had not cared for their health previously (see chapters 3 and 4), and therefore, as Padma so often reiterated to me, “we had never thought to reduce our tension before this breast cancer”.

⁷²No one responded to Lata’s suggestion in the group. Lata had been supporting Neelima for a while, and in separate private conversations with me, Neelima explained that Lata was telling her she could change herself; she just had to overturn her orientation towards her self and others. However Neelima felt she could not manage to do this. When I returned to the field in 2012, I visited Neelima. At that time she had had a recurrence and the breast cancer had metastasised and spread to her bones. Having had more gruelling chemotherapy she had decided to cease all medication. She had also moved out of the flat with her husband and was now living with her son and his wife in the suburbs of the city.

5.3 *The struggle to detach*

Although Padma, a core member of *Sahelī*, desired the same soteriological goal of liberation from cycles of re-birth she found it particularly difficult to reconceptualise her personhood in such a way that she fostered herself through a more singular mode of subjectivity grounded in acts of duty. Even though she told me that *bhagwān* had instructed her to do work of *sevā*, service and charity, she found it particularly difficult to separate or detach herself from her acts of care.

As discussed previously (see chapter 3) Padma had had quite a turbulent life, marred by an unhappy marriage and a series of miscarriages, and she considered that having lived through such ‘calamities’ and endured so much ‘mental’ tension manifested breast cancer in her body. However after joining *Saheli* (which coincided with the death of her husband), she was able to make changes to her life that she had not thought to do before, or considered possible. This included small things such as changing her everyday dress from a sari, the traditional and expected dress of a wife, to a Punjabi suit. She also said she came to realise that she must now reduce her tension, and, through participation with the group, learned that she should care for herself, which she did in a practical way by walking every morning and trying to regulate her intake of sugary, sweet foods. Her participation in *Saheli* also provided her with a deep sense of belonging as the ‘mother’ of the group. However this did not quell her own feelings of loneliness that she experienced from being a widow, ‘*akeli*’ and the isolation and disappointment at the distant relationship she had with her son and daughter-in-law. As I got to know Padma better, she revealed that relations with her son and daughter-in-law were not as she would like. Although she spoke with her son on the phone every week, she felt isolated from her daughter-in-law who, she told

me, did not act towards her like a daughter. This was not only because they physically lived far away in Bangalore, but also because she felt they did not fulfil their obligations towards her. While she described her son as “1st class” in life and a boy who knows the responsibilities of a son to his parents, at other times she shared her concerns with me about a lack of *sevā*. Even though her son phoned her every week, from her tone I could gather that this was just about bearable. She was concerned that, because her daughter-in-law did not treat her as a mother, she was holding her son back and making him a little indifferent. She emphasised this by telling me how upset she was recently because they did not touch her feet (a sign of extreme respect particularly towards elders at auspicious occasions or religious festivals).

Padma believed that, through all the years that she had cared for her son, now that she was widowed and ageing something should be returned to her. In the past she explained people were never alone but now houses were too small and too expensive so the whole family could not stay there. She explained that this was not selfish thinking on her part because the ‘Indian’ family was about give and take. “I gave birth to him. I am his mother. He is my whole and soul. Relationships are about give and take”. While she acknowledged that as *sevābhav*, her duty towards her son as a child was unidirectional and that there should be no ‘give and take’ as she cared for and loved him through intimate bonding, in later life she told me some of this love must be returned to her. Although Padma often described herself as feeling ‘very rich’ in relationships – she had a wide network of friends through her work with *Saheli* and her brother lived nearby with his family – she was unable to reconcile the feeling of being ‘*akeli*’. As a typical housewife she told me she had no ambitions and she never took a job ‘outside’. She told me, “I do for others. I am a mother this is

what I do; for husband, for son and now my husband is expired. My son is settled. Now my duties are completed what to do? Who do I look after now?"

Padma was struggling to come to terms with various ruptures and discontinuities in her life such as being a widow, living alone and having suffered with breast cancer, whilst trying to find ways to manage the disappointment of existing familial relationships to work as they should. The more time I spent with Padma and the more I engaged in discussion with her and the members of *Saheli* about how to care for the self in life after breast cancer, the more I was able to learn how the members were trying to help each other come to terms with wider gendered predicaments of 'attachment' in specific ways.

5.4 Seeing god in everything

One afternoon, Nishu, a post-cancer member of *Saheli* who lived near to Padma's house, came to visit for lunch and the conversation turned to her own experience. As the conversation developed, it was soon clear that Nishu also was inspired by the scriptures and was trying to harness a certain kind of agency through 'engaged detachment' by committing to one relationship with god. She was diagnosed with breast cancer in 1995, and joined *Saheli* around 6 years ago. She was a housewife, with two children. Focusing on the change that breast cancer had brought, Nishu told me that breast cancer was like an 'electric shock' from god. Having been to the edge of death and having felt so much *dar* (fear), her survival gave her renewed faith. She now actively sought to make time for herself because she wanted to cultivate a relationship with Ishvara (God). This was not because of any family difficulty, or feeling of neglect. She told me quite clearly that her family '*pūra support diyā*' (gave her full support). Likewise she did not perceive breast cancer to be caused by stress or

tension. “*Jāvab nahi hai*” (there is no answer), she explained. What was important however was that in her life after breast cancer she had started practicing yoga, mediation, pranayam, and reading the Bhagavad Gita, as well as taking singing classes so that she could sing songs of devotion to the Lord Krishna on her electronic *tablā* player, which sounded out the beats of various ragas depending on the choice of timbre, tone and speed.

These practices of self-care, of making time for herself and engaging in activities that were for her own self-fulfilment, were directed at “*ātman nishkam karma*”, as she referred to it, selfless actions in aid of the soul. Nishu was particularly emphatic about devotion that should be performed from her own *ātmik prem* (divine love). She went on to explain that we must realise that the soul is ‘I’ and we were always giving to the soul through ‘*nishkam karma*’ (selfless action). The body was just an outward, superficial entity and we thought it was right to provide comfort to our bodily needs when really we must comfort our soul. Like Lata, Nishu pointed to the teachings of the Bhagavad Gita and the principle of *karma yog*, of acting ‘*pūra bhagwān ke sath*’ – completely with god – in order to see god in everything and everyone. In her own life Nishu was trying to see god in *sub kuch* (everything) and this included her relations with intimate others, such as her children. She told me that she must see god in her son and daughter because through this gesture god would come to her. This was part of a cultivation of self in which she thought ‘*yeh mera nahi hai*’ (this is not mine). In this way, ‘*uskā pūra credit bhagwān ko jayēgā*’ (all the credit (fruits) would go to god, and accordingly she would acquire peace of mind. She gave me the example of Mirabai, a female saint and poet, as an exemplar for her own cultivation of self-care. Mirabai, who turned away from domestic life and duties to foster piety

and devotion to Krishna, has become eulogised in popular Hindu culture as a *bhakti* devotee of Lord Krishna.

At this point of the conversation, where Padma had been chipping in and agreeing with the basic principles of what Nishu had been describing in relation to the *ātman* and sacrifice, Padma interrupted and said about herself, “It is also my duty to serve, also my *dharma* to do *Saheli*”. However, when it came to her son this was more difficult for her. She explained that while she could ‘see *bhagwān* in her son’, she reiterated that she still ‘expected’ from him. Nishu did not say anything, but after a moment of silence, Padma said, “our paths are *alag alag*” (separate) but that both she and Nishu were doing *nishkam karma* in their own way and she pointed out that this itself is an achievement given the fact that it was *kaliyug*. Nishu agreed, joking that the search for the “*ātman*” is not going to be found in the ‘desktop’ (computer) as she highlighted the impact of modern technology and social change on soteriological pursuits.

5.5 Being *bhāvānik*

Like Nishu, Sharanpal, a post-cancer volunteer with *Saheli* and Padma, also attested to the virtues of harnessing the self through engaged detachment and committing to god in all action, and she hoped this might go some way to alleviate some of Padma’s anguish. Sharanpal also experienced breast cancer as an event of transformation and self-enlightenment. A middle-class Brahmin, she worked in environmental science at the city’s university where she was particularly active in civil rights movements. She was diagnosed with breast cancer in 2001. She had felt the lump but had ignored it, deciding not to do anything about it, until her husband persuaded her to go and see their family doctor. This doctor had told her to have a mammography, but still

Sharanpal ignored it for a few more days because she was busy with her work. Again her husband reminded her about the appointment, after which she discovered it was breast cancer.

Like other ladies in *Saheli*, Sharanpal perceived breast cancer as caused by stress or 'tension'. At the time she did not think she was under any tension because she had a good job, a loving husband, good children, good family relations with all, and good friends too. With hindsight however, she realised that she was always worked up with issues, whether these were related to her work or her family. She explained that she was constantly thinking of the same things and they weighed on her mind while cooking or even when she was sleeping. She said, "I carried the weight on my mind" and this she considered to have manifested in breast cancer. She compared herself to a plant that needed water in order to live; without nourishment, she told me, like a plant with no water it was inevitable that she would suffer.

Therefore after her recovery, she slowly decided to make changes to her life and, like Prema, this involved a renewal of her relationships in order to foster greater self-awareness. About this she commented, "Only after having cancer have I started looking at my life differently. It has given me so much". The path to achieving this was found both through her participation with *Saheli*, where she found support and encouragement to take care and make time for herself by practicing yoga and meditation, but she also started to attend Bhagavad Gita discourses with her husband. About the change she has experienced in her life post-cancer, she told me, 'being a good human being is the utmost for me', and that listening to the Bhagavad Gita gave direction to her aimless life. For while life was still flowing as it was, she was learning to take less tension by doing things for herself, such as practising meditation, and to accept events as they came and be less involved in 'things'. This was important

given the fact that she considered tension to have caused her breast cancer, tension that arose from a condition wherein one had too much ‘attachment’ which then causes the mind to ‘roam’. Accordingly, she was trying to lessen her attachment to the intention or desires imbued in her actions towards others.

After a *Saheli* group meeting one Sunday afternoon, Sharanpal, Padma and I went for an evening walk in a local park. We walked around the small busy park with families taking evening strolls and children running around the winding paths. After some time we stopped to sit. Sharanpal, prompted by my questions, continued to explain to me why so many women took tension in their lives. She asked me, “Do I have to go to a distant cousin’s wedding?” I was unsure what to say, but offered a “yes”. She asked me “Why?” and I replied that I might feel bad if I did not go. She pointed her finger at me, “Why feel bad *nah*? This creates so much tension through our involvement and thinking. We make a decision and act accordingly and should leave it at that”. She gave me an example of a friend who had too much attachment. Her son and his wife had just had a baby, but she was becoming too involved and then was feeling ‘pains’. This was too much attachment Sharanpal informed me. “So I told her, just do whatever action is required of you and then leave. This is a better way”, she stated.

In a similar way, Sharanpal was trying to help Padma deal with her unhappiness and disappointment regarding the failure of transactions of care to flow to her as they should. Sharanpal brought this up in conversation and it was clear that she had been telling Padma she should try and change how she qualified her relations with others so she could become a little more ‘detached’ and so feel more content about herself. Padma agreed, and said that was why she was doing charity work, and her next

project was about going to the mountains in the north of India to teach children. Sharanpal corrected her. “No you have to be happy *here*”.

This conversation stuck in my mind and a few days later when Padma and I were talking about the hurt she felt from unfulfilled familial expectations, I asked her if she was trying to change herself, like Sharanpal had advised, by fostering detachment. Padma evaded the question and for a moment I was concerned I had offended her. But instead, she reiterated her desire to have her maternal expectations fulfilled, to be a mother and that this was who she considered her ‘self’ to be. In response to Sharanpal’s suggestions, she told me “This attitude of doing without care is selfish. I can’t do that”. She told me that Sharanpal and Minu too, kept telling her she was too involved and too attached and this was why she was taking tension and pain about her son. “They don’t get involved in pains”, explained Padma who described them both as very “practical” whereas she considered herself to be more *bhāvānik* (emotional). She said: “*main dil se pyār karti hoon isiliye dil se hi sochti hoon* (I love from the heart so I think from the heart).

5.6 ‘Clicking’ to moksha

As I spent time with Padma, I came to learn how she was managing to try in her own way to foster equanimity and relief from these feelings of *akelīpan* (loneliness) and unfulfilled expectations arising from her familial attachments. Since 2002, Padma had started chanting. The chant has thirteen letters, so it takes thirteen crore⁷³ worth of chants to reach a divine place. Padma explained that by chanting she was worshipping *bhagwān*, whom she perceived as the supreme power that protected her. By chanting

⁷³A crore is equivalent to ten million, or 100 lakhs.

she therefore hoped to realise god and eventually, over the necessary life times, liberate her soul. She told me she did this for “*meri shanti*” (my peace) and to reduce her ‘tension’. In order to aid her in this pursuit, a friend had gifted her a counting ticker, or what she described as a ‘chanting machine’ from Taiwan. This was a small metal box that would clock the number every time you pressed the clicker on the side. One click and it showed a number 1. Two clicks and it showed a number 2, and so on and so forth. Every morning she got up at five-o-clock for her morning walk around the neighbourhood to chant her mantra. For every time she said the chant, she clicked. Sometimes she also ‘clicked’ as she carried out her chores around the house. As she carried clothes to the washbasin, or potted around the kitchen, I would hear the clicks as she walked past. Even though she was always silent doing this, if she needed something from me, she would motion at me, waving her free hand at me, without ever interrupting her clicks. Since 2002 she had reached 1 crore. She told me she had a long way to go if she was going to reach sixteen, and she probably would not make it but she was trying hard every day.

While Padma subscribed to fundamentals about how to be a good and pious human, how to try to perform selfless action by doing one’s duties without accepting the results or *phul* (fruits), she did not agree that this is what she should be doing at all times in her life. “We are not *sannyāsin*” (a renouncer), she told me. “We can’t renounce everything. It’s difficult to do in the everyday”. Although she said that one should not act with greed and desire, because ‘god is there to see’, she thought that to act without care was selfish. Therefore she could not follow the suggestions of other members of *Saheli* who were advising her to harness a more singular mode of subjectivity by separating from others.

Padma's struggle was complex and was not just related to breast cancer but the other traumas or discontinuities that she had experienced over her lifetime resulting in her becoming *akeli* (alone). She felt isolated from the fundamental attachments that made up her very sense of personhood as 'thinking with her *dil*' (heart), and she found it incredibly difficult to foster a sense of self as qualitatively detached from her son. She therefore sought solace through her chants and 'clicks' to *bhagwān* in order to foster some sense of personal harmony and equanimity, as well as through her participation in *Sahelī*. It could be said that perhaps Padma sought to reanimate her desires for attachment through her work of doing 'sevābhav for all' by becoming the mother of the group and embodying all the sorrow of women's pains 'in her stomach' (see chapter 3). Even though she considered her work as a '*mātā*' volunteer to be performed as *sevā* and *nishkam karma* (and thereby should involve no attachment to the fruits), she clearly found qualifying her relations as variously 'detached' particularly difficult, and struggled to harness a more singular mode of personhood. However, at times she clearly did not want foster herself in this way. Thus, while Padma struggled to manage familial relations and transactions, it was through these attachments that she conceived her own well-being. Therefore as she continued to care for others she simultaneously 'cared' for herself by becoming replete through the cultivation of her relationships in *Saheli*.

5.7 Performing *sevā*, harnessing self

This chapter has offered an initial description, albeit on a more philosophical level of abstraction, of the ways in which post-cancer volunteers engage in individual self-cultivations in life after recovering from breast cancer. Here women are trying to harness a renewed or in some case transformed sense of personhood that is

inextricably linked to their suffering with breast cancer and gendered predicaments that have emerged in life post-cancer. As such their self-cultivations speak to wider anthropological concerns with personhood in south Asia. However, the ethnography presented here does not speak to concerns within those debates that have previously sought to locate ‘Indian’ selfhood from within a tension between ‘dividuality’ and ‘individuality’, but rather resonate with what is considered to be the fundamental complementary opposition between the householder and renouncer in Hindu culture (Dumont 1970; 1986; Marriot 1976). The householder is an exemplar of heterogeneous interdependent caste society bound to worldly duties, and the figure of the renouncer has been described as the ‘outwardly’ individual who lives outside of the social world, and is afforded full independence (Dumont 1970). Some of Dumont’s conclusions concerning the nature of Hindu society are now considered to be somewhat unsatisfactory⁷⁴, nevertheless, the identification of the centrality of this tension in underpinning many aspects of Hindu social life remains pertinent. In particular, recent studies, that have revisited the south Asian personhood debate, have suggested that the way by which persons articulate more singular modes of personhood is found through various re-elaborations of this tension, with ascetic practices emerging at the fore. It has been suggested that this emerges through a kind of “spiritual individuation” that, according to Khare, is a fundamental characteristic of Indian society as “a mass moral, trans social presence that links together ritualistic, personal and spiritual domains but is socially latent and needs fostering as a

⁷⁴In trying to understand the ideological foundations of Hindu society in India, Luis Dumont (1970) placed hierarchy, in the form of the pure/impure opposition embedded in the caste system at the core of Indian sociality. This has been criticised more recently because of the way caste and inequality are considered in Dumont’s work to be the ultimate inception of Indian sociality (see for example, Das 1995) and for his opposition between ‘holism’ and tradition to ‘individualism’ and modernity (Das 1995; Mines 1994; see also Appadurai 1986).

conscious moral process” (1984: 58). Or else it has been suggested that ascetic practices in contemporary India persist as ethical ‘resources’ through which to express more ‘individual’ aspects of the self⁷⁵.

While this chapter takes a different approach to these other studies, ethnographically speaking there appears to be some resonance for what emerges from the post-cancer volunteers’ experiences of suffering with breast cancer, as it is also linked to other ruptures and discontinuities in life, is that this tension continues to be confronted, incorporated and re-established in various ways in ordinary social life. For the post-cancer volunteers this manifests in their life post-cancer, where suffering is reconceptualised as a positive opportunity to harness gendered personhoods as ‘prioritised’ by cultivating a more singular mode of subjectivity and engaging in practices of ethical ‘self-care’ in particular ways. This involves harnessing the self in ways that attempt to engage and refigure gendered tensions in everyday life concerning transactions and obligations within the family. As we have seen, this can involve the reconfiguration of notions of self-sacrifice in ways that are dependent on, and reinforce more established forms of self-making such as ‘doing for the family’ (see chapter 4). At the same time, becoming a “grade one citizen”, as Lata claims, requires one must ‘do for the self’ as all action is now conceived of as inherent duty

⁷⁵It has recently been suggested that self-reflexivity emerges through a process of ‘interiorisation’ whereby external moralising ‘forces’, such as residual of the colonial encounter and use of Hindu ascetic devotional poetry, become folded into an internal horizon of ethical subjectivity (see Pandian 2010). Furthermore, Donner (2008) has stated that the adoption of ascetic practices by young mothers in urban Calcutta, whose choice to become vegetarian is linked to controlling fertility, pragmatically reinterprets feminine ideals as the “notion of vegetarianism as a way of controlling sexuality locates its new practices within changing patterns of gendered consumption in the middle-class ‘home’, which actively support neoliberal ideologies of personhood” (Donner 2008: 173). In turn this allows women to speak about their individual struggle to adjust to a new globalising consumer led world.

and selfless service or *sevā*. This is attempted through the sometimes difficult and distressing struggle to manage everyday relations by qualifying instrumental action of *dharma* without attaching to the fruits of these acts. Therefore, where previously ‘doing for the self’ is seen to become an additional modality through which one can continue to do for the family in such a way that it is not perceived to be selfish (see chapter 4), this established principle remains fundamental in the post-cancer volunteers self-cultivations and practices of self-care but shifts in focus. Now self is attempted to be harnessed and fulfilled less through the cultivation of many relationships and through the transactional flows of ‘doing and giving’ that constitute the familial body, but instead is seen to be committed to just one relation as the *ātman*.

What is also significant about these self-cultivations is that there appears to be an important continuity in the post-cancer volunteers’ lives. The opportunity to re-evaluate gendered personhoods and self-prioritise, initiated by recovery from breast cancer, is not directed at overturning relationships, for example by leaving the family and ceasing to enact the proper relationships as wives and mothers. Furthermore, the volunteers are not becoming renouncers and in fact consider this possibility to be extremely difficult to achieve given that it is *kaliyug*. I was told that during this time a person becomes *sannyasin* only once in a *lakh*. And while they speak frequently of ascetic ethics and practices such as *karma yog* and *sevā*, they do so with reference to their participation in Bhagavad Gita classes, and not participation in any other organised religious sect.

As far as I could tell, these women do not want to abandon the family. On the contrary, of their own choosing, they still remain very much embroiled in their family relations. Divorce for example, is considered to be a last option. Many consider it

shameful, including those women I knew who had been through it. Often I was told that outside of the family women have ‘nowhere to go’ and therefore there is frequent emphasis on the notion of ‘adjustment’ within the groups and finding ways to live with compromise as the family is considered to be part of the very sustenance of life, even where there is breakdown and disappointment. In this way the notion of changing from the ‘inside’ takes particular saliency as the work of harnessing a more singular mode of subjectivity, deemed necessary by the event of breast cancer, does not appear to require the rejection or ‘cutting off’ of relations (see Desai 2010; see also Pedersen 2012). Rather this requires the continued qualification of relations in varying degrees of as part of everyday domestic life in which self-prioritisation is now a vital part. All action is now reconceptualised and attempted in practice as *sevā* and *nishkam karma* as part of the work of spiritual attainment. The gendered personhoods harnessed here thus appear to be grounded in the enactment of *dharma* (duty), be this as mothers, wives or charity volunteers, and are dependent upon the cultivation of relationships, either to family (as the volunteers tell patients) or through total commitment to the *ātman* (as the volunteers tell each other and attempt to practise in their own lives).

From this perspective, *sevā* for others and *sevā* for the self, attempted through the struggle to qualify relations as variously ‘attached’ and ‘detached’, now appear as two sides of the same coin; one is a necessary part of the other. It is therefore this aspect of the post-cancer volunteers’ self-cultivations, of harnessing a more singular mode of subjectivity through the qualification of ‘proper’ relations, that can be seen as contributing to the articulation of novel gendered personhoods in life post-cancer as ‘prioritised’. Becoming a ‘transformed’ or ‘better’ person in life-post cancer thus speaks to particularities of gendered values and predicaments concerning ‘seeing’ the

self for the first time, and leads to my interlocutors conceptualising breast cancer as an ultimately positive and in some sense liberating event in their lives.

Certainly these experiences speak to changing notions of gendered responsibilities and roles that are occurring in urban India today (see for example, Thapan 2009; Donner 2008). At the same time the post-cancer volunteers' experiences also intersect with wider discourses and modalities of health that emphasise individual autonomy through self-surveillance. However, this chapter, together with the last (see chapter 4) has attempted to describe that, far from a matter of self-becoming in a straightforward individualistic sense, changing, cultivating and articulating the gendered self as 'prioritised' in life post-cancer is subject to complex engagements and resignification between different values and aspirations that exist among the volunteers within the charitable communities of care. Preoccupations with 'seeing the self' post-cancer emerge as a distinctive form of self-care that is created in a particular time of suffering, and is suggestive of a distinct form of self-realisation or articulation of agency that would appear to be irreducible to Westernisation (see also Mahmood 2005; see also Ventaksen n.d; Desai 2010; Laidlaw 2002), and therefore cannot necessarily be conceived of as simply representative of adaptations to wider globalising neoliberal regimes (see for example, Donner 2008). Rather, the novel health practices and notions of wellbeing pertaining to breast cancer survivorship among the post-cancer volunteers can be conceived of as particular parochial visions of gendered selves and modernities, through which breast cancer care is emerging in locally distinct ways and is circulated in various forms and levels of intensity within the voluntary groups.

Finally, it is here that the nature of their voluntary activities comes to light more clearly and perhaps prompts an initial reflection on the nature of their activities in

relation to Rabinow's concept of biosociality. In chapter 2, I introduced the ways in which the post-cancer volunteers conceived of their charitable work and suggested that, rather than being directly comparable to western notions of activism, they instead conceive of charity as selfless service and duty (*dharma*) and thus constitutes a particular political action grounded in a kind of 'divine' humanitarianism. This chapter has built upon this initial observation to describe the inextricability of action and selves whereby performing charity work as *sevā* is simultaneously part of the very process of harnessing personhood through acts of *nishkam karma* in search of soteriological benefits, however difficult this may be to achieve. This sets the post-cancer volunteers' specific charity work apart from other studies that conceive of participation in women's organisations as either based on specifically defined political imperatives, such as in the feminist women's groups (Ray 1999), or as an extension of 'housekeeping' where participation in social welfare groups reproduces women's domestic roles as wives and mothers (Caplan 1985).

In this specific context the intertwining of *sevā*, *nishkam karma* and *dharma* in visions and practices of survivorship in life post-cancer, where the purpose and vitality of life itself, and indeed into which the suffering and 'tension' of life *ājkal* (nowadays), is seen to feed back and are expressed from within conceptualisations of a cosmogony where there is dynamic interplay between humans, nature and action. This therefore situates the work of the volunteers within a specific set of principles that is distinct from those posited by Paul Rabinow (1996) in his original formulation of biosociality. It has recently been claimed that biosociality is grounded in "one among many other possible cultural biographies of human biology" (Bharadwaj & Glasner 2009: 40-41; see also Bharadwaj 2008). It would seem that this refers to the ruptures of nature and culture whereby nature is 'remade' in particular conditions of

modernity. In this thesis, ‘modernity’ emerges as something not necessarily indexed by rupture, but rather as the continued expression of cyclical dynamisms of ambivalent temporalities that give rise to the inextricability of humans and action; of *prakṛiti* (nature; cosmic substance) and *puruṣa* (universal soul). This speaks to the attempts of the post-cancer volunteers to reconcile those particular tensions as part of gendered visions of modernity, that can be seen as underpinning Hindu values in which a dependence-bound world of duty is seen to exist in an ambivalent tension with the liberation and singularity of the *ātman* (soul) and the fact that ‘*bhagwān ek haī*’ (god is one).

CONCLUSION

This thesis has set out to chart the emergence of associational communities around breast cancer in urban India, and has focused in particular on the experiences and activities of middle-class ‘post-cancer volunteers’ within the urban clinical setting. The thesis has described the ways in which the patient turned ‘activist’ or, in this case, ‘volunteer’ is mobilising around breast cancer in specific relation to the notion of breast cancer ‘survivorship’: the multidimensional aspects of individual suffering and recovery that are imbued in and generative of, the practices and ethos of the post-cancer volunteers activities and breast cancer voluntary groups. What has emerged throughout the thesis is the post-cancer volunteer as a intermediary figure within the urban clinical setting, and the mobilisation of novel patterns of sociality and solidarity as the volunteers are seen to mediate, navigate, translate and negotiate the confluence of different values, aspirations and imperatives that coalesce around breast cancer in urban India.

Throughout the thesis, the mediatory practices of the volunteers have been explored in relation to the emergence of novel forms of belonging, solidarity and personhood interwoven at various intersections that, considered as terrains of dynamic engagement or “problem-spaces” (Collier & Ong 2005: 5), are seen to unfold and be subject to multifaceted forms of resignification in ways that are suggested to be irreducible to westernisation. These intersections include the wider socio-economic context of post-liberalising India, in which cancer care can be compromised and partial, and where changing values of health responsibility and preventative health practices are coming to the fore.

It is within this backdrop that thesis has thus sought to bring together and introduce some of the many aspects of the multifaceted and complex dimensions of urban women's experiences of suffering with breast cancer. What has been revealed is a complex landscape in which different spheres of care, the family, the community and biomedical clinical cartography intersect, inform and shape the ways in which women are attempting to manage to live with the disease. From the outset, in chapter one, breast cancer emerged as an extremely feared disease that is situated first and foremost within the 'familial body'. By tracking the different ways in which patients try to contain the inherent 'motility' of breast cancer, the thesis has thus suggested that, where cancer is ubiquitously conceived of as uncontrollable and inchoate, in India this concept may be usefully captured through the notion of movement, for breast cancer appears to engender movements of 'stretching', 'spreading', 'separation', but also 'stasis' and 'containment'.

Chapter one provided an initial backdrop to the rest of thesis that then turned to explore in particular detail the activities and experiences of the post-cancer volunteers. Chapters 2 and 3 introduced the ways in which post-cancer women have begun and continue to mobilise around breast cancer. Here the thesis described how initial claims to solidarity around the disease emerged from the recognition of a lack of resources, and a partial and uneven health care landscape in which the post-cancer women themselves had received varying degrees of care. This recognition then led to the formation of particular collaborations between patients and their doctors that resulted in the growth of small associative groups and the implementation of novel forms of care within the hospitals. The forms of the groups are diverse and they operate in different ways, but what emerged as particularly significant is the role of the volunteer as an intermediary figure, and a certain form of activist practice as

therapeutic mediation; the medical brokerage of information related to a myriad of practical concerns nascent in suffering with breast cancer. In the everyday work of providing care to patients, the post-cancer volunteer emerges like a local healer, a guru, a great *mātājī* whose liminality and ambiguity, due to having been a breast cancer patient herself, is generative of a kind of lay expertise, grounded first and foremost in a pragmatic solidarity shared with other patients of knowing how, where and when to ‘move’.

The post-cancer volunteers emerge from within the interstices of these different spheres of care as they attempt to negotiate and subvert overarching imaginations of cancer and provide grassroots provision of care. This leads me back to the work of the Biehl (2007) and Nguyen (2010) where nebulous trajectories of patient care and wide scale state absences are inadvertently bringing to the fore novel forms of patienthood as ‘diseased citizens’ or ‘therapeutic citizenship’ through which a few individuals are beginning to mobilise around disease advocacy and provide therapeutic care. In a not too dissimilar way, this thesis has attempted to chart the ways the initial breast cancer patient groups emerged through the work of a few individual pioneers, and has since evolved from the reading of a medical file in the patient waiting rooms, to changing the way post-operative care is provided within the hospitals.

The thesis then built upon this in chapter 3 where the focus shifted from the practical nature of the individual post-volunteers’ work, to examine in more detail the complexities around the patient and the post-cancer volunteer participation in the voluntary groups in relation to the mobilisation of disease affiliation and novel patterns of solidarity. While many patients seek the necessary information that is so often required in managing the practicalities of breast cancer, beyond this, patients

and their families seem to have little desire to affiliate with the groups and post-cancer women. However, where breast cancer is experienced as ‘living death’, and thus feared and shrouded in silence in different ways through strenuous acts of concealment within the family, the post-cancer volunteers seek to instil hope in patients and create an initial solidarity with them by revealing their own survivorship. The thesis has suggested that the initial mobilisation around relations of affiliation and sharing in this way inheres less through ‘talking’ as synonymous with Western self-help cultures, and more through the work of vision. Described as *nazar*, the interactional exchange of emotion of feelings, the work of affiliating around the specific disease of breast cancer is suggested to occur initially through the modality of sight, that turns on a wider notion of the guru-devotee relationship and its invocation of *darśan* as the divine knowledge of ‘truth’ and life.

At the same time however, the ways in which post-cancer volunteers specifically affiliate with each other was further explored in the latter part of chapter 3 in relation to the breast cancer support group *Saheli*. Here much more concrete bonds and a sentimental solidarity is being created and sustained. It is suggested that this derives from the formation of sentimental kin structures that become solidified through the acknowledgement of wider gendered predicaments that are inextricably intertwined with conceptualisations of breast cancer causality and suffering. It is also suggested that relations of sentimentality emergent here contribute to, and reinscribe the saliency of the ‘*mātā*’ (mother) volunteer, which for post-cancer women such as Padma, who are positioned somewhat uniquely being widowed and living *akeli*, potentially speaks to the emergence of novel forms of sociality and patterns of belonging in specific relation to biological conditions.

In light of this, the thesis has suggested that breast cancer 'survivorship' forms a pivotal medium of activist practice and emerges as a generative resource that is certainly being mobilised in various ways by the post-cancer volunteers as a form of lay expertise. However, it is also important to bear in mind that the activities of these groups and individuals are still currently at the peripheries of society, and are yet to reconfigure the public imagination of cancer and overturn the immense fear and stigma of the disease. In this way, the thesis has tried to illustrate the constant and various moves of compromise and concealment, revelation and curtailment that pertain to differently elaborated visions of trying to become well again. The patients and volunteers described here are all working to negotiate the limitations of various relationships in which they are embedded, as well as the normative expectations and sets of possibilities that are made available to them in different ways.

Moreover, the thesis has explored specifically how the post-cancer volunteers are struggling to live with the remnants of illness in their own lives. This is by no means a simple feat as breast cancer emerges as intertwined with wider gendered predicaments within the family that are borne out of the disappointment and sorrow of familial discord, and manifest where expectations of transactions of love and care remain unfulfilled. However, it is also precisely out of this suffering that the disease has become 'feminised' in particular ways. Current gendered concerns about relations of responsibility, duty and self-sacrifice emerge as especially salient in the experience of suffering with breast cancer, and chapter 4 explored the ways more established modes of responsibility, such as 'doing for the family' are seen to provide the framework for and / or exist in tension with more new kinds of, albeit peripheral, 'biological identities' (Gibbon & Novas 2008; Rose & Novas 2005; Rabinow 1996). Here the thesis attempted to capture the post-cancer volunteers' experiences of

recovering from breast cancer as an event through which novel possibilities emerge and certain perspectives of selfhood were brought to light. This focused in particular on a specific and novel singular relation of self-prioritisation that, previously considered unimportant, is deemed to be an essential addition to gendered livelihoods in life post-cancer. In turn this appears to give rise to novel forms of gendered self-care and articulations of gendered personhoods as ‘prioritised’ post-cancer.

Finally, in an attempt to get a real grasp on the meaning of being ‘prioritised’, the thesis described the specific ways in which the post-cancer volunteers attempt to harness a more singular mode of personhood in their lives, post-cancer. Chapter 5 explored how the middle-class post-cancer volunteers are struggling to become certain kinds of subjects in relation to particular ideals of singularity from within shifting frames of responsibility that have been called into question through the experience of suffering with breast cancer. This appears to be harnessed through the work of engaged detachment, which is the specific attempt to qualify the nature of relations from within the familial body by reconceptualising all action as *nishkam karma* (selfless action without regard for the fruits). This attempt to harness a more singular relation of self-prioritisation emerged through the way women attempted to cultivate dutiful relations, either to their family or through total commitment to the *atmān*.

Therefore becoming a ‘transformed’ or ‘better’ person in life-post cancer in India speaks to particularities of gendered values and predicaments concerning ‘seeing’ the self for the first time. The thesis has suggested that rather than conceive of these appeals to prioritise the self as instances of increasing ‘individualism’ among middle-class urban women in India as complicit with adaptations to globalising neoliberal regimes, preoccupations with ‘seeing the self’ post-cancer, and establishing a more

singular mode of gendered personhood emerge as a distinctive relationship that is created in a particular time of suffering and in a specific way. In turn, this would continue to suggest that what is at stake in the middle-class Indian women's experiences of suffering with and recovery from breast cancer, and the cultivation in remission of particular visions of well-being that I have described here, is not necessarily redolent of a "hyper individualism" and / or the realisation of one's own autonomy as ultimate bastion of control as some meta-narratives of cancer self-help 'cultures' might have us believe (see Stacey 1997), but rather the process of self-becoming entails the ability to prioritise a relation with gendered self for the first time, and cultivate it in specific ways that speaks to distinct forms of subjectivity as part of gendered visions of Indian modernity.

It was also in this chapter that I returned to the notion of biosociality. While the charitable activities of the breast cancer voluntary groups and the post-cancer women speak to novel patterns of biosocial patient association, they do so in particular ways. As the thesis has already noted, recent studies have suggested that persons in India seek, access and mobilise around their disease, disability and health care, not necessarily through the formation of associative groups that make purchase on the state as 'liberal biosocial individuals' (Das 2001; Das & Adlakha 2001), but rather forging tactical alliances within and outside of the domestic sphere as 'connected body selves' in relation to the state (Das & Adlakha 2001) and the everyday work of providing care (Bharadwaj 2003). Likewise, what has emerged in relation to breast cancer activism and charitable care is the formation of groups that do not operate in direct conversation with the state as lobbying bodies through which claims to entitlements are being made. While these groups do implement certain changes, they do so through the collaborations and strategic associations created between patients

turned ‘volunteers’, the doctors and networks of kin in order to mobilise themselves to provide grassroots care. Therefore the focus throughout the thesis on the shifting sets of alignments and collaborations has hopefully proved fruitful in capturing the kind of subtleties and complexities that exist here.

At the same taking into account the various aspects of the volunteers’ activities and their own personal experiences of recovering from breast cancer, the thesis has attempted to further think through the implications of biosocial mobilisation in the Indian context. Here patient activism in urban India appears to be grounded in the politics of a divine humanitarianism whereby charity as *sevā* and the cultivation of self through acts of *nishkam karma* and *dharma* are inextricable in life post-cancer. In the final chapter I explored the implications of this in relation to Rabinow’s original formulation of biosociality that holds particular salience in its potential to “remake and to create new life forms” that have subsequently “brought into question long established ideas about what counts as nature or natural” (Gibbon & Novas 2008: 3). Where biosociality is seen to emerge out of a schism or rupture between nature and culture, the thesis has suggested that in urban India ‘modernity’ emerges as something not necessarily indexed by rupture, but rather the continued expression of cyclical dynamisms of ambivalent temporalities that give rise to the inextricability of humans and action; of *prakriti* (nature; cosmic substance) and *purusha* (universal soul) (see also Bharadwaj 2008). This speaks to the attempts of the post-cancer volunteers to reconcile those particular tensions that can be seen as underpinning Hindu values in which a dependence bound world of duty is seen to exist in an ambivalent tension with the liberation and singularity of the *ātman* and pure consciousness (*brahman*).

Finally I would like to contemplate the relationship between cancer and personhood further in light of the issues raised in the thesis, and consider arenas for further research. As a disease of the ‘self’, cancer is said to be life turning inwards on itself in ways that disrupt perceived boundaries of self and other, and in doing so calls attention to those cells that separate themselves from the ‘whole’; to become neither subject nor object for it is both separate from, yet part of the subject (see Stacey 1997). This recalls David Napier’s (2012; 2003) research on Western notions of immunology which he claims are frequently hinged on culture-bound notions of a wholly autonomous self whereby the idea that harbouring ‘nonself’ within you is dangerous. He reconceptualises immunological thinking through non-western notions of personhood so that immunity might be alternatively perceived as a creative attempt to engage difference actively, rather than solely as a battle, in the Western militaristic view of illness and immunity where the imperative is for elimination of other from self. He suggests that it is fruitful to think of the self as challenged and defined at the peripheries so that “we come to know ‘who we are’ by an engagement with difference; the risky, dynamic and sometimes painful process of discovering what we can and cannot accommodate through the potentially dangerous but ultimately creative encounters at one’s boundaries” (2012: 27; see also Napier 2003). He further suggests that it is this aspect of the immunological process that creates the condition for existential change.

The point is also explored by Paul Stoller (2004; 2008) in relation to cancer. Drawing on his own personal experience with cancer and the ethnography he conducted in western African on notions of Songhay sorcery, Stoller explores the virtues of thinking about cancer suffering and recovery as a process of ‘incorporation’ rather than following the path of immunological thinking and trying to ‘conquer’ the disease

by forcing the ‘enemy invader’ out of one’s life. In living in remission when one is never fully separate from the ‘village of the sick’ he suggests a return to embryological thinking via the holism of West African perceptions of health and well-being, as a fruitful mode through which to conceptualise illness as incorporated or part of one’s own being.

There are perhaps two points to begin to reflect upon here in relation to this thesis. Firstly, the notion of disease ‘incorporation’ or indeed that the experience of cancer can be generative resonates strongly with the emergent ethos of the breast cancer voluntary groups, and the post-cancer volunteers, who foster the viewpoint of disease as a ‘guru’ through which the experience can be conceptualised as a ‘gift’ from which one can learn, grow and evolve. As we have seen, the post-cancer volunteers promote the positivity of the illness experience as an opportunity for possible change as a modality of self-care by which one can harness the self in more virtuous and / or beneficial ways in life post-cancer. This resonates strongly with emergent ‘self-health’ or ‘self-help’ ‘cultures around cancer that are becoming a prolific feature of oncological health care in America and the UK (Stacey 1997; Stoller 2008). However, given the axiom of a mind/body non-dualism, and the very fact that, as I was told, *jīvan* (life) flows through cycles of birth and re-birth that are constitutive of a wider cosmos tending towards oscillations of degeneration and regeneration (see Parry 1994), the notion of existential renewal through the experience of cancer as disintegration perhaps has particular saliency here. Viewed from this perspective, the post-cancer volunteers’ articulations of the virtues of surviving breast cancer are perhaps less a reproduction or straightforward regurgitation of globalising flows of ideologies, than, if anything, a re-elaboration of their own principles that have returned from elsewhere repackaged ‘anew’. The prime example here is of gurus such

as Swami Parthasarathy and even more recently Deepak Chopra, a contemporary ‘neo-spiritual’ thinker who has taken axiomatic Hindu principles and applied them in very contemporary way to ‘modern’ conditions and become famous worldwide for his holistic healing philosophies. In this way, the ‘Eastern masters’ have become “a minor archetype in American popular culture” as their esoterica have been rediscovered through Western rationality (see Cohen 1998: 111). Arguably the same point could be made of the many modalities of ‘self help’ that underpin the alternative therapy movement around cancer, that in urban India, are in fact welcomed, readily received and in turn appear to be woven into their own communities around cancer and post-cancer care in the voluntary groups in particular ways.

The other interesting point also relates to the notion of cancer as a process of differentiation. This seems to be particularly pertinent in relation to questions of Indian gendered personhood and breast cancer emergent in the thesis. Napier suggests with regard to immunology that rigid distinctions between self and ‘nonself’ can be reconceived in ways that self becomes known through its engagement and incorporation with the other, and perhaps, in the case of cancer, there are resonances to be considered here. Breast cancer appears to be experienced as different kinds of motility that involve stretching, splaying and separating and through which in life post-cancer the volunteers emerge renewed. For the post-cancer volunteers this leads to the refraction of unique and emergent expression of the gendered self as ‘subject’. This perhaps points to suffering and recovery from cancer as a particular kind of experience: as an ambivalent differentiation of self from other, out of which, as Napier suggests, change can occur and self-formation takes place. However, what appears significant in the post-cancer volunteers’ experiences of suffering with and recovery from breast cancer, is the experience of breast cancer as a process of

differentiation that comes from the work and pain of separating, detaching or distancing the other in order to connect with, articulate or indeed ‘discover’ a singular gendered subjectivity.

As one of the few ethnographic studies of breast cancer in India, the thesis has initially sought to make a contribution where there is a dearth of studies of breast cancer in non-western contexts. In doing so it has offered a tightly focused exegesis of the activities of the charitable communities of care in urban India, and the individual experiences of living life post-cancer among some of the charity volunteers. However this, of course, presents one specific perception of breast cancer survivorship in urban India, and as such it opens up many pertinent questions for more research. This could include further examination of non-volunteers’ experiences of suffering with, and recovering from breast cancer, and specifically those women who do not actively seek to renew the gendered self and cultivate well-being in the specific ways described here. This could also include a new focus on men’s experiences of suffering with cancer, which I think would offer a particularly interesting complementarity to perceptions of the gendered self and practices of self-cultivation, post-cancer, discussed here in relation to notions of sacrifice and responsibility within the predominant context of the ‘familial body’, as well as a further exploration of the saliency of visions of Hindu self-enlightenment in ordinary social life in India today. Finally, one could also expand on the initial insights made here by widening the focus to explore experiences of cancer in a non-urban setting and the relationships there between stigma, silence and fear, particularly at the intersection with notions and practices of caste, in order to give further pay attention to the kind of ramifications that living with breast cancer may have for women and their families.

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