

**Four Days of Light and it's Dark Again:  
Dementia Care in India**

चार दिन की चाँदनी फीर अंधेरी रात

By

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**DEDICATION:**

*To Hazel and Dara Balsara*



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## **ABSTRACT**

As the world ages, the prevalence of age-related diseases like dementia will increase. In South Asia and the Western Pacific regions, particularly India and China, rates of dementia are expected to escalate by 314-336 percent in four decades (Ferri et al., 2005b). Yet there is limited work on dementia in this region – on idioms of dementia and ageing, understandings of rights and entitlements, and experiences of caregiving. In redressing this gap, this thesis adds to the current literature by examining the lives of urban Indian families who care for a person living with dementia. The main research question is: In New Delhi, India, how are people with age-related dementia cared for and what are the barriers to carers to access support?

Data were gathered in Delhi, with additional work in Kolkata, Bangalore and parts of Kerala. A critical ethnographic method was used. From January to October 2008, in Delhi, 20 families caring for a person with dementia were followed to document their understanding and experiences of diagnosis and prognosis, medication management, enablers and barriers to care, and the extent to which this varied by class, gender, caste and age. This was supplemented with 21 interviews with key service providers and approximately 250 hours of observation in home, hospital and community settings.

I argue that caregiving is intimate work and deeply felt but that carers also draw upon broader frameworks – medical pluralism and hope for a cure, the

emotional currency of feeding and eating, and the powerful bonds of kinship and reciprocity – to make sense of their everyday worlds and practices. I describe how carers and people with dementia engage with institutions of health, law and money, which exclude and exploit them at different points but that these practices in turn are shaped by shortages in resources and capacity. Existing systems, inequities and roles are challenged as illness and loss forces changes in identity for the carer and the person with dementia. Ultimately what I will show is that care work is ambiguous; at once full of cruelty, tragedy and exploitation but also hope, kinship, and love. It is only through explicating these aspects of care, can we begin to think of culturally meaningful ways to support families and people with dementia.

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## TRANSLITERATION AND STYLE

All Hindi words are italicised. I used the Digital Dictionaries of South Asia (see <http://dsal.uchicago.edu/dictionaries/about.html>) for the spelling and diacritics of Hindi words in English. Specifically, I relied on Mahendra Caturvedi's *A Practical English-Hindi Dictionary* and John T. Platt's *A Dictionary of Urdu, Classical Hindi, and English*. To be consistent with the dictionary spellings, a few words have not been spelt as they are popularly used (e.g. *cha:y* instead of *chai*). Where I have not been able to locate the word in the dictionaries (e.g. *barsathi*), I have used my own spelling without any diacritics. Only film and book titles are cited as in the original.

When Hindi words first appear they are translated. If the word is only used once and adequately explained in the text, I have excluded it from the glossary for brevity. Hindi sentences and/or colloquial mixtures of Hindi and English are accompanied by English translations in round brackets. Square brackets have only been used to either clarify the speaker's meaning or to illustrate the tone of the speech. All my dialogue is italicised to distinguish it from my participants' speech. All translations of interviews from Hindi to English have been undertaken by me and I alone am responsible for any errors.



## GLOSSARY

<b>A:dmī:</b>	Husband. Can also be a descendant of Adam; a human being; man; individual, person
<b>A:ya:</b>	Maid
<b>Āyurveda</b>	A type of Indian medicinal system ( <i>āyus</i> means longevity; <i>veda</i> is knowledge)
<b>Bahu</b>	Daughter-in-law
<b>Barsathi</b>	A one-room or two-room habitation on the terrace of a building usually for renting purpose
<b>Bechara</b>	Poor thing; a creature to be pitied
<b>Beta</b>	Child; literally means son but is used to address both genders
<b>Bha:bhi</b>	Sister-in-law
<b>Bhaiya:</b>	Brother
<b>Bhojan</b>	Eating and giving food to others to eat
<b>Bhulna</b>	Memory loss; forgetfulness
<b>Bi:ṛi:s</b>	Unfiltered cigarettes
<b>Buddhāpan</b>	Old age
<b>Būṛhā</b>	Old people
<b>Cha:y</b>	Tea
<b>Dada</b>	Paternal grandfather
<b>Dadi</b>	Paternal grandmother
<b>Dal</b>	Lentils
<b>Dekh</b>	See
<b>Dekhānā</b>	To show
<b>Dekhnā</b>	To see
<b>Didi</b>	Older sister
<b>Dikhnā</b>	To be seen
<b>Doctor sāhib</b>	Doctor sir
<b>Gāyatrī-mantra</b>	Highly revered mantra, based on a Vedic Sanskrit verse from the <i>Rgveda</i>
<b>Ghar ka kha:na</b>	Home-cooking
<b>Guru</b>	Teacher, mentor and spiritual guide
<b>Guṣṣa</b>	Anger
<b>Hakim</b>	Doctor in <i>Unani</i> medicine
<b>Hāth-pair</b>	Hands and feet; used to suggest the functionality of the body
<b>Ilāj</b>	'Cure' and 'to treat medically' in Hindi, Urdu, Persian, Arabic and Turkish
<b>Jhāṛ-poṛch</b>	Conjuring, exorcising; incantation, sorcery, hocus-pocus (particularly to cure a disease)
<b>Kala jādū</b>	Black magic
<b>Kāmzori</b>	Weakness
<b>Ḳha:mosh</b>	Silence
<b>Kurta:s</b>	A kind of tunic
<b>Masa:la:</b>	Spices

<b><i>Mataji</i></b>	A term of respect for a maternal figure
<b><i>Nani-ma</i></b>	Maternal grandmother
<b><i>Pa:gaal</i></b>	Mad
<b><i>Parathas</i></b>	Unleavened flat-breads made by pan frying whole-wheat flour. Often served hot and drizzled with ghee
<b><i>Pra-ṇām</i></b>	Blessing from an older person
<b><i>Prasad</i></b>	Food that is blessed from the temple
<b><i>Rotis</i></b>	Unleavened flat-breads made from wheat flour without oil (unlike <i>parathas</i> which are fried)
<b><i>Sarkari</i></b>	Government
<b><i>Sathiyana</i></b>	'Gone sixtyish,' to become senile
<b><i>Seva</i></b>	Service, filial respect
<b><i>Ṭhakur</i></b>	Feudal lord or powerful land owner
<b><i>Vaid</i></b>	Āyurvedic doctor
<b><i>Wallah</i></b>	Suffix used to indicate a person involved in some kind of activity
<b><i>Unani</i></b>	Islamic medicinal systems with Greek roots
<b><i>Ẓid</i></b>	Stubbornness

## THE PROFESSOR

Remember me? I am Professor Seth.  
Once I taught you geography. Now  
I am retired, though my health is good.  
My wife died some years back.  
By God's grace, all my children  
Are well settled in life.  
One is Sales Manager,  
One is Bank Manager,  
Both have cars.  
Other also doing well, though not so well.  
Every family must have black sheep.  
Sarala and Tarala are married,  
Their husbands are very nice boys.  
You won't believe but I have eleven grandchildren.  
How many issues you have? Three?  
That is good. These are days of family planning.  
I am not against. We have to change with times.  
Whole world is changing. In India also  
We are keeping up. Our progress is progressing.  
Old values are going, new values are coming.  
Everything is happening with leaps and bounds.  
I am going out rarely, now and then  
Only, this is price of old age  
But my health is O.K. Usual aches and pains.  
No diabetes, no blood pressure, no heart attack.  
This is because of sound habits in youth.  
How is your health keeping?  
Nicely? I am happy for that.  
This year I am sixty-nine  
and hope to score a century.  
You were so thin, like stick,  
Now you are man of weight and consequence.  
That is good joke.  
If you are coming again this side by chance,  
Visit please my humble residence also.  
I am living just on opposite house's backside.

- Nissim Ezekiel (2000)



## INTRODUCTION

Nissim Ezekiel, a renowned Indian poet, died in 2004 from Alzheimer's disease. In his poem, 'The Professor,' Ezekiel encapsulates the nature of ageing and modernity in India. The ageing Professor Seth, with his 'usual aches and pains,' gives voice to the meanings behind health, family, class and values in a rapidly changing sub-continent. A man of virtue in his youth, the Professor in his old age, has no heart, diabetic or blood pressure problems. With his middle-class sentiments and Hindi-English vernacular, his trials include touches of melancholy and loneliness. His wife has died and in his retirement he rarely ventures out.

Many of the families interviewed in this ethnography are like Ezekiel's Professor: people of means, middle-class, educated, and retired. The men have been military men, accountants and civil servants, the women homemakers and government employees. They've lived relatively quiet lives, snug in their colonies for decades, having 'settled' their children, and prepared for their retirement. For some, retirement is a time to holiday, lie on Greek isles, and visit adult children in Singapore and the US. For others it is a localised change of pace: 61 year old Radha Menon told me, "Retirement means that one should go to the park; in facing old age now and one should fulfil one's aims."

For these families, dementia is a surprise, an unexpected and sometimes unknown illness. But as change transforms their world, all these families have adapted. They lead new lives shaped by illness, urbanisation, altered gender

roles and different understandings of love. This thesis explores these practices. It offers an insight of what is to come, as India – like the rest of the world – undergoes its own demographic transition. Improvements in public health and medical treatment, increases in the age of mortality and reduced fertility are the major factors driving this change. As the number of older people in the population will grow, so too will the prevalence of age-related chronic diseases (Prakash, 1999).

Dementia typically affects people above 60 years, with the highest prevalence (24-33 percent) in people aged 85 years and over (Blennow, de Leon & Zetterberg, 2006). According to Indian census data, the number of people aged above 60 years has grown from 55.3 million in 1991 (total population = 846 million), to 71 million in 2001 (total population = 1 billion), and is expected to more than double to 173 million people by 2026 (total population 1.3 billion) (Census of India 2001). Consequently dementia rates are also projected to triple, from 24.3 million people affected worldwide in 2001 to 81.1 million people affected by 2040 (Ferri et al., 2005a). The areas that will experience the greatest increase will be the South Asia and Western Pacific regions, particularly India and China, where rates are expected to escalate by 314-336 percent in four decades (Ferri et al., 2005a).

Current rates of prevalence for dementia are reportedly low in India, ranging between 0.8 percent to 3.5 percent (Pandav, Chandra, Dodge, DeKosky & Ganguli, 2004). However there are variations in the numbers, with figures ranging from 13.6/1000 people aged over 65 years in Ballabgarh (Chandra et

al., 1998), 18/1000 in Mumbai (Vas et al., 2001), 27/1000 in Chennai (Rajkumar & Kumar, 1996), to 33.6/1000 in Kochi (Shaji, Bose & Verghese, 2005). Such differences can be explained by methodological variances in population groups (urban, rural or tribal), sample recruitment (door-to-door or hospital-based), case identification method (by layperson, health professional or psychiatrist), screening instruments (different survey instruments and questionnaires), case confirmation methods (differing standards for best practice), and statistical procedures used (Gururaj, Girish & Issac, 2005).

These methodological differences are embedded in culturally diverse contexts, and are influenced by factors like location, language, money, education and conflicting beliefs about health (Kalaria, 2003). Statistical discrepancies notwithstanding, given the size of the Indian population, the actual numbers of people with dementia are relatively high. In 2001, 1.5 million people in India were estimated to have dementia, the third highest number in the world (Ferri et al., 2005a). Though no reliable data is available for Delhi, approximately 15,000 people were estimated to be living with dementia in 2007 (Mohan, 2007).

### **What is Dementia?**

According to the *Diagnostic and Statistical Manual, Version IV (DSM-IV)*, dementia is an umbrella term for a number of disorders including Alzheimer's disease, vascular dementia, dementia due to HIV, and Parkinson's disease (American Psychological Association (APA), 2000). The characteristic features of dementia are the development of multiple cognitive deficits that include

memory impairment and at least one of the following cognitive disturbances: aphasia (lack of language abilities), apraxia (inability to perform complex movements), agnosia (inability to recognise), or a disturbance in executive functioning. These cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning, and must represent a decline from a previously higher level of functioning. Causes may include the direct physiological effects of an unrelated medical event (e.g. stroke caused by cardiovascular disease), the persisting effects of a substance (e.g. alcohol abuse), or multiple etiologies (e.g. the combined effects of cerebrovascular disease and Alzheimer's disease) (APA, 2000).

About 50 percent of all progressive dementias are diagnosed as Alzheimer's disease. Although a range of typologies exist, these can be characterized most simply into three stages of symptoms – mild, moderate and severe (Hansberry, Chen & Gorbien, 2005). The first stage involves mild cognitive impairment, with minor alterations in language and memory. In the second, behavioural changes are more visible, including marked cognitive and memory difficulties, increased agitation, wandering and disinhibition, at times compounded by psychosis and/or depression (Kennedy, 2003). Severe or late-stage dementia includes diminished higher cortical, cognitive, executive and motor function. People with late-stage dementia are often incontinent, have limited social skills, severe personality changes, long term memory loss, and at the terminal phase are usually bed-ridden (Kennedy, 2003). They require constant care for all activities of daily living, including eating, moving, toileting and bathing.

The official history of Alzheimer's disease began in 1906, when German neuropathologist Alois Alzheimer documented the case of Auguste Deter, a middle-aged woman whose symptoms began with memory loss and disorientation, followed by depression, hallucination and eventual death. In 1910 German neuropsychiatrist and nosologist Emil Kraepelin labelled these symptoms 'Alzheimer's disease' (AD) and went on tentatively (if falsely) to distinguish AD and 'senile dementia' by age at onset – younger persons were affected by AD, senility struck the old (Holstein, 1997). However at this time, psychiatrists and neurologists did not distinguish senility from normal ageing (Holstein, 2000) and this created uncertainty in the AD paradigm: if senility was part of old age, and AD was simply senility afflicting the young, then what distinguished AD from normal ageing? According to Alois Alzheimer, the answer lay in neuropathology. His research focused on tissue staining to search for neurofibrillary tangles and beta amyloid plaques in the brain. However his second confirmed case of AD, Johann F., was found to have no neurofibrillary tangles in his brain on autopsy. Nevertheless the plaques and tangles theory held, and recent advances in genetics and neuroimaging have made the classifications between dementias more not less uncertain (Whitehouse, Maurer & Ballenger, 2000).

To date, there are no ideal biomarkers able to differentiate, with a diagnostic sensitivity and specificity of more than 80 percent, between the neuropathology of AD and other dementias (e.g. Lewy-body dementia) or even between AD and the neuropathology of non-dementing individuals (Blennow et al., 2006). There is a clinical diagnostic accuracy of around 80 percent sensitivity and 70 percent

specificity in all AD diagnoses (Knopman et al., 2001). Consequently, the term 'age-related dementia' (usually just dementia) is commonly used nowadays (Blennow et al., 2006). In this thesis, the terms 'Alzheimer's disease' and 'dementia' are used interchangeably to underscore the symptoms common across various dementias.

The diagnostic overlap between the categories 'ageing,' 'Alzheimer's,' and 'dementia' requires further scrutiny. The development of AD as a disease category remains ambiguous. Gaines and Whitehouse (2006), taking a processual view (seeing disease development as an ongoing, never finished, social process), have shown that scientific (psychiatric, psychological, neurological and behavioural) and political factors are associated with making AD distinctive as a disease. They point to how epidemiology has been strategically employed to make the case for a 'ticking time-bomb' where, with demographic transitions, millions of people, ageing across the world, become susceptible to AD. The concomitant caregivers' burden, individual and national health, economic and social costs often accompany this apocalyptic view, forming the basis from which to lobby for greater funding for medical research for a 'cure.' There has been an increase in pharmaceutical intervention (and profiteering for drug companies), even though these drugs only target particular symptoms rather than the entire condition. In the public perception, these symptoms can sometimes become proxies for the entire condition. By way of example, cholinergic drugs only target recall memory, a subtype of memory, and have limited benefit for patients, yet these are the *only* drugs approved for AD (Gaines & Whitehouse, 2006).

Gaines and Whitehouse's argument is that while AD should be of concern, the extra-scientific factors – personal biases and strategic manoeuvres – which influence disease construction do not facilitate deeper understanding of the condition itself. AD is not just memory loss, even though it may be most commonly marketed that way – the slogan of the Alzheimer's and Related Disorder's Society of India is *Remember those who cannot remember*.

Kraepelin's initial labelling of 'Alzheimer's' as a disease was influenced by his personal connection to Alois Alzheimer and their mutual interest in benefiting the Royal Psychiatric Clinic in Munich by the 'discovery' of a new disease (Gaines & Whitehouse, 2006). Kraepelin's contribution to psychiatry and psychiatric diagnoses was institutionalized in the DSM by self-styled 'neo-Kraepelin' researchers, who have produced more sophisticated categories of disorder, biological etiology, and prognosis of all psychiatric phenomena based on the original studies on prognosis and syndromes (Good, 1992). A major shortcoming in Kraepelin's work and the DSM is the assumption that the phenomenology of psychiatric illness and the ways in which distress is articulated is universal across cultures. 'Universal,' often western, disease categories have been criticised by anthropologists, who argue that professional nosologies of illness, particularly psychiatric disorders, are entrenched and informed by different cultural perspectives (Good, 1996, 2002; Kleinman, 1980, 1988; Mezzich et al., 1999). Culture, language, income, education and conflicting beliefs about health, alongside neuropathology, determine the symptoms of diseases like Alzheimer's (Leibing & Cohen, 2006).

## Ageing and Memory in India

In India, there is a popular association between ageing and concomitant decline in memory, cognition, and function. Research done in Goa (Patel & Prince, 2001) established that although the symptoms of dementia were widely recognised, these were perceived as a normal part of ageing and not an organic brain syndrome. Shivbaksh Chand (87), who cared for his wife, Helen, said, “It is not a dreaded disease, it’s not like cancer or anything like that. It is a normal disease of old age.” Similar conceptions exist in other parts of India; in Hindi, dementia symptoms can be referred to as *sathiyana* or ‘gone sixtyish’ (Cohen, 1995), *chinnan* (‘childishness’) in Malayalam (Iype et al., 2006), and *nerva frakese* (‘tired brain’) in Konkani (Patel & Prince, 2001).

Research undertaken elsewhere in Asia also identified local idioms associated with dementia and ageing (see Ikels, 2002; Traphagan, 2009). Rather than mere change in terminology, these linguistic difference also signal variations in understandings and symptoms of dementia and more broadly about health (see Leibing & Cohen, 2006). In China, mental function is not equated with cognitive capacity, for as long as a person is doing what is right through the observance of social roles, he/she is seen to be thinking ‘rationally’ with both heart and mind (Ikels, 2002). In Japan, *boke* or senility is not seen as a disease but as a condition preventable through being physically and mentally active and socially engaged (Traphagan, 1998). These beliefs differ markedly from western understandings of dementia as a clinical pathology, and underscore the local biologies at play. Discourses about the body are shaped by the embodied experiences of individuals, which in turn are underpinned by their local biologies and cultures

(Lock, 1993). Lawrence Cohen (1998, p.xv) makes the important point that:

To call things *dementia*, a clinical term, presumes a focus on the pathology of the individual. To call things *Alzheimer's*, a pathophysiologic term, presumes a focus on a particular set of cellular and subcellular processes resulting in a certain neuroanatomical picture. Calling things *senility* leaves open the hierarchy of relations between the varieties of material and social processes at stake in understanding loss, voice, and the body in time.

In focusing on the hierarchy of relations and on how notions of care are imbued in legislative, psychiatric and biomedical knowledge systems in India, dissonances emerge between what dementia care *should be* as interpreted by policy-makers and clinicians versus how it *is experienced* by carers and people with dementia. The socio-cultural and political infuse understandings of bodies, brains and society. Such meanings may conflict with medical prescriptions and hold more sway over patients and families. To dismiss such alternative constructs is also to ignore the discourses about vitality, senility and madness that underpin them (Cohen, 1995, 1998). A computer-savvy carer explained to me how he understood dementia:

It is like an XP® operating system and you have Microsoft Office®. The operating system is separate and then you add whatever is in your biochemical environment interactions or interface. As you grow old, these things you lose but the basic operating system remains the same. The operating system is given in everybody, but what you have learned

in your life and what I have learned in my life is different and this is the only thing that is lost in dementia or in Alzheimer's as you call it.

In these carer's words, we hear an understanding of dementia, rooted in urbanisation, class and age, rather than just the ubiquity of Indian 'culture.' People may go 'sixtyish,' childish, and/or have a tired brain, but they may also be perceived as a man-Microsoft organism, with operating systems and biochemical interfaces. The cultural specificity of a middle-class, middle-aged, well-educated Delhite is heard in this carer's voice, but so too is an understanding of illness which is identifiable to those even with minimal technical know-how across the world. The stamp of capitalism and Microsoft's monopoly is felt, as well as the effects of technology on everyday life. The biomedical-technical lens frames understandings of dementia and provides the logic of how to obtain a cure. The need to move beyond understandings of dementia as pathology or culture is imperative; we need to examine this condition as a dialogic product of medicine, culture and technology. If, as Haraway posits, we are all cyborgs, "chimeras, theorised and fabricated hybrids of machine and organism" (2000, p.296), then in the following pages the nuances between tradition, modernity, technology, culture, India and abroad need to be explored.

### **Meanings of Old Age in India**

Traditionally, like other forms of care in India, elder care was organised under the joint-family system. Parents, their children, and grandchildren all lived in the same house, theoretically (if not always literally) sharing property and

income. The familial structure was patriarchal – men controlled social and economic matters, women managed household and other general affairs (Bhat & Dhruvarajan, 2001; Prakash, 1999).

According to Vedic Hindu philosophy, a person's life was demarcated into four life-stages or *ashramas*, through which the person was meant to progress: *brahmacharya* (studentship and learning), *grahasthya* (married householder), *vanaprastha* (a disengaged forest dweller) and *sanyas* (a wandering ascetic) (Kane, 1930, 1962; Manu & Bèuhler, 1964). The last two phases, which denote the process of disengagement from the minutiae of everyday life and deeper introspection of a more metaphysical sort, rarely occur in practice (Rao, 1993). Instead older people continue to live with their children and remain involved in their lives, and there is a social expectation of care from their children based on intergenerational reciprocity and the importance of doing *seva* (Lamb, 2000; Vatuk, 1990).

*Seva*, literally service, is a layered concept that links the social body to individual ones. It is the intellectual, emotional and physical care of elders based on respect, with such care likened to a form of divine worship (Vatuk, 1990). In the act of seeking *pra-ṇām* (blessing), for example, a younger person bends down to touch the dust of an older person's feet to their head, exactly as devotees do to the figures of their deities (Lamb, 2000). Older people are deferred to and younger people are expected to comply with their requests, seek their advice and follow it, not argue or talk back, and display appropriate respect by always using familial titles to address them (*dada* – paternal

grandfather; *dadi* – paternal grandmother) or the more generic ‘uncle’ and ‘aunty’ for unrelated elders (Lamb, 2000). There are also more tactile dimensions to *seva*. Younger people, most often the *bahus* (daughters-in-law), are expected to serve older family members their meals, indulge them with treats (usually sweets), launder and mend their clothes, and lay their bedding. More physical, intimate aspects of care such as massaging legs, oiling backs, combing and braiding hair, and even bathing and toileting infirm elders are also performed as a part of *seva* (Lamb, 2000).

*Seva* is not a simple hierarchical relationship whereby younger people are subjugated and older people deified. To provide *seva* is also to exercise power, to reveal the decline and decay of ageing bodies, and symbolically to relocate older people to the peripheries of everyday domesticity (Cohen, 1998; Lamb, 2000). The social expectations of performing *seva*, the acts mandated by it – feeding, cleaning, clothing, sheltering, listening – underlie the disciplinary transitions that ageing bodies and ageing identities must undergo: from doing to accepting; from authoritative to ethereal selves. Similarly, *seva* serves to discipline younger family members, to set out the types of activities they should perform and where they should perform them (in the home).

How dementia complicates notions of *seva* by disrupting the ageing dyads of young/old, energetic/passive, deference/advisory will be explored throughout this thesis. The loss of memory, the loss of the ability to give *pra-nāṃ*, the loss of continence, and the loss of ability to care for oneself, irrespective of whether the older person ever formally cared for themselves, shift the perception of ageing

bodies from wise to worn out. This is reflected in local languages used to describe dementia (e.g. tired brain, gone sixtyish). Also there are cognitive assumptions which underpin *seva*. Sylvia Vatuk's (1990) work on ageing in Delhi found that while older people felt they had a legitimate right to be supported and cared for by their adult children, they simultaneously experienced a kind of 'dependency anxiety' that they not be a burden upon the finances, labour and emotional resources of the household. This dependency anxiety only applied in circumstances where the older person felt that their physical or mental health was deteriorating. If that were to occur, then they felt that their position within the family would alter from being in receipt of *seva* to being dependent or subordinate to one's children, i.e., moving from the role of venerated elder to needy person (Vatuk, 1990).

Traditional paradigms of care have been transformed by globalisation and the perceived threats of modernity. Cohen (1998) and Lamb (2000) found a link in popular discourse and in Indians' perceptions of a 'bad' old age and modernity. Migration, urbanisation, consumerism and the changing role of women in contemporary Indian society have raised questions about family dynamics and, by extension, the changing nature of elder care. Migration, whether from rural villages to urban cities or from India to overseas, tends to shift familial structures from a joint familial unit to a more nuclear unit. Such migratory patterns also have implications for the care of older family members who are left behind and, in some parts of India, have given rise to a common acronym – PICA – Parents in India, Children Abroad (Prince & Trebilco, 2005).

Women's roles in India have also changed from home-based primary carer to full-time paid worker, even after marriage. Consequently women have a reduced availability and willingness to care, and families overall are less likely to be able to meet all the medical, social, financial and psychological needs of their elderly (Patel & Prince, 2001). When combined with urbanisation, growth in consumerism and the adoption of supposedly more 'western lifestyles,' there is a perception that older people are not as securely positioned in their family's hierarchy nor are they as revered as previous generations were (Dharmalingam, 1994; Jamuna, 2003; Kumar, 1996; Mahajan, 2006). Sarah Lamb's (2009) work on old age homes in Kolkata, for example, explores changing notions of aged care and the proliferation of old age homes in urban India. Canvassing the vehement positive and negative reactions to this change, she makes the point that "Indians take such emerging and novel modes of serving the ageing to represent a profound transformation – a transformation involving not only ageing per se, but also principles underlying the very identity of India as a nation and culture" (Lamb, 2009, p.89).

Within this context, meanings of dementia are culturally embedded in a discourse where 'senility' is not only a consequence of old age but also of the increasing crises of modernity. Cohen (1998, p.17), in his comprehensive analysis of Indian gerontology, notes when the "universalist' biomedical languages of dementia are interpreted through cultural and moral filters, dementia is not just plaques and tangles in brains but also a senile pathology ... located in family dynamics and cultural crisis." Modernity creates 'bad' fractured families where a lack of respect for the elderly translates into greater

numbers of senile old people. The only way to prevent senility in this paradigm is through the continued respect and reverence for older peoples which is to occur via the preservation of the traditional family (Cohen, 1998). Elder care thus becomes a publicly prescribed intensely private familial duty.

Even in highly industrialised societies, older people, including those with dementia, are usually cared for privately, conventionally by family members, until such time as the demands of care are too great for family members to undertake alone (Gort et al., 2007; Lesage et al., 1994). In countries like India, formal support systems are usually absent and broader socio-cultural beliefs articulate the role of families in caring for older people, so care for people with dementia almost always occurs within the private sphere (Prince & Trebilco, 2005).

### **Thesis Overview**

Differences between institutional and familial ideas of care result in local variations and tension between ideals and practical realities. How Indian families negotiate such tensions, provide care and interpret the meanings invested in the process, has not been widely researched. With the primary exception of Cohen (1998), little ethnographic work in India has focused on the experiences of caregivers or key service providers involved in age-related dementia care. In redressing this gap, this thesis adds to current research around dementia care in developing world contexts. The analysis presented here aims to portray complex montages around age and care. It will aid public health planners in designing culturally appropriate interventions through

understanding the local idioms on dementia and ageing, the personal experience of caregiving, the functioning of stigma in daily life, and the social and cultural barriers in accessing support. The main research question is: *In New Delhi, India, how are middle-class people with age-related dementia cared for and what are the barriers to carers to access support?*

The project aims:

- To describe and analyse lay understandings of age-related dementia, including cause, management and prognosis
- To explore experiences of providing care to people with age-related dementia in New Delhi, and the extent to which this varies by gender, caste, class and age of care provider and care recipient
- To examine how stigma is operationalised in everyday life in New Delhi in relation to caring for a person with dementia
- To investigate support systems available for carers of people with age-related dementia in New Delhi, and
- To explore carers and key service providers experience in accessing support for dementia care in New Delhi, including understandings of rights and entitlements, as well as practical and structural barriers to support.

I have adopted a critical ethnographic approach to address these aims. Understandings of *seva*, body, illness, hope and kinship are positioned within wider political economies, class and gender inequities, and questions of rights, access and citizenship. These key themes run throughout the thesis; each chapter builds on its predecessor to illuminate another aspect of care-giving.

The first three empirical chapters (Chapter 3, 4 and 5) are closely related and should be read as a triptych. They take the reader on a spatial journey from the home to the hospital and back again. Beginning in Chapter 3 with the heuristic processes of diagnosis, of 'seeing' and 'being seen,' in Chapter 4 I seek to contextualise practices such as doctor shopping via an analysis of the history of the doctor-patient relationship in India. Multiple meanings of health are explored: how power and medicine are intertwined, the effects of medications, the hope that people seek from a cure. In Chapter 5, I explore the costs people incur in care work, the subjective emotional hurts they bear and the objective financial outlays they expend. In these chapters, I also describe the environments in which care is given, the resource scarcities of the public health system, the pressures doctors work under, the exploitations by class, and the agency of people in this terrain.

In Chapters 6, 7 and 8, I move away from the medical to explicate social and cultural aspects of care. In Chapter 6, I explore the critical role of food – cooking, feeding and eating – in care work. Food and its links to *seva*, citizenship, hunger, waste and love are examined, as is the role of surveillance and management of the body. In Chapter 7, I build on the theme of surveillance by examining how the bodies of people with dementia are managed to mitigate against stigma. I ask whether there is a stigma against people with dementia and return to the heuristic processes of 'seeing,' discussed in Chapter 3. But the gaze is inverted as one is asked to see normality in abnormality. Stigma, I argue, need not be

dramatic and deep to be grievous; it may happen through small slights which, when combined, create feelings of pain and isolation.

Chapter 8 uses the elements of a Bollywood film to listen to the voices of people with dementia. Through song, dance and poetry, relationships can be formed and people may express themselves in creative and poignant ways. I also explore death and dying in dementia, describing how people conceive of death, the political economy of dying, and the new biopolitics of capitalism and organ donation.

Lastly, I explore the theme of love. Love flows implicitly throughout this work, both in the intimacies that people with dementia and their families share with each other, and in the love I feel for this work. This has been the happiest discovery of my intellectual journey: the personal and professional intimacies to which I have been privy and tried to express. I find myself after three and a half years still very enthused and deeply in love with my topic, just like the people in these pages who, after 30 years or more of marriage, found themselves in love with their spouses.

This thesis is data-driven. Participant's voices are paramount. I have tried to let them speak, to converse within the text to academia, to concur and disagree with each other and their interlocutor. Their speech is interspersed with Hindi, Hinglish (Hindi and English), and with the flavours of British-Indian English; these differences will be evident in the quotes used. The task of reading will not

necessarily be easy, but will yield a deeper insight into India, and help establish a stronger sense of who these people are and how their lives transpire.

This does not mean the thesis is atheoretical. There are many familiars operating at macro, micro and personal levels. Michel Foucault (1975; 1980; 1977) and his ideas of power and discipline, capitalism, economy and class (Navarro, 1976, 1982), Kleinman's local moral worlds (2006) and stigma (Yang et al., 2007). Present too are Veena Das, Arjun Appadurai and Sudhir Kakar, weaving their way throughout the work, teaching me how to think and write, to try and capture the complexity of India, gender, transnationalism, sexuality, food and medicine (Appadurai, 1996; Das, 2001; Kakar, 1990). Cohen (1998), Lamb (2000) and Vatuk (1990) have been my constant companions, trekking through chapter after chapter, well-thumbed and well-travelled. They offer points of similarity and contrast, the yardstick by which to gauge changing ideas of ageing in urban India. I draw too on public health, epidemiology, biomedicine, literature, film and cultural studies. But there is a hierarchy of evidence; I play favourites with the anthropologists.

In the following chapter, I describe the methods used to collect data, the characteristics of the sample I worked with, and the unique aspects of interviewing in India. Like Ezekiel's Professor, I invite you into my humble residence – to read of kinship, health, ageing and love in contemporary urban India.



## CHAPTER 2:

### METHODS



**Figure 1: Experiencing the 'Field'**

I kept diaries from 1<sup>st</sup> January 2008 to 10<sup>th</sup> October 2008. Volumes were filled in coffee shops, temples, stairwells and at my desk, on my fieldwork experiences, frustrations, and longings for Australia and my de facto partner, who was on his own fieldwork adventure elsewhere. These journals gave me great comfort, offering an avenue to vent and tangible evidence of my efforts at gathering data. I am deeply attached to them. To my mind they signal my anthropological rite of passage and offer an insight into the messiness of my personal growth. I see in these diaries honest descriptors of what Nita Kumar (1992, p.1) defines as fieldwork, “that brash, awkward, hit-and-run encounter of one sensibility with others.”

In this chapter, I draw on these diaries to contextualise my experiences and explain the methods used to collect data. While on the one hand, I recount a rigorous, evidence-based approach, I balance this against the specificities of India and the habitus of my participants' lives. The research design, participant recruitment, interviews and observations, techniques of analysis, and limitations of the study will be outlined, alongside the cultural idiosyncrasies of my interviews. My participants often perceived me as a doctor, interrupted interviews, displayed consent in unique ways, and confounded any attempts to categorise them. I return to these themes later.

For me, fieldwork was an intensely personal experience where few things were done purely for 'scientific' reasons. Such an observation could apply to most research projects, shaped by the serendipitous unfolding of funding, priorities, ethics committees, fieldwork demands, and the researcher's own biases in analyses and written representations. These hidden subjectivities and more obvious drivers often create discrepancies between what is outlined on paper and what was enacted in practice. The methods initially proposed may differ significantly from what was done and there can be solid justifications for such changes – cross-cultural differences in conceiving researcher-participant relations, inappropriateness of certain scales and questionnaires to particular contexts, and hitherto unexplored avenues which are only discovered once in the field and which merit further investigation. Additionally in-situ gender, class, and race relations, language proficiencies, and wider forces of globalisation, capital, and politics determine whether methods need to be changed. Such points are not new, well documented in journals like *Field*

*Methods and Qualitative Inquiry* and by authors such as Norman Denzin (2005), Paul Rabinow (1977) and John Law (2004) (to name a few).

But in illustrating the discrepancies between methods-*on-paper* and methods-*in-practice*, there is a risk of compromising the 'scientific' validity of the work and leaving one's credibility open to question. Should a doctoral student write about ruptures in her methods in her thesis? I draw counsel from my anthropological elder Paul Rabinow (1977, p.5) who argues that if the strengths of anthropology lie in its experiential, reflective and critical capacities, then it behoves anthropologists to challenge the positivism of those projects which aim to study human behaviours without accounting for their own humanities.

### **Research Design**

This study used a critical ethnographic approach to explore the lived experiences of families caring for people with dementia in India. The foci are on how culture, political economies, class, gender and illness shaped understandings of care and its practices. Ethnography was the most appropriate method to explore such issues. Defined as "that form of inquiry and writing that produces descriptions and accounts about the ways of life of the writer and those written about" (Denzin, 1997, p.xi), ethnography elucidates people's viewpoints from an insider perspective. Using 'thick description' – describing the minutiae of detail, fleshing out context – the ethnographer shows how she reaches particular interpretations. Simultaneously, she acknowledges that her perspective is only one amongst many and, therefore, is 'intrinsically incomplete' (Geertz, 1975, p.29).

Critical ethnography incorporates observation and interviews and a dialectic relationship with the discipline of anthropology itself. It has grown out of sharp appraisals of early anthropology's connection to colonisation and empire, and how western anthropologists tended to represent the non-western 'native' (see Marcus & Fischer, 1986; Said, 1978). Equally influential have been postcolonial feminist writers (see Harding, 1987; Spivak, 1995), who have championed researcher reflexivity and alternate modes of representation. Critical ethnographies focus on relationships, language, and objects of encounter in local and transnational settings, seek to elucidate flows of power, document the effects of political and economic forces alongside culture, and advocate ethnographer reflexivity (Herzfeld, 1987; Marcus, 1995).

I applied this approach in my data collection and analysis. My aim was to try to capture people's worlds and the structures that underpin them. Reliability and validity were ensured by the triangulation of interview (n=74) and observational data (approximately 250 hours), discourse analysis, and document reviews (Angen, 2000; Whitemore, Chase & Mandle, 2001). I collected data from multiple groups (e.g. families, people with dementia, clinicians, Non-Government Organisation (NGO) workers, and government officials), and have compared and contrasted their views throughout this thesis. I observed in clinical settings and families' homes as well as in the broader community. Representations of caregiving in government documents, medical bodies, and film narratives have been analysed (see Brijnath & Manderson, 2008, Appendix 5.1). These methods, when compiled, provide a complex

montage which expiates the differences between how care *should* be given and how it *is* given.

### **My Spiritual Museum for Character Building**

Data were collected in Delhi, augmented with brief work in Kolkata, Bangalore and parts of Kerala. I also travelled to smaller north Indian cities like Dehradun, Amritsar, and Jaipur. During these trips I interviewed key service providers, observed caregiving in different contexts, and gained insight into the multiplicity of Indian societies by geography. Sometimes these cities began just as an escape from Delhi.

In total I spent 9.5 months in Delhi and 10.10 months in India. I selected Delhi as the principal field site for a number of reasons: the paucity of research work on ageing in the region since Lawrence Cohen's (1998) study, the cultural pluralities of the city, and my familiarity with the surroundings. Much of the work on dementia in India is undertaken by members or affiliates of the 10/66 Dementia Research Group, an international network of over 100 researchers (Prince et al., 2004). In India, their work has been concentrated in the western and southern regions, in places like Goa, Kerala and Tamil Nadu. Many 10/66 researchers reside in these states and have established linkages with the Alzheimer's and Related Disorders Society of India (ARDSI), which supports people with dementia (discussed later). ARDSI Chapters in the south and west tend to be better resourced than their northern counterparts, and it is easier to mobilise participants and conduct research on dementia in these areas. By way of example, nine of the twelve epidemiological studies undertaken to ascertain

the prevalence of dementia have been undertaken in these regions. The north and east of India are relatively unexplored. I was also keen to ascertain how understandings of dementia in urban north India had changed since Cohen's work in the early 1990s.

Delhi and north India differ markedly from the rest of the country because of variations in language, local economies, education, politics and the role of women. With a population of 12.7 million people, Delhi is the third largest city in India after Mumbai (16.3 million) and Kolkata (13.2 million) (Census of India 2001, 2006). But this figure is misleading: Delhi is part of the National Capital Region (NCR), approximately 30,000sq km of conurbation which includes parcels of land from neighbouring states Uttar Pradesh, Haryana and Rajasthan (NCR, 2010). The genesis of the NCR can be traced to the Delhi Master Plan of 1962, where to alleviate pressures on existing resources, nearby villages were rapidly industrialised to become satellite cities (NCR, 2010). But the agglomeration trend has even older roots. Since the 15<sup>th</sup> Century, Delhi has been the site of empires built, conquered, abandoned, plundered and rebuilt. The city is said to comprise seven cities – Quila Rai Pithora, Mehrauli, Siri, Tughlakabad, Firozabad, Shergarh and Shahjehabanad – and is often dubbed a 'city of cities' (Vidal, Tarlo & Dupont, 2000).

More recent additions to Delhi's metropolis include Gurgaon, Noida, Faridabad and Ghaziabad. In close proximity to Delhi, these locales are linked via public transport, commuters flow across the borders on a daily basis, and there is little difference between them and 'old' Delhi in terms of urbanisation. There are of

course differences according to socio-economic status.<sup>1</sup> It is difficult to estimate the actual population of the NCR. Official figures put it at 16.6 million in 2007, and unofficially at 21.5 million for the same year (Sharma & Haub, 2007). These numbers make Delhi the largest city in India and growing; population increases are projected at 102 percent from 2001-2026 (Census of India 2001, 2006). In real terms, that is an increase of 1 million people every three years (Luce, 2006). The capital has experienced the highest rate of demographic growth consistently since 1951.



**Figure 2: Delhi**

Delhi's growth can be attributed to the influx of people from other parts of India, especially the neighbouring states of Haryana, Punjab, Rajasthan and Uttar Pradesh. Young people, mostly men, come to Delhi in search of

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<sup>1</sup> Some of the markers of difference between wealthy and poor suburbs include density of living (there are bungalows in richer suburbs; apartment blocks squashed together in poorer ones), the size and state of the roads (wide, smooth roads versus crumbling roads with potholes), and the supply of services like gas, water and electricity (poorer areas will get considerably less than wealthier ones).

employment in the formal and informal labour economies, while women migrate predominantly for marriage and as part of migrating families (Dupont, 2000). Though young people under 25 years constitute the majority of the population (49.48%), the proportion of people over the age of 60 years has also been increasing (Government of National Capital Territory of Delhi, 2006).

Currently, there are approximately 829,000 people in Delhi over the age of 60, about 5.5 percent of the population (in 2001, the percentage was 5.2). Older people aged 60-69 years make up 65.68 percent of the older people in Delhi, thus making the population relatively young-old (Government of National Capital Territory of Delhi, 2006). Just over half (51.8 percent) of the elderly live with their spouse and children, a third (27.6 percent) without their children, 14.4 percent without their spouse and only with their children, and the remainder live with others (whether extended family or friends). Of those elderly who live alone or with their spouse, nearly 40 percent live in the same building as their children, 28.5 percent live in the same area, and about 30 percent live in another town or village (Government of National Capital Territory of Delhi, 2006). Seventy percent of the elderly in Delhi are financially supported by their children, 22 percent rely on their spouse, a marginal 2.7 percent look to their grandchildren for financial aid and 4 percent are supported by others (Government of National Capital Territory of Delhi, 2006). Such figures indicate that despite the 'perils' of modernity, families have adapted and found ways to support and live within pseudo joint-family systems in urban environments.

Although it is the fastest growing city in India, Delhi is renowned for inspiring indifference and dislike from many of its residents (Vidal et al., 2000). Even the Chief Minister, Sheila Dixit, has described Delhi as “the most crass and show-offish city of the current times” (Dixit cited in Soofi, 2008). Personal safety is a key issue, contributing to the city’s reputation as hard and dangerous. Such perceptions are borne out by statistics: in 2008, 22.4 percent of all reported rape cases, 30.5 percent of kidnappings, 15.3 percent of dowry deaths, and 15.4 percent of all reported molestation cases in Indian cities occurred in Delhi (NCRB, 2008).

During my 2008 stay, the grisly story of 14 year old Aarushi Talwar made headlines. The teenager was found in her bed with her throat slit and several stab wounds to her face. The Indian media sensationalised the story and the local police corrupted most of the forensic evidence. Subsequently, the case remained unsolved and died its own ignominious death. I remember discussing the case with a carer, Shilpi Mukherjee (72), who clucked her tongue and said, “In Delhi these days...”

Growing up in Kolkata (1982-1993) and Delhi (1993-2000), I recall Delhi as an aggressive city publicly overlaid by a kind of hypermasculinity and consumerism. As a teenager and then as a young woman, I remember having to manage not only my own body and sexuality, but also those of the men around me when I went out. ‘Eve-teasing’ (verbal and physical harassment) on the street was commonplace. When I returned in 2008, I anticipated similar experiences. My initial attempts at finding a place to stay met my worst

expectations. Many housing agents showed me horrible places, and landlords were quick to establish 'extra' terms and conditions upon discovering that I would be living alone. Some wanted me to be 'pure vegetarian,' others to impose a curfew and have me home by 10:30pm or else remain locked out all night; still others would neither permit houseguests nor visitors with the exception of my parents or close female friends.

These tactics were irritating and a huge blow to my feminist heart. They seemed to conform to my worst assumptions about how women were perceived. But as time went by, I realised that the city had changed in the near decade since I had moved away. We had both matured, becoming stronger and less aggressive. The eve-teasers had dropped off in numbers and life seemed a little less Hobbesian than before. As I gallivanted around this uneasy city by myself, earning the nickname *Ghumantru* (wanderer) from ARDSI staff, I felt safer than I ever had in the past. Post fieldwork, as the sweet glaze of nostalgia overlays my memories, I see the city as my spiritual museum for character building (See Figure 1).

I also soon came to realise that the 'extra' terms that landlords laid on me reflected local ideas of morality, femininity and tenancy, and are embedded in a discourse of reciprocity and kinship. The standard line often went: "*Beta* (child), you will be like a daughter in this house. Anybody can come and go, no problem – but no boys." While this made these terms neither equal nor fair, in these reciprocal relations, I did come to be daughter in many houses and *didi* (older sister) in others. Claiming kinship is common in India. People are connected to each other through terms of address like *bhaiya*: (brother), *didi* and *mataji*

(mother). Being connected is important because through such networks all manner of activities, legal and illicit, transpire. Class, gender, age, social capital, income, ethnicity, and education are implicit within this paradigm. In Delhi, one must be and is connected, whether by fair means or foul, and in a city of millions, though one may sometimes be lonely, one is never alone.

I eventually found a place to live in a steamy *barsathi* (two rooms on a terrace) in central South Delhi. My landlord, senior Mr Papneja, who I called 'sir,' though initially uninterested in forging kinship alliances, inevitably became family. I often found myself babysitting his great-grandchildren during their summer holidays and being fed *ghee-parathas* by his wife, whom I called *mataji*. When I was not around, my mail and my ironing would be left in their house; and when I ran terrified from the lizards, Papneja senior installed a mesh screen on my windows. I came to know the family quite well – Sir and his wife *Mataji*, their son and daughter-in-law Kuku and Sheelu, their grandchildren Summi, Aditya and Vicky, and their great-grandchildren, Neeti, Suresh and Noddy.

The *barsathi* was my haven, tucked in the bottom of the lane with only a silk-cotton tree for company. However, as the heat increased, more residents arrived – lizards, ants, bees, birds, mosquitoes, an assortment of other bugs, and the occasional cat. By summer, the vegetable prices had soared, cold water came out of the hot water tap because the water in the geyser was cooler than the water in the tank, and the fans whirled relentlessly. The *loos* began to sweep through the city and these dust storms exacerbated the existing dust, turning clear 43 degree skies grey-blue and the vegetation brown.



**Figure 3 (left): The silk-cotton tree outside my *barsathi***

**Figure 4 (below): Delhi on the move**



Only the inner sanctums of the city, enclosed between the Inner Ring Road and Connaught Place in South Delhi, remained gorgeous. Diplomats, politicians, senior government officials and old money lived there on wide, spotless roads, behind guarded green fences. For these people, seasonal changes entailed not many alterations in lifestyle – they were buffered against power-cuts, water shortages and blistering heat by their political and literal connections to generators, water tanks and air-conditioners. These Delhi elite easily switched from pegs of whisky and polo-necks in winter to gin and linen *kurta:s* in summer. The rest struggled with chronic electricity and water shortages, and were grubby in their vests and shorts.

Amidst the inequality and heat, there are redeeming qualities to the city, noted also by others (see Dalrymple, 1994; Singh, 1989). As the political capital of

India, ministries, public offices, headquarters of national airlines, railways, census boards and archives are located in Delhi. Media empires are clustered here alongside major universities, corporations, and hospitals, including the widely regarded All India Institute of Medical Sciences (Cadène, 2000). I visited many of these sites as I collected data. There were also film festivals, playhouses and old friends to keep me company. The construction of metropolitan rail, shopping centres, highways, and bus lanes gave the city movement, helped along by unceasing traffic. The din floated into my *barsathi* every evening, along with the tunes of the latest Bollywood hit, *Mauja, Mauja!* (naughty fun). During this time the lizards and I battled it out for supremacy over the terrace. I repeatedly lost.

### **The Alzheimer's and Related Disorders Society of India (ARDSI)**

I recruited my participants through The Alzheimer's and Related Disorders Society of India, Delhi Chapter (ARDSI-DC). The advantages to working with ARDSI were fourfold: (1) people with dementia were already clinically screened and diagnosed, (2) families had a pre-existing relationship with biomedicine and were able to comment on the quality of treatment, (3) ARDSI's volunteers worked closely with people with dementia and their carers, and had knowledge of the family's history, which assisted in identifying potential participants; and (4) ARDSI was there to provide support to families should they become distressed during the research, and was able to act as a source for any complaints about the research process (though fortunately neither happened). This approach strengthened the collaborative process and introduced a measure of transparency and accountability to participants.

ARDSI is a relatively young organisation, established in 1992 by Dr. Jacob Roy and a number of other doctors, most of who come from Kerala in south India. At the time of writing (2010), Dr. Roy is still chairman, the head office is based in Kochi, Kerala, and the ARDSI Board still comprises many original members, mostly neurologists and psychiatrists. The aims of the organisation are to provide information and services for people with dementia and their families across India. These aims are in line with the goals of Alzheimer's Disease International, an umbrella organisation of national Alzheimer's associations throughout the world, of which ARDSI is a member. ARDSI has 14 Chapters based in cities across India, and offers a range of services such as day care, domiciliary care, geriatric care training, caregivers' meetings, and guidance and counselling. However not all services are available at every Chapter, because each Chapter has to source its own funds and is reliant on local donations and the goodwill of volunteers. Paid staff and continuity of funds are scarce, and this impacts on each Chapter's capacity to offer services (ARDSI, 2006).

In approaching ARDSI, I first gathered the support of the chairman Dr Roy, when I met him at the 2007 Alzheimer's Australia Annual Conference in Perth. In this early conversation, we tried to map how ARDSI could help, but since I was dealing with the semi-autonomous Delhi Chapter, this was never entirely clear. Once I arrived in Delhi, the ARDSI Delhi president gave me a list of tasks with the gentle caveat, "Perform or be on the periphery and redundant." Fortunately this ultimatum was in line with the services I had planned to volunteer, and so these demands were not onerous. I found myself writing newsletters, filling log books, mobilising volunteers, assisting with functions,

preparing grant submissions, and dispensing strategic advice. I gained insight into how the organisation functioned – the office politics, finances and quality of service delivery.

The Chapter was small, staffed only by three workers paid via donation, a handful of dedicated volunteers, and a perspicacious president. It was sustained through material and monetary donations. In 2008, two old computers, floppy disks and one cranky printer were the only technical equipment available. The volunteers were in their fifties and sixties, and came from affluent backgrounds. Women tended to be housewives and the men semi-retired. Often their children and grandchildren were married and settled elsewhere. Working for an NGO was one amongst many pursued activities, like kitty parties,<sup>2</sup> book clubs and golf. There were a few disgruntled key service providers who perceived these volunteers as ‘high society ladies’ dabbling in charitable endeavours. But based on my observation there was little doubt of their hard work and commitment. Volunteers travelled long distances across Delhi in heat, traffic and dust; bullied, cajoled and wheedled funds from their rich friends to donate to ARDSI; and gave generously of their own money and possessions (air conditioners, computers, tables, chairs, curtains, examining tables and so on). Many had parents or friends who had died from Alzheimer’s disease. Some had been carers and recipients of ARDSI services prior to joining as volunteers, and these people were especially dedicated.

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<sup>2</sup> Kitty parties are women-only social gatherings typically held on weekdays during the daytime. They are usually attended by middle-class and wealthy housewives either in individual’s homes or at a public venue (e.g. restaurant). Kitty parties are notorious in Delhi for being gossipy and materialistic.



**Figure 5: ARDSI volunteers training poor women to be home attendants**



**Figure 6: ARDSI raising awareness about dementia in a local Delhi school**

Free medicines were dispensed to poor people, the volunteers trained women living in slums to become home-care attendants, and awareness raising sessions did take place in low income neighbourhoods. But by and large, the membership of ARDSI-DC consisted of middle-class families and common social understandings of class between the volunteers and families enabled volunteers to most effectively counsel these families. These families were most likely to attend caregiver's meetings and champion their rights. Poorer families had neither the inclination nor the resources to travel to ARDSI-DC's office. They would not attend functions such as World Alzheimer's Day or ARDSI-DC's Founders Day. For them, the location of these events, in elite parts of south Delhi, were barriers themselves. The need for ARDSI-DC to expand its purview to better include poorer families was recognised by people within the NGO. The

Delhi Chapter President and staff began to forge partnerships with other organisations which worked with lower income groups. When I left, these relationships were in their infancy but I have little doubt that with more money, mature partnerships and professionalisation, the organisation will achieve great things.

## **Participants**

### The Families

Families caring for people with dementia were members of ARDSI-DC who had been recruited via volunteers. I accompanied volunteers on visits to people's homes (n=13 families recruited), attended official functions and meetings (n=4 families recruited), and spent many hours in two public hospital Out Patient Departments (OPDs) (n=3 families recruited). These OPD sessions, which I describe in greater detail in subsequent chapters, also functioned as ARDSI-DC 'Memory Clinics' on designated days. The two doctors, who ran the OPDs in their respective hospitals, were well-known specialists and board members of ARDSI-DC. They gave me permission to observe in their consultation rooms and from their referrals, I managed to recruit three families.

Face-to-face contact was critical to successful recruitment. In six cases, volunteers had obtained consent over the telephone from families to pass their details onto me. Despite repeated follow-up and explanation about my project, these interviews never occurred. People would indirectly rescind through claims of not having enough time, household renovations, and preoccupation

with other tasks. If I was put off twice, I would remind people of my mobile number and ask them to contact me when they were available. None ever did. Conversely, those with whom I had face-to-face contact gave consent and made time for our interview soon after. These early meetings were an important opportunity for potential participants to judge me, establish rapport, and ask questions about the project and my personal life.

In total, 46 interviews were conducted with 20 families over 10 months. The sample was relatively cross-sectional: there were 17 Hindu families and one family each who were Christian, Muslim, and Sikh. Twelve families were from north India (e.g. Punjab, Uttar Pradesh, Kashmir), four from south India (e.g. Kerala, Andhra Pradesh), one from West Bengal, and two Punjabi families had migrated from Pakistan during Partition.<sup>3</sup> Geographically the families were spread across Delhi; eight families lived in south Delhi (including Gurgaon), seven in the west (including Dwarka), four in the east (including Ghaziabad and Noida), and one in the north (see Figure 7).

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<sup>3</sup> When British India was partitioned in 1947 into India and Pakistan, approximately 14.5 million Hindus, Muslims and Sikhs cross these newly drawn borders to where they felt they were in religious majority. Muslims went to Pakistan, Hindus and Sikhs to India. Delhi received the largest number of refugees for a single city; its population increased by almost a million from 1947 (917,939 people) to 1951 (1,744,072 people) (Butalia, 2002).



**Figure 7: The National Capital Region**

Given the composition of the ARDSI-DC database, the majority of families were middle-class (n=15), the remainder affluent (n=5). Ascertaining monthly income was not viable because many carers had retired and relied on their children and/or pensions for financial support, and so their monthly incomes fluctuated considerably. In my observations, wealthy families tended to live in bungalows or large apartments in very exclusive suburbs. They had chauffeurs who drove their Japanese or German cars, holidayed annually or bi-annually in places like Europe or Singapore, and had additional rental properties elsewhere in the city along with share and investment portfolios. Middle-class families lived in apartments in colonies, usually had one modest hatchback which they drove themselves, holidayed within India or nearby Bangkok, and tended not to

discuss their additional assets (if they had any). Among those who were in the middle-class bracket, three families were lower middle-class and struggled to make ends meet; the rest were financially stable. Those who struggled were thrifty – they rarely went to the movies or shopped for new clothes, took buses rather than auto-rickshaws, and often bought diapers and medicines on credit. For example, Suneeta Sadhwani (41) would bring her 74 year old father with dementia to the ARDSI-DC office on a crowded bus, because she could not afford the Rs 70 (AUD 1.70) it would cost to come via auto-rickshaw.

Caste was not cited by any of the families and in my observations, the vertical interdependence of caste did not appear to explicitly structure families' interactions with the wider community. Dumont's (1980) *Homo Hierarchicus*, with its strict accounts of purity and pollution, seemed well and truly displaced by other measures of inequity such as wealth, income, education and occupation. Such findings have been reiterated in other studies, which also note the increased competition among caste groups for limited political and economic resources (see Ali, 2002; Beteille, 1997; Fuller, 1996). While as an overt category, caste did not resonate in my thesis, this does not mean it was absent; in chapter 5, I describe how it was articulated within the domestic politics of the household.

Among those I interviewed, there were more men with dementia than women (n=12 to n=8; mean age 76.05 years). Epidemiological findings from urban India reveal that dementia is associated with increases in age but not gender (Shaji et al., 2005; Vas et al., 2001). In line with the feminisation of care, the primary

carers were mostly women (n=17; mean age 52.65 years), including the wives (n=7), daughters (n=6) and daughters-in-law (n=4) of the person with dementia. This does not mean that men played no role in caregiving, rather that they assumed more supportive or secondary roles. But even here, women almost doubled men as secondary carers (n=11 women to n=5 men).

Categorising family members into primary and secondary carers is problematic, however, because in some families, more than one person saw himself or herself as primary caregiver. In the Sen–Hamdari–Kaul family, for example, Kumud Kaul lived above her parents, Mr. and Mrs. Hamdari, and would oversee the cooking, cleaning, and the care of her mother, Mrs. Hamdari (who had dementia). Nayantara Sen, Kumud’s younger sister, lived a short distance away but visited her parents everyday to supervise the administration of medications, check the medical supplies, organise refills, and accompany her mother to doctor’s appointments. Mr. Hamdari, though responsible for almost no aspects of his wife’s care, spent all day with her and knew the most about her personality and mood swings. To categorise their efforts as primary, secondary or even tertiary diminished the important work each person performed, and undermined the collective nature of the care given to Mrs Hamdari. Nevertheless I have arbitrarily coded one family member into each category to compile basic demographic information about the overall sample. This has been done for easy understanding of the relations between families and has only been mapped so deterministically in Table 1. In the remainder of the thesis, such distinctions have not been made. All names and identifying details have been changed to protect participants’ anonymity.

### Key Service Providers (KSPs)

I have defined a key service provider as any person providing in a formal capacity direct health, care or social support to people with dementia and their families. Initial participants were recruited via purposive sampling and from there, snowballing techniques were used. Interviews (n=21) were conducted in Delhi, Kolkata, Kochi and Bangalore with clinicians, NGO workers, paid attendants, government officials and the police. Most KSPs had dual responsibilities such as a medical practice and working for an NGO or government department. For example, 10 KSPs had a clinical qualification, and six of these were also members of ARDSI. Additionally, there were more male KSPs than women (12 and 9 respectively), and men tended to have much higher positions of authority than women (e.g. of 10 clinicians, 7 were men and 3 women).

**Table 1: Demographic Data of Families (Pseudonyms have been used)**

PED <sup>1</sup> Name	PED age	PED's PC	PC <sup>2</sup> name	PC age	PED's SC	SC <sup>3</sup> name	SC age
<b>Mrs. Meenakshi Ranjarajan</b>	78	Daughter	Mrs. Parviti Gowda	43	Son	Mr. Gopal Ranjarajan	-
<b>Mr. Rajesh Kumar Menon</b>	71	Wife	Mrs. Radha Menon	61	Daughter	Mrs. Rajni	-
<b>Mr. Sudhanshu Talwar</b>	78	Daughter-in-law	Mrs. Savitri Talwar	-	Son	Mr. Hemant Talwar	
<b>Mrs. Helen Meena Chand</b>	82	Husband	Mr. Shivbaksh Chand	85	-	-	-
<b>Mrs. Meera Chopra</b>	80	Husband	Mr. Kundan Lal (K.L.) Chopra	88	Daughter-in-law	Mrs. Rubina Chopra	-
<b>Mr. K.P. Aggarwal</b>	69	Wife	Mrs. Sita Aggarwal	63	Daughter-in-law	Mrs. Mamta Aggarwal	-
<b>Mrs. Lakshmi Kumari Kochar</b>	92	Daughter-in-law	Mrs. Sarojini Kochar	69	Attendant	Ms. Sonu	21
<b>Mr. C.K. Sethi</b>	81	Daughter-in-law	Mrs. Chandana Sethi	-	Wife	Mrs. Sonali Sethi	
<b>Mr. S.T. Pillai</b>	87	Daughter	Ms. Nandini Pillai	52	-	-	-
<b>Mrs. Hema Jaiswal</b>	85	Daughter	Mrs. Bhageshwari Srivastava	41	Daughter	Ms. Gayatri	-
<b>Mr. Gautam Mukherjee</b>	88	Wife	Mrs. Shilpi Mukherjee	72	Attendant	Mrs. Sandra Anu	39
<b>Mr. A.P. Arora</b>	79	Daughter-in-law	Mrs. Vandhana Arora	38	Wife	Mrs. Mrigakshi Arora	74
<b>Mr. Hari Prasad Sadhwani</b>	74	Daughter	Ms. Suneeta Sadhwani	41	-	-	-
<b>Mrs. Sheila Tandon</b>	58	Husband	Mr. Govind Ballabh Tandon	58	Attendant	Ms. Payal	22
<b>Mr. Karanjit Bhagat</b>	75	Wife	Mrs. Nina Bhagat	70	Son	Mr. Vikram Bhagat	-
<b>Mrs. Shanti Hamdari</b>	80	Daughter	Mrs. Nayantara Sen	58	Daughter	Mrs. Kumud Kaul	60
<b>Mr. Surinder Dharam Singh</b>	56	Wife	Mrs. Josephine (Josie) Dharam Singh	52	Attendant	Santosh	-
<b>Mr. Harinder Singh</b>	60	Wife	Mrs. Jaspreet Kaur	55	Son	Ajit Singh	28
<b>Mr. Qasim Omar Khan</b>	65	Wife	Mrs. Shafia Khan	54	Son	Naseer Khan	21
<b>Mrs. Anjali Sood</b>	83	Daughter	Ms. Namita Sood	53	Daughter	Ms. Aditi Sood	-
1. PED = Person experiencing dementia		2. PC = Primary carer		3. SC = Secondary carer			

## **Procedures**

Interviews were semi-structured and while broadly focused on dementia care, questions were adjusted according to participants background and settings. For example, police were not asked about diagnosis, management and prognosis of dementia, just as clinicians were not queried about crimes against the elderly. All KSPs were asked about the impact of gender, caste, class and income in families' health-seeking behaviours, the role of stigma (if applicable) in lay perceptions of dementia, the support systems available, and the barriers (if any) which families and KSPs encountered when accessing such systems. Interviews with KSPs and family members were generally about one hour long, after receiving informed consent. Where permission was granted, interviews were recorded and transcribed. KSP interviews were conducted in their workplaces and all interviews with families took place in their homes.

Non-participant observation was undertaken in some KSPs' workplaces, i.e. two government hospital Out Patient Departments (OPDs) in Delhi. With the permission of hospital clinicians, I attended these OPDs to observe standard clinical care practices for people with dementia, doctor-patient communication, and the impact of factors such as time, patient load, multiple work demands, and availability of resources, on these processes. Each observation session was approximately two hours and detailed field notes were taken immediately after I left. Approximately 21 hours of observation were undertaken, spread over 10 months.

Topics covered with families included diagnosis, treatment, management of symptoms, pleasures and difficulties of carework, experiences with neighbours, friends and broader society, and changing relationships within the home. While interviews with families tended to last for approximately an hour, each visit to their home lasted between two to four hours. During this time participant observation was undertaken, meals were shared, and friendships built. I noted how carers and people with dementia experienced care in the private familial setting, the routines, restrictions and negotiations around particular activities, communication strategies, and techniques of containment. I had initially planned to follow the non-participant observation approach used by Briggs and colleagues (2007; 2003) in their work on dementia care, at home, in England. But I quickly realised (as they did) that becoming 'part of the furniture' during observation in such settings is impossible. While Briggs' participants tolerated and sometimes even forgot the researcher's presence, my arrival in people's homes was an occasion, marked by food, conversation, and in the early days, a carnivalesque atmosphere. The first time I went to interview Chandhana Sethi, her two sisters-in-law, mother-in-law, and father-in-law were there during the interview. Tea, biscuits and sweets were served, everyone wanted to be recorded, and MRIs and medical histories were pulled from dusty cupboards. Similarly, in my second interview with Shivbaksh Chand, a friend from the local health dispensary across the street was called to witness and participate in our interview.

Once I realised the carnival (and therefore the gravitas) of my interviews with families, I knew non-participant methods would not work. A more organic

stance had to be embraced, which offered space for multiple realities, playfulness, irony, pastiche and parody (Grbich, 2007). I often found my interviews and observations neither went to plan nor conformed to any textbook prescriptions on how to do an interview. What I thought would happen rarely did. Instead there were three distinctive features which disrupted traditional interview paradigms: (1) people's assumption that I was a medical doctor (2) the lack of privacy and frequent interruptions during the interview, and (3) the unique ways consent was given for the participation of people with dementia in this study. I deal with each of these in turn.

### **“Madam Has Come, the Doctor Has Come”**

By doing research on a health-related subject, I was often assumed to be either a medical doctor or, at least, a medical student. Accordingly an array of health problems and information were presented to me: leg pain, back pain, weakness, depression, heart problems, MRIs, X-rays, and test results. Despite telling people that I was not a doctor, they persisted in treating me as such.

Such behaviour cut across gender, age and education. Lower middle-class people would typically call me ‘doctor *sāhib*’ (doctor-sir) or ‘madam,’ as they told me in graphic, unsolicited detail about their various ailments. Higher-income groups would address me by name rather than as ‘doctor,’ but implicitly assumed that I had a wealth of medical knowledge which could help to alleviate all kinds of distress. Specifically with dementia, families would frequently ask how they should understand the dementia diagnosis, manage medication, deal

with difficult behaviours (such as violence, incontinence, paranoia, and sleeplessness), what to do in palliative care, and how to treat co-morbidities (like cataract, diabetes, and diarrhoea).

Initially such questions caused me considerable anxiety, and numerous referrals were made to doctors and NGO workers. To me, these questions signalled a lack of awareness about dementia and reflected the poor communication between doctors, NGOs and people. Yet I persisted in referring people to health services, convinced this was the only ethical way to proceed. After a while, such referrals came to seem foolish. If health services had consistently failed to communicate effectively, then sending people back there again and again, with neither new information nor confidence to ask new questions, was a waste of their time and health services resources. I had to be more proactive in assisting families and to intervene directly in some cases. The Indian health system is hierarchical and a 'researcher' has more access, acceptability and authority with a doctor than patients or their families. So I began to accompany many families to the doctor, made suggestions to them at home, and functioned as a source for them to express their frustrations. I never dispensed medical advice but in some cases – such as where drug dosages for anti-psychotics had remained unchanged for over three years – I would encourage carers to go to their doctor and ask purposely about these practices. In the following chapters, I will show how I intervened – how I helped the Hamdaris with medication and the Chands with script refills – and how these families (and I) grappled with the medical uncertainties of care.

I also came to realise that people addressed me as ‘doctor-*sāhib*’ not just because they conflated medicine and medical anthropology, but also because it was a way to show respect. People generally had deep admiration for doctors and those who were called ‘doctor-*sāhib*’ were located in a biomedical paradigm. In traditional medical frameworks, practitioners are more likely to be referred to as ‘*vaid-ji*’ or ‘*hākim-ji*’ (Jain, 1969). In calling me ‘doctor-*sāhib*,’ families situated me in the biomedical camp. This was further cemented by my transnational background (Indian-Australian), high levels of education, and ease with the English language (Chapter 4 describes the class differentials between biomedicine, traditional and transcendental medicine). Families were appreciative of the efforts I made to understand their perspectives, some like the Chopra family perhaps a little too much – they tried to pay me Rs500 for interviewing them and were only dissuaded after I promised teary-eyed Kundan Lal that I would return and accept *prasad* (food that is blessed) from their local temple.

### **The Interrupted Interview**

In this study there was no such thing as an uninterrupted interview. Phone calls, visitors, cooking, and household chores always occurred simultaneously. In doctor’s clinics, patients, files, and consults all occurred at the same time as the interview. Interviews were frequently paused, and an hour of tape could sometimes take two hours to record. In one case, a KSP halted our interview midway to dash off to a conference and we were only able to resume our conversation the following week.

In addition, there were a number of surprise additions to the interviews. Participants would brief their colleagues, friends or extended family about the research project and invite them to participate. I was never informed about these additional subjects, who would often arrive halfway through the interview, sometimes to participate and at other times to observe. Occasionally the person with whom I had arranged the interview, would get up and leave halfway, and this secondary person would enter as the new subject and keep the conversation going.

Trying to obtain prior informed consent from these secondary voices under such circumstances was not possible. Rather than disrupt the interview to brief them on the project and get their consent, I would silently check with them that I could use the tape-recorder. Once the entire interview had concluded, then I would brief these participants on the project and ask if they were happy to participate or have their contributions excluded from the transcript. None rescinded.

But while people were happy to give verbal consent, publicly disclose medical histories (whether solicited or not) and reveal body parts, there was a profound distrust of written consent. Irrespective of their education and life experiences, people did not want to sign the consent form. None of the families and many KSPs declined to sign. The documents were perceived as threatening, with potential legal ramifications. In one of my interviews with a clinician (who also has a research profile), a legal representative, dubbed a 'well-wisher,' was present during the interview. The representative only left once the participant

was assured that he did not have to sign the consent form. Participants' unwillingness to sign consent forms also highlights different notions of consent and researcher-participant relations as compared to western countries. Researchers have noted that consent in many developing nations tends to be collective, follows from extensive consultation, and is perceived as an opportunity to build relations between researchers and participants over time (Gikonyo, Bejon, Marsh & Molyneux, 2008; Marshall, 2006). Communities in the Asia-Pacific region hold to these ideas, and colleagues and I have described the dissonance between ethical review processes in Australia and the challenges of obtaining consent in this part of the world (see Czymoniewicz-Klippel, Brijnath & Crockett, 2010, Appendix 5.2).

### **The Failed Protocol**

There is increased criticism of ethics committees and research projects that focus on dementia but exclude the participation of people living with this disease (see Bartlett & Martin, 2002; Dewing, 2007; Hellstrom, Nolan, Nordenfelt & Lundh, 2007; Swain, Heyman & Gillman, 1998). However in my initial research design, I did not intend to actively recruit people with dementia. Trying to shape a path that gave voice to the experiences of people living with dementia, while building in safety nets in the event that they became distressed, was not straightforward. As I will show in subsequent chapters, in India, there is a documented lack of proper medical care and little formal support; the onus rests entirely on the family. The challenge was how to include caregivers and people living with dementia into the project, while satisfying the university's

Ethics Committee's requirements to minimise participant distress and do no harm in what were inherently distressing situations.

Thus a complicated procedure was developed: first the person with dementia had to initiate contact with their primary carer and/or me to express their desire to be interviewed. Then the primary carer had to agree and abide by a *Protocol to Minimise Interview Distress for People with Dementia*. The protocol involved the following: after the primary caregiver gave permission to access the person with dementia, the basis for consent was to be established by identifying the usual presentation of the person with dementia and, more importantly, the early signs of distress. The time and place under which initial consent was given was to be recorded. Then, the interview would commence with ongoing monitoring for signs of distress or withdrawal of consent. Both the interviewer and primary caregiver (who in theory could see but not hear the interview) were to be engaged in this, and, finally, debriefing and provision of feedback and support for both the person with dementia and the caregiver was to be offered by me (if necessary). The protocol echoed Dewing's (2007) 'Process Consent Method,'<sup>4</sup> but lacked the organic seamlessness of her approach and relied too much on the participation of the carer and not the person with dementia. If the former declined to assist, then the interview with the latter could not proceed. The protocol actually risked excluding people with dementia.

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<sup>4</sup> Dewing's (2007) method for interviewing people with dementia is as follows: background and preparation, establishing the basis for consent, initial consent, ongoing consent monitoring, and feedback and support.

In practice the Protocol was ineffective and never used. Two reasons explain why: (1) identifying the primary caregiver and (2) caregivers' use of my presence to validate themselves as 'good' caregivers and 'good' human beings. I have already discussed how categories such as primary and secondary were problematic because multiple people saw themselves in these roles. Such sharing of responsibilities, though common, made it difficult to identify from whom to seek permission to access the person living with dementia.

More importantly people with dementia were immediately accessible to me when I visited families' homes. There was no opportunity for them to approach me and express a desire to be interviewed; instead people with dementia were bathed, powdered, perfumed, and dressed in their good clothes before I had arrived. Those who were mobile would often be seated in their living rooms or would otherwise be propped up in bed. Families would insist I meet and talk to the person with dementia immediately. Then they would demand a response from me on the appearance and character of their loved one. I was frequently asked, "How does he or she seem to you?" These practices were part of the heuristic techniques used to manage images of normality, disruption, and mitigate stigma. I discuss this dynamic in detail in Chapter 7.

Initially these displays were confronting, and in the early days I would stammer to find a neutral answer. Later, as my relationships grew stronger with families, I was more forthright. I realised if I was to be 'doctor-*sāhib*,' then I might as well use this power and authority to effect some change, rather than simply collecting stories of care and only offering recommendations in a thesis four

years later. So in these later interactions, advice about additional medical consultations, new activities to pass the time together, and offers to accompany people to the clinic were made.

Consent from caregivers to talk with the person with dementia was often rooted in a need for self-validation rather than research altruism. Caring could be lonely and exhausting, with neither adequate feedback from health care professionals nor wider social support. And while caregivers, by putting their patients on display and inviting me to engage with the person with dementia, gave consent to these interactions, people with dementia either consented or rescinded in their own fashion. They would either verbally or through their body language indicate disinterest and an unwillingness to participate. I expand on some of these tactics in Chapter 8 when I describe how I learnt to listen to what people with dementia were telling me. Through cases such as Helen Meena Chand and Meera Chopra, I will show how those constructed as silenced and impaired, when heard and seen, were intelligible, irascible and filled with *joie de vivre*.

### **Professional and Personal Ethics**

Ethical ways of doing research can be classified roughly into two categories – institutional (formal) and personal (informal) (Guillemin & Gillam, 2004). In a formal sense, I obtained approval for the study from Monash University Human Research Ethics Committee, the Alzheimer's and Related Disorders Society of India, and the Government of India, which on issuing me with my Overseas

Citizen of India visa, advised that no further research clearance would be required.

In the field, my ethics were constantly tested. The previous sections have well described the difficulties associated with obtaining consent, the conflation with being a doctor, the lack of privacy in interviews, and my level of involvement in people's healthcare service. In the following chapters, I illustrate my inability to offer people hope, to intervene and ease the last days of people's lives, and to console those in mourning. In what I did (or did not do), I was not always who I like to think I am. The personal and the professional did not match; neither did the rhetoric and practice. Instead I found myself in what McLean and Leibing (2007) so evocatively call, 'the shadow side of fieldwork,' that ambiguous topography, full of light and shadow that frames how we view the field and our practices within it.

But if the intent is "seeing what frames our seeing" (Davies et al., 2004, p.364), then I need to further elucidate my position in this research. I am a member of a transnational family providing care to my grandmother with severe dementia. I have cared for her and am familiar with some of the complexities that imbue the caregiving process. These experiences have shaped my analysis and affected my relations with participants. In the field, I never shied away from discussing my grandmother and our family's experiences, but I did not seek to base my relations with my participants on such foundations. In subsequent analysis, I have tried very hard not to overlay my own caregiving experiences on those of my participants. My own family's journey – bonds of kinship, guilt, power,

citizenship and access – have been dealt with in earlier work (see Brijnath, 2009, Appendix 5.3) and I will leave it there. Reflexivity can quickly lapse into self-indulgence if overworked, and this thesis is very explicitly about the experiences of these families who I came to know in Delhi.

Lastly, I worked hard to build empathy and trust with all my participants, yet I cannot say that I became friends with them. My youth, gender and worldview in an urban, conservative, north Indian environment proved strong barriers (even though I tried hard to shut up and blend in most of the time). But I did build intimacy. The depth of connection between families and myself, forged at its own natural pace with some issues, emerging organically and in the intimacies of friendship (not researcher-subject), echoes what Tillmann-Healy (2003) describes as ‘friendship as method.’ These have made the stories rich and I am privileged to have shared them.

### **Analysis – Can You Smell the Writing?**

Interviews were conducted in Hindi and English, tape-recorded, then translated and transcribed in English, and imported into NVivo ver.8 for coding and thematic analyses. A similar process of transcription and data management was followed for the field notes. All identifying features of persons and places have been removed. In many places, words and phrases have been left in Hindi to capture their cultural specificity and complexity.

Analysis incorporated data immersion, data reduction, and identification of common themes (Askham et al., 2007). Field diaries were read multiple times,

before being typed and coded into broader categories, and then compared with the interview data sets for repetition and comparison, similarities and differences using inductive methods (Markovic, 2006; Ryan & Bernard, 2003).

Codes were identified using techniques of repetition, indigenous typologies, metaphors, transitions, missing data, and theory-related material (Olszewski, Macey & Lindstrom, 2006). From this, common themes began to emerge which were then subdivided where necessary (e.g. one subset of the 'Diagnosis' theme comprised 'tests' + 'theories of cause'). Meta-themes were created by relating data sets with cohorts or settings (e.g. 'tests' + 'KSP'; 'tests' + 'hospital'+ 'families') and re-examined in relation to the peer-reviewed literature. Such techniques ensured the rigor and validity of the data analysis.

Such a technical, mechanistic approach to categorise data has (hopefully) not been brought to bear on the quality of the writing. Rather the philosophy underpinning representation has been, "Can you (the reader) smell the writing?" A hermeneutic line of inquiry has been pursued to understand the dialectic between care practices and the discourses that frame them. Caregiving and care-receiving are complex processes that are determined by cultural, economic and political scripts. People draw on these scripts in their everyday lives to interpret their realities and act accordingly. In the thesis, I seek to explain such interpretations as historically situated and practically oriented. Thus an interpretative social science has been followed (Rabinow & Sullivan, 1987).

## Limitations

I do not consider the challenges outlined earlier – being confused for a doctor, interruptions during the interviews, and techniques of obtaining informed consent – to be limitations of the study. To my mind they represent the unique features of conducting interviews in India and are alternate ways in which mature, adult relations can be built and respect accrued. Such challenges are not hindrances to the validity or reliability of the data. In such settings adherence to a textbook pro forma of how an interview should be done, belies the fundamental points of an interview – to *listen* to what people have to say and to how they say it. Rigidity does not ensure the rigor of data; it only guarantees that while some mythical auditor’s checklist is ticked off somewhere, the people who participate in the study are less likely to consider participating again.

Nevertheless, there were some issues where the nature of my interviews did influence the kinds of questions which could be asked. For example, I never asked about sex. There is a dearth of work on the subject of dementia and sex anywhere; and limited work on sexuality and ageing, under any circumstances, in India. Sarah Lamb’s (2000) work shows that with age, there are somatic and sexual changes in identity. Women are meant to move from the ‘heat’ and ‘openness’ of the reproductive phase of their lives to a cooler, dryer post-reproductive life. Sexual energy is to be transformed into creative heat or *tāpas*, which can then be channelled into potent blessings and/or curses (van der Veer, 1989). Such changes are not gender-specific; men are also meant to be sexually ‘cooler’ and disengaged from everyday life in old age. Becoming ‘cooler’ and celibate marks the elder’s right to receive *seva* and ability to give *pra-ṇām*

(blessings). Diet is implicit within this paradigm, and increased simplicity and plainness of food is believed to control sexuality and enhance asceticism.

However in practice, people do not always adhere to this blueprint for ageing. More immediate needs of illness and intimacy may take precedence. Does sexual intercourse gradually stop because a spouse has dementia? How do marital relations change when demands for sex are increasingly made by the person with dementia? What if someone other than a spouse is propositioned? What are the alternate ways of enjoying intimacy? Such questions are not voyeuristic, but highlight points of transformation in caregiving relationships between spouses.

Families may also experience embarrassment because of inappropriate sexual behaviours, and although no family ever broached the topic with me, according to Paul Issacs, a neurologist I interviewed in Kerala, sexually inappropriate behaviour was far more common than admitted. Yet even he, with years of experience, could only recall one case where a family arrived in great distress because the 75 year old father with dementia was exposing himself to all the young women in the community. Sex and sexuality were rarely discussed by my participants and I could not ask about these deeply sensitive issues. They were inappropriate both because of the repeat interruptions and nature of the interviews, and because of my youth and gender in a relatively conservative city. The closest I got to talking about sex was in conversations around food, sugar and love. Even here, discussions were allegorical, inferences at best.

Another limitation to this study is that no poor families caring for a person with dementia were part of the sample. As explained earlier, the sample was middle-class and elite. The recruitment method, via ARDSI-DC, resulted in my coming into contact with few poor families. I tried to branch out and spent time in the government hospital OPDs to get a few more referrals from low-income families. But I had little success. I visited a district mental health clinic but the doctor was overworked and busy dispensing medications to a long line of people with schizophrenia and depression. No people with Alzheimer's were there either.

I also visited two slums on multiple occasions, and consulted the community health services serving these neighbourhoods. But these services focused on maternal and child health, immunisations and capacity building; the community nurses could tell me how many abortions, pregnancies and babies each woman had, but the old were not in their ambit. When I began to query the women in the slum, many described circuits of migration; older people returned to their village while younger members migrated to the city. A few younger members would remain in the village to care for the elderly and do *seva* for them. Every three months or so, women would migrate to and from the village to work in the city and to care for children and the elderly at home. If I 'really' wanted to talk to poor elderly people who might have dementia, I'd have to head into the rural interiors. But by this point it was April, I had been in India for four months, and I had already found my interlocutors. I decided that this was a research topic for another day. I have included material on attendants and domestic servants, and have tried to broaden the analysis on class by referring

to the peer-reviewed literature and my general observations. But such representations are one-sided, and there are no voices of poor families caring for a person with dementia.

I wish too that I had been able to pursue in greater detail logics and practices around transcendental medicine. I wanted to visit the practitioners that my participants had seen, but many had moved, stopped practising or were located in other cities. I did talk to an interlocutor who was familiar with the practices of Islamic transcendental healers but was not a healer himself. I unsuccessfully tried to persuade a community development worker from a local NGO in Nizamuddin to take me to the *dargāh*<sup>5</sup> and introduce me to various healers, and I harassed a friend to take me to another site in Delhi where another pocket of transcendental healers were rumoured to be. No luck with either person. I eventually visited the Nizamuddin *dargāh* myself, only to joyously learn about the *qawwālī*;<sup>6</sup> I returned many times over the year to hear these songsters. But I never saw the transcendental healers; most likely I did not know what I was looking for or at. Eventually I realised that I could either focus on dementia care, within the limitations of the biomedical paradigm, or, like Alice wandering down a rabbit-hole, spend my days in search of the exotic at the expense of what was right under my nose. I chose the former. But there is a lot to be said about transcendental medicine alongside the motivations which prompt anthropologists to go off in search of them.

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<sup>5</sup> A *dargāh* is a shrine where a saint is buried and is a site of worship. The Nizamuddin *dargāh* is where the renowned Sufi saint Nizamuddin Auliya is buried. Also located here are the tombs of Amir Khusro (Sufi mystic) and Jehan Ara Begum (princess), and nearby is the tomb of Inayat Khan (Sufi mystic).

<sup>6</sup> *Qawwālī* is a 700 year old form of devotional Sufi music popular throughout south Asia.

In the following pages, biomedicine is privileged. So is the middle-class and there is silence about sex. I have tried to counter these limitations with greater attention to class politics, discussions around love and relationality, and by situating biomedicine within the social and cultural context of Delhi and India. I have tried to be evocative, analytical and emotive in my writing. I want you, the reader, to come away moved but also feeling uncertain, unsure about India. No easy answers. In short, I want you to smell the writing.



## CHAPTER 3:

### DEKHNĀ: DEKHĀNĀ: DIKHNĀ:

My eldest daughter's father-in-law died and we all went [for the funeral] but he [Omar] wouldn't sit there. He was anxious about something. He would keep sitting down and standing up. From everything we could see, something was not right in his mind, something had become spoiled.

[Then] He went to Saudi [Arabia] for the Haj and when he came back, we could see from his eyes that something was troubling his mind. His mind wasn't working properly. He would confuse 1 lakh and 10 lakhs;<sup>7</sup> he would sometimes say the right thing and sometimes say the wrong thing. He would wear his clothes either inside-out or the wrong way round. In the beginning this was happening. Then at one time I had some land that had to be sold, and he experienced tension over this matter. "Bring the money," he said, which he had never said before. "Get the money from your mother and bring it. You've sold the land, now get your share and bring it to me." We wondered what had happened to him because my family were his relatives as well. I said, "Look at the way you're talking to your family. This is not the way," and I realised that there was something troubling him in his mind.

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<sup>7</sup> 1 lakh= AUD 2413.81; 10 lakh = AUD 24,134.35.

[So] we showed him to the neuro. Because what was happening was he would go out, he would travel all over Delhi but forget the way, he would drink a glass of water and forget that he had drunk it. We experienced a lot of problems at that time. And he would walk in the middle of the road, not on the side, and Delhi is such a city, that we would feel scared to send him alone. From these things, we felt that he was in some difficulty. So we showed him in the hospital. They did all the tests, it took a lot of time, we were in the line, and we thought it's better to show him in one day. They saw him and said, "He's not hurt, he's not in any pain, he has this kind of illness – Alzheimer's – and it is the kind of illness which is not going to get better. There is no medicine for this."

At that point, wherever anyone would say, we would show him there. We showed him here, we showed him there, there was no place we left or where we did not show him. We showed him in Apollo [hospital], in Ram Manohar [Lohia hospital], in Pant [hospital], in Safdarjung [hospital], everywhere we showed him. But they all said the same thing. No one said that he was going to get better. That was it (*Shafia Khan, 54*).

He is 56. Its four years since it has been diagnosed but it's been much more. I think it's been about 6 years since the symptoms started manifesting themselves. So [he was] 49, late 49, when I realised that things were just not right. He became very argumentative. You see suddenly from a very rational person, any inconsequential topic he would pick up, [and] would turn into almost a vicious argument. And if I

happened to be at fault, then it might turn into something physically violent which was very unlike him. I thought that my marriage was going to seed. It was frightening. And every time it used to happen, I used to cry fiercely and think, what is happening? Is he beginning to dislike me? What has gone wrong?

Then my daughter had this terrible problem [brain injury which required surgery] and we went to Trivandrum and he just didn't help me. He just receded into the background and there I had to explain everything to the doctor. And I was telling the doctor, "Doctor, he is not himself" and out of the blue, the doctor said, "Why don't you see a neurosurgeon?" I didn't realise what he was getting at because I was telling him the symptoms and he said, "Just go to this doctor and he'll check." And I went to Dr. Iyer who was supposed to be a specialist in dementia, and they asked him questions and said, "We'll just do these tests. We'll do a SPECT scan which hones into the area which is impaired." And lo and behold, they discovered that he had the symptoms of dementia (*Josie Dharam Singh, 52*).

Shafia Khan and Josie Dharam Singh live in south Delhi. They are women in their 50s, caring for their husbands, who are in the late stages of Alzheimer's disease. At the time of writing, Josie has already lost her husband; 'Su' (shortened from Surinder) has died. In all likelihood, Shafia is now a widow too. Both struggled to care for their husbands, and will now struggle with widowhood and a new way of living at mid-life. They have both lived with

Alzheimer's disease and sickness, managing not only their husbands, their families and themselves, but accomplishing the financial callisthenics necessary for caring on a shopkeeper and school-teacher's salary respectively.

There are many parallels in Shafia's and Josie's lives – marriage, children, illness, caring, widowhood, and the genteel poverty of middle-class families on meagre wages. But there are also many differences: Shafia is a still and contained woman, her voice even and resolute; she is Muslim, from a small town in Uttar Pradesh, who had an arranged-marriage to a member of her extended family with whom she had five children. She is with limited means but has pragmatically channelled her sewing talents into a little shop opposite her house, where she stitches 'suit pieces' for local women in her neighbourhood. Josie is a musician. She teaches piano at school and in private tuition, and plays in the Church choir where she devoutly goes every Sunday evening to reaffirm her faith. Her voice is like her piano; it can be sharp or flat as it lilts and flows. She is a spritely woman, leaping to tend to things, most especially her beloved Su, her Sikh husband, with whom she had a love-marriage and two children. Josie – Josephine – is originally from Andhra Pradesh in south India, and has little family in Delhi. Her parents are dead, her sister is overseas, and her children are grown, married and live elsewhere. Her in-laws, who live in Delhi, have not really given her strong support.

Neither woman has met the other, nor, with the exception of Alzheimer's disease, would they have much to talk about if they did. Josie can be broadly located as upper middle-class and Shafia would be classified as lower middle-

class. This is a question of capital and identity where gender, class, and religion “converge and produce instances of contestation and ambivalence” (Fernandes, 2006, p.166). On a more literal terrain, Shafia lives in a neighbourhood where there have been police ‘encounters’ (shoot-outs) with alleged terrorists. Josie lives about 3km away, in an area where security guards sit at the front of individual houses to prevent ‘encounters’ with miscreants.

Women such as Josie and Shafia illustrate that Alzheimer’s disease is not stratified by class, religion and socio-economic status. It afflicts people irrespective of their professional and moral careers, and is often not diagnosed until the second stage when behavioural symptoms become more prominent and carers are less able to ignore the social disruptions these produce. Yet early diagnosis is critical for better management of dementia. Finances and care plans (including palliative care) can be organised and with medication and therapies, a certain quality of life can be preserved (Alzheimer's Australia, 2007; Brodaty, 2005). “No time to lose!” is the catchcry for Alzheimer’s Disease International (2009), and picks up on the importance of greater public awareness of dementia, early diagnosis and optimal care, improved access to healthcare services, and of the rights of people living with dementia and their carers and families. These goals fit within broader frameworks on access, awareness and rights in healthcare. Questions on this framework are posed throughout the thesis, especially in Chapters 4 and 5.

In India, there are significant barriers in the public health system to obtaining a diagnosis and adequate treatment. There is little awareness in the Indian

medical fraternity, excepting specialists such as neurologists and psychiatrists, about how to diagnose and treat people living with dementia. This is due to the very limited inclusion of dementia in medical curriculum (although this is presently changing) and the acute shortage of mental health professionals (0.2 psychiatrists and 0.05 neurologists per 100,000 population) (WHO, 2005). Existing services are also under-utilised because of professional barriers (inability to diagnose or misdiagnosis, inability to treat), systemic barriers (poor infrastructure, inadequate supply of drugs, too few trained staff, and the use of culturally-inappropriate treatment models), and patient barriers that are either self-imposed or generated within the family or by its circumstances (stigma, distance from clinics, inconveniences of long-term treatment, and the low incentive because no cure is available) (Gururaj et al., 2005; Thara, Padmavati & Srinivasan, 2004).

Moreover, research has consistently shown, in India, that dementia and its primary symptom 'memory loss' have been perceived as a normal part of ageing (see Emmatty, Bhatti & Mukalel, 2006; Patel & Prince, 2001; Shaji, Kishore, Lal & Prince, 2002; Trivedi, 2003). *Sathiyana* or 'gone sixtyish,' in north Indian local vernacular, was identified by Lawrence Cohen (1998) in the 1990s, as broadly describing the mental symptoms of dementia – memory loss (*bhulna*), stubbornness (*zid*), increased aggression (*guṣṣa*), paranoia and suspicion.<sup>8</sup>

*Sathiyana* is a cultural category, and exerts a powerful influence in the construction of symptoms of social disruption and medical disease (Kleinman,

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<sup>8</sup> There is no specific word for paranoia or suspicion in everyday Hindi. It is explained via an analogy or through direct example.

1980, pp.76-77). While disease – objective signs and symptoms – may occur in a universal manner, illness – the experience of the disease, its symptoms and disruptions – is shaped by a specific context of norms, symbolic meanings, and social interactions (Kleinman, 1980, *ibid*). Amongst the families and people with whom I interacted, most of who were in their sixties and seventies, the term ‘*sathiyana*’ was rarely used. Causes for this research discrepancy include location (Cohen’s work was largely based in Varanasi, mine in Delhi), local cultures (Varanasi is a religious centre for Hindus, Delhi the political capital of India), changes over time in people’s attitudes (from the early 1990s to 2008), and different research cohorts (Cohen’s work focused on understanding meanings of senility, age and madness amongst a cross-section of Indian society whereas mine were largely middle-class and elite families).

Nevertheless, the term *sathiyana* serves as a useful analytic tool to conceptualise ageing, voice, and body in India and I use it as such in my analysis. *Sathiyana* is flexible, located within the broader cultural category of old age or *buddhāpan* in India. Old age, like middle-age, youth or childhood, is never just a chronological and biological marker of the life process, but also reflects culturally specific values, beliefs and practices determining the behaviour of people among and towards *būṛhā* or old people. In one’s *buddhāpan*, one may experience illness but one may also have gone sixtyish. Bodily decline and degeneration, which requires medical intervention, can co-exist alongside ‘normal’ ageing, which allows for physical infirmities and dysfunctions that require familial and not medical care.

This chapter examines heuristic processes whereby the cultural category – *sathiyana* – is translated into Alzheimer’s disease. Variations of the Hindi word ‘*dekh*’ (see) are used to show how families move from social understandings of memory loss to a biomedical pathology of degeneration. It will be argued that diagnosis is not a straight-forward process but occurs with time and in stages. This usually begins with a crisis leading to presentation at the clinic. Physiological and psychological tests follow, the diagnosis is determined based on these test results, and the family is informed. Violence and resistance from the family to such news are typically the initial responses. Acceptance of the disease is gradual; so are families’ explanations as to why this happened to their relative.

### **देखना – Dekhnā: To See**

According to the *Diagnostic and Statistical Manual Version IV (DSM-IV)* (APA, 2000), an early indicator and key diagnostic feature of dementia is memory impairment. Memory impairment, when coupled with either aphasia, apraxia, agnosia, and/or diminished higher executive functioning, may be diagnosed as dementia. These clinical features must manifest over a period of time; they must significantly impact on social functioning; and they must constitute a decline from the earlier capabilities of the patient. Refinements follow to categorise the dementia into its sub-types such as Alzheimer’s disease, vascular dementia, or multi-infarct dementia, via a battery of neuro-psychological, laboratory and other tests (APA, 2000).

But at the same time, as outlined in the introduction, memory loss, cognitive and functional decline are seen in India (and elsewhere in Asia) as the normal social markers of ageing. Ageing and becoming *būṛhā* are the basis for the receipt of *seva* by older people from younger family members. Consequently in many families with a relative with dementia, the initial symptoms were ignored in part because they were seen to be part of normal ageing and because of the care scripts governing *seva* (e.g. younger women cook for older people; sons might do their parent's bank work).

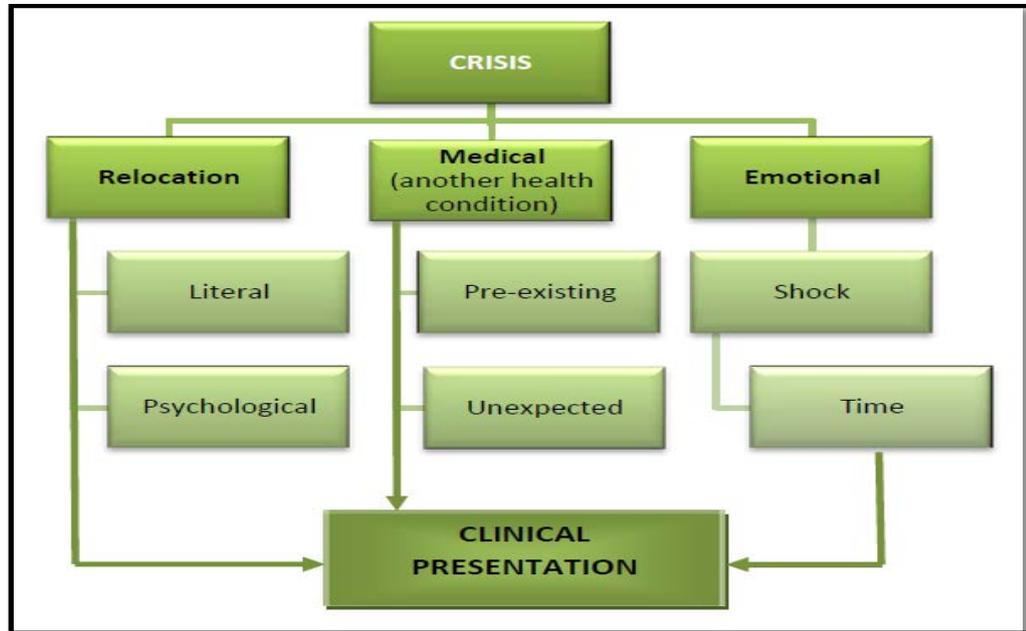
In Shafia's and Josie's cases, early symptoms were perceived as socially disruptive but were not seen to have a pathological basis. Josie initially believed her marriage was 'going to seed.' She thought Su's gradual withdrawal, increased argumentativeness, and violence were indicative of something having gone wrong with *her*. She only realised the problem lay in him, and not her, when they went to Trivandrum for their daughter's brain surgery. On that trip, Josie suspected that something was medically wrong with Su because he packed only three of each personal item (three shirts, three trousers, three pairs of socks etc.) even though they planned to be away for some weeks. Compounding this, he was reticent to talk to the doctor, which Josie found incongruous, given his dominant role as an officer in the army and prior decisive behaviour in their marriage. Other families had similar experiences of early symptoms, either ignored or interpreted as a normal part of ageing until there was some kind of 'crisis' or event that necessitated a visit to the doctor. Nandini described how

she recognised things were not right and when she decided to take her father to a doctor:

He had picked a lot of fights in the neighbourhood so they were all very anti-him and he was being very aggressive. Secondly, things like personal hygiene; he was a person who even in the severest winter will have an ice-cold water bath twice a day. I could see that it wasn't [happening]. And he wasn't concerned that I have come from far [to visit him]. Normally he is like, "Have you had your breakfast?" These were small, small things but I could see that they weren't getting well... And one thing – one of the neighbours stopped me during that visit and said, "We'd like to know what your phone numbers are. Your father's been disturbing us a lot and we're thinking of hospitalising [him] and calling you."

The neighbour's threat to Nandini, whether real or faked, served to reinforce her caring responsibilities. The threat implied both that she had not been a 'good' daughter because she lived in another city to her father and that she needed to be shamed into fulfilling her responsibilities of a good daughter. Threatening to hospitalise her father also invokes the stigma associated with institutionalisation, as I discuss further in chapter 7. In the diagnostic context, a threat such as this prompted Nandini to reinterpret social misdemeanours as biological distress. For families, there were three events which created this transformation: (1) a crisis of relocation (2) a medical crisis for another health condition, and (3) an emotional crisis (see Figure 8). These typologies are

artificial in their separation. Families typically experienced all three to varying degrees and these were grounds for medical intervention.



**Figure 8: Crises leading to clinical presentation**

Crisis of Relocation: Relocation was physical and/or psychological, and either shifted responsibility of care to another family member or reaffirmed an existing family member's responsibility for caring. Symptoms became disruptive to a point where they could no longer be ignored or contained. For example, Parvati Gowda (43) took responsibility for her mother – Meenakshi (78) – moving her from Kerala to Delhi, because her mother could no longer keep account of her daily spending or manage the household budget. Parvati said, “She was not having any [idea about] how much she was giving and what she had. That’s when then we thought that she needs full time care, so we brought her here.” In this case, physical relocation was also influenced by psychological fears around Meenakshi’s isolation. Meenakshi’s husband had passed away many years ago, and after this, Parvati took on greater

responsibility for caring for her mother. Spouses play a critical role in caring and covering for each other. Children, with the presence of both parents, tend to assume a secondary role, and only really take on full responsibility when one parent has died or is incapable of providing care.

Money was common to relocating or reaffirming care in parent-child and spousal relationships. Exigency centred on safeguarding financial security as families worried about how the person with dementia was handling everyday finances or vice-versa. When Shafia sold her land, Omar's reaction to her obtaining her share of the money, and bringing it to him, was the culmination of a series of unusual behaviours on his part. Disruptive behaviours, like forgetting the way home and wearing one's clothes inside-out, could be downplayed, but Omar's confusion over money signalled that Shafia had to intercede and take him to the neurologist. In this case, financial responsibility from husband to wife was transferred via a medical diagnosis.

Concerns about safeguarding financial security bespeaks of wider anxieties around money, deception, family, and class in India. Popular culture often draws on the negative imagery of children stealing property, frittering away hard-earned resources, and then denying care and *seva* to older parents. There is a kernel of truth to this image: of the 518 murders registered in Delhi in 2008, the motives for 9 percent of them were family disputes and a further 11 percent were over property and money matters (Patnaik, 2009). According to Inspector Tyagi in the Delhi Police's Senior Citizen Cell, over 50 percent of the Cell's complaints came from lower middle-class elderly people and were about civil

matters. The bulk of these complaints were about denial of food, not being served on time, pressure to sell the family property or to sign over the property. “There is not much we can do,” said Tyagi, “but we always advise them to *never* sign property over, to always keep it in their control because the moment they do, the children stop caring. They won’t do anything for them then.”

Medical Crisis for another Health Condition: In this category, the diagnosis of dementia occurred because of a pre-existing health condition or sudden injury. The family and the person with dementia were already involved in the healthcare system, often with either a psychiatrist or neurologist. Examples include situations such as Josie’s. The surgery required for her daughter brought the family into the clinical purview of specialists such as neurologists, psychiatrists, neurosurgeons and the like. Su’s retreat into the background caused Josie to grumble, “Doctor, he is not himself.” Clinical presentation and diagnosis were opportunistic and tangential, as another health condition – in this case, their daughter’s surgery – took precedence over the diagnosis.

Medical crises could also be unexpected. Consider Govind Ballabh Tandon (58) and his wife Sheila (58). Her diagnosis occurred after she suffered a head injury from a road accident on her way to work. Tandon recalled that following the accident, Sheila’s temperament changed and “she used to repeat the same thing. She took time to follow actions [instructions].” Having recently interacted with doctors because of Sheila’s accident, biomedicine provided the most recent framework to interpret her behaviour. This made it the first avenue her family sought.

Emotional Crisis: In this category, the person to be diagnosed with dementia experienced a level of shock and/or depression. Often this shock resulted from the death or abandonment by a loved one. No one had discerned K.P. Aggarwal's (69) symptoms of dementia, even though he was ailing for many years. After his father died, K.P.'s wife, Sita (63), recalls, "He became so quiet." K.P.'s silence was readily accepted by his family until he developed a problem with his balance. According to Sita, "something went wrong in his walking, he walked like an alcoholic. Everyone thought he was drinking." Alcoholics are stigmatised by many middle class families, within as well as outside of India (see Bradby, 2007). To avoid community censorship, the family took him to the doctor.

Nayantara's mother, Mrs Hamdari, on the other hand, was only taken to the doctor after a prolonged period of grief, which showed no signs of diminishing in its intensity. Mrs Hamdari (80) had watched her younger sister die a painful death and wept everyday for over a year. According to Nayantara, "Every morning when the maid used to come that was the story, '*Nani-ma* is crying' – she was crying all the time. I think, from what I remember, from the hospital cards, a year later I took her to the doctor."

In these two cases, grief, whether quiet or noisy, was only reinterpreted as a medical symptom because it exceeded the culturally appropriate time to grieve and had a disruptive effect on the household. Mrs Hamdari's constant weeping and K.P.'s stumbling, over an extended period of time, attracted attention and commentary from outsiders like the maid, neighbours, relatives and friends.

With no signs of healing or closure, K.P.'s and Mrs Hamdari's continuous bereavements or 'shocks' prompted their families to seek medical advice.

Through all these crises – relocation; medical intervention for another health condition; emotional trauma – families began to 'see' that something was not right. 'Seeing' was accumulative in that families saw numerous oddities which they were able to compile, post diagnosis, into the symptoms of the 'disease' dementia. Pre-diagnosis, families were unaware of the pathology, prognosis and implications for care. What they would have seen would have increased their fears of the unknown, and the additional responsibilities they would have to shoulder. As long as symptoms of the disease were viewed as part of *buddhāpan* and *sathiyana* for which *seva* was to be provided, families operated within a social framework which allowed for contestation and conflict. Without a formal diagnosis, the dementing person could behave irrationally and aggressively, argue over money, be weepy or violent. In short, they might have 'gone sixtyish.' Even so, some people with dementia identified that something was not right in themselves:

In the initial stages she would cover up. She would say, "There is nothing wrong with me, I'm 76 years old, I'm doing pretty well for someone who is 76." But then one day she told me, "*Char deno ke chandni pher andheri rath*" [four days of light and then it's night again] (*Namita Sood, 53*).

Initially I thought he was joking that he couldn't remember and that nothing was there. But he would just sit around and look at the TV and

wouldn't interact with anyone so I thought, "What's this?" (*Nina Bhagat, 70*).

### **दिखाना – Dekhānā: To Show**

Families often followed two pathways to the neurologist's door – either through direct consultation, or rarely through referral from a local doctor who recognised the broad brushstrokes of a neurological impairment. There were few neurologists (6-7) in Delhi who were qualified and willing to diagnose and manage people who had dementia. Those in the private sector largely shunned this task despite the chronicity of irreversible dementias, because the lack of a cure and because concomitant degeneration reduced profit margins. Though this contradicts the commonsense logic of long-term care equalling a steady income for doctors, Dr Bose, a geriatrician in a public-hospital explained:

After a while it becomes very difficult to ask for money from the patients. If they [practitioner] have seen someone three times or four times it becomes very difficult to ask for money on the fifth, sixth, seventh or twentieth time. After all it is very embarrassing for the practitioner and [there] is some amount of pain and shame. You can't be a vulture...you have to have some feelings. So there's not much business in it.

In the public health sector, ARDSI-DC had linkages with two government hospitals, where designated Out Patient Departments (OPDs) also functioned as 'memory clinics.' If a dementia diagnosis was made in these clinics, the neurologists, also members of ARDSI-DC's Governing Board, would refer the

families to the NGO. In the rare event the family came to ARDSI-DC prior to obtaining a diagnosis, the NGO would send them to the memory clinic to get a confirmed diagnosis. As a matter of course, the NGO made appointments for families in these OPDs. Typically appointments are not made in OPDs and people are seen on a first-come-first-served basis. In theory, this was a strategy whereby families would not have to wait before seeing a doctor.

The Central Government of India has been running these two government hospitals since the 1950s. Both are teaching hospitals which offer general and specialist services like cardiothoracic surgery, neuroscience, ophthalmology, emergency care, and paediatrics. The doctors are knowledgeable and skilled; most senior registrars and consultants have a clinical research profile and have published in prestigious international and domestic medical journals. Many have worked in rural and urban India as well as overseas. As staff in a public hospital, their services and consultations are offered at little to no cost, and so the poor and marginalised arrive in their millions each year. In the OPDs where I did my observations, 1.2 - 1.5 million patients are treated each year. The doctors I directly observed, in an average OPD session of two hours, would see about 50-150 patients.

In OPDs, people waited for hours in uninviting halls on hard metal chairs. The chairs were black, in rows, and under harsh fluoro lights. People waited without complaint to be seen for two minutes by a doctor. Poor and lower middle class people wore their best clothes – polyesters and synthetics of brassy pinks, greens, blue, grey, black and white. Wealthier people preferred private services

and tended not to visit these hospitals; when they did, they wore faded cottons, linens and denims of bourgeois understatement. Doctors conventionally wore white lab coats, pharmaceutical representatives had on expensive cologne, and grubby student anthropologists wore comfortable sandals. These hospitals were noisy, crowded, frenetic places. The basic equipment was meagre, the buildings worn; time short for the staff, and tempers ran high. There was no air-conditioning or heating; only the proverbial dust.

The process of diagnosis within the government hospital setting was arduous and time-consuming. There were a series of tests to be administered, which commenced with a detailed case-history and neuro-psychological tests that examined the cognitive features of memory, praxis, visio-spatial capacity, planning, judgement, and money handling. Scales such as the Mini Mental State Exam (MMSE) were readily used in these settings. This is problematic because, as I have discussed elsewhere (see Appendix 5.4a, 5.4b), cultural and systemic factors affect score results and call into question the methods used to diagnose dementia (see Iype et al., 2006; Mathuranath, George, Cherian, Mathew & Sarma, 2005).

Following neuro-psychological tests, there was a detailed medical history for stroke, hypertension, thyroidism, and seizures; then an assessment of risk factors such as alcohol and smoking; an evaluation of the patient's diet (whether they were vegetarian or not); a complete blood count to rule out liver and renal diseases, and finally, neuroimaging. These tests required the input of neurologists, psychologists, laboratory technicians, radiologists, nurses, ward

staff and administrators. Seamless transitions through each test to the next were rare. Some patients were able to obtain hospital-stay, during which time the entire gamut of tests were run, but those families who lived in Delhi were often encouraged to come and go as per the appointment times they managed to schedule. This was perceived as less stressful on individual families and hospital resources. But long hours were spent waiting for doctors, tests, and hospital administrative services – a well-documented complaint across nearly every public hospital in India (Mukhopadhyay, 1989; Peters, 2002; Purohit, 2004).

Many families, like Shafia's, made the strategic decision, based on factors such as the health of their loved one or time away from work, to try and complete all the tests in one exhausting day, rather than over a period of time. Often this time period, whether over one day or one week, was when the clinician spent the most (sometimes the only) time with the person experiencing dementia. Although follow-up with the patient was meant to happen every three to six months to trace the progress of their disease, the current symptoms, the need for drug management and to counsel the family, in practice this rarely occurred because of time constraints and patient numbers. The implications for treatment and management of symptoms will be discussed in the following chapter.

When asked, families spent little time describing the diagnostic process despite the challenges they faced. Instead, for them, neuroimaging was pivotal, especially the MRI (Magnetic Resonance Imaging). In contrast, doctors

described the MRI as one of the least important and last tests that they administered, one done more to confirm, than to guide, their suspicions.<sup>9</sup> For families with whom I worked, neuroimaging served as a marker of the doctor's credibility and a signifier of good clinical knowledge and practice. Thirteen families explicitly mentioned the MRI and another three specifically named the SPECT (single photon emission computed tomography) scan when asked to describe the diagnostic process. As Josie said after Su's SPECT scan, "Lo and behold they discovered that he had the symptoms of dementia."

The MRI as the penultimate point in the diagnostic process reflects the indigenisation and appropriation of this particular biomedical technology within India. Appropriation as defined by Hahn (2004) and extended by Granado et al. (in press) is syncretic and procedural. It involves the appropriation of an object or idea to begin, then its objectification within an established local dialectic, followed by the incorporative actions related to this new object or idea, and finally its transformation which redefines it according to local customs and norms. Put simply, the appropriation of neuroimaging into local understandings was how the cultural stamp of approval was given to a clinical diagnosis. Having an MRI validated for families that their relative was receiving all the benefits of biomedicine, and this in turn reinforced the notion that to be treated 'properly' was to have an MRI or other brain scans. Mark Nichter (2008; 2002) found that the process of obtaining a scan in India serves

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<sup>9</sup> An MRI scan is usually obtained to rule out other possible conditions (like tumours and reversible dementias) and to supplement clinical diagnoses. It also allows better differentiation between mild cognitive impairment and Alzheimer's disease, and enables tracking the development of the former to the latter (Knopman et al., 2001; Scheltens & Korf, 2000).

as an idiom of concern by families and an idiom of distress by patients. Similarly Van Hollen (2003) and Pinto (2004) found that particular pharmaceuticals (oxytocins) and technologies (injections) were bound in cultural discourses of power and legitimacy. In South India, women's demands to receive oxytocins to induce labour were linked to ideas of women's strength and their capacity to courageously suffer the pains of childbirth, as well as shorter labour and therefore truncated hospital stay (Van Hollen, 2003). In north India, the ability to administer injections was how *ersatz* practitioners demonstrated technical ability, access to institutions and biomedical knowledge (Pinto, 2004). Thus legitimacy and power are articulated through embodied exchange and metaconversations about access to, versus administration and interpretation of, particular technologies (Pinto, 2004, p.353).

For the families in my study, the MRI and the SPECT scans offered, literally, direct insight into the mind of the person experiencing dementia. It did not matter that families could neither read these scans nor interpret the highly medicalised language in the accompanying reports. Simply obtaining the MRI or the SPECT became a critical step through which families began to convert social misbehaviours into a biological pathology, *sathiyana* into Alzheimer's disease, social knowledge into neurological illiteracy, the known into the unknown.

Integral to this process was the use of language; the doctor's capacity to be able to read the scan, to identify the 'dark spots', to translate the technicalities in the report, and to distil it into simple language, became a means by which their authority and pronouncement of the diagnosis was validated. Language also

played an important role in determining what families understood from these explanations. Often family members switched from Hindi into English and then back again during the course of their explanation, although the key words were always spoken in English. Chintu explained her mother-in-law's dementia; "Cell-vell weak *hai*, cell damage *ho gaya aur weak hai*" (her cells in her brain are weak...in some cases her cells are damaged and in others they are weak). Similarly Mamta Aggarwal said: "Brain *mei thoṛa: shrink hota: hai, sārā* body parts *kā:m karne bānd kar deta hai*" (there is a little shrinkage in the brain, and all the body parts stop working).

Images, like 'shrink' and cell death in the brain, when linked, created a trajectory of decline: cell weakness and damage led to eventual cell death and shrinking of the brain. The use of English words such as 'weakness,' 'damage,' 'cell death' and 'shrink' also became a method by which Alzheimer's disease and dementia were distinguished from its Hindi counterpart, *sathiyana*. Such use of language varied according to age and gender. Younger women, particularly daughter-in-laws, keenly absorbed whatever the doctor's explanation was and reproduced the words verbatim when I spoke to them. Older family members did not dwell on the patho physiology of a person with dementia; for them, the causes of the disease had social rather than neurological origins. These etiologies usually developed following the acceptance of the dementia diagnosis and I return to their viewpoints later.

## **Delivering the Diagnosis and Prognosis**

For 12 families, the delivery of the diagnosis was the first time they heard the words 'Alzheimer's' or 'dementia.' Doctors had the dilemma of just how much of the prognosis to reveal. This is a universal concern for physicians with three factors affecting truth-telling practices: (1) the anticipated harmful and beneficial consequences of the truth (2) belief in the patient's rights and autonomy and (3) the physician's sense of duty and responsibility (Vanderpool & Weiss, 1987). In western countries, where the culture of individualism dominates, terminal patients are always included in discussions about their diagnosis and prognosis. However in other contexts, such patients may sometimes be shielded from this information by their families and doctors. For doctors, in these settings, the focus is not on truth telling or ascertaining patient wants but on preventing distress and giving the patient hope (see Ghavamzadeh & Bahar, 1997; Kaufert, 1999; Malik & Qureshi, 1997).

In my study, doctors often delivered their diagnosis and prognosis in one sitting, in settings defined by time pressures, competing patient demands, lack of privacy, and strict medical hierarchies. Here the doctor was the main authoritative figure, and the families were passive quiet recipients of this medical knowledge. Tandon describes how he was informed of his wife's dementia:

We took her to the neurologist at the hospital. He told me that she has dementia, Alzheimer's. I was hearing these words for the first time. I didn't even know what dementia or Alzheimer's was. That was at the initial stage and I said, "Let's see what the doctor has to say." The doctor

told me, “This is a progressive disease, incurable and not curable.” That was the first thing he said to me. Then, “You have to care for her, you have to do it” (*Govind Ballabh Tandon, 58*).

They saw him and said, “He’s not hurt, he’s not in any pain, he has this kind of illness – Alzheimer’s – and it is the kind of an illness which is not going to get better. There is no medicine for this” (*Shafia Khan, 54*).

At this stage, there was little realisation among families of the far reaching impact of the diagnosis. While there was an acknowledgement that life would change, the intensity and depth of these changes (such as managing finances, dealing with incontinence, cleaning feeding tubes) were only realised incrementally as the disease progressed. Little information was made available to families, often they were referred to ARDSI-DC where usually they were given a caregiver’s handbook either in Hindi or English. Compiled by one of the neurologists on ARDSI-DC’s governing body, the book details how the disease progresses, management strategies for challenging behaviour, activities of daily living, and stimulation for people with dementia. Some found the wealth of information overwhelming: “I didn’t even finish the book, I just read like two pages and was really worried. I said, ‘I’m not reading anymore, I’ve got to show him to a doctor’” (*Suneeta Sadhwani, 41*).

Giving families pamphlets, books and other printed materials rather than face-to-face delivery of such information was common even in private medical

practice. Sunil Bhatnagar, an eminent neurologist in private practice in Delhi, described how he delivered the diagnosis:

There is a book which I give all the families. First I send the patient out because I genuinely believe that you never know how much your patient understands and how much your patient doesn't understand. Then early in the diagnosis I tell them [the family], "Look, there is some concern about the memory issues and that is why you have come to me." I am very well known. [Then I say] "We're not going to make the diagnosis right now. Let me see him again in three to six months so then we know." And then time tells, the family comes to know themselves. So you don't have to hit them on day one, "Look, this is what the person has, it is Alzheimer's disease, thank you, now go away."

Bhatnagar's approach differed from what occurred in *sarkari* (government) hospital settings and was more in line with the DSM-IV recommendations for tracking symptom development over time (APA, 2000). But both he and the *sarkari* doctors tended to deliver the diagnosis to the family and not to the person experiencing the dementia. Such an approach to the communication of chronic or terminal illness diagnosis and prognosis fits within a broader South Asian setting wherein patients are shielded from such knowledge by their doctors and family in a bid to maintain their optimism and prevent them from losing hope (see Bennett, 1999; Lang, 1990; Li & Chou, 1997). A study from neighbouring Pakistan, on physician truth-telling in cancer, found that patients were usually not informed of their diagnosis, often at the family's request (see Malik & Qureshi, 1997). Families feared such news would devastate the patient,

worsen his/her quality of life, and hasten death. Doctors, in turn, withheld discussing such information with the patient, citing reasons like strong family support (kin members could communicate such news), fear of miscommunicating or introducing misconceptions, feelings of frustration and despair in dealing with cancer, and the effects of therapy (Malik & Qureshi, 1997).

In Alzheimer's disease, the chronicity and degenerative nature of the condition influenced the treatment doctors prescribed, which was not medical management but a social mandate to care. How the prognosis was framed, the manner in which it was delivered, and the environment in which it was delivered, affected families' receptiveness to this information. Even those who had heard of Alzheimer's disease and dementia struggled to accept the implications of diagnosis-care *fait accompli*. In five cases, the diagnosis itself was initially rejected.

Disappointment with the news of the diagnosis, combined with the family's experiential knowledge of the *sarkari* hospitals, resulted in feelings of disappointment in the doctor and many sought alternatives elsewhere. Such feelings are commonplace, especially in the mental health sector, as demonstrated in studies done on depression and schizophrenia in south India (Raguram, Weiss, Keval & Channabasavanna, 2001; Saravanan et al., 2007).

## दिखना – Dikhnā: To Be Seen

Disappointment, denial and resistance to the diagnosis often led to doctor shopping. Doctor shopping includes the practice of people seeking multiple clinical opinions for the same health complaint; here I use the term specifically to refer to the practice of obtaining second (and third) opinions from allopathic doctors. ‘Doctor shopping’ is typically deployed pejoratively in the west, referring to prescription drug-seeking behaviour (Hall et al., 2008; Martyres, Clode & Burns, 2004). In India, doctor shopping is part of a pluralist (albeit hierarchical) healthcare system and has a historical basis; this will be detailed in the following chapter. In the Asian theatre, doctor shopping has been linked to chronicity (if the illness is recurring and/or progressive), the inability of patients to understand the doctor’s explanations, and scepticism about the doctor and the treatment plan (Hagihara, Tarumi, Odamaki & Nobutomo, 2005; Sato, Takeichi, Shirahama, Fukui & Gude, 1995). When families decided to switch doctors they reiterated these findings:

He [doctor] didn’t have anything to communicate. He would act like he knew everything and we just had to listen to his prescriptions and do what he told us (*Nayantara Sen, 58*).

I went to the doctors and they said, “It looks like he’s not going to get well.” That was enough for me and then I met another doctor who told me, “Oh ma’m, be prepared, the worst is yet to come.” So he told me the same thing. Then my son took him to Singapore and had him checked

there also. And he [doctor] said, “Oh yes, be prepared for the worst and how far it goes” (*Nina Bhagat, 70*).

There is a correlation between class and allopathic doctor shopping; studies from Hong Kong (Johnston et al., 2006) and New Zealand (Barnett & Kearns, 1996) have found that poor people are less likely to engage in this practice while those who are willing to pay have a greater propensity to do so. Conversely in India, while people’s ability to change allopathic doctors is influenced by their income and capacity to pay for services, it is also mediated by broader understandings of public and private services. Long queues and overcrowding in government hospitals for free medicines and consultations are balanced against the immediate availability and fees associated with the private practitioner. Decisions to utilise particular services are based on income, time, qualifications and professionalism of the practitioner, and the kinds of medications dispensed (e.g. analgesics and antibiotics) (Das, 2003; Van Hollen, 2003).

Doctor shopping also has cultural roots in *seva* and the sick role. Despite a defined illness, doctors were unable to offer hope of a cure and only a script to care. Many families resisted their new roles by desperately seeking a different outcome from another doctor. Also, through seeking different opinions, families were able to display publicly not only how desperate they were for a different diagnosis, but also how much *seva* they undertook for their loved one. In the Khan’s case, despite receiving a diagnosis from one hospital, Shafia and her children took Omar to ‘show’ him in a number of other public and private

hospitals across Delhi. Given the family's limited financial resources, accessing services in a private hospital affected their savings but nevertheless was spent to show people outside the immediate family just how much they cared for Omar. Shafia, unwittingly channelling the Scarlet Pimpernel, said, "Wherever anyone would say, we would show him. We showed him here, we showed him there, there was no place we left or where we did not show him."

To show or to take a sick person to the doctor are public acts which draw on the emotional and material currency of *seva*. In the Khan family, they were able to show their extended family and friends how much *seva* they were willing to do for Omar, by travelling all over Delhi with him. *Seva* for Omar within their home was private, i.e., the onus rested on other people to come and see how much *seva* they were doing, to validate that they were good carers and moral people. Taking him into the public arena to show him to a doctor, enabled more people to make this judgement swiftly. Yet this showmanship is temporary, because as the person begins to decline and doctors reiterate the same message of incurability, families are forced to accept the diagnosis. Shafia herself conceded, "[When] no one said that he was going to get better; that was it."

### **Patients and Carers: Caring and Patience**

In accepting the diagnosis, families began to resign themselves to their roles as 'carers'. This was not an easy process. Concomitant with resistance to the initial diagnosis and subsequent doctor shopping was violence and aggression. Feelings of frustration, confusion, denial of the disease, and an inability to cope

mounted as carers learnt through trial-and-error how to care. Violence was often a part of this process.

Nina Bhagat, even seven years after the diagnosis of her husband, Karamjit, could not bring herself to accept his dementia. She felt her husband was 'pretending,' the doctors were unduly pessimistic, and a cure could be achieved. She made Karamjit undertake speech therapy, yoga, golf, and reading and writing, in addition to giving him allopathic, *Āyurvedic* and herbal treatments. Through all these activities, Nina felt that Karamjit's brain could be re-activated and he would be fully functional again. When Karamjit resisted these activities or failed to complete them, Nina would become so angry she would hit herself. She describes these '*maha*' (huge) fights:

Even now when he doesn't listen, fighting comes automatically to me. He literally starts trembling when I get into this mood and then he holds me so tight that I can't breathe. He will tell me, "No, no, you will not be this angry, you will not hit yourself." I start hitting myself, I don't know what else to do. So he holds me so tight that I can't breathe [and says] "No, No," till I calm down. Now each time we have a fight he holds me tight.

Alongside the activities she arranged for Karamjit, Nina also used violence as a way to discipline him. She admitted to hitting him when he made *faux pas*, like coming out naked from the bathroom or not using the commode when he had to go to the toilet. Nina's violence also bespeaks of her desperation to find an alternative to the narrative of decline. For her, accepting Karamjit's dementia meant conceding defeat and giving up:

I felt it was wrong for them telling me to be prepared that he's going to be a cabbage in 10 years or he's going to be a cabbage in 15 years. I am not prepared to accept that. It is wrong. In 5 years or 15 years, whether we are cabbages or not, I will keep fighting. Whatever happens, will happen, there may be some deterioration but I still have hope, and I still feel he will come back to me. I have not given up because mentally he is becoming more and more alert.

Not all carers were like Nina. For many, inflicting violence on the person with dementia was a major turning point in their struggle to accept the diagnosis. Nayantara described the initial period following her mother's diagnosis as 'terrible,' because this was the time when she, her sister and her father struggled to come to terms with it. Her father, Mr Hamdari, was particularly aggressive as he struggled with managing his own high blood pressure which was exacerbated by the repetitive behaviours of his wife. The turning point came when he hit his wife. He said, "Finally, she hit me, and I [holds up right hand] hit her back. This happened twice. Then I felt very guilty [pauses and then whispers], very guilty."

Mr Hamdari's violence against his wife prompted his change in attitude. His remorse at his own actions induced greater acceptance of his wife's dementia and though his frustrations occasionally boiled over, he never hit his wife again. For most families, inflicting violence on the person with dementia was a major turning point in their struggle to accept the diagnosis. With acceptance came a

reduction in violence on the carer's part, and increased recognition of the diminishing capacity of the person with dementia.

When the scenario was reversed, i.e., when the person with dementia was violent or hostile, the behaviour was dismissed as the pathology of the disease and not with social triggers. The tempo of the household was unaffected, even though there were instances of injury. Few sought respite by sending the person with dementia to another family member or to an institution. Josie was the only exception, because of the extent of her injuries, but even here Su's displacement was temporary. As will be discussed in Chapter 5, families' reluctance to relocate the person with dementia was closely tied to their dislike of age-care institutions, desire to give *seva* and to show to the outside world how much they cared for their elderly kin.

### **Brain and the Social Body**

With acceptance of the diagnosis came the beginnings of a social etiology of dementia. The old critique of urbanisation, modernisation, industrialisation and westernisation, all linked to dementia and Alzheimer's disease (see Cohen, 1998), still echoed in some service delivery circles. Among families this etiology was linked to the patho-physiology of the disease (discussed earlier) and a broader lamentation about the vagaries of contemporary urban life. As mentioned, older family members did not talk about brains drying, shrinking, becoming weak or damaged. For them the disease had social rather than neurological origins.

Urban life, in Delhi, was defined by time, tension and loneliness – and all were underpinned by a complaint about the increasing tendency towards individualism. Having ‘enough time’ served as a measure of family members’ ability and willingness to engage. Younger people, usually women, rarely seemed to have enough time, engaged as they were either in paid employment or the more laborious itineraries of housework and childcare (no matter the age of the children). Many primary carers (usually older women) accepted that lack of time was a justification for the tertiary roles that younger women assumed in caregiving. Sita described how her daughter helped her to care:

If we have to go to the hospital then she’ll send the car. If I am in any jam then she’ll send the car. If there is any work she will do it. She helps me a lot. She calls almost every day and we talk. Or I’ll call her. She doesn’t come a lot, maybe once in 20-30 days [because] *she doesn’t get time*. I was supposed to go today but it wasn’t possible, so I’ll go tomorrow. *She has a busy life and not much time* (emphasis added).

Related to a lack of time was an increase in tension or stress. ‘Don’t take tension,’ was frequently counselled in everyday conversation and directed to people who were seen to be ‘taking tension’ or experiencing high levels of stress. Too much tension was believed to lead to dementia, depression and psychosis, findings which have been made elsewhere in India (Parkar, Fernandes & Weiss, 2003; Saravanan et al., 2008; Saravanan et al., 2007). Tandon linked his wife Sheila’s dementia to time and tension:

In city life everyone is busy. Everyone locks up their houses and goes off to work. There is a lot of tension in life – my two sons were working and

I was busy with my business, I had to go outstation most of the time. Everyone had their own keys, came and went at their own time. Maybe this is one of the causes. Tension was present.

Implicit within this etiological paradigm was loneliness. 'Too much tension' when coupled with little time led to people feeling stressed and alone; this in turn, was seen to lead to dementia. Said Suneeta:

Based on what I have seen within my own family, loneliness seems to be the biggest reason. My aunt's husband [had just] died when she started experiencing this problem. All her children were busy in their work, her grandchildren were busy in their work, there was no one for her to talk to.

Josie's children also felt that their father's illness was brought on by "utter loneliness." Josie recounted that she and Su spent most of their married lives apart as she cared for various ill family members and he served in the armed forces in various warzones. But she balked at the idea of loneliness leading to dementia, based on her own experiences of being alone and self-reliant. In contrast she perceived Su had adequate social support while he was in the army (friends, camaraderie, team sports and social outings). Nevertheless she accepted Su's experience of being lonely may have been different from hers, just as Tandon accepted that Sheila 'took more tension' than he did when he recalled their working lives. At this level, carers adopted a phenomenological understanding of the lives of people living with dementia, i.e., they accepted that their loved one's social construction of the world was different to their own

worldview and that their loved one's experiences of being alone could have led to their dementia.

Carers also sought to distinguish between themselves and the person with dementia. To begin, whether openly acknowledged or implicit, some deficiency in lifestyle and/or individual personality of the person with dementia was assumed, leaving them unable to cope with modern urban life, and therefore vulnerable to the disease. Deficiency, however, was not blame, merely a platform through which carers could highlight their own strengths and benevolence in coping and caring. Carers did not equate deficiency with blame because it could also highlight their contributing roles in their social etiologies. Thus Tandon admitted that he worked too long and was away too much, not that this contributed to Sheila's loneliness. Josie conceded that Su might have been lonely but did not link it to her prolonged separation from him. There was delicate silence around such an obvious link.

## **Conclusions**

This chapter has focused on the diagnostic journey on which families embark, from the initial onset of the symptoms of dementia to the ultimate acceptance of a diagnosis. Three types of 'seeing' have been used to describe how families experience this process (1) *dekhnā*: (to see) (2) *dekhānā*: (to show) and (3) *dikhnā*: (to be seen).

Initially, families had 'to see' something was wrong. They had to differentiate a medical pathology in a cultural category and separate dementia from *sathiyana*.

This was done through a compilation of strange behaviours, leading to crises and eventual clinical presentation. Then families had 'to show' their elderly relative to a doctor. Their experiences with neuroimaging played a key role in how they began to see the dementia and conceive of the illness. The MRI, in particular, was related to the linguistic and social separation of *sathiyana* and Alzheimer's disease. Families' experiences were also shaped by institutional cultures and resource shortages in hospitals. This affected their level of acceptance towards the diagnosis and many resisted the idea that there was no cure and only long-term caring. This often prompted people into seeking solutions elsewhere; denial and doctor shopping were common. Doctor shopping was also linked to the public display of *seva*, as some families sought 'to be seen' to be pursuing all avenues and being good carers.

With acceptance, social etiologies began to be developed. Families began to fold the biological into the social to develop an integrated framework which accommodated both neurological and social pathology. Daughters-in-law used English instead of Hindi to reproduce what they had understood from the doctor, whereas older spouses tended to resort to the discourses of tension, time and loneliness in modern Delhi life.

The diagnostic process becomes the signifier of upheaval in families' lives and marks the beginning of a road of caring for a person living with dementia. It leaves its influence in the long-term, in how often a family will visit the doctor, comply with medicines, seek alternatives, and which health system they will

ultimately put more faith in. I describe these treatment pathways in the following chapter.



## CHAPTER 4:

### इलाज - علاج - ILĀJ

I am following the science daily [and] any day now some treatment will come. It hasn't come till now but it will happen. Up until now no one cared about this disease – now everyone's energies are on it, so the treatment will emerge. It maybe that we don't get the benefit, that we're not capable but I keep hoping that we can, that in between something can happen...there is a lot of effort being made in medical science. God knows. This is my ultimate objective, I have no mission, no life, no earnings, this is it – that there is some treatment. I look at the website daily, I correspond daily, I keep looking, I keep researching... (*Govind Ballabh Tandon, 58*).

Mrs Sethi: *Iska ilāj hai kuch?* (Is there any *ilāj* for this?)

*Nehi* (no)

*Koi ilāj nehi de sakta?* (There is no *ilāj* that you can give us?)

*Till now – I'm not a doctor and I can't give a 100 percent guarantee – but till now in my research, in all that I have read, there isn't any*

*Hamne vēsa chhora nehi Dilli mē, koyee ilāj nehi chhora* (There is nowhere in Delhi that we have left, there is no *ilāj* that we haven't tried).

*Ilāj* (pronounced e-laaj) means ‘cure’ and ‘to treat medically’ in Hindi, Urdu, Persian, Arabic, and Turkish. It is frequently used and articulates a dream of regeneration against a backdrop of slow degeneration. Every family sought an *ilāj*. For some, like Tandon, it had become the ‘ultimate objective’ which defined their lives. The quest for an *ilāj* was also a search for hope, and usually began during diagnosis, when families went doctor shopping in a bid to find an alternative to the narrative of chronicity, decline, and long-term care which confronted them. Long after the diagnosis had been accepted, this search continued as behavioural symptoms of the disease and unrelated co-morbidities (like cataracts, diabetes or heart problems) rose and abated. To search for an *ilāj*, a powerful marker of *seva*, reiterated the family’s devotion and love for the person with dementia. Mrs Sethi said, “There is nowhere in Delhi that we have left, there is no *ilāj* that we haven’t tried.” For Mrs Sethi, *ilāj* was also a lament about the inability of health practitioners to provide any kind of a cure; merely an instruction to care. Her frustration stemmed from broader beliefs in the power of medicine to cure all ills as she could not understand how such a powerful epistemology could offer no hope.

Biomedicine’s capacity to offer a cure and/or improved medications has become the foundation of hope in dementia. Charities and non-government organisations press for donations to fund medical research, and governments allocate considerable sums to medical researchers to come up with a vaccine or cure. Moreira and Palladino (2005) argue that biomedicine is shaped by two contrary temporal logics, ‘regimes of hope’ and ‘regimes of truth.’ ‘Regimes of hope’ are uncertain, risky, and linked to new technologies. It is future-oriented –

the hope that a cure is in the ‘pipeline.’ ‘Regimes of truth’ are present-oriented, premised on the existing evidence and past outcomes. Specific to dementia, to date neither cure nor effective medication has been achieved and death is inevitable. In a regime of truth, patients and families are positioned as consumers and autonomous agents in determining palliation. In a regime of hope, they are more desperate and risky, costly and closely monitored treatments are more likely to be sought. But truth and hope are unevenly juxtaposed in India; hope takes precedence over truth and is central to maintaining relations between doctor, patient and the patient’s family.

In this chapter I examine how people perceive of an *ilāj*, persist in their search of one, and the socio-political context of medical care in contemporary India. The power relations between doctors and patients, and the immediate and gradual outcomes of these interactions are critical to the search for an *ilāj* and I also examine this dynamic. In the trials and tribulations of everyday life in Delhi’s public health system, *ilāj* is part of a biomedical montage which propagates the abuse of power through the normalisation of bureaucratic hierarchies and insufficient resources. This will be explained by drawing on my observations in neurology OPDs, and carers’ reports of their experiences in government hospitals.

When families move from the hospital to the home, the power of *ilāj* – embodied on this journey as pharmaceutical drugs – reverberates in its physiological and relational effect. The physical and psychological side-effects of these drugs heighten carer surveillance of the person with dementia. Families’ experiences

with pharmaceutical drugs influenced how often they visited clinical doctors, complied with medicines, and sought traditional and transcendental healers. Ultimately which health system they trusted was based on its outcomes for both the health of the person with dementia and the entire family.

I begin via a circuitous route into the etymology of *ilāj* because it is necessary to understand the history of medical pluralism in India and the doctor-patient relationship within these systems. This history will contextualise how class, gender, religion, and education are deployed in experiential understandings of illness and care. It will also define the scope of terms such as ‘health practitioners’ (biomedical, traditional and transcendental) and ‘patient rights’ in their past and current application, and highlight the complexity of the challenges confronting Indian medical care.

### **The Etymology of *Ilāj***

*Ilāj* is an Arabic word, and its incorporation into Hindi underscores the cultural, linguistic, and political fusion between the Middle-East and India, of which medical pluralism is an offshoot. Even before the Arabs reached Indian shores in the seventh century, Indian medicine within the boundaries of the subcontinent was diversifying. *Āyurveda*<sup>10</sup> (*āyus* means longevity; *veda* is knowledge) was a complex epistemology that had absorbed the class

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<sup>10</sup> Although I only cite *Āyurveda* and *Unani* in this section, traditional medicine is much broader and according to the Ministry of Health and Family Welfare, Government of India, includes *Āyurveda*, Yoga and Naturopathy, *Unani*, *Siddha* and Homoeopathy.

stratifications of the post-Vedic *Dharmashastra* texts,<sup>11</sup> the humanist ideologies of Buddhism, and the inclusion of metals in its pharmacopeia (Bala, 2007). Its permeability reflected its medico-pantheistic origins, which combined religion, magic, physiology, anatomy and pathology. The literary foundations of *Āyurveda* were articulated in the *Rgveda* and *Atharvaveda*, two of the four *Vedas*, and the earliest sources of medical literature in the world, in circulation from around 2500-2000 BC. *Āyurvedic* practices had an even earlier genesis in the third millennium BC in the ancient cities of Mohenjo-Daro and Harappa, where municipal sewage and drainage, public baths, and the use of plants had health preventative and therapeutic value as well as religious value (Bala, 2007; Leslie, 1969).

The arrival of the Arab traders in the 7<sup>th</sup> Century AD heralded an exchange of medical knowledge and practices, along with cardamom, ebony and silk, between India and the Levant. These cross-pollinations were reflected in the writings of Islamic physicians from the 10<sup>th</sup> and 11<sup>th</sup> centuries onwards, and the introduction into India of *Unani* medicine, itself a syncretism of Greek, Arabic, Persian, Indian and Chinese influences (*Yūnān* means 'of Ionia or Greek'). In 1279, with the Latin translation of Muhammad B. Zakariyya Al-Razi's magnum opus *Kitab al-Djami 'al-kabir* or 'Great Medical Compendium,' elements of Indian medicine made it into the European clinic (Goodman, 2009). In India,

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<sup>11</sup> The Dharmashastra texts are a set of treatises developed between 200BC and 200AD which lay out the fundamental principles of living and modes of behaviour or dharma for every living creature, every kind of human being, and each stage of life through which a high class man transits to and from (Trawick, 1995). According to the *Manusmriti*, the most famous of these texts, there are four classes of men: the *brahmanas* (brahmins) (serving as priests and teachers), *kshatriyas* (duties of administration, battle, and law enforcement), *vaishyas* (customarily agriculture, commerce, and cow-protection), and *shudras* (who provide service to members of the other three classes) (Kane, 1930, 1962; Manu & Bèuhler, 1964).

following the founding of the Mughal Empire in 1526, *Unani* medicine began to be organised into a discrete system which existed alongside *Āyurveda*. However *Āyurveda* was the medicine for the masses and *Unani* for the ruling class (Patterson, 1987).

During this time, what is commonly now called ‘folk’ medicine was also practiced. Folk medicine tends to comprise a set of sympathetic magico-religious practices which include mantras, curses, and miracles typically practiced by *Gurus*, *Babas* and *Pīrs*<sup>12</sup> (amongst others) (Langford, 2003). The term ‘folk’ is problematic in the Indian context, as it neither sufficiently captures the theological richness and complex practices of this kind of medicine nor defines the socio-political location of the various ‘folk’ who access it. Don Bates (1995) has argued that biomedical and traditional epistemologies stake their legitimacy in literary texts, medical textbooks and professional training, unlike faith healers who often rely on revelations and oral histories. This distinction is contestable in India as texts like the *Qur’an*, the *Bhagavad-Gita* and the Bible contain moral precepts which transcendental medicine practitioners either draw on as *Gurus*, *Babas* and *Pīrs*, or set themselves in opposition to as *kala jādū* [black magic] practitioners. In addition, there are particular logics and practices which are common to particular healers, suggesting a level of ‘professionalisation’ and training. When *Maullanas*, for example, put a *tabeez*<sup>13</sup> in water and tell patients to drink that water over many days, until all the script

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<sup>12</sup> A *guru* is a teacher, mentor and spiritual guide. A *baba* was the head of the order of monks called *Calendars* or *Qalandar* but the term is used nowadays to refer to all manner of *fakirs*. *Pīrs* refers to Muslim saints.

<sup>13</sup> A *tabeez* is an amulet with an inscription from the *Qur’an* meant to ward off curses and djinns.

has disappeared, the *ilāj* is imagined as one literally ingesting the word of God to ward off the effects of curses that had led to the presenting physical and psychological ills.

‘Transcendental medicine’ is a more appropriate term and I use it to delineate ‘folk’ medicine from traditional medicines (e.g. *Āyurveda*) and biomedicine. Such conscious use of terminology emphasises the power plays which eventually resulted in a hierarchical (re)organisation of biomedicine, traditional medicine, and transcendental medicine in India. ‘Biomedicine’ deliberately replaces ‘Galenic’ medicine to reinforce its hegemony rather than its historical roots; ‘traditional’ has replaced ‘indigenous’ medicine to reinforce its chronicity and cross-pollination rather than its nativity to India; and ‘transcendental’ replaces ‘folk’ to evoke the religiosity embedded within it.

Despite constant vigilance, these three medicines have fluid alliances and bleed into each other. For example, transcendental medicine, which has had both a historical link to traditional medicine in India (see Kakar, 1991; Langford, 2003) and biomedicine in Europe (see Porter, 1997, 2002), also formed a bridge between these two in India. Early timorous ventures by the Europeans, first by the Portuguese in the 16<sup>th</sup> century and later by the English in the 17<sup>th</sup> century, mobilised religion in healthcare. British chaplains touted Hindu’s abstinence from alcohol and meat, their high fibre diets, and light dress as evidence of their piety. These dietary and lifestyle maxims are found in Hindu scriptures and in texts (Wujastyk, 2003). The British chaplains’ exhortations, however, were not driven by a quest for a higher morality but by a search for lower mortality as

the European diet of meat, copious amounts of alcohol, and heavy ceremonial dress saw an unsurprisingly high number of white people die from 'tropical' disease (Arnold, 1993; Patterson, 1987).

By the late 19<sup>th</sup> century, the English affection for gin and tonic to ward off malaria and other tropical malaise also signified an increased knowledge of tropical medicine (Arnold, 1996; Manderson, 1996; Rosenthal, 2001). Biomedicine, by this time an arm of the colonial project, was associated with enlightenment and modernity; traditional medicines and transcendental medicines were constructed as backward and unscientific. However the rhetoric of biomedicine did not match its practice and far from colonising the 'natives,' was itself largely confined to the British military until the early 20<sup>th</sup> century (Harrison, 1994). Multiple factors – a bubonic plague in the 1890s, advances in medical science and sanitary practice, growing Indian involvement, and the rise of the women's medical movement – forced biomedicine by the 1920s and 1930s, to look beyond the barrack walls of the British army to the Indian population (Harrison, 1994). This was helped along by the Indian Congresses' Nehruvian zeal for science and technology as a symbol of progress and development (Arnold, 1996). These were the foundations of contemporary health technologies – like diagnostics and testing (e.g. the MRI, see previous chapter), and transnational health services (e.g. blood testing, transcription services for doctor's notes) – and the means by which boundaries were defined between 'real' doctors (who were *au fait* with technology) and 'quacks.'

Transcendental medicine – seen as quackery and superstition, irrational and preying upon the ignorance of the masses – was delegitimised and cast out of institutionalised medicine by the early 20<sup>th</sup> century (although it has always echoed in medical practice) (Khan, 2006; Khare, 1996). Traditional medicine suffered a similar albeit less devastating fate. It was progressively ‘unmade’ and increasingly seen as ‘unscientific’ through chronic underfunding of its training and research practices. Traditional medicine also came under intense regulation and bureaucratisation under the pretext of ensuring scientific validity and public safety. It was no coincidence that the deprofessionalisation of traditional medicine was concomitant with a growing preference among India’s elite for biomedicine, and this changed the traditional practitioner’s clientele from the ruling to the poorer classes (Bala, 2007; Leslie, 1976). Despite attempts at revival by Indian Nationalists (like Gandhi), the trend continued: a small but significant scholarship describes how traditional medicine continued to be dismantled by the state after Independence (see Banerji, 1981; Jeffery, 1988; Khan, 2006; Nandy, 1995). It is only recently (1995 onwards), that traditional medicine has been institutionalised, with the establishment of the Department of *Āyurveda*, Yoga and Naturopathy, *Unani*, *Siddha* and Homoeopathy (AYUSH) within the Ministry of Health and Family Welfare (Government of India).

### **The Doctor-Patient Relationship: Past**

Bates (1995) argues that the fundamental difference between biomedicine and traditional medicine is the approach of the two to knowledge and knowing. Biomedicine privileges the ‘epistemic’ – the methods by which knowledge is

created, constituted and certified – whereas traditional (and transcendental) medicine favours ‘gnostic’ knowing – knowledge gained through initiation, experience and elaboration. Epistemic knowledge is about expertise, gnostic knowledge is about the expert (Bates, 1995). These pedagogical differences are critical to understanding how doctors in all three systems are perceived in India and *ilāj* in its everyday parlance as a verb – *ilāj karna* – provides a gateway to the doctor-patient relationship in India.

Historically, the doctor, known as the *vaid* in *Āyurveda* and as the *hakim* in *Unani*, was perceived as a healer and holy man who combined theology and everyday living advice in his treatment. More than the patient, the onus was on the healer to lead a moral life. Vāgbhata in AD 600 wrote in his *Aṣṭāṅgahrdaya* or *The Heart of Medicine*, the preeminent text on Indian medicine:

The physician is skilful, educated in the discipline by a master, has practical experience, and is pure...The patient is wealthy, obedient to the physician, informative, and has endurance (as translated by Wujastyk, 2003, p.209).

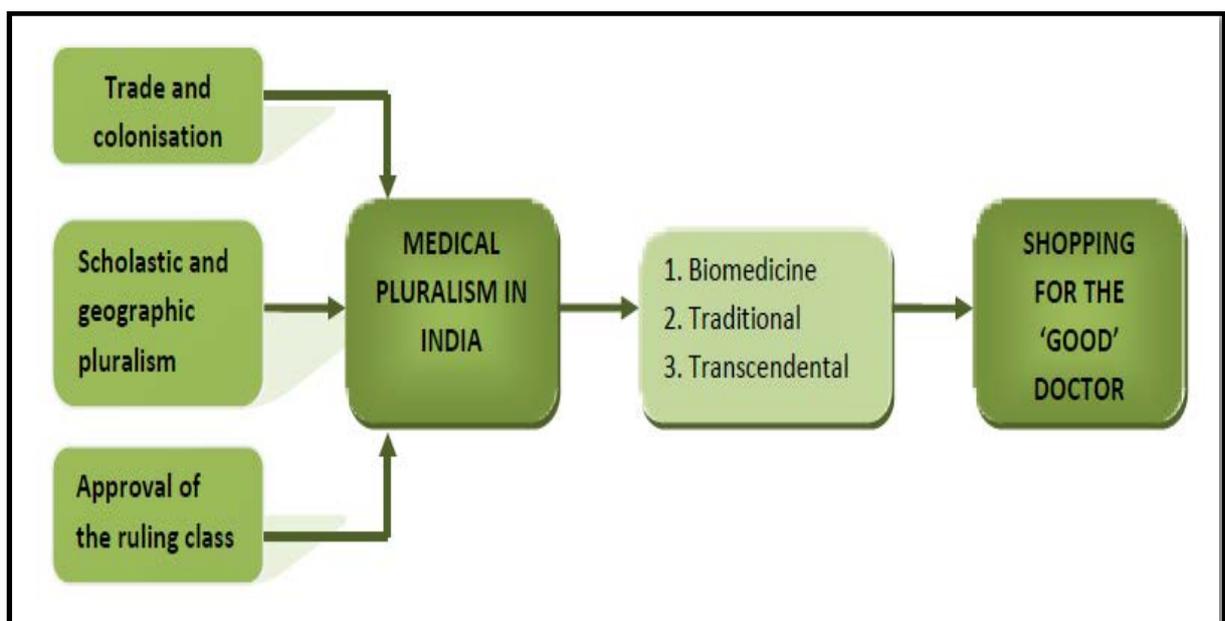
The purity, skill and pedigree of the healer created an expectation that the *vaid* was omniscient and wholly trustworthy, and the patient, bolstered by wealth and fortitude, was to behave meekly and gratefully (von Schmädel & Hochkirchen, 1987). This dominant-subordinate relationship was bound in class politics as most healers were Brahmans, a literate, priestly class who saw themselves as closer to God than most *Āyurveda* patients, who tended to be

poorer and from a lower class (Trawick, 1995). Ethics and consent, within this didactic relationship, were situational and implicit, i.e., by virtue of coming to the healer the patient and his family tacitly agreed to participate in the therapeutic encounter. The family was meant to place complete trust in the *vaid* and follow whatever he recommended. However, this was not a cessation of patient power, for the healer, as designated arbiter of morality and medicine, still had to forge an ethical therapeutic strategy that retained the patient's trust and gave him or her hope (Khare, 1996). It was accepted that patients who felt ill-treated could go elsewhere and many did so, thus illustrating that doctor shopping has always been a part of the Indian therapeutic landscape.

Biomedicine's construction of the patient as passive, although stemming from contrasting ideologies of positivism, Cartesian dualism, and quest for a single etiology of disease, was nevertheless integrated into India's therapeutic systems. But where biomedicine sought to divorce the doctor-patient encounter from its context, exacerbating its dramaturgical nature and the autonomy of each actor, traditional and transcendental medicine explicitly situated themselves within a *mêlée* of social and class relations (Finkler, 1994). This disjuncture was resolved by the 'Indianisation' of biomedicine along the practitioner-patient praxis; a 'good' doctor was (and is) one who personally engages with his patients (Gould, 1965; Khare, 1996).

Practical departures from this theoretical 'good' doctor have ranged from the solid shades of abuse and corruption to the ephemeral colours of power and indifference. But notions of ethics, consent, patient-centred care, and shared

decision-making, based on individual autonomy and patient rights discourse, which have emanated from Europe and North America in the past 60 years, also need to be judiciously applied and assessed in India. For this brief sojourn into the etymology of *ilāj* has illustrated that: (1) medicine in India has always been plural (2) this pluralism is epistemic (combining religion and science) and geographic (Indo-Arabic-European) (3) a political economy dictated by trade and colonisation has framed it (4) the imprimatur of a ruling class is explicit in the (de)legitimisation of a medical system (5) doctor shopping is a normalised practice within this framework and (6) the doctor-patient relationship is framed by morality, medicine and class (see Figure 9).



**Figure 9: Medical Pluralism in India**

### **The Doctor-Patient Relationship: Present**

The doctor-patient relationship structured by these factors remains a dominant-subordinate one in India. I use the word ‘doctor’ loosely here, for based on my observations, people who were associated in an official capacity

with a health service, irrespective of their qualification and experience, were cognisant of the responsibility and power invested in them. “Say something positive,” I was instructed by the local ARDSI volunteer when I visited Kottayam in rural Kerala. I had just met a poor woman, Gerri-amma (75), conscious of her fading memory and desperate for a cure. Her unsuccessful dealings with allopathic, *Āyurvedic* and homeopathic medicines had been replaced by daily visits to the Church. She repeatedly asked me for a cure, whereupon I was given this instruction. In Delhi, I observed a volunteer debate the healing successes of a popular Guru with the Mukherjee family. The volunteer discussed the Guru’s daily television programme which showed miraculous cures for chronic ailments (no cases of failure were mentioned) and outlined his own fitness regime every morning (a walk and yogic breathing exercises).

Neither case was about peddling a commercial agenda nor about privileging particular medical systems. Rather, these reflected a tendency among people to give hope to families, which itself was emblematic of their frustration at the lack of an *ilāj* to cure this chronic disease. Similar findings were made in Thailand (see Bennett, 1999), where the truth about terminal illnesses was ‘softened’ by doctors, family members and the patients themselves. Dying was never discussed and even till the end stages, promises of a cure circulated. The underpinning rationale was to protect patients’ psychological integrity and give them hope. Surbone reminds us, “that we all have a responsibility towards hope...and that it [hope] does not need to have ‘cure’ as its object” (1997, pp.74 and 79). Offering hope and the possibility of recovery is critical to formulating a relationship between doctor and patient, even when the possibility of recovery

or return to normality is slight (Del Vecchio Good, Munakata, Kobayashi, Mattingly & Good, 1994; Mattingly, 1994; Warren & Manderson, 2008). The alternative of profound hopelessness is never really an option. When doctors failed to give hope or were challenged by their patients, reprimand was swift, as was illustrated in a Delhi *sarkari* (government hospital) OPD:

A woman in her 60s has come to get her script refilled. She is well-dressed in a clean pink and lavender sari, her grey hair is combed and coiled into a bun. Dr. Kumar eliminates some of her medication and she begins to protest, “*Sugar hai, heart ke leya hai*” [for my diabetes, for my heart]. Dr. Kumar replies that these medications are not related to her illnesses and one should not take medications *befikaar mei* [unnecessarily]. She continues to protest and the doctor gets irritated and yells at her: “*Tu khud apna ilāj kar le. Hamaree baat tō tu maanne ko tayar nehi hai...jaao!*” [You cure yourself. You’re not ready to accept our advice. Go!]. Kumar says this twice in the ensuing argument. He isn’t going to fill her script or write or sign off on anything. Who was the doctor here – him or her? If she was so convinced that these medicines were essential, then why had she come to him? She should just treat herself. *Chhor* [forget it], he wasn’t signing off on anything (*Field notes, 29<sup>th</sup> February 2008*).

Within these expectations and enforcement – of how patients should behave in an OPD, how volunteers should relate to families, and how positive a researcher should be – lives India’s medical history. Morality and power are vested in health authorities within pluralistic systems where clinicians such as Dr Kumar

wield considerable power. In the above vignette we may read an example of 'medical dominance;' a term which refers to the power that doctor's exercise because of their clinical roles in diagnosis and treatment, ability to supervise the work of other health professionals, and the privileged status of medicine compared to other health professions (Freidson, 1970). A key feature of medical dominance is the autonomy that doctor's enjoy, what Friedson described as the "authority to direct and evaluate the work of others without in turn being subject to formal direction and evaluation by them" (1970, p.135).

But castigating the clinical approach of Dr. Kumar, using the medical dominance paradigm, presupposes that he is in the business of domination not doctoring. In fact Kumar, as a doctor, represents medicine's capacity to offer an *ilāj* and hope to people. This is why doctors are held in such high esteem and patients want to consult them. Medicine's capacity to enhance human productivity also explains why it has been subsumed by the state, invested with power, and appropriated at various points in history to control the masses (Foucault, 1975). No doctor-patient relationship occurs in a clinical vacuum (Navarro, 1976). In the politics of talk between Dr Kumar and his patient existing social hierarchies are reinforced through the methods of communication (authoritarian-subordinate) and the institutional settings (resource poor) in which this conversation occurs. The protocols around behaviour and authority are stringently adhered to with punitive consequences for those who balk at these unwritten rules (Pinto, 2004). As Navarro (1978, 1982, 1988) has argued, medicine reproduces the class, gender and race power relations of the wider

society in which it operates. The task is to understand the wider political-economic forces which frame these clinical encounters.

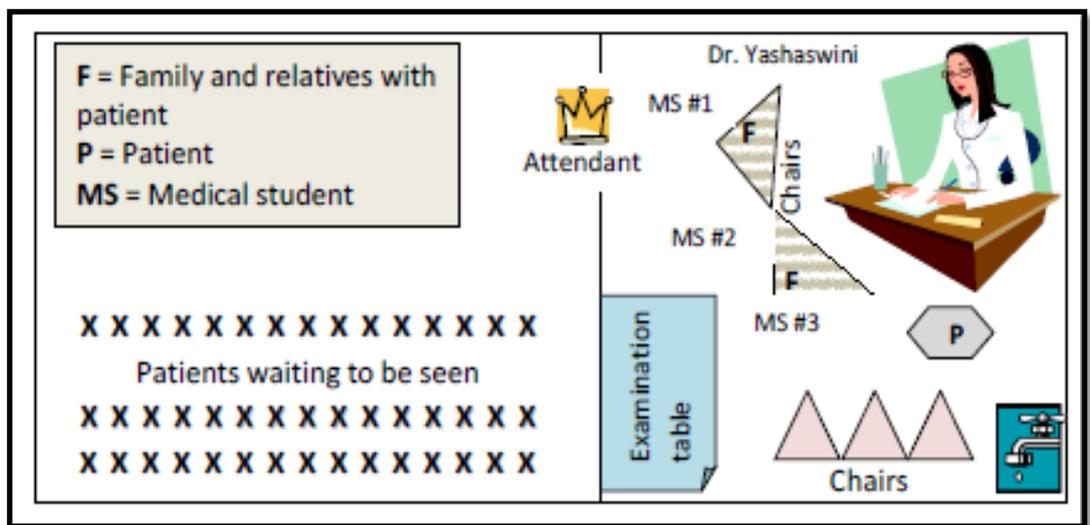
**“You have to be a Little Bit Mad to Work in a Place like This”**

“The only thing that there is no shortage of around here is people,” says Yashaswani drily. She sits behind her desk, tall and stern, neurologist first and woman second. She wears little make-up, minimal jewellery, and comfortable shoes. Even her sari swishes in an orderly way beneath her white lab coat when she strides. She has a brusque, booming voice which she uses to demand for systematic administrative processes, for patients to come into her OPD room, for good quality drugs and treatment, for social workers to help poor families, and for laboratory technicians to produce cleaner and better reports.

She sees approximately 1000 patients and their families per month from places like Bihar (47 percent literacy), Jharkhand (53.56 percent literacy), Uttar Pradesh (56.27 percent literacy), and Jammu and Kashmir (55.52 percent literacy) (Census of India 2001, 2006). These are small town people fretting over their children’s epilepsy (60 percent of cases), their relative’s head injuries (20 percent), their own psychosomatic complaints (10 percent), and their parents’ dementia (less than 10 percent). Yashaswani brusquely assesses them, “Answer properly! When we ask you questions, if this is the sort of answers you give, then what will we do? We’ll treat him accordingly. You people also!”

Patients, families, pharmaceutical representatives, hospital administrative staff, and other doctors troop in and out of her OPD as she grows more irritable,

“Haa, haa just barge in, we are all sitting in here having a party. Wait outside please, I will call you.” An attendant guards the door, a human blocker to humanity’s clamour for an *ilāj*. Her OPD consultancy room is meagre: a desk, two chairs and a cold metal stool on which patients sit when they are examined. Three plastic chairs line one wall, an examination table covered by a dusty paint-splattered blue sheet rests against the adjacent wall, and nestled in the far corner is a basin with a shabby soap dispenser (See Figure 10).



**Figure 10: A *sarkari* OPD**

Yashaswani works hard and tries to improve the system. A family from Patiala has been waiting for six months to get the results of an MRI of their son’s brain, and she tells them to complain formally. A private MRI facility provides poor quality images at high prices so she telephones and yells at them, threatening to report them to the health authorities. When patient files go missing (as they often do), the File-in-Charge<sup>14</sup> opens new ones at her behest (OPD patient

<sup>14</sup> English term for an administrative clerk who manages patient records and files and is spoken in English even if the remainder of the sentence is in Hindi.

records are written not computerised). A family explains that the medication she prescribed was not available so the chemist gave them an alternative. She is infuriated: “Do you know that nearly 50 percent of the drugs available in the market are illegal? They don’t do what they claim to. God knows what effect they have, and they’re not even registered. Who knows what *desi dava*:<sup>15</sup> [local medicine] you’ve picked up and brought here? It doesn’t even come in a box, they’re selling it to you lose and you’re giving it! I’m writing this again, you please buy it and don’t substitute it with anything else.” She writes ‘no substitute’ on the script as well.

Yashaswani’s story is neither unique nor particularly dysfunctional for a *sarkari* hospital. By comparison with other OPDs I visited, where 150-200 patients would be seen in about two hours by four or five doctors, her OPD was organised and efficient (usually only about 40-50 patients were seen in 2 hours). The concerns she confronted – high patient demand, few resources, work overload, hospital bureaucracies, inferior quality tests and drugs – were themselves symptomatic of India’s public health infrastructure (Jeffery, 1988), which like the public health of most developing nations, is shaped by the forces of class, history, globalisation and institutional power.

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<sup>15</sup> *Desi dava* is used to refer to the range of indigenous medicines which may be included in traditional medicine. Colloquially, it is also used with reference to the efficacy of such medicines and the ad hoc manner in which they are manufactured and distributed. *Desi dava* may be unregistered, unlisted medicines which may be sold by pharmacists, traditional practitioners, and religious healers.

Delhi has 71 *sarkari* hospitals<sup>16</sup> and 100 private facilities.<sup>17</sup> Yashaswani works at a premier teaching hospital but in comparison to the private hospitals, hers is under-resourced and grappling with the health needs of millions of poor Indians who cannot afford private biomedical healthcare. Approximately 1.5 million outpatients and 80,000 inpatients are seen here every year. Concurrently, the number of *sarkari* doctors is dropping. The Planning Commission of India (2007) estimates a 600,000 shortfall in doctors across the country, a figure projected to increase as more registered doctors emigrate and students opt into higher-paying jobs in engineering and business. Indian doctors in the USA, UK, Canada and Australia – about 60,000 in total – constitute about 10 percent of the total doctor population of India and are the largest émigré physician workforce in the world (Mullan, 2006).

Patients in *sarkari* hospitals typically spend long hours waiting only to have less than two minutes with the doctor and interruptions are commonplace during the consultation. This depressing finding has been reiterated since the 1970s (Das & Das, 2006; Jeffery, 1988; Murthy & Parker, 1973; Seth, 1973). It is symptomatic of the skewed doctor-patient ratio nationwide (1:1800) (Government of India, 2007). Additionally, the socially enforced behaviour for *sarkari* patients – obsequious, cooperative and mild – has been linked to pressure for ‘voluntary’ gifts and informal payments for hospital admissions, bed availability, and subsidised drugs (Jeffery, 1988; Peters & Muraleedharan,

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<sup>16</sup> This figures includes neither Registered Nursing Homes (N=606) nor Unregistered Nursing Homes (N=1550) <http://health.delhigovt.nic.in/Health/index.html> accessed on 21 July 2009.

<sup>17</sup> Due to a lack of data, this figure is based on the number of private facilities recognised by the Central Government Health Scheme in Delhi and does not capture the actual number of private hospitals which may be higher.

2008). While I never observed such exchanges or such pressures in Yashaswini's OPD, patients were dissatisfied with their experiences:

In a government hospital it is not a happy situation, it is a depressing situation. Taking mummy there that day was really excruciating. It was the end of February and sitting there on those uncomfortable chairs from morning to evening, for me, I suppose it is ok but at her age, she is not used to it, it is terrible...I don't know how things are organised, the doctor comes, then suddenly they disappear and they come back. What they do – whether they have to take their rounds of the wards at that time – I don't know. The management and the discipline is hopeless, really, really hopeless (*Nayantara Sen, 58*).

Overall about 36 percent of patients are less than satisfied with their *sarkari* experience and 44 percent of those using private providers feel that the latter are more receptive to their needs (National Sample Survey Organisation, 1998). This finding has been made elsewhere in Asia; in Cambodia, people preferred private practitioners not because their treatments were necessarily effective but because the services were always available, located closer to home, the practitioners were willing to make home visits, and fees could be paid via instalment and/or bartered with goods and services (Khun & Manderson, 2007).

In India, 60-80 percent of all healthcare (biomedical, traditional, transcendental) is sought from the private sector (Duggal, 2000). This is largely due to the consistent failure of the public system to meet the needs of its

citizens in both cities and villages. The National Sample Survey Organisation (NSSO) (1998) has shown that high income states in India, despite having greater per capita government expenditures on public health dispensaries, hospitals and hospital beds, have a similar number of untreated cases in urban (9-19 percent) and rural (10-26 percent) areas as do low and middle income states. A comparable 24 and 21 percent of survey respondents also cited financial difficulties as a reason for non-treatment in rural and urban areas respectively. Urban poverty is also on the rise and the National Urban Health Mission, in parallel to the longstanding Rural Health Mission, has recently been established to meet the needs of more than 42.6 million people who live in slums (Government of India, 2007).

Studies on poverty and health-seeking behaviour, from other low income countries, show people seek a range of therapeutic interventions based on what they can afford and the severity of their illness (e.g. Khun & Manderson, 2008; Meessen, Van Damme, Tashobya & Tibouti, 2006; Van Damme, Van Leemput, Por, Hardeman & Meessen, 2004). Costs associated with public and private health services, availability of drugs, perceived quality of care, level of household resources, and indirect costs (e.g. time off from work) influence whether public or private health services are accessed. These factors determine the strategic choices that people make in their health seeking behaviour and in such a model, private health may be a more viable option than public services (ibid).

In India, biomedical private health is driven by profit and mainly targeted at the middle-class and elite (Purohit, 2001). The sector has grown exponentially due to the structural adjustment programs of the 1990s and liberalisation of the economy. Private health includes various health insurance schemes, new hospitals, sub-speciality care, medical tourism, pharmaceuticals, and investment in medical equipment (MRIs, CT scanners, X-ray). All of these are supported in various ways by tax incentives, public-private partnerships and trade agreements (Purohit, 2001). This pharma-economy, which will be analysed in the following chapter on the economies of dementia care in India, adds another layer to the existing complexity of medical pluralism in India, for alongside the three systems of medicine there is also a public-private, rural-urban, poor-rich divide.

For doctors like Yashaswani, who choose to remain in *sarkari* hospitals, work is gruelling – twelve hours a day, seven days a week and every alternate Sunday off. Her health, clinical, and human qualities are affected. She knows she cannot adhere to any imaginary gold standard:

It is not like the west where you see two or three patients and you spend an hour and a half with each patient. You cannot do that. You don't have time to spend. It's probably the first evaluation which is the most detailed and after that it's more of a short amount of time that we can give them. The major challenge is time management for patients, time management for your own work, your own research, your family...

Yashaswani experiences migraines, conjunctivitis, dark rings under the eyes, and lethargy during the months I sit in her OPD. When we finally have our interview in her clean air conditioned office, she is harried and hungry. Her answers are fired like bullets interspersed by people who storm in and out, yelling about admissions, MRIs, and bed availability. She yells back. As I leave, she smiles wryly and says candidly, “You have to be a little bit mad to work in a place like this.”

### **What Role for Human Rights?**

For patients and their families who have to be admitted into a *sarkari* hospital, the experience is an ordeal. The hospital hierarchy positions patients at the bottom rung and privileges the institutional relationship between hospital and patient over the familial relationship between carers and people with dementia. When Harinder Singh (60) was admitted into the neurology ward by Yashaswini, only his wife Jaspreet was allowed into the ward with him. His son Ajit was told by the ward security guard, “He is our patient and if you go up, you will disturb all the other patients.” Consequently Jaspreet was left to deal singlehandedly with her husband’s wandering and incontinence.

They just washed their hands of us ... He wouldn’t stay in bed and every 10 minutes he was doing his bathroom on the bed and this became a big concern. Sometimes he would get on someone else’s bed, or touch someone else’s bottle, [and] the whole day I was with him trying to manage this.

The ward staff gave Jaspreet two bed sheets and when Harinder soiled them, she was asked to wash them. When she requested a rubber sheet or a condom catheter, she was refused, and was told to take Harinder to the toilet. Meanwhile, Ajit would wait for hours in the hospital foyer, with food his sisters had prepared, periodically telephoning his increasingly hungry mother. The guard would not allow him to give the food to Jaspreet and when mother and son met at the entrance of the ward, the guard monitored them so closely that Jaspreet had to ask him to step back. Finally, after two days, Jaspreet had had enough:

After all of this distress I said, "We can take better care of him at home" and we brought him back. He made such a mess that for two to three days after I brought him back I was still washing his clothes. There how would I wash his clothes? They wouldn't let someone else stay with him, so how could I leave him and do it? I would just change him and put the soiled clothes in a plastic bag.

The family were angry and embittered by their experience. Harinder had picked up an infection while in the ward, which gave him severe diarrhoea, and the family were still managing this when I went to visit them nearly two weeks after he had been discharged. Additionally, his balance had been affected following a spinal tap, and he periodically fell down. But for the Singhs, their anger was directed to the guard.

The guard, a real and symbolic embodiment of institutional authority, is also an indicator of the depth of medical dominance in India, which is enacted at all

levels of the biomedical institution. Yet the Singh's frustration with him reflects lay people's impatience with those who wield authority without knowledge. Ward guards, administrative staff, door attendants in OPDs, and hospital clerks were perceived by families and patients as having the same social status as them not in terms of class, caste or income, but knowledge – they knew nothing of the *ilāj* – and therefore their power was continuously undermined by patients who would argue and barge past them into the doctor's office. Doctors, nurses, and occasionally doctoral researchers occupied a different power terrain because of the perceived knowledge they had. So I could squeeze into a crowded OPD while 200 people waited outside; I could dismissively stride past a guard into the neurology ward. Class is always implicated in this dynamic, reflecting the power and capacity of some, more than others, to pursue doctoring, doctorates and other symbols of institutional power. Nita Kumar has written of her dealings with the Varanasi police in the early 1990s: "My clothes, coolness, and confidence in going up to the doorman immediately marked me as someone from the top rather than from the bottom classes, and everyone in such circumstances is judged by these things" (1992, p. 221).

The clothes and the lack of confidence of the Singhs marked them as unimportant to the guard, and they were treated accordingly. Such judgements chalk out inequities and deny access to care to those who need it the most. Such blatant disrespect for the rights and dignity of people is symptomatic of what Paul Farmer (2003) has termed the 'pathologies of power,' the structural violence that permits such human rights violations. Having already discussed the political economic factors that structure such violations, one could easily

situate the Singh's experience within class politics, colonisation, and the historic nature of doctor-patient relations. That argument could be bolstered by the short history of the application of human rights to *all* humans. It is only in the last 100 years that the rights of the Other (for example, female, non-white, homosexual, and disabled subjects) have been given credence and even these rights have been applied to varying degrees in different parts of the world (Donnelly, 2003). Within this paradigm, the treatment of the Singh's and those of millions like them is unsurprising, having always had an historical basis.

But this is to confound explanation with excuse, and cultural legacies with cultural immobility, a trap into which the 'Asian values' argument has fallen (Bauer & Bell, 1999). In Asia, historically and presently, individual rights are eschewed in favour of collective duties to the state. The sacrifice of political and civil rights in the short-term is purported to lead to faster economic development and improved quality of life overall. Yet as Amartya Sen (1999) has argued, the entire notion of 'development' needs explication. He has defined 'development' as "a process of expanding the real freedoms that people enjoy... [by] the removal of major sources of unfreedom: poverty as well as tyranny, poor economic opportunities as well as systematic social deprivation, neglect of public facilities as well as intolerance or overactivity of repressive states" (Sen, 1999, p.3). Nussbaum (2005), extending Sen's work, argues from a social justice and entitlement perspective. She advocates for the fulfilment of ten human capabilities – lifespan, good health, bodily integrity, sensory and emotional engagement, practical reasoning, play, affiliation and ability to live respectfully with others (including other species), and legitimate political and material

stakes in society. When a society has not ensured these capabilities for all its citizens, social justice has not been achieved.

Nussbaum's (2005) capabilities approach is also a political theory for wellbeing and echoes what is encapsulated in the Universal Declaration of Human Rights. If we accept definitions such as hers and Sen's, the relationship between health equity and political freedom is axiomatic and proportional. India's commitment to human rights, though bloodied in many parts, is represented nationally and internationally in its constitution (established 1950), the National Human Rights Commission (established 1993), and in its signing of the Universal Declaration of Human Rights (contributing towards the draft document and adopting it in 1948). The state, the source of the greatest structural violence against its citizens (e.g. police brutality, endemic corruption, violence in Kashmir), has also pledged itself to overcoming inequity. We may take hope that this is the world's largest democracy with a free press and vociferous civil sector, which holds the government to account and forces the state to respond to its demands for equality (e.g. greater inclusion of scheduled castes and tribes in political representation, overturning laws which made homosexuality a crime, and legislation giving citizens the right to information of state documents).

At a grassroots level, structural and institutional struggles for equality and dignity are relational struggles. For the Singhs, this was a failed relation between them and the guard, and is a yardstick for how much change is necessary in India's health system. Support for the integration of human rights

into the health infrastructure is widespread and fought for at macro and micro levels. All those who are oppressed respond positively to such struggles:

She [mother] was in the aggressive stages [and] she would tick off all the doctors: “You’re an idiot; you don’t know your job.” If the guy was bald she’d call him ‘baldy’ and things like that. So every time we would leave a hospital we’d have all the patients and all the lower staff coming to say bye-bye to us because she had acted in a subversive way with all the doctors, and sort of stripped them of a lot of their authority (*Namita Sood, 53*).

### **“We Fail Them”**

Four pharmaceutical drugs are recommended for the treatment of dementia – donepezil (Aricept®), galantamine (Reminyl®), rivastigmine (Exelon®) and memantine (Admenta®) (Alzheimer's Australia, 2008). The first three drugs are cholinesterase inhibitors which aim either to increase levels of acetylcholine (an important neurotransmitter for memory) or strengthen nerve receptiveness to acetylcholine. At the time of interviewing, Galantamine was not legally marketed in India. Currently a number of applications by pharmaceutical companies are waiting approval from the US Food and Drug Administration to market Galantamine in India (FDA, 2009).

Memantine targets a neurotransmitter called glutamate by preventing the build up of calcium in the brain cells, which can cause further damage. Additionally, anti-psychotic medications may be prescribed to manage behavioural

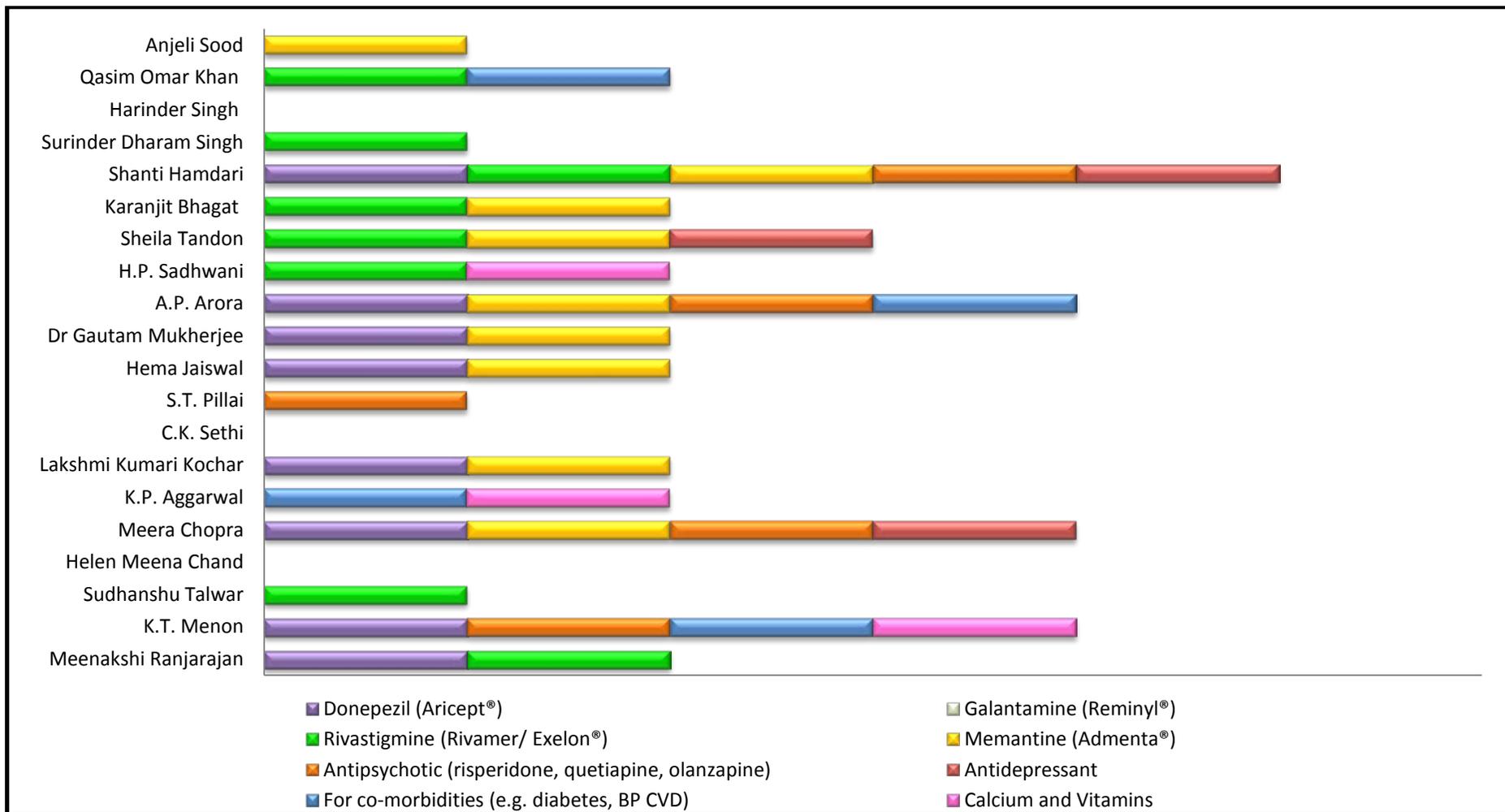
disturbances like hallucinations and aggression, and anti-depressants for depression and anxiety (Alzheimer's Australia, 2008). Given the correlation between ageing and dementia, often these medications form part of a cocktail which may include medications for co-morbidities (like cardiovascular conditions and diabetes) (see Table 2). Among the 20 people with dementia who formed part of this study, there was an approximately equal use of donepezil, rivastigmine and memantine. Only three people were not on any medication – Helen Meena Chand (who refused to take any) and C.K. Sethi and Harinder Singh (whose families opted not to give them any).

There is growing concern about the efficacy of dementia drugs. A systematic review of 22 randomised-controlled-trials of cholinesterase inhibitors found that flawed methods and small clinical benefits undermined the scientific validity of the recommendations for their use (Kaduszkiewicz, Zimmermann, Beck-Bornholdt & van den Bussche, 2005). Many of the scientific assumptions made about dementia have also come under scrutiny. A recent study (Greenberg, 2009) examined the belief that  $\beta$  amyloid, a protein accumulated in the brain in Alzheimer's disease, is produced by and injures skeletal muscle of patients with inclusion body myositis. The study found citations were often distorted through citation bias (ignoring studies that weakened this belief), amplification (drawing on studies which presented no studies addressing this belief), and invention (presenting study hypotheses as results).

The administration of anti-psychotic medications have also been criticised, with evidence showing worsening of symptoms and increased mortality for patients

with Alzheimer's disease (Ballard et al., 2009; Tariot et al., 2006). Yet the continued prescription and consumption of these drugs highlights the few options available to doctors and patients as well as the political economy of these medications. The prescription of a drug for dementia is part of a larger pharmaceutical biography of invention, testing, patenting, production, marketing and distribution in global settings, influenced by multinational companies and nation-state politics (Farmer, 2003; van der Geest, Whyte & Hardon, 1996). The economic costs of an *ilāj* to families will be discussed in the following chapter on caring economies. For now, I concentrate on the physiologic and relational effects of these medications.

**Table 2: Forms of Biomedical *Ilāj***



A prescription for medication was usually obtained following diagnosis, with follow-up visits every three to six months to *sarkari* OPDs for script refills. In theory, these visits were to monitor the disease progression, review and adjust the medication, and counsel the family on what to expect next. The person experiencing dementia was meant to be seen by the doctor at least once a year. In practice however, people with dementia rarely returned to the OPD following diagnosis, and instead their relatives would go to refill their scripts. Few got the opportunity to speak to the doctor, due to time restraints and competing patient demands.

Doctors generally signed the refill prescription while signing a host of other scripts without reviewing or adjusting the medication. Consequently, many people with dementia were on medications whose dosages had not been altered for years, and/or were on antipsychotic medications which should have not been administered for more than a few months. Mrs Hamdari, for example, had been put on olanzapine (an anti-psychotic drug approved for treatment of bipolar I disorder and schizophrenia) following a bout of aggressive behaviour when she had slapped her maid. Although olanzapine was marketed off-label for dementia patients (Spielmans, 2009), in August 2008 it was shown to increase mortality among dementia patients by 1.6 to 1.7 times compared to those who were on a placebo (Lilly USA LLC., 2009). When I first met Mrs Hamdari, in April 2008, it had been more than 18 months since her first dosage. Her aggression had dissipated and she was experiencing increased levels of lethargy and drowsiness. Her daughter Nayantara attributed this change to the

medication and was becoming increasingly concerned about the side-effects but did not feel confident about adjusting the dosages on her own.

Finally in July 2008, with prompting from me, Nayantara returned to Yashaswini to ask for the medication to be reviewed, whereupon olanzapine was removed. Though I was able to intervene on behalf of Mrs Hamdari, most families navigate this field on their own. Among the sample, Mrs Hamdari was on the most medication, but the symptoms she experienced were part of an iatrogenic litany that families and key service providers reported. Again and again, families complained of the nausea, diarrhoea, aggression, weeping, drooling, and unsteady gait that the person with dementia experienced as a result of taking cholinergic inhibitors drugs and anti-psychotic medications.

There were few if any positive effects, and only K.L. Chopra had felt his wife Meera had improved, i.e., was calmer, with medication. Many, like Nandini Pillai, felt that antipsychotic drugs made caring more difficult:

His [father] life changed completely in the sense that even his gait wasn't steady and he was drooling and obviously what he was saying wasn't very clear. There were times that he fell, the number of times that he fell...There was a time I went to the market, came back and he was sitting under the tap waiting for me to come home to lift him up. Once he locked himself inside the bathroom and we had to call the carpenter to break open the door.

Typically the deleterious effects of medications far outweighed any supposed benefit not only physiologically but also relationally. While the dementia undeniably and irretrievably changed relationships, the administration of medications tended to sharpen the carer's gaze on the body of the person living with dementia. When medications were administered (before or after meals), how it was administered (swallowed whole, crushed and disguised with food, chewed as it was) and the effects it had (such as increased nausea, sleepiness, drooling) all required carer input, surveillance and management of the body. Medicines became an embodiment of discipline for both carers and people with dementia. Giving and taking medicines was part of the routinisation of care, alongside activities such as feeding, bathing, and exercising. ARDSI volunteer Somya Ghosh explained the disciplinary function of antipsychotic medications:

Unfortunately I feel that there are some families who are very happy for the doctors to give antipsychotic drugs and make the person very numb and drowsy. That way the problems of wandering, the problems of lying, the problems of repeating oneself are gone. "I can manage him this way. I am alone; I have to manage him this way. You tell me, what is my predicament? If I go to the doctor and stop all his medication and the person does all these things, then what do I do?" We sometimes don't know what answers to give, we fail them.

Yet most carers balked at privileging a docile physical body (through medication) at the expense of social relations. Ultimately many reduced if not stopped the medication altogether. This was gendered: female carers tended to be ambivalent while male carers were zealous about medications. For women,

medications were part of the caring gamut; this is in line with work done on HIV/AIDS which found that for women, drug regimens had an intrusive effect on everyday life and that social relations strongly impacted on their ability to comply with medications (Johnston & Mann, 2000; McDonald, Bartos & Rosenthal, 2001). Older women's experiences with medication administration are often problematised as 'adherence' and 'error' (Arlt, Lindner, Rosler & von Renteln-Kruse, 2008; Col, Fanale & Kronholm, 1990; Sorensen, Stokes, Purdie, Woodward & Roberts, 2005). Such language obfuscates the complex decision making behind such 'errors' and fails to acknowledge the impact of adverse drug reactions. In the USA, more people are admitted to hospitals for adverse drug reactions than non-compliance (Heath, 2003), and in the UK about 11 percent of hospitalised patients suffer an adverse drug reaction with greater risk of mortality following such an episode (Eaton, 2002). In India, though pharmacovigilance has had a 20 year history on paper, chronic underfunding has left it largely ineffectual in practice (Biswas & Biswas, 2007). Nevertheless, Indian studies have shown that adverse drug reactions can and do happen, often with fatal consequences, and the elderly are especially vulnerable (Malhotra, Karan, Pandhi & Jain, 2001; Ramesh, Pandit & Parthasarathi, 2003).

In my study sample, only six women administered medications as a matter of course; the rest sought alternatives elsewhere (n=6) or reduced the dosages of their own volition (n=5). None put great stock in the capacity of a biomedical *ilāj*, and in some cases (n=5) doctors themselves discouraged these women from administering medicines. Vandhana Arora was candid about her expectations for her father-in-law:

Basically we cannot expect any recovery from this. It provides certain stability to the behaviour and maybe the progression is not very fast. But to expect recovery in a case like this is foolishness. I think more than the medicines, it is the handling of the patient which will direct his further behaviour and symptoms. It is a degeneration.

Men, in contrast, often tried to administer various medications to their wives. For them the pursuit of an *ilāj* – obtaining a script, getting a refill, buying the medication, and offering and administering a range of pills – was a way of retaining control and performing *seva*. Mr Chopra medicated his wife for all manner of ailments, much to the consternation of his sons and daughters-in-law. Shivbaksh Chand, the most recalcitrant and beguiling person I met in Delhi, had filled half of a small carton with an assortment of drugs, most in strips, with the packaging long lost. In his first interview, he declared that he and his wife Helen had dementia, “but she more than me.” Whether this dementia was the *sathiyana* of ageing, or a neuropathology that affected them both, or a hybridised dementia whereby he mimicked her symptoms to obtain treatment because she refused to leave her home, eluded me. I never managed to ascertain who had dementia and at what stage. Shivbaksh and Helen proved far too wily.

I am eating my medicines. Look how many medicines I am taking every day.

[High-pitched voice] *So many medicines!*

Yes that’s why I am still alive [Riffles through box]. I am a blood pressure patient also; see these are the medicines I take for that. And see this medicine, and this one... [Addresses his wife] What time of the day is it?

Helen: it's daytime, around noon.

[To BB] she's said the right thing. It's about to be 12 'o clock. [To Helen]

Here eat this calcium tablet.

Helen: No, I don't want it.

Shivbaksh took half his medicines and unsuccessfully attempted to feed Helen the rest. He was diagnosed in a *sarkari* OPD amid hundreds of other patients, and had never visited a neurologist's office. He spent his days in search of many kinds of *ilāj* and once asked me to get his script refilled. When I returned with the refill, I discovered that I was not the only person pressed into this service, for a young man from the main *Āyurvedic* dispensary in the adjacent suburb had also come to drop off medication. For Shivbaksh, medicines were a means to illustrate how much *seva* he performed for Helen, even though she spurned all of the medications he brought her.

For Helen, medicines would prolong a life she had long grown weary off and she told me on two separate occasions of her desire to die. Thus *ilāj* was cure and imprisonment in this household, a disciplinary signifier by virtue of its social and chemical compositions. Chemically *ilāj* as a pharmaceutical drug could 'cure' or minimise the behavioural and psychological symptoms of dementia, and so restore (to a degree) the normal social order of things, although in practice this was not the case. But these 'normal' social orders were also the disciplinary structures of Helen's life, which she resisted by doing no housework, refusing to leave her home, not seeing a doctor, and not taking any medication. Pound and colleagues (2005) have argued that despite widespread

belief in the benefit of drugs, individuals also resist consuming medicines in various ways (e.g. self-modification of dosages, symptomatic use only) because of the coercive power of drug regimens. Helen's resistance of all forms of *ilāj* was also a resistance to her life. She refused to be housewife and patient, and sought to step outside the disciplinary project through death. Shivbaksh did his utmost to try and make her live.

Avoiding death and degeneration was also the purpose of Govind Ballabh Tandon's life. Like Shivbaksh, he spent his days stoically searching for an *ilāj* for his wife Sheila, who was in the late stages of dementia. But in his final interview he tragically conceded:

I consulted the doctor and all the doctors are of the opinion that the medicine works in the initial stage but is ineffective in the later stages. So whether you give it or not, it is useless. So for the past four months I have been reducing it. For five years I was increasing it and now I am reducing it...Within six months I want to stop all her medicines.

Reducing and ultimately stopping medications was for families an acceptance of the inevitability of death. This realisation occurred with time as hope gradually faded. Hope is a central feature of the administration of any medication, and for families, the hope for an *ilāj* was a driving force in their doctor shopping. This finding has a broader resonance with studies from the US (Lindstrom et al., 2006) and Canada (Rockwood, Graham & Fay, 2002), showing that patients and families living with dementia hoped for improvements or at least stasis in function, cognition, leisure, behaviour and social interaction through

medication. But when biomedical forms of *ilāj* failed to deliver, unlike in the western context where doctors are meant to fight to the end, in India, both doctors and families were fully and freely able to recognise the role of God, religion and faith in the person with dementia's welfare (Khare, 1996). As the stories of Vandhana, Shivbaksh and Tandon illustrate, the search for *ilāj* is a combination of hope and desperation in the face of degeneration and chaos. Biomedicine is but one part of this broader search, and traditional and transcendental medicines also play an important role in managing dementia.

### **Traditional Medicine and Temperance**

Fourteen families used traditional medicines. Treatments from multiple traditional systems were often simultaneously used. *Āyurveda* and homeopathy were the most popular combination (n=10 and 8 respectively), but an assortment of other therapies such as yoga, acupuncture, reiki, herbal medicines and magnetic therapy were also used by families. Unlike in the West, where such therapies are accessed as 'alternatives' or 'complementary' to biomedicine (Astin, Marie, Pelletier, Hansen & Haskell, 1998), in India these treatments, reflecting a medically pluralist society, are accessed in conjunction and are administered alongside biomedicines (Tandon, Prabhakar & Pandhi, 2002).

In India the number of registered traditional medical practitioners (n=725,568) currently supersedes the number of registered allopathic doctors (n=695,254) (Department of AYUSH, 2009; Medical Council of India, 2008). Traditional practitioners are usually private practitioners and shoulder much of the burden

of healthcare in rural India. Even in urban centres, they share the load equally: for example, of the 939 dispensaries in Delhi, 454 are allopathic dispensaries, the remainder are a combination of *Āyurveda*, *Unani*, *Siddha*, homeopathy and the like (Government of National Capital Territory of Delhi, 2008).

Colonial and developmental discourses which underpin contemporary Indian society have linked modern industry-biomedicine and nation building as efficient, stable models amenable to bureaucratisation. Traditional medicines are seen as intermediate and associated with particular religious or ethnic groups (Nandy, 1995). Because traditional medicine is not viewed as analogous to biomedicine, but as part of a complete Indian therapeutic landscape, biomedical doctors accepted that their patients used traditional medicines and rarely discouraged them from doing so. But there was a hierarchy of knowledge and biomedicine ranked above traditional medicine. Yashaswini said:

We don't discourage them from taking *Āyurvedic* or homeopathic, we just tell them that it should not have harmful metals. They do experiment. Some of them claim that they are better with these medicines.

*What do you think?*

I am sure that there is something there which works. It is only that we haven't investigated them in a scientific manner; these herbs are well known from ancient times. They could improve the memory. In fact research on turmeric, cumin and some of the herbs is going on in western settings.

Ashis Nandy (1995) has argued that the appropriation of techniques and ingredients from traditional medicine by biomedicine is part a process of delegitimising these epistemologies by rendering them 'unscientific,' while simultaneously absorbing, assimilating or marginalising certain aspects of traditional medicine. Families accepted this knowledge hierarchy and adjusted their expectations accordingly: traditional medicines were viewed as more suited to chronic disease management than biomedicine because, even though they were perceived as less effective, they had fewer side-effects (see also Chacko, 2003; Dalal, 2000). For emergencies, biomedicine was still the first port of call, even among carers who were strong advocates for traditional medicines:

If there is a crisis, like if there is a terrible chest infection, you have to give the antibiotics, there is no other way about it...Then it is best to take the person off the *Āyurvedic* medicine for that period because the antibiotic will do its work . So just take it off until the crisis is over, and then get back on it for the chronic (*Namita Sood, 53*).

Intriguingly, traditional medicine's second tier location bolstered its veracity in my study, as families had reduced expectations of an *ilāj* and therefore their dealings tended to be more fruitful. Namita Sood, Nandini Pillai, Nayantara Sen, Bhageshwari Srivastava and Nina Bhagat all put great stock in their homeopaths, herbalists and *Āyurvedic* doctors because none had promised an *ilāj* but all had managed to affect positive changes such as increased calm, improved functionality and greater energy among people with dementia. Nina said of Karamjit's treatment:

Everything had gone *gheech-peechee* [topsy-turvy], but this medicine we are giving him has brought his strength back. This herbal medicine – we are giving him a very powerful dose which the astronauts take so that he builds his inner strength up. Once he builds his inner strength he will have more confidence and if he starts playing good golf then he will ask his friends to play.

Two key points stand out in Nina's words: (1) the establishment of the potency and integrity of the herbal medicines by highlighting its use by astronauts, and (2) the effect of these medicines in improving relations, i.e., one can play good golf with friends. Both points are underwritten by class. All these carers were highly educated, English-speaking women, who resided in the wealthy suburbs of south Delhi. They were astute and gauged the effectiveness of their traditional doctors by the latter's professional qualifications and refusal to give hope. This contrasted with their experiences with biomedicine, from which they initially wanted hope and an *ilāj*. Those traditional practitioners who promised a cure were viewed with scepticism, as 'quacks' who made extraordinary claims. Families were dismissive:

I've never met a homeopathic doctor who's said, "We don't have the treatment for this disease." Of all the doctors I've seen the allopath ones will tell you, "These are the medicines I have and whatever effect they have we'll see because there is no cure for this illness." But the homeopaths, the number that we have seen, even the famous ones will say, "With our medicines he'll be fine. Any day now he'll start playing football" (*Mamta Aggarwal, 38*).

If the power of biomedicine was undermined by the prudence of its doctors, then the power of traditional medicine rested on the circumspection of its practitioners. Such an equation reflects the location and professionalisation of traditional medicine. By a refusal to give an *ilāj* traditional medicine distances itself from quackery and its claims to cure all. By Nina's comparison of the medicines with those which the astronauts take, one can see how traditional medicine seeks to yoke itself to scientific institutions and accrue legitimacy.

The professionalisation of traditional medicines, most especially *Āyurveda*, commenced at the turn of the 20<sup>th</sup> century when its practitioners sought to mimic biomedicine by establishing their own colleges, associations and pharmaceutical firms (Sivaramakrishnan, 2006). If imitation is the best form of flattery, then such a move reaffirmed biomedicine's hegemony. But as Jean Langford (1999) points out, if professional *Āyurveda* is only partially reproductive of biomedicine, parody and challenge is also possible. Whether consciously or not, traditional medicine occupies both locales; it has borrowed heavily from biomedical diagnostic techniques through use of blood tests, histopathology, x-rays and stethoscopes, only then to prescribe its own treatment and disease aetiologies. It also crosses into the domain of transcendental medicine in how it mythologises the savant-like capacity of some of its practitioners (Langford, 1999, 2003). Shivanni, a homeopath, said:

Here there are many quacks...That is why the reputation of homeopathy is a little down. Otherwise [there are] many well-known renowned homeopaths, [and if] you read their prescriptions, they are excellent. Even today there are some homeopaths who, when the patient enters

the room, the medicine will come into their minds immediately. They have no need to ask them anything. If the patient speaks on his own they'll listen, but they've determined the medicine the moment the patient entered the room.

Traditional medicine's overlap of biomedicine and transcendental medicine has caused quiet rancour among some within the Ministry of Health and Family Welfare. Arvind Jaitley, a young but embittered bureaucrat, dismissed *Āyurvedic* and homeopathic medicine, questioning the efficacy of traditional medicine (or lack thereof as he saw it) and the methods used in diagnosis. "Without a side-effect is there any effect?" he argues. Jaitley worked in the mental health field and had a clinical qualification. A number of *Āyurvedic* medicine students had approached him to train them in psychiatric diagnostic techniques because there was no equivalent in *Āyurveda*. "How can this [*Āyurveda*] be an effective science?" he said disbelievingly, "yet there is a government ministry dedicated to it!" However Jaitley's circumspection excluded critical reflection on contemporary diagnostics in mental health and the conditions under which diagnosis is made (see previous chapter).

Unlike Jaitley, the Indian government and the WHO have increasingly recognised the potential of traditional medicine and have sought to incorporate traditional medicines into national health programmes and policy, ensure the safety and efficacy of traditional medicines, their rational use, and affordable access. Most families in my study were impressed by traditional medicine because of its effect in reducing the symptoms of social distress, such as

aggression, wandering, and listlessness. Where biomedical drugs created docile physical bodies at the expense of social relations, traditional medicines tempered the effects of biomedicine and facilitated the reintroduction of social relations. Nina said, “Herbal medicine I will not recommend anyone, unless he or she is dedicated and the activities are followed – then it has effect.” Activities for Nina included reading, writing, counting, yoga, golf, massage, morning walks, and hot and cold compresses for her husband Karamjit. Through all of these activities she could interact with him, monitor his development and adjust her strategies in her fight against his dementia.

While Nina’s story was one of some success, and most families had positive experiences with traditional medicine, one man came away bitterly disappointed. Tandon had taken Sheila for acupuncture treatments for nearly a year, only to find that she was deteriorating faster than he expected. He said:

This man had promised me, 100% to treat her. Whenever I go to a doctor the first thing I ask is whether it is possible to cure her or not. He had told me, “Yes there is a cure and in 90 sittings she will be cured.” He was asking for Rs.1 lakh. I said, “I’ll give you a lakh but you give me a promise that she will be cured.”

This purported cure involved the insertion of about 70 needles into Sheila’s head and neck, through which 20 volts of electricity would be passed for about 30-45 minutes. Each sitting was about six hours and was very painful for her. During our first interview, Tandon showed me a video on his mobile phone of Sheila receiving the treatment. She repeatedly murmured, “Go away, go away.”

For Tandon, the failure of acupuncture was the failure of yet another *ilāj* – he had already tried biomedicine, *Āyurveda*, homeopathy, and reiki. He had quit his job and reversed gender roles, spent his days searching for a cure, to no avail. He sought relief from his failure through self-analysis, watching TV, listening to music and playing games on the computer. Yet he never ceased hoping and, though a firm believer in science, he turned to religious healers for an *ilāj*.

### **Cosmopolitan Transcendental Medicine**

At the core of religion and medicine is suffering, distress and disorder, a cry for help and salvation (Kleinman & Seeman, 1999). Despite staking its claim in a rationalist discourse, medicine cannot escape its moral and soteriological dimensions. Suffering and salvation go to the heart of medicine, are woven throughout its history and praxis, and manifest in complex ways in daily life (Good, 1994). If religion and medicine are so closely connected, then transcendental medicine, also known as ‘religious healing,’ with its overt claims to religion and medicine, is an ambiguous hinterland. To try and separate religion and healing or medicine and the transcendent could well be like trying to separate the *dal* and rice from a *khichri*,<sup>18</sup> the two are inextricable. Nevertheless, I make this crude attempt, if only to distinguish between what families derived from the transcendent and transcendental medicine. The former was constructed by families as a prism through which meanings could be made while the latter was a source of cure. Nearly all the families mentioned the role of God and religion in helping them build resilience, patience and

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<sup>18</sup> *Khichri* is made by boiling lentils and rice together. It is equivalent to a stew in English cooking. To clarify the analogy, trying to separate religion and religious healing is like trying to separate the egg and oil in mayonnaise.

strength in managing their loved one. Faith and resilience were the primary goals that families sought from religion. But transcendental medicine, while borrowing heavily from the mythologies of religion and culture, was where an *ilāj* was explicitly asked for. Here the purpose of the divine was not to relieve but to actively intercede through the medium of the religious healer. Such healers were thus presumed to be omniscient and able to deliver miracles.

The Khan family consulted a number of *jhār-porīch* practitioners (*jhāṃa* means to sweep or dust; *porīchna* to wipe) in a bid to cure Omar's dementia. These practitioners are conventional sorcerers who conceive of illnesses as a result of curses or jealousies, and seek to sweep or dust away these evils, often using brooms in their rituals. Illness as the effect of *kala jādū* [black magic] has a long history in folk medicines across the world, but what distinguishes the *jhār-porīch* who the Khans consulted from other shamans and folk healers was his recommendation that they also sacrifice a goat. This notion of sacrifice comes from the Qur'an, when Allah commanded Abraham to sacrifice that which he loved the most – his son – which Allah then replaced with a goat. The slaughter of the goat itself is symbolic, i.e., one sacrifices that to which one is closest and most attached; the fable itself is also significant in Judaic and Christian texts. The Khan's *jhār-porīch* practitioner, along with his broom, also combines mythology and literature in his treatment. Islamic transcendental medicine is of course far more complex than these practices (see Cammann, 1969; Gardner, 1993; Pfliederer, 1988).

Only three families other than the Khans sought transcendental medicine: Nayantara, the Talwar family and Tandon. The Talwars had a prior relationship with their guru in south India, while the remaining healers were sought through personal referral. This is in line with Veena and Ranendra Das (2006), who point out that individual illness experiences are brokered through various filters and are contingent on what influence and treatment can be activated, rather than directed by a defined explanatory model for treatment (Kleinman, 1980). Three families came to transcendental medicine in an ad hoc manner – extended family entreated Shafia Khan to visit the *jhār-ponch* practitioner, a friend mentioned Dr Francis to Nayantara, and Tandon came across Guru Ramdev through the media.

Nayantara and the Talwars felt they had had some success, not so much in the outcomes for the people with dementia but more from the sense of peace they derived from visiting their healers. While this skirts along the borders of the priest-parishioner relationship, the families' curative goals and the nature of the interactions were distinct from religious pastoral care. There was the notion of a magical 'healing touch' – the Talwars, for example, believed that after their guru raised his right palm towards 78 year old Sudhanshu, his dementia halted, and there had been no deterioration since. Similarly Nayantara said of her faith healer Dr Francis:

When you're near to him, [it's] very calm and peaceful and it's very nice. You barely stand for a fraction of a moment, he just does this [raises her palm and moves it in a circle]. He makes you sit down if you have a

photograph and he said that mummy's phosphorous level is very low. He is a doctor, in the sense that he is an allopath but he has studied many, many alternative medicines, he's been all over the world.

Just as traditional medicine challenges biomedicine through imitation and divergence, transcendental medicine challenges biomedicine and traditional medicine. Nayantara's experiences with Dr Francis highlights again the relationship between credibility, medicine and healing. Dr Francis' credibility rests in his status as an allopathic doctor and in his knowledge of alternative medicines. He is both spiritual healer and world traveller, combining the historicity of the doctor-patient relationship in India and a claim to authenticity that rests on globalisation.

The established autocratic healer-patient relationship, which predated the arrival of biomedicine in India, was reflected in Nayantara's perception of Dr Francis. Like the *vaid*s of old, the purity of Dr Francis' character and the peaceful feelings he engendered became the foundation of his healing powers (his magical touch) and these in turn influenced the time he gave to Nayantara, 'a fraction of a moment,' and her acceptance of this very limited interaction. Broader issues of class and globalisation were also implicit in this dynamic, not only in the resources that Dr Francis mobilised to travel around the world and educate himself, but also in the location of his practice in an exclusive south Delhi market. This market, favoured by the European expatriate population, is surrounded by elite suburbs in which diplomats, politicians and wealthy industrialists lived. While Dr Francis did not directly charge his clients (it was

up to them to make a donation on every visit), given his location he would have made a tidy profit.

Yet in comparison with other religious healers, Dr Francis' ambit was minuscule. There is a much larger political economy, as Tandon discovered when he went to the holy city of Haridwar, a therapeutic beacon in north India, layered with religion, morality, healing and money. Tandon's excursion to Haridwar was to see Swami Ramdev, founder of the Divya Yog Mandir Trust which promotes yoga and *Āyurvedic* treatments. Ramdev is rich and famous; he created a transcendental medicine corporation which sells its own pharmacopeia of drugs based on his recipes, and an assortment of DVDs on yoga. He has TV shows on yoga that are screened in India and abroad, and holds yoga camps worldwide, including one at the residence of the President of India (Yoga Headlines India, 2009). Ramdev's global popularity reflects the multiple beliefs that people from the subcontinent have in relation to experiences of health and illness, the range of practitioners they seek as a consequence, and the falseness of the assumption that only people with low levels of education access such practitioners – findings which two other studies have also made (Rao, 2006; Rhodes, Small, Ismail & Wright, 2008; Small, Ismail, Rhodes & Wright, 2005). Ramdev's followers claim to have been cured from cancer, hepatitis and obesity, among other diseases. Tandon's reasons for visiting him were grounded in this political economy and the ready availability of his medicines:

I didn't meet him. He doesn't meet you, his *hakim* meets you. His prescribed his medicines and they are available in Delhi also. I took her

for a consultation so that afterwards whatever medicines Ramdev has given, I can buy.

Alongside the consumption and marketing of *ilāj* and doctor-patient relations that frame it, the medical pluralism in India is again illustrated. Swami Ramdev, whose practices and treatments derive from Hindu philosophy and is located in a holy Hindu city, has a *hakim* (*Unani* doctor, Islamic origins) and not a *vaid* (*Āyurvedic* doctor, Hindu origins) dispensing medicines. Even if Tandon had conflated the terms, the intermingling of different religions by practitioners and patients is evident. Transcendental medicine in India is not contained as specific denominations neither go only to their particular religious healer, i.e., Hindus to *vaids*, Muslims to *hakims*, nor have national borders ever stopped this flow (Alter, 2005). Rather these are polysynthetic systems where people access a variety of healers based on their perceived credibility and power. So Nayantara, a Hindu Brahmin, goes to Dr Francis, a Christian; Tandon went to Swami Ramdev who employs *hakims* and not *vaids*; and the Khans consulted a *jhār-porñh* practitioner who told them to sacrifice a goat based on a tale that has Islamic, Christian and Judaic roots.

## **Conclusion**

*Ilāj* in its etymological, physiological, and relational definitions has been used in this chapter to contextualise the history of medical pluralism and the current state of play in India. Shaped by trade and colonisation, class politics, and scholastic and geographic epistemologies, medicine in India is segmented into

biomedicine, traditional, and transcendental medicine which play out in urban and rural environs, public and private settings, in different and multiple ways. When searching for an *ilāj* to dementia, families operate within this landscape through doctor shopping and through concurrent engagement with different systems. These engagements are both exploitative and edifying: the *sarkari* doctor's indifference due to patient demands and few resources, the traditional doctor's greed and ignorance, and the faith healer's arrogance and futility are balanced against the positive effects they generate, whether it is in Yashaswini constantly striving to improve her hospital, the increased interactions Nina enjoys with Karamjit, or the sense of peace that Nayantara derives from visiting Dr Francis.

I have tried to show that through all of these transactions, the search for an *ilāj* is also a search for a 'good' doctor. Cure and social relations go hand in hand in India, and unlike in the west, most health practitioners here are cognisant and tolerant of this search. The doctor-patient relationship which has historically been regimented and dictatorial is increasingly challenged by families, people living with dementia, academics, and the state. There is a long way to go in achieving a more equitable alignment of relations and this itself is bound within larger power-plays of money and agency. The direct costs associated with the pursuit of an *ilāj* have not been explored and will be untangled in the following chapter. It is sufficient at this point to note that these costs are objective and subjective – and families have to dig deep monetarily and emotionally to pay them.

To date there is no cure for Alzheimer's disease or any age-related dementia. Degeneration and death are inevitable. For many this is hard to accept and some never entirely give up hoping for a cure. For people like Tandon, finding a cure is the defining purpose of his days. He had two large plastic bags filled with papers containing information on Sheila's medical history, his correspondence with doctors all over the world, journal articles on cholinesterase inhibitors, newspaper cuttings and so on. His investigations were an emotional quest and he continuously reiterated his need to "remain hopeful, to be positive, to have positive thinking." He believes that a cure will be found, that the disease can be reversed, that dead cells can somehow be recharged. But he is anxious about whether the cure will be found in time for Sheila. In the deep corners of his heart and mind, he knows this probably will not happen. In my last interview with him, as I was walking out of the door, I stopped:

*Cough. Beware of cough. If that happens it could progress into something more.*

I know. It [cough] could mean a respiratory infection, a chest infection and that comes at the last stage. That will happen in the end.

*I know you don't think doctors are very cooperative but you need to think about what you want to do then. A hospital's job is to keep the patient alive at all costs. One of my people ended up in the hospital and there were feeding tubes and oxygen and everything else. The other died in his bed at home. Whatever you think about either, you need to think about what outcome you want for her.*

[Nods and smiles] I know this, I am aware. But I have to be positive, I have to have hope. Positive thinking is what I must do.



## **CHAPTER 5:**

### **THE ECONOMIES OF CARE**

Early anthropological scholarship highlighted the materiality, symbolism, circumstances, and nature of economic exchange in various cultural contexts (Firth, 1939; Malinowski, 1922; Mauss, 1923, 1966). The underlying premise was that theories of scarcity, rationality, and equilibrating price mechanisms found in western capitalism did not necessarily echo in other societies. Market forces were regarded as a recent phenomenon and not emblematic of the entirety of human economic experiences (Polanyi, 1944). Moreover, costs were not just monetary sums as imagined in neoclassical economics, but included a range of outlays not readily quantifiable.

In his seminal work, Karl Polanyi (1957) defined three types of distribution as the institutionalised processes of economy – reciprocity in egalitarian relationships, redistribution in hierarchical relationships, and commercial exchange in anonymous relations of the marketplace. His work sparked heated debate and a cleavage within his discipline of scholars into formalist and substantivist camps. Formalists typically sought to quantify economic exchanges through mathematical predictive modelling to ascertain how individuals allocated finite resources like time and money, while Substantivists counter-argued that economies were constituted by and results of particular societies whose primary function was to meet the material desires of its citizens in culturally specific ways (Earle, 2008). Though the debate has since declined,

the basic tension of cost – as monetary output or metaphysical angst or both – has not.

With technological advancement and the supposed arrival of modernity and development, and then with globalisation, economies across the world have grown and shrunk, transformed the scale of production and consumption, and re-scripted the value of goods and services. The value of a good in small-scale societies was theoretically contingent on an economic-cultural-personal symbiosis of taste as shaped by need and availability of the product. This was altered in large monetised societies, as a result of increased homogeneity and commoditisation, to a good whose value was dependent on taste, scarcity, and market price (Appadurai, 1996). This transformation changed notions of identity from shared ideas of taste and aesthetic (which contributed to stable, culturally ascribed identities within particular social structures) to identities as multiple, in flux, contestable and uncertain (Kopytoff, 1986).

Such categorical notions of identity and exchange are sometimes used to distinguish ‘developed’ from ‘developing’ nations. However these polarities are chimeras, for societies tend to straddle both positions simultaneously (Kopytoff, 1986). Rather than making such binary allocations, intellectual inquiries have instead focused on the sociality of objects, their role in creating identity (Appadurai, 1996), and the hidden costs of these objects (Langlois, 2006). Uncovering these secret costs, which are typically incurred by other people during production and transaction, has also entailed critical reflection on modes of consumption and identity. A large literature documents the exploitative costs

that poor and marginalised people pay in the production and distribution of goods like sugar, oil, or shoes for use by wealthier people as part of the latter's experiential practices of identity (Ballinger & Olsson, 1997; Fentiman, 1996; Mintz, 1985; Reyna & Behrends, 2008; Scheper-Hughes, 1992). This work in turn has informed philosophies behind the identity-consumption nexus and underscored the need for ethical forms of consumptive practices.

My intention is neither to delve into the finer points of these kinds of consumptive practices nor to expand upon the theoretical intricacies associated with consumption and cost. In establishing the range and complexity of intellectual inquiry into economics, I set the parameters in which the economies of dementia care in India will be explored. Three concepts are used to understand the economy of dementia care in India – cost, identity and exchange. Cost is understood as the value associated with the material objects used in care (e.g. medicines, diapers, catheters) and the subjectivities of care (e.g. physical and emotional health of carers). Subjective costs, I argue, are hidden costs, tied to the marketplace and emotional work of care. These are the costs to the personhood of carers and the people with dementia, those secret tallies which either render identity ambiguous and uncertain, or reinforce existing notions of identity. Commoditising care, whether within the home or the public sphere, involves exchanges which are commercial, reciprocal and redistributive (Polanyi, 1957). I explore the exploitative relationships between institutions, carers, and paid attendants but also the hidden benefits of the institutional costs of care, the pharma-economy of care, and the domestic politics within households where paid attendants are employed to care. Ultimately what will

become visible is that even when carers engage in practices of consumption which are assumed to be beneficial to them, there are always costs to be paid by someone. In documenting the economies of care and its effects, the chapter is negatively-oriented. This is not to deny the positive side of care work and later chapters address these happier aspects. But I firmly believe if a complete picture is to emerge of dementia care in urban India today, then we must begin with an analysis which includes warts and all.

### **“This is Not a Disease for the Poor”**

In 2005, based on a global prevalence of 29.3 million people with dementia, the estimated costs of care were USD 315.4 billion. The cost of informal care was USD 105 billion. Although 77 percent of these total costs were incurred in developed nations, which only have 46 percent prevalence, even in developing nations like India the costs are huge. Based on an estimate of 3.1 million people with dementia in 2005, the total costs (direct costs + costs of informal care) were predicted at approximately USD 15.9 billion for 7.4 hours of informal care work per day (Wimo, Winblad & Jonsson, 2007). As India’s prevalence rate is expected to grow by more than 300 percent by 2040, there is a need for greater health investment and bolstering of health and care resources (Prince, Livingston & Katona, 2007).

In the 11<sup>th</sup> Five Year Plan (2007-2012), the Government of India allocated Rs. 95 million<sup>19</sup> to meet the health needs of its older citizens. The funds were earmarked for: (1) comprehensive preventative, curative and rehabilitation

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<sup>19</sup> As of 13 September 2009, AUD 1= INR 41.85.

services for older people, (2) professional training and research in geriatrics and gerontology, and (3) the establishment of a National Institute for Ageing to coordinate health and ageing initiatives with other national health programmes (e.g. the Rural Health Mission) (Government of India, 2007).

But enmeshed within the legendary red tape of India's bureaucracy, these funds will take time to reach communities. In 2007, three chapters of ARDSI – in Delhi, Kolkata, and Chennai – secured government funds to set up day care centres for people with dementia (10-15 people per centre). When I arrived in January 2008, there were plans to locate an appropriate property for the new day care centre in Delhi. When I left in October 2008, the location had been identified, but the funds had not yet been remitted and were still being filtered through central and state government departments. Midway through 2009, money and endeavour met, and since then, the day care centre in Delhi – presently serving eight people – has operated. Meanwhile other chapters have managed to establish their own day care centres with funds sourced elsewhere. For some ARDSI workers, like Somya Ghosh, advocating to the government is not worth the effort:

It's not in terms of fixing an appointment and talking, it's after that, how it gets taken care of. The file gets lost somewhere. Very frankly, we as an organisation rely on local fundraising. We want local people to contribute to their community. Government funds are appreciated but we don't depend on them. You see, an organisation like us, that is run by three to four people, to pursue a high government level – I don't know how many hours a job like that would be. We don't have time and if I

have to spend an hour sitting at a window to get a pink pass to see a bureaucrat, I would not really be inclined to do that. In that time I would rather see a family.

Delays in transfer of government funds meant that these chapters were perennially underfunded, under-resourced and facing extinction – concerns shared by NGOs all over the world. ARDSI-DC's reliance on funding from government sectors and private donor agencies meant that their programs were often shaped by funding agendas, and these did not necessarily address the hardships that families experienced. For example, the monthly cost of diapers was akin to the monthly cost of medicines – Rs 1800 – if only two diapers were used per day. The Khan family received free medicines for Omar from ARDSI-DC but struggled to buy diapers and often purchased them on credit. With little positive effect and multiple side-effects, Omar's medications were eventually stopped. The family now wanted the costs associated with free medicines (approximately Rs 2000 per month) to be transferred to subsidise the cost of his diapers. However ARDSI-DC, fearing audit, refused. Their funders had donated money specifically for medicines and not diapers, even though the latter had equal (if not greater) utility to families.

The constant scramble of funds thus impinged on the capacity of the organisation to broker a relationship between families and funders. Often the funders were privileged over the families. Quarterly newsletters which detailed ARDSI-DC's activities and the latest research and developments in dementia were mailed first to donors; if enough money was left over, then copies were

sent to families. When ARDSI-DC commemorated its founder's day at an exclusive club, accolades and mementos were disbursed to management and patrons, but no carers or people living with dementia participated. When ARDSI-DC commemorated its founder's day at an exclusive club, accolades and mementos were disbursed to management and patrons, but no carers or people living with dementia participated. For celebrations of World Alzheimer's Day in 2008, the names of all speakers were printed in the program guide, except for the carers who were speaking; they were clustered as 'carers' under the heading 'caregiver's dilemma.'

These practices, neither novel nor unique to this organisation, are symptomatic of the absurdities of aid flow and the pragmatic response from the sector. NGO's, like government bureaucracies, are political bodies with their own agendas, power elite, management problems, lack of sustainability, low replicability, and minimal reach. The only difference, as Paul Streeten has argued, is that "NGOs may be doing less harm than governments in this field and may even be doing some good" (1997, p.210).

### **Who Can Afford That?**

Given the slow trickledown, most families cared alone and the majority privately bore the costs of care (n=13 out of 20). Only seven families received any formal assistance: three from the Central Government Health Scheme, which subsidised the cost of pharmaceutical drugs and medical treatments for these former employees of the state; and four from ARDSI-DC to purchase medicines. Of the families receiving aid from ARDSI-DC, two were lower middle-

class (the Khans and the Sadhwanis) and the other two were wealthier (Sen-Hamdari and the Kochars). All had been referred for free medications following consultation at one of two ARDSI-DC memory clinics (OPDs in government hospitals). The chaotic circumstances under which such referrals could be made have been discussed in the previous chapter.

Most families purchased medication at their own cost. Public health expenditure in India is amongst the lowest in the world, at only approximately 1 percent GDP. Private spending is one of the highest worldwide, and about 5-6 percent of household expenditure is spent on health (National Sample Survey Organisation, 2004). Sickness and care are privatised, and citizens mobilise their own resources, according to finances and levels of social support, to secure treatment. Among the 20 families, sources of income tended to coalesce into three overlapping categories: investments and savings (n=8), pensions from government and private industry (n=6 and n=5 respectively), and contributions from children (n=13). In line with the global gendered division of work into paid and unpaid forms, typically women perform the latter and men undertake the former, and women with dementia were more likely to rely on financial contributions from their family and personal savings (n=5 out of 8) while men also received a pension from former employers (n=8 out of 12).

Despite being middle class, many families struggled financially with the costs of care. Recurrent expenditures for allopathic medicines, diapers, a paid attendant and miscellaneous goods (like cotton wool, talcum powder and condom catheters) were about Rs 11000 per month (see Table 3). This figure excludes

other ongoing costs for lost days of work, traditional and transcendental medicines, nutritional supplements, activities (like physiotherapy or doing yoga), transport to and from doctor's consultations, and doctor's fees. Also absent are non-recurring costs that families might sustain for medical tests, health procedures, and care equipment (e.g. rubber sheets and wheelchairs). At Rs 11000 per month, these costs associated with caring are conservative, and the entirety has not been captured.

**Table 3: Cost of care for a person with dementia**

Item	Rupees/month
Medicines	1500 <sup>1</sup>
Diapers	1800 <sup>2</sup>
Attendant	7500 <sup>3</sup>
Miscellaneous (Cotton wool, powder, condom catheter etc.)	500 <sup>4</sup>
<b>Total</b>	<b>11300</b>

1. Calculation based on average cost as reported by ARDSI-DC.
2. Calculation based on Rs30 per diaper with 2 diapers used per day, i.e. 60 diapers x 30days.
3. Calculation based on agency rate of Rs250 per 12 hour shift, i.e., Rs 250 per shift x 30days.
4. Approximate costs

It is impossible to gauge a mean cost of the expenses because these figures oscillated significantly depending on income, class, identity and the health needs of each individual. Suneeta Sadhwani (41 years), a single woman with no siblings, spent almost nothing caring for her father, Hari Prasad (74 years). They received free medicines from ARDSI-DC, could not afford to hire an attendant, and since Hari was able to toilet himself, spent nothing on diapers. Father and daughter stayed together in their own small two bedroom flat in

west Delhi and lived off Hari's retirement pension. Suneeta supplemented this by tutoring neighbourhood school children and described her earnings as "our pocket money for extra expenses." They did not own a car or scooter and rarely went out to restaurants or bought luxury items. Suneeta's recreation included reading magazines which her friends gave her, watching television, and crochet. Thus, even though financially the Sadhwani were lower middle class, the monetary costs of Hari's care were not onerous.

Conversely, Namita Sood, also a single woman, homeowner, and teacher, came from a wealthy background, but struggled to make ends meet. With her younger sister, she had spent seven years caring for her mother in their family bungalow in south Delhi. The Sood sisters had leased the top floors of their property to bring in additional income, but still experienced financial strain as Namita had quit her job to care full-time and had hired a physiotherapist, masseuse and nurse attendant during the day and two nurses at night. The sisters spent Rs 90,000 - Rs 1 lakh per month on their mother's care, and to meet these expenses, eventually Namita returned to work part-time.

The contrast between these families illustrates the difficulties in measuring the monetary costs of carework. How does a poorer, more vulnerable family like the Sadhwani have fewer financial pressures than a wealthier one like the Soods? While the obvious answer lies in the kinds of goods and services purchased (e.g. no attendant versus five paid staff), the links between consumption, identity and imagination are also relevant. It was not that poorer families did not have attendants and richer ones did; nearly all families had

some level of paid assistance in their care work. The difference was in the scale of assistance sought. Nina's search for a cure for Karamjit exemplifies this:

He had this stem cell medicine for which we went to Cologne [Germany]. We were there for nearly four to five days, although it only took 20 minutes one day and 20 minutes the other day. [The doctor] said, "Don't expect wonders at all, it is not a magic formula." I said, "Look I cannot lose him, I have to get him well." It was quite a packet of money – so what? You know the care that he is getting, nobody can get it. Why? Because daily I am spending between 500 to 600 Rupees.

Nina and Karamjit paid for their travel to Cologne, while their younger son paid for the stem cell treatment. Though Nina never disclosed the entire amount of this treatment, she intimated that it was thousands of Euros. The resources spent on this venture indicate Nina's quest for an *ilāj*, and the consumption-identity correlation. In India, consumption has been described either as central to modern national identity (Breckenridge, 1995; Fernandes, 2006; Rajagopal, 2001) or as the flamboyance and self-seclusion of a few in the face of the blatant impoverishment of many (Das, 2001; Varma, 1998). For many middle-class Indians, consumption is understood in moral terms; van Wessel's (2004) ethnography in the north Indian city of Baroda found that consumption was defined in opposition to ideals of elder care, the joint family and community.

However, in cases like Nina's, consumption is explicitly linked to elder care, family and intimate relations. It becomes another measure of *seva*. A good carer was one who would consume health and care services in her pursuit of an *ilāj*, and the only difference between poorer and richer families was the scale of

their consumption as determined by their resources and imagination. When families consumed less than what they should, there were criticisms:

He [Karamjit] goes to the barber and I would put the exact amount of money in his pocket. He would bring it back. He would fight at the shop saying, "No, I won't give you, I've already given you" and that chap would come here saying, "I haven't got my money and he is creating a ruckus in my shop." He said, "Either please stop him or please explain to him." So I explained to him: "For a meagre 30 Rupees you are shaming me; that lady doesn't give him money and he only has so much. Do you realise that it is a shame on me and us that we are not paying 30 Rupees?" (*Nina Bhagat, 70*).

Nina's awareness of her class status and wealth are evident, but also at play is what Nussbaum has called a 'constructive shame' (2004, p.211). Shame operates as a moral compass to remind Nina and reiterate a wider claim that poorer people make on richer ones in India about their right to wealth and time from the rich (*ibid*). For Nina, shame was a disciplinary emotion that was internalised; she was cognisant of the interdependence and mutual responsibility that she and the barber shared with each other in their care of Karamjit. For her, Rs 30 was meagre but to the barber it was of value, and she was conscious of her privilege and the barber's lack. To avoid shame, and the accusation of exploitation of the poor by the rich, a distribution of resources occurs between Nina and the barber. But when set within the wider context of urban India, such redistribution occurs on a grossly unequal playing field.

### **“If I Get Depressed, Who Will Handle Him?”**

If the costs of care associated with goods and services are difficult to measure, then the subjective costs to familial relations, carer’s health and the personhood of the individual with dementia are nigh impossible. Objective costs may be boiled down to a monetary figure, but subjective costs are the small and large slights that people experience which cost them in dignity, emotional wellbeing and physical health. These may include the distress that carers like Josie and Shafia felt when their marital relations fundamentally and irrevocably deteriorated, or the indignities the Singh family experienced when trying to get adequate service in a *sarkari* hospital, or the fraught terrain of failure that Tandon negotiated in all his endeavours to find a cure for Sheila. These slights may also be in the minutiae of everyday life, for instance, when Bhageshwari’s mother could not remember her name despite her daughter’s insistence that she could, or in K.P. Aggarwal’s indifference to his wife, or when Nandini came home to find her father had fallen down under a tap in the bathroom and was waiting for her to pick him up. These are small, hidden stories about change, loss and sadness – themes throughout this thesis. Their costs to carers are both physical and emotional.

A large body of research exists on the impact of dementia on family carers. Caring for a person with dementia can be stressful and depressing, creating financial worries, loss of employment and family conflict.<sup>20</sup> Carers for people

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<sup>20</sup> For research in India see: Dias et al. (2004), Emmatty et al. (2006), McCabe (2006), Patel and Prince (2001), Prince and Trebilco (2005), Shaji, Smitha, Lal and Prince (2003), The 10/66 Dementia Research Group (2004), and Varghese and Patel (2004). For work internationally see:

with dementia are twice as likely to have a common mental disorder (typically depression) compared to carers or co-residents of people with depression (Patel & Varghese, 2004). Qualitative work from rural Kerala ascertained that carers were usually educated middle-aged women who had been forced to either reduce or stop paid work to care – a decision which created significant strain on the family budget. These women were also mothers, and the work of caring for two generations left them tired, depressed and isolated. Many reported serious physical and psychological problems, managed through anti-depressant medication, self-harm, or violence and abuse towards and from the person with dementia. Exposed to aggression and violence, these women felt they deserved such abuse (Shaji et al., 2003).

Many of these factors were evident in the 20 families with whom I worked, whose members all complained of exhaustion, frustration and pain. Carers had health concerns – heart problems, cataracts, hip pain, back pain, Parkinson’s disease, cancer, and hyperthyroidism. Whether these were the end results of particular lifestyles (work stress, poor diet, and lack of exercise), the by-products of age, the costs of caring, or unexplained acts of the universe, was irrelevant to them. While carers might develop theories for the cause of their loved one’s dementia (as discussed in chapter 3), they rarely speculated about the causes of their own health problems. For them, the assumption of the ‘carer’ role meant that they were to be supportive of the ‘sick role’ of the person with

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Annerstedt, Elmstahl, Ingvad and Samuelsson (2000), Braekhus, Oksengard, Engedal and Laake (1998), Brodaty and Green (2002), and Hux et al. (1998).

dementia. Most felt they must be stalwarts of care, irrespective of the costs to them. For them, illness was a luxury they could not afford:

It [depression] happens but I cope with it myself. I do something or the other to keep myself busy. I watch TV or whatever talents I have in my hands I use them. Because if I become depressed myself, who will handle him? (*Suneeta Sadhwani, 41*).

Whatever has to be done has to be done. *Baas* [that's it]. As long as we're here, as long as there's *sā:s* [breath], there's *a:ya:s* [effort]. My only prayer is that my *hāth-pair* [hands and feet] keep working because if my *hāth-pair* don't, then who will do this work? (*Sita Aggarwal, 63*).

Sita defined her capacity to care for her husband in terms of her working hands and feet. She had back pain, hip pain, and leg pain, and had been advised by her doctor not to bend much. But she soldiered on. As she described caring for her husband, K.P., her life seemed to transpire at a subterranean level: K.P. slept on a high bed with three mattresses, while she had a skinny mattress on the floor; when she prayed during her *puja* she knelt on the floor and bowed; and when I interviewed her, I sat on her living room sofa while she perched on a low stool. Her dedication to caring for K.P. was anchored in her own working body, in her muscles and her bones. Four times in a 45 minute recorded interview, she emphasised her desire for her hands and feet to work, "I just pray, '*Hai Bhaghvan* [Oh God], let my *hāth-pair* work so I can lift him up.'"

A productive body, defined through working hands and feet, is widely invoked in India in conjunction with ageing bodies. Old age or *buddhāpan* entailed a social reorganisation of power relations wherein older people relinquished their roles within the household and younger member's assumed greater responsibility through the provision of *seva*. This restructure is based on the recognition of the bodily changes associated with age, described in the literature as *kāmzori* (weakness) and a failure of one's *hāth-pair* (Cohen, 1998; Lamb, 2000; Vatuk, 1990). Cohen (1998) argued that when an older person's hands and feet stopped working, they were considered to be incoherent and unproductive. But Sita's distress was rooted in K.P.'s silence. It was not that K.P. could not talk; it was that he did not, and was totally indifferent to her ministrations: "I can just keep talking and get no answer so I [snap! She clicks her fingers]. I'm like a dog that just keeps barking and barking. I can keep crying, he'll say nothing, I can laugh, he'll say nothing, I can say "I'm going" or "I'm not going," and he'll say nothing. He doesn't say anything."

If silence and a loss of engagement were part of loss and degeneration, then the costs associated with these symptoms were transferred onto carers' bodies and were expressed through the language of pain. Leg pain was frequently mentioned and described as swelling in the legs, dry skin, and pain in the outer thigh area. When I asked Shivbaksh Chand how his health was, he said he had become very weak and lifted his *dhoti* all the way to his mid-thigh to show me one long skinny brown leg. Similarly, when I visited the Chopra family, Rubina, the daughter-in-law, said she experienced terrible pain in her legs which

affected how many times she could climb up and down stairs. Suneeta Sadhwani said her legs felt 'weak,' but that her health was otherwise fine.

*This weakness in your legs, can you describe it?*

It's like an exhaustion. It feels like my legs are going to break, that I need to take some rest. I feel very tired sometimes, like as though there is no life in me

*To keep going?*

*Haa*, but then I force myself to do it. But sometimes if I could just rest for a little while, if I could just rest, then it will be alright. It's not like my health is very down or anything like that.

Enough evidence has accumulated in India and elsewhere in Asia to demonstrate that psychological symptoms of distress may be somatised in the body as physical aches and pains (see Kleinman & Good, 1985). In India, 51 percent of all somatic complaints fit within the diagnostic criteria of common mental disorders (Patel et al., 1998). Depression especially tends to elicit somatic complaints, primarily from women. Body aches, autonomic symptoms, gynaecological symptoms and sleep problems, and 'weakness' and tiredness, are ubiquitous in clinical consultations (Pereira et al., 2007). But the leg pain that these carers cited bears further scrutiny – why leg pain? Why not pain in hands or backs or wrists, which are also body parts that can experience strain as a result of caring?

Leg pain sits in an ambivalent juncture of culture, medicine, bodily disruption, ageing and loss. While it may be a culturally appropriate idiom for clinical

depression and a physical manifestation of the psychological toll of confronting degeneration and loss on a day-to-day basis, the inverse is just as applicable. Leg pain may be just that – a pain in the legs that is a result of the physical stressors associated with caring. Instead of a confrontation with the bodily degeneration of the person with dementia, it may be a confrontation of the ageing of one's own body. Most carers were women in their fifties trying to manage men in their seventies, and the physical labour necessary for such care is demanding. Caring includes manual handling and heavy lifting, cooking and cleaning, and dealing with institutions and bureaucracies in hospitals, banks and NGOs, in heat and cold, through dust and fog, in the density of people, money, family, and social commitments. The work is not frenetic but constant, rolling in peaks and troughs as the days, weeks, months and years pass by. Such work will take its toll on the body.

For carers, leg pain becomes a way to stake a claim to the 'sick' role without the loss of personhood that such a position entails. Carers' identities are reshaped by the illness of another, who by virtue of being sick is unable to fulfil his or her social roles. If the person with dementia's *hāth-pair* no longer work, then the carers' hands and feet must now work for two. Multiple responsibilities must be fulfilled and carers get tired. Leg pain is a temporary means to claim the debility of non-working *hāth-pair* without the associated loss of power and voice. As Suneeta said, "It feels like my legs are going to break, but it's not like my health is very down or anything like that."

## **Breakages and Cost**

But low points in health do happen. In the literature, this is described as the 'breaking point' for carers; in western nations it is typically at this juncture that the person with dementia is institutionalised. Factors contributing to institutionalisation are severe cognitive, functional and behavioural disturbances as the person with dementia advances, combined with physical, psychological, emotional, social, and financial stressors for his/her primary carer, and little personal and social support from extended family, friends and the community (Banerjee, Murray, Foley & Atkins, 2003; Hebert, Dubois, Wolfson, Chambers & Cohen, 2001; Luppá, Luck, Brähler, König & Riedel-heller, 2008).

A systematic review of dementia research undertaken in USA, Europe, Australia and Canada found that institutionalisation is detrimental to people with dementia, their carers and national budgets (Luppá et al., 2008). In aged facilities, people with dementia tend to deteriorate faster, their carers' decision to admit them is fraught with feelings of guilt, sadness and failure, and governments worry about the burgeoning costs of institutionalisation. Consequently, there has been a strong policy push, within these countries and in India, for dementia care to occur within the home and to be undertaken by unpaid carers, usually family members, with secondary support from governments, NGOs and paid attendants (Luppá et al., 2008). Accordingly, numerous initiatives have been developed. In countries like Australia, these include short-term respite care, financial assistance, legal advice, support groups, day care centres, home visits by social workers, volunteers and nurses,

and programmes like art, gardening and music which the carer and the person with dementia can enjoy together. In India, short-term respite care, day care programmes, and home-care attendants are most common.

Previously, in analysing legislative and policy documents, I illustrated that dementia care in India has been privatised and that people are denied access to institutionalised forms of care by the state (see Brijnath, 2008, Appendix 5.5). People with dementia are largely excluded from aged care facilities as the general admission criteria is that a client, described as an 'inmate,' must be physically and mentally competent (Patel & Prince, 2001). This goes to the heart of access and citizenship, where those most vulnerable and least able to advocate for themselves, are denied care by the state. As a result of this Catch-22, people with dementia can either be cared for by their families or, if they are alone (for whatever reason), face either the street or confinement in a state psychiatric facility. Drawing on research conducted in Goa (Prince & Trebilco, 2005), I concluded that alongside the privatisation of care, there was a lack of systemic support for families. 'Breaking points' for families are a privilege which few can afford as recourse elsewhere is extremely limited.

Requiring further inquiry and missing from my earlier work, many Indian families experience profound ambivalence about admitting a relative into any kind of a facility. Less than two percent of Delhi's elderly population live in old age homes (Government of National Capital Territory of Delhi, 2006), nationally the average is 2.73 percent (Jamuna, 2003). Even in western nations, elder care occurs within the home: in Australia, only 6.7 percent of older people are in

aged care facilities (ABS, 2003) and in the USA it is 7.4 percent (Federal Interagency Forum on Aging-Related Statistics, 2006).<sup>21</sup>

In the study sample, almost all the families abhorred institutionalised care. Nina Bhagat described aged care facilities as a “jail,” Radha Menon broke off friendships when her friends suggested “rehabilitation” for her husband, and most carers seemed appalled by the notion of admitting their relative into any facility. Their feelings were based in an idealisation of family and *seva*, and the horror of India’s psychiatric institutions (where people with dementia might be institutionalised). In India, elder care is traditionally meant to occur within the family and the growing presence of old age homes is interpreted as a marker of social degeneration, the ‘dumping’ of aged relatives, and the commercialisation of love (Bhat & Dhruvarajan, 2001; Jamuna, 2003; Kalavar & Jamuna, 2008; Lamb, 2009).

Also influencing families’ strong reactions to institutionalised care is the slippage between dementia and madness. I explore this relationship in chapter 7; here it is sufficient to note that the two are constantly blurred in everyday parlance. For example, when I tried to explain the nature of my work to my *dhobi* (washerman), he remained nonplussed and unconvinced, “Oh *didi*, these are not old people you are studying,” he said, “These are people who have gone ‘mental.’”

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<sup>21</sup> However notions of home differ considerably between India and Australia or the USA; as highlighted in the Introduction, in India, joint families are commonplace with many generations living in the same property and sharing (theoretically if not always literally) income. In the USA and Australia, children neither typically live with their elderly parents nor share their finances.

In India, forgetfulness is normalised because it draws on the epistemology of ageing and senility (Cohen, 1998), while mental illness is stigmatised because it is rooted in ideas of madness (Wig, 2000). Institutionalisation was a sign that a relative had 'gone mental' rather than 'gone sixtyish.' And if slippages between these categories were widespread, then the efforts made to distinguish them were constant: "It is important not to label people with Alzheimer's as mad; they are *ya:dda:sht ke mari:z* [the memory patients]," said an ARDSI volunteer to the residents of a Delhi old age home.

The taint of mental illness has global and local roots. Globally, the historical set of practices which combined medicine and morality created the asylum and defined the roles of rational disciplinarian (institutionally powerful) and mad subject (institutionally powerless) (Foucault, 1967). Within these spaces, the opportunity for exploitation and vulnerability was amplified not necessarily because of the pleasures of torture or pain, but because of the potential for productivity and gain. That the 'mentals' could be studied, experimented on, and possibly rehabilitated was an exciting enterprise for the state, generating employment, knowledge, power and an entirely new epistemology which by the early 19<sup>th</sup> century had coalesced into 'psychiatry' (Foucault & Sheridan, 1977).

It would not be hyperbolic to characterise long-term government psychiatric institutions in India as terrible places. Dank, harsh, prison-like and with appalling human rights records, such facilities reflect the worst aspects of colonial psychiatry and incarceration of the ill (National Human Rights Commission of India, 1999). Given the negativity they elicit from nearly all

sections of society, none of the relatively affluent middle-class families with which I worked had any direct dealings with them. Except for one outlier – Josie.

Josie's story is harrowing and well rehearsed. On the two separate occasions I heard this account, the narratives were near identical. The question is not of truthfulness, but of catharsis. Through repeat narrations of the story using the same words, Josie managed to infuse drama into the tale and simultaneously distance herself from the experience. Like Josie, I have found myself telling this story again and again, using her language and voice. It is neither easily told nor readily forgotten; the emotions it invokes make analysis particularly difficult as anthropology has not yet developed a language sophisticated enough, "to subject emotions (i.e. the wild) to analysis (i.e. rational civilization) without them losing their specificity as emotional 'wilderness'" (Hage, 2009, p.77). I cannot claim in the accompanying analysis to have civilised this narrative – indeed, I too am lost in the emotional wilderness of this story and have not yet found my way to a rational shore.

### **"Mrs. Singh, Think Twice Before You Bring Him Here"**

On this baking April afternoon we sit on her living room floor where it is coolest. The fan swings furiously overhead and the tape recorder is switched on. Glasses of water rest on our sides. Josie, tall and slim, with short curly grey hair and a lilting voice, speaks in English:

There was this doctor who approached the Alzheimer's Association and said, "Look, mine is the only home which has a space for Alzheimer's

patients. We have all the facilities, trained attendants, we do a jolly good job, it's clean and hygienic." So I approached him because at that time it was going from bad to worse. I said to myself, "Never again will I keep him in this house, never again, it's my life" – suddenly that surge of hate – "That man [Su] is awful." And I remember going to the doctor and he said, "Mrs. Singh, think twice before you bring him here," and I said, "Doctor, I have made my decision, he has to go," because the kind of physical violence was so frightening that the maid just took off from the house. He was like a demented caged animal. There were times that my entire head was swollen and it was tender for days and painful to the touch. My arm was sore because I was hurled against the panel, and I don't even know when my nose was broken because my arm was raised and I had hit my head on the wall.

He [doctor] said, "Look, since it's for you, and you are an army wife, I will give it to you for Rs. 35,000 but for the rest it is Rs. 50,000." I said "Ok, anything for my sanity." I worked round the clock, gave more tuitions to keep it going. It was a home for psychiatric patients, schizophrenics, drug addicts, alcoholics and patients with other mental disorders, all put together. They were almost in a cage. You could not talk to your patient. You had to talk to him through a glass window. And then I put my foot down and I said, "Sorry! An Alzheimer's patient needs interaction. I have not put him here because I want to dump him. I've put him here because I am scared." It was because of this violence that I kept going from one doctor to the other doctor, from this hospital to that hospital.

The first day when we went to leave him there, it was one of the most terrifying days of my life. He screamed and he ran amuck because he knew he was being put into a hospital. They strapped him down. He whacked them, they whacked him back. And then they just injected him when he was strapped. The next day he was like a zombie and for the next three days they just drugged him. He lost all his sense of bearing, but I think that is the breaking into [integration into] the hospital for all patients because for alcoholics and drug addicts, the withdrawal symptoms can be very severe. So they did the same thing to him to break him in. But every time I saw him, I remember, it was heartbreaking. I could only see him on a Sunday because apparently it would upset the routine of the others. That's what the doctor said to me and he took a down payment from me for two months because he knew I was a discerning woman, I would catch onto him.

Apparently when he used to pass potty, they used to wash him down with a hosepipe and the hose with water used to have bits of sand in it. He used to scream in pain. Imagine if you are being washed down with a hosepipe and you have these particles in the water, because it was ground-water, hitting you. There were wounds all over his body and I used to ask the doctor, "Why are there wounds?" and he would say, "Oh, it is part of the disease." I accepted it because then I did not know what Alzheimer's was like. It is only now that I realise that he was being physically attacked. If he ever turned violent, they used to physically handle him. I told you about the lacerations all over his bottom, having

the mug hit him, it was the back edge of the mug hitting his tender skin and there were wounds. I used to ask the doctor, "Why are there wounds on him?" and he said, "Oh ma'am he wriggles in bed." I said, "If he wriggles in bed then all the skin should have peeled off his back." He said, "No! Mrs. Singh don't ask us such questions, we're doing our best." But I feel that these homes have to be questioned because his attendants were awful. Dirty, filthy, uneducated people, picked up straight from the road and dumped in there, given Rs. 2000 [per month] with food and told, "Look after them." They messed up his pants. They used to keep it [dirty pants] on till night, and as a result he developed a severe fungal infection in his groin. It took me a good 20 days to one month to just de-infest him. Round the clock we gave him massages so as to bring him to some amount of normalcy.

I needed to write about it but I thought that it would have been very ruthless on my part to write about the doctor and his home as he came to my aid. And the second time again, when the violence continued. He was there altogether for almost six months, but staggered. First, for two months when he turned very violent. It was heartbreaking and the emotions are still there. Whenever I was leaving, I used to hug him and kiss him because that was all I could give him and one day he said, "Come back, come back. Take me with you."

[She weeps]

“Take me back, just take me back.” Now I wish I had taken him back, I could have been with him, but then I couldn’t.

[Weeping]

But I tell you Bianca, each day he was in the hospital, I used to go through torture. I wish I could explain it to you – it doesn’t give the caregiver any solace to send away your loved one, especially if you cannot share these moments together. It doesn’t give you any solace. It tears you apart because you cannot turn a deaf ear, a blind eye, you cannot close your heart. Here is a man who needs you but, because you are helpless, you cannot do anything for him. It burns you each day.

### **The Institutional Costs of Care**

At the heart of Josie’s disturbing story is a complex relationship between exchange, cost, and identity. Exchange here is as Polanyi (1957) described: monetary – Josie pays the doctor, reciprocal – the doctor comes to Josie’s aid, and redistributive – Josie hands Su’s care over to paid attendants because of his violence. In these exchanges, the costs she incurred were financial and emotional. She broke Su’s financial bonds, spent his pension, and gave extra tuitions to pay the Rs 35,000 per month. As an objective cost and a high monetary sum, nevertheless it faded in comparison to the subjective costs which Josie paid. Su’s admission into the facility, Josie’s realisation of the kind of care he received, his discharge and subsequent re-admission, and his final

release when he returned home, was a process through which Josie's own sense of identity changed. She experienced and acknowledged her own failings, grief, depression, rage, and guilt, what Nussbaum has called, 'shame and its relatives' (2004, p.206).

Guilt and shame are to be distinguished here. The former is a type of self-punishment, anger at being unable to cope, whereas shame is self-flagellation through a focus on one's imperfections and defects. Guilt is action-oriented, it is the feeling of being helpless or inadequate to do something, but shame is an existential examination of one's own integrity and capacity (Nussbaum, 2004). Josie experienced guilt but not shame about what happened to Su. She described feeling 'helpless' and 'burned;' unable to be with her husband even though she wanted to, her guilty emotions lingered. But she was never ashamed of her decision, explaining, "Here was a man who needed my complete attention but, because I had no choice, I was stuck with feeling guilty."

Exploitation, so cutting within this story, was neither just the economic exploitation of Josie by the doctor nor the abuse of Su by the attendants in the facility – though both stand out vividly. There were also underlying class inequities. In the outsourcing of care to poorer people, whether at home (when the maid was there) or in an institution (to untrained attendants), the re-assignment of labour tells a broader story of who does what work, when and how, and the deprivations which underpin these interactions.

The chronic shortage of resources and a trained mental health workforce has been well documented in India, as have the tatters of India's mental health system (Goel, Agarwal, Ichhpujani & Shrivastava, 2004). The use of untrained, unqualified, poor people as attendants, while a substitute for this labour deficit, create the conditions of abuse and violation because these attendants are deployed within institutional settings that are built on and continue to perpetuate the worst of biomedicine's history of mental health treatment (see Berrios & Porter, 1995; Gilman, 1996; Scull, 1993; Shorter, 1997). The results, as in Su's experiences, are disastrous for patients. It is more that madness is created than mental illness is treated. Institutionalisation and exploitation also occur of attendants, who were paid Rs 2,000 a month (according to Josie) while the doctor, to whom she complained, charged her Rs 35,000 a month, and instructed her not to ask questions.

The hierarchies within healthcare as shaped by class are visible. Health is stratified both in doctor-patient relations (discussed in the previous chapter) and between health workers. Health care providers are keenly aware of each other and their status, as determined by their claim to knowledge, skills, salary and capacity to wield real and symbolic power (Nichter, 1986). Banerji has been particularly scathing of the exploitative power of health practitioners:

It is now gradually being realised that, in addition to being used as an instrument for alleviation of the suffering caused by diseases in individuals and in communities, health services have also been used as a political device to increase dependence for exploitation of one class by another and to promote certain vested market interests (1978, p.924).

The task, as Banerji (1978) points out, is to identify and alleviate such exploitation. Josie's story, pitched at the angry red of the spectrum, is an obvious and terrible case. Within the walls of a psychiatric institution, the miseries and abuses, the objective and subjective costs are readily identifiable. Less straightforward are the exchanges between Josie, the doctor, the attendants, and the transformations in Josie's identity. It is in these ambiguous zones that the boundaries are blurred. To try and clarify the links between exploitation, exchange, and cost-benefit – and even the applicability of such language – I examine how they are operationalised in the pharma-economy of dementia care.

### **Pharma-Economies of Care**

Three factors affect production, distribution and consumption in the Indian pharmaceutical setting: (1) the commoditisation of health goods and services within a pluralist health system (2) the metamedical meanings associated with health products and (3) the impact of health policy on the profitability and hence production and distribution of medicines (Nichter, 1996b).

Considerable work has been undertaken in the anthropology of pharmaceutical practices in areas of 'irrational' drug use, self-medication, pharmacy-based practices, and the marketing of allopathic and *Āyurvedic* drugs.<sup>22</sup> Pills, potions, and tonics from biomedicine and traditional medicine are widely available as

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<sup>22</sup> For irrational drug use and self-medication see Deshpande and Tiwari (1997), Greenhalgh (1987) and Patel, Vaidya, Naik and Borker (2005); for pharmaceutical practices see Kamat and Nichter (1997, 1998) and Nichter (1996a, 1996b); and for advertising and marketing of allopathic and *Āyurvedic* drugs see Cohen (1998) and Langford (2002).

discrete concoctions and in multiple combinations. About 70,000 kinds of drugs are estimated to be available in the Indian market, a figure 200 times greater than the 350 drugs listed on the World Health Organization (WHO) Essential Drugs List (Patel et al., 2005). This proliferation is especially remarkable because of the short history of the drug market in India; though production and marketing commenced in the 19<sup>th</sup> century, it was only post-independence that this pharma-economy significantly expanded (Leslie, 1989).

The pharmaceutical industry is extremely profitable in India because the notion of an *ilāj* is conflated with drugs. This is part of schismogenesis, a cyclical process whereby the medicalisation of a problem increases demand for drugs, drives supply up and causes more medicines to flood the market. The greater availability and visibility of these medicines in turn raises consciousness about the problem and further exacerbates demand (Nichter & Vuckovic, 1994). As a case in point, the social sign of ageing – *kānzori* (weakness) – has been medicalised, and there is an increased expectation amongst some middle-class elderly people that drugs can cure or reverse this symptom. Eighty-eight year old Kundan Lal Chopra felt he was less energetic than he used to be, and took medicines for his blood pressure, nerves, depression, bones and breathing in a bid to cure his *kānzori*. Still not satisfied, he sought further medical advice:

I went to a private hospital, I saw a surgeon, I did an ultrasound, [and] the doctor said, “Who said to do all this?” I explained it all and he said, “Weakness happens.” I said, “Give me something for it.” Finally the doctor told me, “The weakness you feel is because of age.”

Chopra's constant demand for medicines and search for an *ilāj* reflects the power located in medicines, the hope that doctors can give patients through drug prescriptions, and the pervasiveness of drug taking in India. Such beliefs and practices are helped along by a political-economy in which the government has actively courted private investment in healthcare. Tax incentives (low to no tax), transferring the administration of healthcare centres to NGOs, sub-contracting auxiliary services like cleaning and catering in public hospitals, allotment of land to build private facilities, and low import duties on equipment and parts for diagnostic technologies (like MRIs, CT scanners, x-ray) are just some of the strategies (Purohit, 2001).

For their part, the private sector has embraced India's health markets. Foreign investment in the pharmaceutical sector has an annual growth of 20-25 percent and the pharmaceutical retail market is estimated to be worth USD4.5 billion (Livemint.com and Wall Street Journal, 2009). Sub-speciality hospitals and pharmaceutical chains have been established by corporations across India's megacities with plans to expand into smaller cities and towns. Private health insurance is booming; between 2006 and 2007 there was about 98 percent real growth and the insurance market is now worth approximately USD 42 billion (USAID, 2008). Within this lucrative political economy, supported by government and private investment, characteristics of India's health system, like medical pluralism, doctor-shopping, and the deliverance of hope through a pharmaceutical *ilāj*, also acquire a commercial overlay and are informed by the distribution and division of resources in urban-rural areas and among the rich and poor.

In India, drug companies of varying scopes and sizes rigorously compete to promote their products. As has been noted in other developing nations, doctors are encouraged to increase prescriptions in exchange for gifts and favours (see Carpenter et al., 1996; van der Geest & Whyte, 1988). Such practices can result in over-prescriptions (polypharmacy) and incompatible drug combinations, termed 'irrational' drug use (Linden et al., 1999; Sarkar, 2004; Srinivasan, 2004). 'Irrational' drug use also refers to the frequency and dangers of the popular practice of self-medication (Deshpande & Tiwari, 1997; Greenhalgh, 1987; Sarkar, 2004). Drug resistance and widespread need to use more powerful medications is believed to be caused by irrational drug use (WHO, 2009).

However, the term 'irrational' fails to capture the logic of practice by stakeholders in specific times and spaces. Pharma-economies are characterised by complex chains of relations between patients, doctors, pharmaceutical companies and pharmacists (Kamat & Nichter, 1998). These relations are governed by claims to different kinds of capital – social, cultural, financial, and symbolic – which are hierarchically structured and change according to settings. The order of these capitals is contingent on social relations rather than economic criteria. Agents through a set of bodily and social practices enact their claims to particular kinds of capitals, reinforce existing modes of domination, and create specific and temporal logics of practice (Bourdieu, 1990). The centrality of doctors in OPDs, for example, was based on the privileging of knowledge and symbolic capital as evinced in doctor's capacity to read scans, diagnose disease, and prescribe medicines. All other players in the OPD

accepted this power of doctors and adjusted their behaviours accordingly. But in other settings where the power of the doctor was diminished, people's behaviour towards doctors also changed. At ARDSI-DC functions, for instance, doctors' praise for the NGO's services were used to produce the social capital necessary to garner more support from policy makers and funders. In these settings, the NGO, not the doctors, took centre stage.

But in *sarkari* OPDs, the doctor was omniscient, and patients, families, attendants, medical students and administrative staff played their roles in establishing this power hierarchy. This authority, rooted in knowledge and symbolic capital, also had an economic base. To understand this economic chain of relations, it is necessary to introduce one more set of actors into the OPD milieu– the representatives from pharmaceutical companies who are colloquially known as 'med reps.'

The practices in which med reps and doctors engaged differed according to hospital, doctors and settings. In Yashaswini's OPD, med reps were rare and never stayed long. The observations I describe below are from another *sarkari* hospital called 'Cornwall.' The Cornwall Hospital has colonial roots and dated facilities against which the present enormity of patient demand is a stark contrast. In this hospital's OPD, four to five doctors clustered round a desk for two hours, while 100-200 patients would arrive mainly for prescription refills (no more than about 20 percent of the presentations were new cases). Like in Yashaswini's OPD, epilepsy was the most common cause of presentation, followed by headaches, psychosomatic complaints and neurological concerns in

which dementias were classified. The chronicity of such diseases and the prescription refills their management necessitated made the Cornwall OPD particularly attractive to med reps.

On average five med reps – sent by subsidiaries of companies like Ranbaxy® and Pfizer® – were present throughout the consultations. They distinguished themselves from doctors and patients through their embodiment of financial affluence. Unlike patients who dressed in bright colours and doctors who wore white laboratory coats, med reps were always formally attired in sober colours, with polished shoes and the latest mobile phones clasped at their belts. Their expensive colognes contrasted with the dusty, sweaty odours that emanated from everyone else. This image itself is a dated cliché; Kamat and Nichter (1997) made remarkably similar observations over ten years ago about Mumbai's med reps. Like the med reps in their study, most med reps here were also men (only once did a young woman come from a pharmaceutical company) and held degrees in general science (rather than clinical qualifications). These men presented themselves as young, gauche and uncertain, and always seceded to the power-knowledge of doctors. Although the med rep's behaviour changed according to the doctor's age, sex, qualifications, experience and speciality (see Kamat & Nichter, 1997), in the Cornwall OPD, with its neurology focus and specialist senior doctors who were predominantly men, med reps were always deferential. They seldom approached clinicians in the OPD and instead would stand in a corner of the room while the doctors sat in the middle. Aside from marketing, they also managed patient flow, organised patient files, and bought coffee and cold drinks for doctors when required.

Med reps disliked being referred to as such and preferred the label 'product executive.' While I have used the term 'med rep' for expediency, it is uncomplimentary and obfuscates another layer of marketers – the *test-wallahs*. These are agents employed by local private pathology and neuroimaging centres to market to doctors and patients. When a doctor prescribed an MRI scan, he could either recommend the *test-wallah* to the patient, or the *test-wallah* will directly approach the patient and hand over his business card.

A hierarchy exists between med reps and *test-wallahs*. The former were contemptuous of the latter because of the percentage of profits *test-wallahs* shared with doctors. Med reps gave up to 20 percent of their earnings from each OPD session to the doctor, but *test-wallahs* from smaller and more precarious businesses could offer 30-40 percent. This was according to Nitin, a cheerful and forthcoming senior med rep, supervising a number of 'field boys.' His job was to court doctors in Delhi's hospitals to prescribe his company's medications. *Sarkari* hospitals were preferred over private facilities because the high volume of patients netted bigger profits and a large drug company could earn about Rs 80000 worth of business per OPD session.<sup>23</sup>

For doctors, the profit margins were generous and they could earn between Rs20,000 to Rs150,000 per month from drug companies. However, to maintain the hierarchy of capital, the power-knowledge of the doctor's authority, and to avoid the stain of medicine for money, an etiquette had developed around 'gifts.'

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<sup>23</sup> Each government hospital has about two to three neurology OPDs per week.

Doctors could ask for expensive medical textbooks, conference funds, and overseas trips for their families instead of and in addition to money. Even when money was to be given, discretion was paramount and cheques were preferred over cash. These could be slipped into one of the many product reports which med reps were continuously giving to doctors. As Nitin explained to me:

*Arre* madam there are hundreds of ways to do *juga:r* [manoeuvrings].

Each of these doctors has ten-ten relatives. Some of the cheques are in daughters' names, wife's name, mother's name and the accounts are then all linked.

Giving gifts to doctors in India has a long history, and the pharmaceutical industry is a relatively new player in this arena. Cooperation, flattery and gifting are practices which patients and families have used to personalise their relationship with doctors, improve the quality of their treatment, and to make bribes to secure speedier services (Jeffery, 1988). These practices are located in the historic doctor-patient relationship where giving a gift, in addition to commercial exchange, invoked a bond of moral reciprocity between the doctor and patient. Mauss wrote of the etiquette of gifting in India:

Contracts, alliances, transmission of goods, bonds created by these transfers – each stage in the process is regulated morally and economically. The nature and intention of the contracting parties and the nature of the thing given are indivisible (1923, 1966, p.59).

In *sarkari* hospitals where gifting is illegal, one source of doctor's incomes have been eliminated. Doctors cannot, and in my observations did not, charge their patients fees. In the context of their working lives, long hours, and patient demands, their salaries were meagre; a junior doctor could expect to earn Rs 25,000 and a senior consultant Rs 50,000 per month. For these doctors, 'gifts' from pharmaceuticals were important sources of income and prestige. This is not to say that all doctors accepted 'gifts' or asked for money; some had refused such overtures and med reps steered clear of them.

Within this complex pharma-economy of care, drugs represent the Janus-face of cost and benefit. Costs, objective and subjective, are incurred by people with dementia who experience the side-effects of drugs, their families who manage these side-effects, the NGO which may subsidise the cost of drugs, the doctors who might compromise their clinical standards through over-prescription for commercial gain, and the pharmaceutical companies and med reps who pay kickbacks to the doctors for such prescriptions. But benefit may also be present in the alleviation of distressing symptoms for the person with dementia, the comfort families derive in knowing they are trying every *ilāj* possible, the funding that NGOs garner to continue delivering services, the hope which doctors are able to provide through prescriptions, and the possibility that the pill which pharmaceutical research has developed does mitigate against distressing symptoms.

Ultimately it is neither theoretically useful to situate doctors at the polarities of corruption and sanctity nor practical to call for an end to gifting – the

phenomenon is global. Both positions disregard the economic and working lives of *sarkari* doctors as well as the sociality of a gift in India. And as the last chapter and this one have illustrated, health and care have moral, political and social meanings, which are articulated in the materiality of everyday relations between doctors, patients, families, and med reps (to name a few). It is more productive to focus on the micro-economic realities of these interactions and ask, as Mark Nichter has done, “Rational for who and rational in what contexts?” (1996a, p.252).

### **Domestic Economies**

Nowhere perhaps are the ambiguities of care rendered more obvious than within the home, when paid attendants are hired to care. Within this space the complexities of exploitation, exchange, and cost-benefit come together to inform practices of identity and notions of family. Of the 20 families, nine had hired full-time attendants specifically to care for their relative with dementia and two had part-time assistance. Full-time attendants that lived with the families (n=3) were unmarried, in their early twenties and came from cities and villages elsewhere in India. In the remaining six cases, full-time attendants worked 10-12 hour shifts, were married, in their mid thirties, and lived in Delhi with their families. Additionally, all families had servants who provided some secondary support by cooking, cleaning, and washing. Five families could not afford to hire an attendant to care, while some hired attendants despite the financial stress this could create. Josie and Nandini, for instance, struggled with the costs of care but hired attendants so that they could remain employed and keep earning.

The decision to hire an attendant was largely based on household income and women's workloads. Women's labour encompassed paid and unpaid work. Women like Vandhana, Sarojini and Bhageshwari were not employed, but hired attendants so as to manage their other responsibilities of housework and childcare. Such a market transfer of care is common among families in the region and beyond (Baldassar, Baldock & Wilding, 2007; Brijnath, 2009; Hochschild, 2000, 2003; Lan, 2002; Srinivas, 1995).

In all cases paid attendants were poor and had limited formal education. Attendants were distinguished from domestic servants by terminology, salary and care-oriented tasks. The English word 'attendant' applied to those who were paid to undertake care work for people with dementia, while Hindi words like *a:ya:* (maid) or *didi* (older sister) were used to refer to domestic servants. A live-in attendant could earn up to Rs 10,000 per month while a live-in servant earned up to Rs 4,000. Attendants focused on the physical and mental aspects of care for the person with dementia; servants were charged with overall housework and childcare. However attendants could commence working in a household as a servant and then be asked to care for a person with dementia. Bhageshwari's maid was often asked to sleep in Bhageshwari's mother's room at night and to take her to the toilet, for which she was paid additional money. The oscillation between the category of 'maid' and 'attendant' illustrates the overlap in job roles and the similar class-orientations of both groups. Attendants and servants were poor people with few opportunities.

At the request of a community health centre, ARDSI-DC trained women from a slum called 'Kamini,' located on the north-east fringes of Delhi to become paid attendants in families' homes. Kamini housed around 64,500 people over 200 acres. These residents were either displaced from the gentrified sanctums of inner-city Delhi during the Clean Delhi Drive initiative of the 1970s<sup>24</sup> or were impoverished villagers from the failing farmlands of neighbouring Uttar Pradesh. Kamini's women, in addition to seeking employment as attendants, were also domestic servants, makers of incense sticks, decorators of *bindis*, and seamstresses. Their husbands were vegetable vendors, daily labourers, and auto-rickshaw drivers. Their older daughters sometimes assisted them with housework and childcare; their sons might be rag pickers and rickshaw-pullers. Kamini's residents, by virtue of their financial vulnerability, led more fragile lives and comprised part of the 42.6 million people (approximately 15 percent of the total urban population) who live in slums in India today (Government of India, 2007).

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<sup>24</sup> Clean Delhi Drives are a recurring event by the Delhi Government where based on gentrification, income, and purported development, people are moved out of their existing homes into re-settlement colonies. Most often those moved are people who live in slums; these moves typically leave them worse-off as they have fewer economic opportunities and access poorer infrastructure in their new fringe dwellings.



**Figure 11: Kamini's women, training to be paid attendants**

The disparity between attendant's background and those of the families for whom they worked created points of tension. While the families had money, purchasing power, and plentiful choices to spend their Rupees on, they also grappled with the consequences of the growing rift between the affluent and the poor, especially in urban settings. As Pavan Varma succinctly puts it, this is "the middle class of a poor country" (1998, p.172), where the walls between classes are stringently guarded and involve much more than just the denial of opportunities to the poor. As I described in chapter 2, the frustrations of inequality contribute to an increased sense of danger in everyday Delhi life. According to Inspector Tyagi, the main perpetrators of crimes against the elderly in Delhi are their domestic servants; "Robbery is the main motivation and in rare cases it is a crime of passion. There is invariably assault, battery,

murder.” The Senior Citizen’s Cell cautions, “Don’t allow servants to have access to your cupboards, safes etc.” (Delhi Police, 2008).

Families and attendants notions of each other were shaped by these wider forces of class, and both parties resented their interdependency. Josie felt like she was held to “ransom,” Nandini described being “rooked,” and Vandhana was determined not to be dependent on any paid carers. Such feelings are commonplace in master-servant relationships in India, and are based in the instability of power relations between families and servants. Trawick wrote of an “intuitive recognition of Sartre’s dictum that in reality the master is the slave,” when she described her interactions with her Tamil family – “Thus when I said to Anni that I felt she was treating me like a queen, she replied, “A queen has no freedom”” (1990a, p.55).

Caste, in this context, was not explicitly articulated and discriminations based on ‘untouchability’ were largely absent. However caste barriers were reinforced in other ways; traits such as thievery, laziness, ineptitude to learn new things, and uncontrolled fertility were associated with attendants and domestic servants. Pinto (2004) made similar findings in rural north India and the Jefferys’ have pithily noted, “money itself discriminates” (2008). Families’ discontent was based in the high rate of absenteeism among attendants, the salaries they charged (Rs 250- Rs 300 per shift), and attendant’s laxity to activities like bathing, toileting, and mobility. Namita Sood, who had had relatively positive experiences, said:

You know that whole business of coming for duty, not coming for duty, they had personal problems, they were not willing to learn new techniques...But when someone doesn't know what to do and is not willing to learn...We were very fortunate that for five years we had a team which was pretty well managed.

The Sood family were an anomaly because they recognised the demands caring could make on a single person, and so opted for a team approach. Most families, unable to afford this, instead made heavy demands on individual attendants. Shifts were typically ten to twelve hours long, excluding commuting time to and from work, which could result in a 14-16 hour day. For example, the cheapest way to travel between Kamini and south Delhi (where the majority of families lived) was a two hour bus ride each way. Many of Kamini's women could not manage such distances on a daily basis, while meeting the needs of their own homes and children.

Some attendants tried to redress the barrier of geography by living with families. But this presented problems too as attendants were then available 24 hours a day. And if the distances of geography were difficult on a daily basis, then the barriers of inequity were near impassable. Attendants might have had their food, shelter, and salary provided, but did not eat with the family, or sleep a room of their own, or wear similar clothes, or earn anything relatively proportional to what was sometimes asked of them. A small but telling example was the lack of surnames among attendants. Their names – Saroj, Sandra and Santosh – contrasted with the names of the middle-class men whom they cared

for – K.P. Aggarwal, A.P. Arora, and S.T. Pillai. It was a standard practice that an elderly man's first name might be synthesised into initials and only his last name retained while a poorer person's first name retained and their surname forgotten.

However, attendants did have power and agency, which they exercised through strategies of reciprocity, redistribution and monetary exchange. None explicitly articulated such methods, but in the grumblings and disgruntlements of families, the forcible sharing of power can be seen. Families talked about attendants' expectation of gifts and bonuses in addition to salaries:

It was Rs 5,000, then after a year we increased it, this year again we increased it. Like this we keep increasing it – Rs 500, Rs 500, and then Rs 300, Rs 300. Otherwise nothing would work. On his birthday I give them a gift, on their birthdays I give them gifts, I make a cake, like this, like this (*Shilpi Mukherjee, 72*).

I got rooked badly. Initially I used to have this travelling job. They (attendants) come for two days and understand the entire vulnerability of this family. The first one I had, I used to get all these high protein diets for dad, and she didn't give him any, she whacked it all off. No fruits being given. I mean these were two things where nutrition was concerned. So every time I would come back the doctor would have to be called in because he was very weak or he's got aggression (*Nandini Pillai, 52*).

Theft was used as a means to share value through the redistribution of goods. Again, attendants did not express this, but families complained of missing nutritional supplements, silver, and cameras. Paradoxically these losses, while sustainable for families, were frowned upon but passively tolerated. Families, mired in relations of interdependency, had little choice but to accept theft, if they wanted to retain the attendant's services. This ran contrary to the Brahminical ideas of personal property and gifting, where property is assumed to be an extension of the self, to be given (rather than taken) to enrich others (Mauss, 1923, 1966). Bhageshwari explained this contrary logic:

What started happening was things started disappearing from the house – upstairs, downstairs – [in] both houses things started disappearing. I lost my silver from my kitchen, my sister lost her camera. So you have to be very careful. But then you can't keep a check on them every time...These women, they're having a tough time in life because they're also doing this work.

For attendants, the desire to be treated humanely and to receive adequate payment for their services was important. Saroj, from Kamini, stated:

See we are poor people. We need enough security so that my husband and my children are [secure]. I should get enough salary so that the people at home can live on it, and that it covers the rent and everything else. We give them so much help, we do so much for them, they should at least give us enough so that we can support our own homes and feed our children.

In addition to money, attendants also layered their work through claims of kinship, reciprocity and *seva*. People with dementia were often referred to as ‘uncle,’ ‘aunty,’ ‘*mātaji*’ (mother) and ‘*papaji*’ (father) rather than ‘sir’ or ‘ma’am.’ This signalled attendant’s respect for their employers and elders, and simultaneously avoided the pitfalls of class and a detached employer-employee relationship (Vatuk, 1969). Attendants explained their work as doing *seva* for a parental-figure and through their claims of kinship derived meaning from the work they performed. It was a way to try and gain the “attendant affection, rights and obligations’ of other family members by providing care like family and doing what family does” (Karner, 1998, p.70). Many had a deep love and affection for the people they cared for.

I like doing this work. It is *seva* for the old and elderly, and in your own heart also you get a relief knowing that this person – who is like my mother – [that] her body is also working (*Saroj*).

Work is work and everyone must find meaning in it. There is no such thing as *chhoṭa* [little] work or *baṛa*: [big] work. Doing work for the patient in their home, this is *seva*, I’m doing *seva* for a helpless person who can no longer do their own work (*Sandra*).

Claiming kinship, as daughters and nieces, enabled women attendants to overcome gender barriers. They could care for men and women, unlike male attendants who could only care for men. During fieldwork, the gender of paid attendants matched with the gender of people with dementia (male

attendants=5; female attendants=4) but this was not always the case and many families reported hiring women to care for elderly male relatives.

Nevertheless, the strategy of fictive kinship, while an exercise of power and agency, was still made from a position of vulnerability. It was a double-edged claim for it also exposed many attendants to being exploited for additional kinds of unpaid labour (Lan, 2002). Paying for care relieved the families' burden of care by relocating it onto poorer, more marginal bodies. Jahangir recalled: "This has happened to women I know, where they go to do this work and the family is very nice to them, does a little *chamcha:giri* [flattery] and then they are doing all the work. This way our work just keeps increasing and increasing."

Increased demands led to an escalation of physical and emotional stress and eventual fatigue and burnout. Many attendants resigned and sought work elsewhere. Even so, for some the bonds of kinship still held. Sandra, an attendant for seven years, recollected:

That old lady died about two years ago. I could not go [to the funeral] because I was working [here]. But I would always call *bha:bhi* (sister-in-law, but here refers to Sandra's employer) and keep asking, "How is ma's state? How is she?" Even though she gave me so much trouble I remember that family very fondly.

As Sandra's story illustrates, claims to kinship were rooted in the emotional work of caring and *seva*. Even when attendants left their employ, such feelings governed their understandings and continued contact with previous employers.

Those attendants who stayed and cared till the person with dementia died experienced profound loss. In addition to feelings of grief, they also had to confront loss of employment and income. The death of the person was also a demise of the reason that validated the claim to kinship. Relationships with families now changed and few could revert or become domestic servants within these households. Death also ironed out the ambiguities in power relations, for families could afford to dismiss attendants. But this was often a mutual dissolution and when attendants sought work elsewhere, families helped by seeking new employment for them, providing referrals and extra money for the transition.

## **Conclusion**

Using three concepts – cost, identity and exchange – I have examined the economy of dementia care in India. The space within these terms has been explored through their application in the broader social spaces of Delhi. The home, the psychiatric institution, the OPD, and the pharmaceutical industry have been populated by families, people with dementia, attendants, doctors, med reps, and NGO workers, to explain the complexity of this economy. I have moved beyond questions of affordability to try and capture the relationality and emotions which underpin economic exchanges. Cost, as was shown, is associated with specific objects – drugs, diapers and catheters – and with hidden subjectivities, like feelings of sadness, fatigue, and guilt but also *seva*, duty and reciprocity. What, at first glance, is beneficial may have darker undertones, whose price is paid in intangible ways. Josie’s admission of Su into a psychiatric facility because of his violence, families’ hiring attendants to help

manage care work, and doctor's prescriptions of medicine to give hope and relief, have their accompanying shadows: Josie's guilt about how Su was treated, families' exploitation of attendants, and doctor's acceptance of 'gifts' from pharmaceutical companies.

Identities within these exchanges are ambiguous, fluid and uncertain but also (re)fashioned and cemented according to notions of care and love. Exploitation and agency, hope and mercenaries, love and money, inform the commercialisation of care through market exchanges, the reciprocity in giving and receiving gifts, and the redistribution of power and materiality through the bonds of kinship. It is not that there are equal and opposite narratives for every story; rather across a landscape of inequity, at different points, people share, exploit, dominate, subjugate and are kind to each other. Using the same examples cited above – Josie, families and attendants, doctors and drugs – these factors are also evident.

In mapping such complexities of cost, exchange and identity, a balanced analysis is not possible. In the macro economy of care, the gaps in service, the politics of delivery, and the risks of outsourcing care are visible. When set within the larger picture of diagnosis and treatment, such costs seem wholly negative. While this chapter has explicitly focused on these negativities this is not the total picture and it is important to also encapsulate the quiet satisfactions and joys of caring. The following chapters seek to elucidate more 'positive' aspects of care through food, *seva* and love in daily life.

## CHAPTER 6: GHAR-KA-KHA:NA

### घर का खाना



**Figure 12: An Indian meal  
(Photo by David Hagerman)**

This is a chapter of many ingredients – memory and nostalgia (Appadurai, 1988, 1996), kinship (Manderson, 1986), relationality and pleasure (Mintz, 1985), domestic citizenship (Das & Addlakha, 2001), and the sensory experiences of ingestion, excretion and its management (Jackson, 1989). The body is the vessel in which these ingredients are mixed, its orifices and pores open to inclement weather; fingers that smart from crushing too much chilli into a bubbling vindaloo; head numbing ice water on a 45 degree afternoon when the sweat trickles down knees; or the mouth-pooling saliva when the sourness of pickled mango seeds are sucked stringy for the last vestiges of flavour. This chapter is

concerned with such a sensory anthropology, of how taste, touch, sight, sound, and smell, affect physical and emotional health in people with dementia and their carers, and of how food invokes sensations of power, happiness, and loss.

The body is taken as the “subject of culture...the existential ground of culture” (Csordas, 1990, p.5), not just the mechanics of digestion. Tongue, taste buds, stomach and intestines are ways of processing food but also the means by which food is felt and experienced. Tangy curry, pungent turmeric, and crunchy red onions can turn rancid when absorbed and amalgamated into the body and gas, cramps, and bloating alongside fullness, contentment and laziness are part of the degustatory experience. Eating is rooted in bodily processes of discomfort and pleasure. The fond remembrance of a meal lingers in the tastebuds, the overeating of nostalgia lies in a full belly, and the heartburn of an ageing body reflects the chagrin for bodies that can no longer eat as they used to. These are also examples of how the medium of food can invoke memory and vitality against the loss associated with age and degeneration.

The title of this chapter – *ghar ka kha:na* – home-cooking, symbolises when the hearth and the home are not what they used to be, and a nostalgic connection to the past is made through home cooked meals and juxtaposed against contemporary family life and food purchased from outside. Food cooked within the home is part of the disciplinary project of care enacted both on care-giver and care-receiver. For as long as the person with dementia eats, the work of surveillance, routine and containment is ongoing, threading discipline into kin relations within a wider social milieu and on the body and bodily processes. It is

a relation of power and citizenship within the home (Das & Addlakha, 2001), a status accorded to carer and the person with dementia. But implicit in this disciplinary project and undermining it are memory and nostalgia. I distinguish them through taste; memories are tasteful and tasteless, bitter and sweet, whereas nostalgia is always sweetly melancholy. As the unspoken memories of loss, famine, deprivation and hunger, whether actually endured or collectively imagined enters into the domestic sphere, anxieties ensue around hunger and wasting. Carers experience such emotions when the person with dementia stops eating. I return to this later.

On assembling these ingredients, as yet raw and unassimilated, the recipe is as follows: first, some preparation to link food and Indian identities; then to combine and complicate the relationship between food, *seva*, discipline and domesticity; separate the health discourse imbued in it; discard the waste that is generated; and finally feast on the sweet pleasures of feeding.

### **Food and Identity**

Gastropolitics in India has undergone a profound change in the last three decades, incorporating the long-established moral and medical taxonomy of food into a more recent global gustatory landscape focused on consumption, identity and change. Traditionally, the organisation of food and eating aligned with relations of class, caste and ageing, with attendant politics of purity and exchange. Food in India has had multiple meanings beyond mere sustenance; it extends to cultural, economic and legal claims of rights, responsibilities, complaints and conflicts as well as the structuring of caste-ordered substances

(Khare, 1998; Khare & Rao, 1986; Marriott, 1976; Smith, 1990). Who can eat what, where, when, and prepared by whom is determined by a complex capillary network that transcends discrete categories and roles of 'Brahmin priest,' 'Kṣatriya warrior' or 'Shudra leatherworker' (Marriott, 1976).

Marriott's work (1976) in particular highlighted that the transfer or exchange of food in trade, alms, or feasts was also an exchange of bodily-substance codes. If gifting in Hinduism was giving a part of oneself (Mauss, 1923, 1966), then eating was the literal ingestion, absorption and amalgamation of that personhood. Within such a paradigm there were stringent boundaries around purity, pollution and dirt in food exchange. But as Appadurai (1981) points out, such rules were also a response to the homogenising effects of food. Sharing a meal, eating together – mashing hot starchy rice between fingers, slurping yoghurt into one's mouth, commenting on the saltiness of a dish – invokes a deeper relationality beyond the parameters of polite conversation. Sharing food is a way to make memory and to build social relations. When I went to interview Kundan Lal (K.L.) Chopra for the first time, his entire family was present and I was served breakfast, tea and two steaming *gobi-parathas*<sup>25</sup> slathered with *ghee*. Chintu, K.L.'s younger daughter-in-law, who made this meal, explained:

I hardly get the chance to do this – we're all busy: I'm at work, with the children; my husband's in his shop, we're always busy. It's rare that we

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<sup>25</sup> Fried unleavened bread made from wholemeal flour and stuffed with cauliflower.

get to sit together and just have a chat. But whatever time we spend together we try to make it memorable.

Food was critical to memory-making, hospitality and the structure of all my interviews with families. Vandhana Arora and I met over her *pao-bha:ji*, *gula:b jammuns*,<sup>26</sup> grapes, tea and Limca®, Suneeta Sadhwani and I ate *rajma-cha:val*<sup>27</sup> on her living room carpet after our second interview, and Bhageshwari Srivastava offered me homemade chocolate cake while I interviewed her. But while eating was symbolic of my relations with families, tea had soaked into the foundations of my fieldwork. Tea was ubiquitous, drunk with key service providers and families, and to refuse an offer of tea was inconceivable:

Do you want to drink tea?

*No, no, it's ok. I have water [point to my bottle]*

[Shocked] You don't drink tea?

*[Placating] I do*

[Decisively] Fine, then I'll make tea

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<sup>26</sup> *Pao-bha:ji* is a Maharashtrian snack which comprises a *pao* or bread and *bha:ji*, typically a potato-based curry. *Gula:b jammuns* are deep fried balls of cottage cheese (or other milk solids) soaked and served in a rose-infused sugar syrup.

<sup>27</sup> *Rajma-cha:val* is a popular north Indian meal of red kidney beans cooked with spices and served with white rice.



**Figure 13: Hot *gula:b jammuns* and *cha:y*  
(Photo by David Hagerman)**

*Cha:y*, sweet, hot, silky, flavoured with green cardamom, boiled and boiled, often with milk-skins floating on top, arrived during the course of the interview. I hate tea. But I quickly learned that drinking it proved less disruptive to the interview, and with secret grimaces and a clenched stomach I swallowed it. *Cha:y* was a social lubricant, building mutual respect through the acceptance and ingestion of personhood and even in the Cornwall OPD, doctors would ensure that med reps brought tea for me. If my ethnography is about stories of care, then drinking *cha:y*, feeling the sugar widen my eyes and lift me from the lethargy of heat, was how I acquired the energy to listen.

But to return to Appadurai's (1981) point of the homogenising effects of food: eating together can also be dangerous because it can threaten existing social hierarchies. Rules around food preparation and consumption reflect the dangers of cooking and eating for food is also associated with dirt, taboo, and fears of the unknown outside the home. *Ghar-ka-kha:na* is as much about the

nostalgia for a home cooked meal as it is about the perceived excesses and impurities of restaurant and street preparations.

Concurrently dirt in food is tacitly accepted and folded into dietary practices, often in the form of jokes. The health risks which arise from eating dirty food are often packaged as jocular warnings, a strategy which can be traced to colonial Anglo-Indian domestic home-companions (Procida, 2003). Food and dirt were and continue to be matched together; in colonial India, English women were advised not to visit their kitchens for fear of the conditions under which their food was prepared by native cooks (Chattopadhyay, 2002), just as in more contemporary times 'Delhi belly' is the expected consequence of eating Indian street food in the traveller blogosphere. There is little doubt of the unsanitary conditions in Delhi's commercial kitchens and food prepared by street vendors – stale oil, bacteria-rich water, simultaneous handling of raw and cooked meats, rats and roaches, and the personal hygiene of cooks themselves – are gastronomic dangers which any eater of 'outside' food will confront in India. Such are the health risks and their effects that event planners fear an outbreak of Delhi belly will ruin the success of the 2010 Commonwealth Games (Nelson, 2009).

However, the dangers of outside food also represent a more secular, anonymous exchange of marketplace and bodily substance-codes. In not knowing who, how and under what circumstances food is prepared, eating out becomes an exchange of bodily-substance codes across religions, caste, class and spatial barriers in exchange for money. Ironically, the affluent urban

middle-class within and outside India, powerful and with the most to lose within the class hierarchy, is the driving force behind this change. The Indian middle-classes desire their own regional *ghar-ka-kha:na* – like Bengali *dum-alu*, Punjabi *parathas*, and Tamilian *dosa* – alongside culinary exoticisms such as sushi, tacos, and pasta (Srinivas, 2007).

Transnationally, the availability of pre-packaged, popular nostalgic foods marketed “as mother made it” in places such as Boston and Melbourne, but also Bangalore and Mumbai, strengthen links between homeland and diasporas (Srinivas, 2006). Such foods and marketing techniques complicate geographies of home and abroad, and rules around caste and class. Definitions of home cooked and exotic meals are now so blurred that as Tulasi Srinivas writes, “It would appear that authenticity is not questioned, as long as the copies that appear authentic are provided, as symbolic anchors on which identification can unfold” (2006, p.207). In short, the aspirational urban Indian and the nostalgic diaspora want their cake and to eat it too, alongside pickles, *dal*, and pizza. Within this culinary montage, identity is uncertain and sometimes risky, circulating between insider and outsider, home and abroad, there and back again. In her first interview, Parvati Gowda (43) said of the changing identity of her 78 year old mother, Meenakshi:

Initially she used to like pizza and stuff, and there was a stage where she was, “No I want rice.” If we go out, she would want rice. She would insist, “Call the waiter and ask him – I want rice.” Now she’s *back*. Now she doesn’t mind eating anything (emphasis added).

## Ageing and Eating

Within this flavoursome landscape, the ageing body represents the gendered embodiment of nostalgia, through the benevolent and kindly mother or grandmother preparing home-cooked meals. Ironically, while this kindly old figure might prepare ‘hot’ foods – spicy and fried – these cooks are not meant to consume these dishes, instead eating ‘cooler’ more age-appropriate foods. Traditionally in the *vanaprastha* and *sanyas* life stage, an older person’s disengagement from everyday life was symbolised in part through increased regulation and austerity of diet. Older people were meant to eat simpler, plainer food, and their appetites have been described through frugality and wholesomeness: Cohen’s (1998) poorer participants ascribed weakness to their elderly relatives through the few *rotis* they could feed them, Vatuk’s (1990, p.75) elderly claimed to only want “two pieces of bread a day” to survive, while Lamb’s (2000, p.138) village participants spoke disparagingly of a 90 year old woman’s desire for mangoes, sweets and cottage cheese.

If displaying overt interest in food is seen as age-inappropriate, then eating has long been a strategy by which older people transgress their life course. This is best evidenced in the epicurean richness of Indian fiction which features older people eating and demanding age-inappropriate foods (Raja, 2005). For example, in the film *Pather Panchali* (Ray, 1955), based on the 1929 novel by Bibhutibhushan Banerjee, the old aunt Indir is first introduced to the audience by her hands, feet and appetite. We see her crouched over her bowl of *dal* and rice, which she mixes and mashes with gusto before enthusiastically devouring it. Her obvious relish and joy, for treats like guavas and bananas, sits in contrast

to the poverty of the household, and prompts rebuke from the young mother of the house, “You eat the fruit ... you should know better ... you think you can do as you please living with us.”

In my sample, in a south Delhi suburb, another *Pather Panchali* was unfolding: 92 year old Lakshmi Kumari Kochar’s family complained of her constant demands for food, juice and tea. For Lakshmi, these were performative aspects of *seva*, and she claimed food as her right based on her non working *hāth-pair* - because of her dementia and her age. Her hunger fluctuated according to her age – she claimed to be 18, 50 and 80 years old, on the multiple occasions I met her – and as her age increased, so did her appetite. Also on the increase, was her family’s concern about managing her weight, mobility and urinary incontinence. They repeatedly tried to control her diet, but to little effect. Lakshmi remained insatiable and intractable, complaining to neighbours and guests that her daughter-in-law did not feed her. Embarrassment and anger were inevitable. By my third visit to the family, they no longer conversed with Lakshmi, but commanded her, “Get up, change your clothes! Come out of the bathroom, stop wasting water!” Lakshmi ignored these instructions and in addition to demands for food, insisted that her hair be dyed black. This caused further rancour. Her 69 year old daughter-in-law grumpily remarked, “In nineties, what need is there for all this image consciousness?”

The real and imaginary stories of Lakshmi and Inder respectively illustrate that eating is a powerful way to continue to hold onto life, unsettle identity and resist the transitions of age and the losses that accompany it. For older people

no longer the centre in household affairs, eating is pleasurable, vital, therapeutic and symbolic of intergenerational reciprocity and *seva*. Vandhana Arora (38) highlighted this when she described the epicurean interactions between her mother-in-law, Mrigakshi (74), and her oceanographer father-in-law A.P. Arora (79):

She is in the kitchen cooking and he is in the bedroom. From there he is shouting, and the best part is he calls her “Darling.” Anyway, so from the bedroom, he’s calling her, “Darling” and asking, “Is the food ready? Is the food ready?”

### **Gender and Discipline**

Cooking and eating are ways to give and receive care, organise daily life, and retain citizenship within the domestic sphere. These are also gendered divisions of labour as it is women, especially daughters-in-law, who are meant to show *seva* to their elders through the preparation of food, deference to their husbands by eating after them, and love for their children by nurturing them with their own hands and breast milk in infancy (Chaudhary & Bhargava, 2006; Lamb, 2000).

Much has been written of the changing role of women in urban India, their careers, consumption, increased independence, and changing expectations of familial, marital and romantic relationships (see Das, 1988; Kakar, 1988; Lau; Thapan, 2000; Uberoi, 1998). Undoubtedly Indian women and men across the chronological scale are negotiating changing gender roles in a time of heightened global flux and socio-cultural and economic interchange with other

(often Western) nations. Amid these processes, there is a burgeoning realisation that the established 'shifts' that women perform in the West are also impacting on middle-class Indian women's capacities to undertake paid work, housework, childrearing, and to manage the health of husbands, children, and elders. In a television advertisement for women's Horlicks® (malted milk powder) a young woman is featured planning her day – organise her husband's office party, supervise the housework, handle her colleague's heartbreak, carpool for her children, write to her aunt – until she suddenly realises: "*Apne se list me, apna naam nahi* [that my own name is missing from my list], Women's Horlicks®, because your body needs you too."

Within this paradigm, bodies become the site of care, the source where love is taken and given. Women's bodies are often the primary source of care work; their arms cook for the elderly, their stomachs are hollow when they fast for their husbands and their breasts heavy when babies are to be fed. The power in cooking, feeding and fasting echoes Foucault's (1980) maxim that power is everywhere, exercised by everyone. Women's bodies, like the bodies of men, children and the elderly, are written upon and enter into a mechanics of discipline, invested, marked and trained for care work (Foucault & Sheridan, 1977). But if the arms, hunger, and breasts of women (re)produce disciplinary foods, then the stomachs of men, children and the elderly must also be disciplined to eat these foods. Yet as the Horlicks® advertisement suggests, this is not a one-way transfer of strength: women's bodies need replenishment and nourishment in order to provide this labour. A productive, healthy body rather

than a sacrificial one is emphasised. Thus the advertisement concludes with the young woman running and doing yoga, being fit and healthy.

Just as the bodily strength of women is appropriated to care and bolster others, so too women are mobilised to supervise the dietary needs of people with dementia. In the majority of families (n=18), women either cooked or oversaw the cooking by others (e.g. domestic servants or younger women). Their days were structured by food routines, which though commonplace amongst many families in India, was not invisible work. Women and their families recognised the importance of cooking and eating. However it was only when I encountered an anomaly – Shivbaksh Chand – that the complexities involved in daily food preparation became evident. Because of his wife Helen’s dementia, 87 year old Shivbaksh had become the chief homemaker. He described cooking for Helen as the most important and valuable task he could do:

#### *Breakfast*

I get up at 5am in the morning. Then I make tea, then I go for a walk to buy the milk, then I make *khichri* for us – I feed her – then I walk again. Then I do the sweeping and the swabbing, then I go and read the paper. Then I make tea and drink another cup.

#### *Lunch*

At about 12pm I soak the rice for lunch and start cooking. I start cutting the vegetables, boiling the *dal*, peeling the garlic and putting it and the *masa:la:s* in the mixxie [blender]. I’ll make *dal*, I’ll make rice or I’ll make the *rotis*; I’ll eat one *roti* and she’ll eat two.

### *Tea*

In the afternoon I rest till 3:30pm, then again I drink tea – in the evening again it [cooking] starts. I'll put the milk on to boil in the small cooker; I'll put it on slow so I don't have to keep an eye on it. After it is heated then I set the *dahi* [yoghurt]. I keep some aside for later in the night.

### *Dinner*

Then I sit and talk to her, we eat and drink and I have a little alcohol. Here see this [shows his bottle of whisky]. *Haa*, I drink one peg [every night]. At 10pm we both drink one-one cup of milk and go to sleep. Then get up in the morning, *chalta hai* life [like this life goes on].

Shivbaksh spent his days in a routine of soaking, chopping, kneading, grinding, and stirring, procuring milk and setting yoghurt, making *rajma* in winter and *lauki* (bottle gourd) in summer, parsimoniously drinking one peg of whisky every night while Helen freely smoked her *bi:ri:s* (unfiltered cigarettes). In cooking and caring, there is power and discipline in producing and consuming food, adhering to routine, monitoring the person with dementia, and self-surveillance for managing time and completing daily tasks. Cooking required detailed planning of daily menus to ensure nutritional-balance and variation in main meals, snacks, and beverages. The seasonal availability and affordability of ingredients affected these plans as did geography. Many families sought to prepare food that invoked their regional homeland or 'native place' – Keralite Radha Menon cooked tomato rice on Tuesdays, Jaspreet Kaur from Punjab

rolled hot *parathas* for breakfast, and Bengali Shilpi Mukerjee ordered fish for lunch a few times each week.



**Figure 14: Shivbaksh Chand cooking**

Alongside the efforts required to plan and procure ingredients and their nutritional and nostalgic capacities to evoke particular regional identities, the freshness and tastiness of food were also disciplinary measures. Dishes tended to be prepared everyday and before each meal, rather than just once a day. The fluffiness of rice, the heat and moisture of *rotis*, the crunchiness of *pakor*s, were all contingent on the immediacy of their preparation and were tied to *seva*. A caring household was one where there was a daily tri-cyclical performance of preparation, serving and flavour in each meal. These performative aspects not only informed gastropolitics around family dinner tables but also served as markers of loneliness in social policy. A senior member of India's largest elder care NGO, HelpAge India, explained:

The grandmother may be given food on a plate in a very disdainful way like you would throw food to the stray dogs. Then you're not giving it with love ... this leads to isolation and loneliness because a human being is a very social animal and is very perceptive of all this.

Consequently, pre-packaged or ready-made foods were rarely bought and microwaves were an unusual appliance in families' homes. In conjunction, because all the families (except Shivbaksh) had some form of domestic help, these servants would at the very least wash dishes and in other cases help to cook and serve meals. But for most families, cooking and preparing meals consumed their entire day. K.L. Chopra's older daughter-in-law, Rubina, who prepared food everyday for K.L. and his wife, was not quite so enthusiastic as her younger sister-in-law, Chintu, about the pleasures of cooking:

In the morning I give them breakfast, then I send tea, then in the afternoon I give them lunch, then in the evening tea, then the food for dinner, and then the milk at night. So in the course of preparing all their food my whole day goes ... It is a difficult situation.

### **Health, Waste and Domestic Citizenship**

The importance of food as *seva* underscores the domestic citizenship that people with dementia experience. As defined by Veena Das and Renu Addlakah, domestic citizenship is:

A focus on kinship not as the extension of familial relations into community, but as the sphere in which the family has to confront ways of disciplining and containing contagion and stigma [that are]...located not

in (or only in) individual bodies, but rather as “off” the body of the individual and within a network of social and kin relationships (2001, p.512).

The domestic sphere, argue Das and Addlakah, is constantly at risk of becoming overtly political and needs continuous management by caregivers to maintain a status quo. Subsequent work has shown this concept is a way to link the physicality of the body with personhood and identity politics for individuals and families (Mehrotra & Vaidya, 2008), a strategy of simultaneous inclusion and exclusion by families towards disabled family members (Gammeltoft, 2008), and a way to think through how families shuttle between domestic and public spaces in meeting the rights and entitlements their relatives with a disability (Dossa, 2006).

Specifically with dementia, as the disease progressed, so did the risk of disruption. Relationships changed but people with dementia rarely became invisible in their homes even though they might experience heightened techniques of sequestration through reduced mobility and growing incontinence. Even as their role within the household shifted from elder statesman to managed subject, a transformation which I discuss in greater detail in the following chapter, they still continued to occupy a place and space within household affairs. They were very much citizens in their homes with rights and to whom duties were owed. Through the tacit acknowledgement of their status, families sought to fulfil these obligations. As has already been illustrated, a wide array of services were sought whose quality and variety was

contingent on affordability – diet, doctors, diapers, attendants, and medicines, each with their own associated object and subjective costs. For many families, these services eventually coalesced into a disciplinary project of containment and surveillance, and further underscored that people with dementia were at once powerful and powerless in the care dynamic.

Food, in addition to being a medium of *seva* and discipline, was also imbued with medicinal properties and functioned as a meeting point for biomedicine, traditional and transcendental medicines. Nearly all health practitioners recommended dietary changes to help manage bodily decline. Allopathic doctors suggested fruit, juice, and vegetables for digestion; traditional practitioners prescribed coconut water, walnuts, and almonds for memory; and transcendental healers offered an assortment of spices, chillies and lime to exorcise djinns and other malevolent forces. Albeit neither typical ‘drug foods’ like tobacco, sugar, tea, and coffee<sup>28</sup> nor of equal potency, the fruits, nuts and spices mentioned above were meant to function in a similar capacity as sedative or stimulant. Just as drug foods have been used to enhance worker productivity and minimise bodily distress within a capitalist economy, so too these ingredients sought to enhance carer’s moral quotient and minimise disruptive risks within a care economy. In seeking, procuring, and preparing these ingredients, physical and emotional labours were emphasised within the domestic sphere. But unlike the more definite pills, powders and processes of an *ilāj*, carers did not discuss the effects of these foods on the person with

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<sup>28</sup> See Bradburd and Jankowial (2003), Mintz (1996), Nichter & Thompson (2006), Stromberg, Nichter and Nichter (2007).

dementia. Rather, as Das and Addlakah (2001) point out, these become management techniques for care and containment, concerned more with fulfilling duties and giving *seva* to an elder citizen within the social relations of the household than with the healing properties of these foods on the bodies of people with dementia. In that sense they are “off” the body. This link is evidenced in Nandini’s description of using ‘drug foods’ to manage her father’s dementia:

One got to know about electrolytes. I, as a routine, used to get the electrolyte test done – so he [doctor] used to laugh and say, “Now you’ve understood. Suddenly if he [father] gets into a major aggression, you go and check his electrolytes. You’ve got the hang of what to do.” So when sodium and these imbalances are there, aggression goes up. Then the homeopathic doctor helped me with the diet. Like what kinds of things you should give ... things like curd being given in the night helps his sleeping. Even if he does not eat any of his food, make sure a bowl of curd goes in or a *lassi* goes in and a banana.

In managing aggression and sleep through diet, Nandini uses biomedical and traditional medicine techniques and explicitly ties diet and voice together within a health discourse. Such a strategy was not uncommon within my sample, but it was more in managing incontinence that diet and health were linked. Fifteen families grappled with urinary and faecal incontinence on a daily basis. In 12 families women were the only cleaners, in two the cleaning was shared between women and men, and only in the Chand family did Shivbaksh help Helen to clean herself. Bar a few cases, incontinence, though a trying task,

was not mentioned unless explicitly asked about. However, unlike the families in Lamb's (2000) work which viewed incontinence as an accepted part of old age and *seva*, most carers dealing with incontinence found it an emotional rather than physical challenge which left them angry and drained.

Nowhere is the work of containment and emotional management more visible than in the invisible work of cleaning. A large body of literature has accumulated to illustrate that dealing with dirt and its associates – urine, faeces, vomit, sweat, pus – is a form of care work rarely discussed, physically and mentally distanced by those who perform such work, and highly sequestered from everyday society (Isaksen, 2002; Lawton, 1998; Lee-Treweek, 1997; Peake, Manderson & Potts, 1999; Shaji et al., 2003; Twigg, 2000). Such dirt threatens the established order, the discreteness of individual bodies, and evokes fear of contagion and the sensation of disgust. Intellectually and morally, people are squeamish about such a topic, and sensory anthropology may well have found its descriptive limitations, for little has been written sensorially about excretion. But such an anthropology must focus on the symbolic and visceral, in all its sensuality and sordidness (Holtzman, 2006). The grinding work of care can neither be wholly understood if we are to shirk away from one of its most onerous tasks nor can one appreciate the dirty depths of love and *seva* that people perform for those who have forgotten how and where to go to the toilet:

Touch wood his [husband] potty is not thin. If he gets diarrhoea then it's very difficult, everything becomes filthy. At least if it's normal then it's just his clothes that are dirtied. The smell is there. He's an adult and if

you go to the toilet once every seven to eight days, then it is going to smell. The whole house stinks. What to do? I have to clean it. See I don't know when he's going to do it, so who can I call to clean it? He can go today, tomorrow, now. Day before yesterday he did a little. I saw it and changed him. Then I checked a little later and there was more. So I cleaned it again. Two hours later, I asked him, "Has your latrine come?" "No." But when I checked there was so much. Then I had to scrub and clean everything, put Dettol®, soak it all. I normally have tea and bread in the evening but that evening my throat was – Anyway now it won't come for another three to four days. Last year in January for eight days, he didn't urinate or excrete. The catheter wasn't on then. For eight days there was nothing and he wouldn't even drink water and would scream with pain. Then after the enema he couldn't stop for two days, his system was so blocked. It was terrible, terrible and it was cold. Touch wood this year that didn't happen (*Sita Aggarwal, 63*).

Disgust is the typical sensory response to dealing with human waste, and much care work is centred on minimising disgust by managing dirt. Disgust has had a long, albeit implicit, history in anthropology; Steiner (1956) wrote about taboo and the sociology of danger, Douglas (1966) about dirt as disorder and matter out of place, and Miller (1997) has described disgust as sensorial and relational. It is sensorial in that it is located in our bodily responses to disgust – grimacing, spitting, and shuddering – and relational because it is other people's dirt, rather than our own, which is viewed as polluted. Isaken (2002) has argued that disgust is also time-sensitive and that as one engages constantly with taboo

bodily fluids over time, feelings of disgust cannot be avoided. In addition to the definition and evolution of disgust – as dirt, sensorial, relational, taboo, and time-bound – disgust is also spatially prescribed and a part of stigma. There are dirty and disgusting spaces in the domestic and public sphere (e.g. toilets and garbage bins), for which techniques of isolation and management have developed to minimise disgust, reinforce stigma, and contain contagion. These links will be explored in greater detail in the following chapter.

Tempering feelings of disgust is part of the complex emotional labour carers perform when cleaning. As Sita described, this work is harrowing and deeply intimate. Only she changed her husband. This was not unusual, for though nearly all families had some level of assistance, in only six cases did the attendant help with toileting. Families strived to avoid ‘accidents’ whenever possible, but mess was inevitable at one point or another. Then, as Nandini describes, it could take up to three hours to clean the mess:

You’re dealing with his emotions, you’re also dealing with your own emotions at the time because you’re really cut up with yourself, with all that has happened, you’re cut up with everybody, you’re angry with everybody. Part of your brain is saying, “Ok, just shut up and deal with this.” So you tell him, “Lift your leg here, lift your leg this side” and he’s not able to because he is in that panic mode. It’s not just about cleaning up. It’s also about that state of mind that the person gets into, this pressure that has built around it.

In spite of the difficulties associated with changing and cleaning, carers continued to perform this task. Contrasting with reports of residents in nursing homes and other institutions, in the west and in India, being left in their own faeces and urine for hours, among many families where there was hyper-vigilance and constant monitoring for bedsores, groin rashes, and bacterial infections. When describing daily routines, nearly all the families mentioned massages and exercise, bathing, sponging, and regular turning on the bed. These activities, when combined with cooking and feeding, illustrate the complicated daily routine that carers and people with dementia were engaged in, the recognition of rights and the fulfilment of duties. It also highlights that carework has many tempos: the brassiness of diagnostics, prescriptions and OPDs rests alongside the hum of citizenship and *seva* within the home, and in-between “regimes of normalcy and ways of being are fashioned [which] capture both the densities of localities and the rawness of uniqueness” (Biehl, 2004, p.478).

### **“I Want Her to Eat”**

Famine?

Where is famine?

Sticking charred to the palate of this land

roasting in the burning sands

you unfortunate dwellers of villages and hamlets

of huts and hovels,

why did you take birth in this infernal land?

- *Ká/*, Rawat Saraswat (1970, translated into *Famine* by I.K. Sharma)

Eventually people with dementia stop eating. There are many reasons for this – distraction during mealtimes, refusal to eat, neurological difficulty in recognising food, diminished olfactory sense, inability to open one’s mouth, reduced levels of plasma and brain neuropeptide Y and brain neuroepinephrine (which stimulate appetite), depression, and acceptance of death (Marcus & Berry, 1998). Inability or refusal to eat amongst elderly people with dementia tends to be viewed as the starting point for discussions around end-of-life care in the west. Carers are given choices between tube-feeding versus no feeding and pain minimisation. Some people opt for the latter based on ideas of comfort, quality of life, and a ‘good’ death.

In India, however, the notion that the inability to eat might signal a family decision around time and means of death was incomprehensible. No family within my sample considered such an option – all those whose relatives were in the late to end stages of dementia chose the nasogastric feeding-tube. As Shivbaksh (87) stated unequivocally, “Whether you understand this as *seva* or as her being with me, being together, *I want her to eat*” (emphasis added).

Starvation and the diminishing appetite leading to it were viewed with grave concern. Though families repeatedly mentioned this to me, I never fully appreciated the import of these anxieties until I received a phone call at 10:30pm on a balmy Saturday night. The caller was Garima Dawar, whom I’d met four months ago in the Cornwall OPD where I’d unsuccessfully tried to recruit her into my study, as a carer for her elderly father. Rushed and uninterested at the time, she perfunctorily took my phone number but when I

followed up, she questioned her suitability as an interviewee explaining that her father had Parkinson's disease and that she had no knowledge of Alzheimer's disease or any other dementia. Taking my cue, I thanked her for her time, assumed that was the end of our association, and hung up. But with this phone call, Garima, voice high and stressed, renewed our connection and sought advice. Her father's memory had deteriorated; he was anxious, paranoid, and violent, experiencing urinary incontinence, but worst of all, according to her, he refused to eat. Near tears, frustrated and desperate for an answer, she had telephoned every Cornwall doctor she knew – I was the last desperate straw she clutched and the only one who had answered my phone. She was feeding her father *rotis* and oats every few hours, successfully coaxing down only a few mouthfuls. What should she do?

With little advice to dispense and no one to call upon at that hour, I advised her to put a rubber sheet under her father, to try and feed him something nourishing every few hours rather than a full meal, and not to argue with him but to let him talk about old memories. I promised to send her the caregiver's booklet in Hindi the following day, told her that someone from ARDSI-DC would contact her, and encouraged her to persevere in trying to contact the Cornwall doctors the following morning. More placated through talking than my advice, she hung up, promising to call back should she need to. But she never did and I spent the night despairing about the futility of anthropology, wondering instead why I did not become a doctor.

This profound distress that families experienced when people with dementia stopped eating requires elucidation, for a shift occurs from the sweetness of nostalgia, the yearning for home-cooking or food as ‘mother made it’ to a more bitter palate shaped historically by deprivation and hunger. Though they are separate words in English, in Hindi, the word *bhu:kh* denotes starvation and hunger. Rejecting food signalled physical and social decline, denied a critical component of *seva*, and upset domestic routines and markers of citizenship. Six months after my first interview with her, Parvati Gowda’s (42) mother stopped eating. Said Parvati:

It’s the eating part which is causing a lot of tension. She is not eating enough. I have to make sure that she is eating properly and every few hours because if I forget, she’s not going to tell me she is hungry. Before, every few hours she used to say, “I am hungry.” But now I have to really monitor.

Shafia, whose husband Omar was on a nasogastric tube when I met them, described how she began to handfeed Omar:

Once he stopped speaking, when he would eat, sometimes it would go in his mouth and sometimes it would fall down, even dry *rotis*. We put a napkin on him and the food on a tray but he still could not eat it, he dropped it. Slowly we realised that his stomach would never be full, he would become *kāmzor* [weak].

The visible bodily process of hunger – growling stomach, thinness, *kāmzori* – occupies a powerful place within the Indian social imagination. Two reasons

explain this preoccupation: (1) a shared history and memories of famine and the continued lived reality of hunger and malnutrition, and (2) the 'right to food' within Hinduism.

In India, famines, hunger and starvation have had a long history,<sup>29</sup> which in part has influenced the development of such a complex structure around food and eating. Unlike in Brazil where Nancy Scheper-Hughes (1992) writes of *delírio de fome* as a kind of hunger madness and desperation in which people teetering on the border between life and death make unimaginable choices, in India, as Khare points out, a myth of 'immanent abundance' has needed to be perpetuated in order to prevent societies from collapsing into a desperate 'culture of scarcity' (1976, p.169).

India's last substantial famine was the Great Bengal Famine in 1943, estimated to have resulted in the deaths of 1.5-3 million people (Sen, 1981). With Independence, investment and technological innovation in the agricultural sector, famines have declined with grain hybrids, higher yields and greater crop resilience to drought and floods. Yet hunger has not disappeared. Famine and starvation must be distinguished for starvation still occurs within a time of plenty. "Starvation," writes Amartya Sen, implies "poverty, since the absolute dispossession that characterises starvation is more than sufficient to diagnose poverty, no matter what story emerges from the view of *relative deprivation*"

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<sup>29</sup> Bhatia (1967) estimates that there were 14 famines in India from the 11<sup>th</sup> to 17<sup>th</sup> centuries which killed millions of people (exact numbers not available). In the latter half of the 19<sup>th</sup> century, there were about 25 major famines believed to have killed between 30 and 40 million people.

(1981, p.39). In collaborations with Jean Drèze, Sen (1989, 1990; 1995) has further demonstrated that starvation is more a question of affordability and access to food than shortages in supply.

Endemic hunger, persistent malnutrition and starvation continue to effect India's populations with the root causes of poverty, corruption, high food prices, and ineffectual storage and distribution mechanisms (Currie, 2000; Mooij, 1999; Radhakrishna & Subbarao, 1997). Currently nearly half of all Indian children under three are malnourished and half of all Indian women are anaemic; these figures exceed those reported in Sub-Saharan Africa (where the latest famine was in Kenya in 2009) (UNICEF, 2009). Localised famines continue in India, driven by drought, preference for cash over food crops, and poverty. Famines are now linked to debt and the disturbing rate of farmer suicides. Many farmers, neither able to repay loans for seeds and pesticides nor able to feed their families, kill themselves by ingesting pesticides, drowning or hanging. From 1997-2005, approximately 150,000 farmers killed themselves, a trend mainly concentrated in four states (Maharashtra, Andhra Pradesh, Karnataka and Madhya Pradesh) and showing signs of increasing rather than abating (Sainath, 2007a, 2007b).

But while so much of the country goes hungry, Hindu philosophy stresses that, "*Bhojan* (eating and giving food to others to eat) is one of the most important subjects treated in the *Dharmasastra* works" (Kane, 1930, 1962, p.757). Khare's (1998) analysis of Hindu philosophy indicates that four interrelated factors influence the politics around hunger and eating: (1) *Apadhama* – self-

preservation in order to fulfil one's duties to others in times of normality and distress, (2) *Palana-posana* or the need to nurture and protect dependents and the needy, (3) *Yogaksema*, faith in rulers and the divine to protect and provide for the marginalised and (4) *Annabrahma* (food is God), the notion that to feed others is to feed God. Feeding others, especially the poor, is important in Hinduism, Islam, Sikhism, and Christianity. Makeshift tents affiliated with local charities and religious centres dispensing hot meals for free are commonplace in Delhi's landscape. Figure 15 is of the popular '*Aap ki rasoi*' (Your Kitchen) programme in Delhi, a state-sponsored initiative to provide a hot midday meal to the poor.



**Figure 15: Delhi's '*Aap ki rasoi*'**

Amongst the families in my study, feeding those less fortunate was fulfilling one's *dharma*; to celebrate Karamjit's 75<sup>th</sup> birthday, Nina and he, accompanied by 22 extended family members, decided to feed other people. Nina (70) recounted:

He was the man of honour and you should have seen him, he was lapping it up, the attention, he was having wine! My God you should have just seen how he was lapping it up, the importance given to him! He loved it, oh my God! You see he's never ever hurt anybody, never ever called anyone names, he's never been nasty, so people have a lot of love for him. All his family – we went to Mathura for his birthday and we fed 6,000 people. He was feeding them – 6,000 people!

Given the centrality of eating and feeding within India politically, economically and philosophically, starvation then represents profound unease and unhappiness in the social imagination. Poverty, hunger, and starvation are lived realities on India's streets for *all* its citizens. It affects those who are deprived and marginalised in life expectancy, health status, economic opportunity, and lived inequalities. Its impacts are more symbolic on those with full bellies, for the faces of hunger also represent the greatest failure of more powerful people and government to sufficiently fulfil their duties to the dispossessed. Anxieties around starvation in Alzheimer's are framed against these backdrops and represent a failure outside and inside the home, an inadequacy of middle-class families not only in effectively responding to the needs of public citizens but also to their immediate domestic citizens.

## Sweetness and Play

Appadurai (1981) has noted that gastro-politics in India is akin to Geertz's description of cockfighting amongst the Balinese – it is a state of “deep play” involving the moral and medical taxonomy of food with considerable stakes. Because feeding and eating reveal so much about age, identity, gender, discipline, power, hunger, domesticity and citizenship, the risks are so high as to be almost impossible for families to successfully negotiate. Indeed all the families experienced censorship and failure, at one point or another, in nearly all aspects of procurement, preparation, and consumption of food. Jaspreet intercepted Harinder eating soap, Savitri hid bananas and oranges from her father-in-law lest he eat them whole before she peeled them, and Chintu found her mother-in-law eating stale *rotis* in the kitchen. Success was a delicate dance on such shaky ground and there was much at stake. When done ‘right,’ the rewards of feeding made it the most pleasurable aspect of caring for families and nearly all the carers I asked said feeding was the activity they enjoyed the most.

Sweetness and the pleasure of feeding and eating were explicitly linked by seven families who talked about the happiness they derived from feeding and eating sweets. The preference for sugary products among people living with Alzheimer's disease has been noted, but little has been written on the relationality and fun of sugar in such a dynamic. Sugar was a ‘treat,’ a small deviation from the heavy disciplines of health management that families could indulge their loved ones in. Scattered amidst the scripts of diet and care, sugar was a fine, crystallised pleasure. Josie gave Su chocolate, describing it as “little

luxuries,” Savitri gave her father-in-law sweets so that he would say “*achchhe se thē* (it was good),” one of only two phrases left in his vocabulary, and Suneeta put sugar in her father’s *dal* so that he would find it tastier.

Eating sweets together was an act that spouses especially enjoyed. Nina said, “Yesterday we were having ice-cream and I said, “You’ve had your fruit, will you have some ice-cream?” and he said, “Oh yes!”” There is a close link between food and sex especially in the subcontinent. Sudhir Kakar reminds us, “That in the Indian consciousness, the symbolism of food is more closely connected to sexuality than it is in the West” (1990, p.78). Eating and sexual enjoyments have the same etymologic root in Sanskrit, *bhuj*, and perform the same task in prescribing and maintaining social order. A growing body of literature explores the connection between food and sex in the Asian theatre.<sup>30</sup> However in my analysis, this connection can at best be inferred in the intimacy and pleasure of feeding, for no carer explicitly linked food and sex and I lacked the courage to ask about this delicate subject. Moreover, as many interviews were frequently interrupted and took place with various family members concurrently participating, the subject could not easily be broached.

Nevertheless, for spouses, eating sweets together were sites of pleasure and romance. In his slow methodical voice, Tandon initially described his wife, Sheila’s, routine to me – a regimen of healthy diet, medication, exercise and personal hygiene. He and the attendant shared the care work together, but at

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<sup>30</sup> See Farquhar’s (2002) work in China, Liechty’s (2005) in Kathmandu, and Alter’s (2000) in India for example.

around 8pm every night, once Sheila was put to bed, the attendant departed and he was alone. Lying in the twin bed next to his wife, he would put on the TV, hoping that Sheila would hear something to make her laugh so that she would smile as she drifted into sleep. Eventually he too would sleep but hoped to be awakened at around 3am by Sheila's laughs. This was the time when she was most responsive and talkative; he would sit, talk, and feed Sheila her favourite sweet – ice-cream. Tandon's mouth crinkles and smiles at this memory, this is the best part of his day:

Sitting with her and talking to her. Uplifting her spirits. Feeding her gives me a lot of [happiness]. It is my heart's desire to feed her, to feed her from my heart, in peace, with love, to give her food. These are my most favourite activities. She knows that I am feeding her from my hands. She responds to me, I can see her reaction, talk to her.

Feeding and eating are sites of deep play also because they represent the flavours of deep love. In the oceanographer asking his darling "what's for lunch?," Josie feeding Su chocolate, Shivbaksh's all-consuming cooking for Helen, the Bhagat's dinner-table desserts, and Tandon's secret interludes in the wee hours of the morning, love in all its zest and sweetness is visible. The tongue and the tastebuds become erogenous zones because of memory not sex. Tasting, feeding and eating are ways in which marriages which are irrevocably changing are held onto. They are also ways in which husbands and wives can transgress the roles of 'carer' and 'person with dementia' and claim the intimacy of giving and receiving pleasure from each other. Sensory anthropology is at its richest here for the sweetness of sugar is experienced bodily and symbolically.

Husbands and wives smile, talk, and make sounds (like 'mmm') to each other, to connote pleasure with food and each other's company. Symbolically sweetness also temporarily alleviates the bitterness of memory and function loss. In deep play, sugar sits at the unfathomable bottom, in a hard to reach place, neither mired in health nor citizenship, promising sweetness and love. Little wonder that the stakes are so high and families strive to overcome them.

## **Conclusion**

On assembling the ingredients, defining their properties, mixing, and separating, we see that when combined, feeding and eating are part of a contradictory feast. It is sensory, rooted in the body but also "off" the body, the site of discipline yet transgression, power and also love. Food, in India, is not merely sustenance but the material representation of identity in age and gender as well as a currency of personhood in social exchanges. Cooking, feeding and eating are acts of dominance and subservience, markers of *seva* and care, which appropriate not just bellies but also breasts, hands, and voice. Starvation and hunger frame the backdrop of this gustatory experience, bringing famine, death and poverty to the table, reminding the feasters that inequities linger more acutely in other physical and social bodies and that eating is as much a political act as it is a pleasurable one.

In taking the body as "the existential ground of culture" (Csordas, 1990, p.5) and building from there, the body as a lived, social and political system begins to emerge. This is a living organism, corpulent and stringy, pestilent and healthy, at once at war and reconciling with itself. This is a contradictory body, a site for

creativity and prescription, wherein carers can engage in techniques of management and surveillance of the self and people with dementia. Rather than just a source of sustenance, in the sub-continent, food and the appetite are central aspects of care.



## CHAPTER 7:

### STIGMA AND LONELINESS IN CARE

Indian society doesn't put a stigma on Alzheimer's disease or dementia; it is a part of the ageing process and can happen to anybody. So not much of stigma, just the burden of caring, the load of caring (*Dr Bose, Sarkari Geriatrician*).

Of course there is a lot of stigma. A lot of times we are told, "Don't come through the front door; come through the rear door because the neighbours will see that there is this kind of patient at home." So we tell them, "This is nothing to be ashamed of. Tell your neighbours and your friends that there is a patient like this who has lost his memory" (*P.K. Singh, Volunteer, ARDSI-DC*).

What Alzheimer's disease is, people don't know. How it happens, what age it happens in, people don't know. Often I'm asked what work I do. I never say I work with Alzheimer's patients, I say that I care for mental patients, I handle them (*Sandra Anu, Attendant*).

Sometimes I get tired, "What a life I have got *yaar*" (*Suneeta Sadhwani, Carer*).

There is confusion about whether people living with dementia, and their families experience stigma. Families and doctors often said that there was no stigma against dementia, while ARDSI would insist that stigma affected relationships in the home, and families' relations with the world at large. Though it might be argued that ARDSI had a vested interest in claiming stigma existed – to garner more funds to raise awareness of their organisation – this does not present the complete picture. Many within ARDSI also worried whether stigma existed, and these anxieties reflect the complex and contradictory picture that emerges when stigma is examined in India. I often noted in my interviews and observations how carers reported high levels of social support from their communities, while simultaneously describing lonely lives. Many carers were refused offers of marriage for their children, and they and the person with dementia were increasingly distanced from the wider community. Equally, people complained of being neglected and alone as a steady stream of visitors flowed in and out of their home. Shivbaksh Chand said he was alone but made daily visits to the local dispensary across his street to chat with his peers, entertained visitors, and tolerated anthropologists in his home. Suneeta Sadhwani said her neighbours were “very helpful,” but in her daily routine cared for her father largely unaided.

The apparent inconsistencies in these stories are largely due to the contrariness of the disease itself. Dementia sits in the juncture between ageing and mental illness, and its symptoms may lend themselves to either category. *Sathiyana*, stubbornness, and anger in one's *buddhāpan* or old age were accepted with ageing (see chapter 3). Yet behaviour disruption, violence and disinhibition

were more readily interpreted as signs of madness/mental illness and could become grounds for institutionalisation. Categories such as 'ageing' and 'madness' constantly risked collapsing in on each other, and were separated only by the efforts of families and the NGO. "We tell them, we educate them that this is a disease, this is not madness," said Kavita Mehta, an ARDSI-DC volunteer.

Families' states of stigma depended on how others perceived them and where they positioned themselves on the scale between ageing and madness. In this chapter, I describe these performative acts of positioning and illustrate how stigma is internalised and deeply felt, externally visible and publicly executed. I do this through an analysis of three local worlds and their moral stakes: individual relations, social processes, and political machinations. This analytic structure is derived from Schepers-Hughes and Lock's (1987) conceptualisation of the body as individual, social and political. Individual body refers to the phenomenological body-self, social body to relationships in nature, culture and society, and the body politic to the body as an artefact of social and political control. I do not directly apply Schepers-Hughes and Lock's model because at the individual body level, there is insufficient data to do a phenomenological analysis of stigma. Here 'individual relations' refer to how normality and madness are seen in bodies and behaviour. Families are engaged in the tasks of maintaining and containing identity. These efforts are concentrated on the body of the person with dementia in a 'project to preserve the normal.' This is a risky venture because there are slippages between chaos and order. If too good a job is done to maintain normality, the authenticity of the dementia becomes

questionable, and a different type of social censorship is brought to bear on families.

‘Social processes’ refers to how families (dis)engaged with their social worlds in everyday life, struggled to broker important events like marriages, and experienced isolation and loneliness. Institutions, such as the law, finance and healthcare, frame the environment in which stigma circulates through the exercise of power and political control. Analysing individual relations, social processes and institutions allows for an analysis of lived experiences, and in this context, the exercise of power and discrimination.

But families have agency, and they exercise choice in responding to and resisting stigma in different ways. Families and people with dementia stigmatise others (and each other) for perceived ‘defects’ or marks. Being judged did not preclude them from judgement. Suffering, contestation and advocacy form strange alliances; high stakes reflecting states of deep play. In mapping the social geography of stigma it will be shown that stigma is a space in which structure and agency rub against each other in contradictory and uncomfortable ways.

### **Defining Stigma**

Erving Goffman (1963, 1986, p.3), in his seminal work, defined stigma as a deeply discrediting attribute located not so much in an individual as within social relationships. A person is assigned a negative characteristic – physical abnormality, failure of character, tribal stigma (like race, religion, nationality) –

which a larger social group then uses as the basis to discredit and exclude. Such an interpretation of stigma has been widely applied across disciplines and topic areas. Jones (1984) added to this definition by describing attributes that 'marked' people as deviant within particular social contexts, and Crocker and colleagues (1998) extended it to show that stigma was socially constructed and that an individual's social identity was devalued in particular societies in specific ways.

These definitions of stigma have been criticised for centring too much on individual attributes and characteristics, without attending to the structural factors that exclude and discriminate against them (Parker & Aggleton, 2003). Albeit closely related, stigma and discrimination are not the same. The former is a deeply discrediting attribute; the latter is a set of actions by which the stigmatised individual's life opportunities are reduced (Reidpath, Brijnath & Chan, 2005). Discrimination and stigma tend to flow along established rivulets of power and inequality, and evidence (from the HIV/AIDS literature for example) shows that institutions tend to discriminate against people not only on the basis of their stigmatised attribute but also by class, gender, and race (Parker & Aggleton, 2003). Any discussion of stigma also needs to examine institutional discriminations to understand the mechanisms of social control and its deleterious effects on the lives of people who are stigmatised.

Link and Phelan (2001) have incorporated these criticisms, arguing that stigma is a process comprising five interrelated stages: (1) initially people distinguish themselves from each other through labels (e.g. race, gender, sexual

preference), (2) a negative stereotype is then assigned to particular labels, (3) those who are labelled are then separated from 'us,' (4) they are viewed as less than 'us' and experience a loss of status and (5) they are likely to be marginalised through the institutional power of the state.

Link and Phelan's work has resonated with Arthur Kleinman's on social suffering, local worlds and moral exigencies. Kleinman (1991; 1999; 2006) delves into how social experiences are lived in particular local worlds, identifying the stakes, strategies and pragmatic responses of people to threats and dangers. To be stigmatised, he argues, is to experience social suffering – a term he, Lock and Das (1997, p.ix) describe as the “assemblage of human problems that have their origins and consequences in the devastating injuries that social force can inflict on human experience.” Violence and trauma constitute part of the suffering people and societies may inflict on each other to preserve an established order. Also emphasised is the role of state apparatus in creating suffering, stigma and social death. Kleinman's work from China shows that social death can mean the disintegration of the existence, value and perpetuity of the individual and the family (Lee, Chiu, Tsang, Chui & Kleinman, 2006; Yang & Kleinman, 2008).

Recent collaborations between Link, Phelan, Kleinman and their colleagues (2007) have centred on amalgamating moral experience into stigma theory. “Moral experience,” they write, “refers to that register of everyday life and practical engagement that defines what matters most for ordinary men and women” (Yang et al., 2007, p.1528). Stigma, they argue, threatens what matters

most, occurs in an inter-subjective space between people, and also in individual bodies whether consciously acknowledged or not. It necessitates multiple methods and perspectives in order to fully capture its complexity in theory, social attitudes and praxis.

To this definition of stigma, I would also add that moral experiences vary according to their local worlds *which transpire in particular socio-geographical spaces*. What is at stake in the clinic is not the same as what is chanced in marriage negotiations nor what is experienced within a household when bodily disintegrations are perceived as polluting. In each setting physical and social boundaries change, as do techniques of avoidance and boundary maintenance (Douglas, 1966). Thus different forms and gradations of stigma play out, executed in words and in acts, which mobilise bodies differently in public and private spaces. To understand these mobilisations, their significance and the use of space, a deliberately under-deterministic language is necessary. Stigma may be blatant in institutions and some human relations but can also be subtle, understated gestures which when compiled show a deep, long-term, grievous hurt. Similarly, acts of exclusion and insult, which can be seen as stigma, may have their genesis in other paradigms. In the clinic, when families are asked if their elderly relative has psychosis, in front of med reps and other patients may be because the patient is seen to be mad, but can also be explained by an authoritarian doctor-patient relationship, high patient demand and the pressure to multitask to manage workloads. Similarly, prescriptions for antipsychotics may not be because the person has psychosis, but because a

doctor receives kickbacks from pharmaceutical companies. Things are never what they seem in voice when contextualised by space. As Deleuze puts it:

Something strange happens, something that blurs the image, marks it with an essential uncertainty, keeps the form from 'taking,' but also undoes the subject, sets it adrift and abolishes paternal function. It is only here that things begin to get interesting (1997, p.77).

### **Preserving the Normal**

Many families were engaged in a project to preserve the normal. Through the acts of daily living, such as bathing, dressing, and feeding, they strived to maintain identity and contain disruption. In the early days of my fieldwork, people with dementia were presented to me in particular ways: K.P. Aggarwal was dressed in an immaculate white *kurta*: when I first met him, Mrs Hamdari had on her pearl earrings, and K.L. Chopra took out silk suits for his wife Meera to wear on the day of my first visit to their home. The beautification was done just prior to my arrival in families' homes. Often people's hair was still damp but neatly combed, there was a fresh smell of soap, white powder was dusted on their necks, and there were no wrinkles in their clothes. People who could no longer walk were propped up in bed; those who were still mobile would be brought in for the duration of the interview or towards the end for me 'to see' them and comment upon their care. Though disconcerting, this was a strategy whereby families maintained a veneer of normalcy towards strangers. In my second interview with Bhageshwari, she brought her mother, Tara, into the

room and spent 15 minutes attempting to get Tara to recall her (Bhageshwari's) name. Finally Tara remembered.

My name starts with 'B.' I know you'll tell me. 'B'

Bhageshwari's your name

See, you know my name. I know you can't forget me. You can't forget my name

If that's your name

[To BB] *See?* Touchwood that way she's very cheerful (emphasis added)

Families worked hard to steer their relatives clear from the label of madness through invoking the sensory measurement of sight. People with dementia were not mad; they were normal and if one sat down and engaged with them, one could *see* this. Asking people to engage with people with dementia to see how normal they were, was a technique by which those who might stigmatise could verify through their own experiences how far removed people with dementia were from madness. Families used the sight metaphor as a measure of this engagement – they used words like '*dekhnā*' in Hindi, 'see' and 'face-to-face' in English. Seeing became a tactic through which to subvert the gaze that would label madness. Radha Menon, who struggled with her husband's violence and fluctuating moods, said:

*Pa:gaal* means to walk around the street without clothes. But he doesn't take off his clothes. *You've seen?* He talks in a good way. Just his behaviour we have to manage a little. I have to have patience, to talk properly, to talk in a peaceful manner [emphasis added].

Yet the quagmire for carers and ARDSI was that the symptoms of dementia, in addition to ageing, lent themselves to mental illness. Sexually inappropriate behaviour, defecating or urinating in living rooms or guestrooms, undressing in public – these were also the visible signs of being *pa:gaal* [mad]. Foucault (1975, 2003) showed how madness was yoked to criminality and danger, and psychiatric medicine charged with the authority to intervene under the guise of public hygiene and social protection. Even where the madness was scarcely perceptible, gentle, and inoffensive, medicine is tasked to oppose disorder and pathology. Failing to comply with norms makes people unpredictable, disrupts social conventions and creates uncertainty. The arms of medicine intercede to reinforce rules of conduct through disciplinary measures (e.g. medication, incarceration) and a medico-judicial framework is brought to bear on those who are abnormal and deviant (Foucault, 1975, 2003). To be seen as mad or mentally ill incurs stigmatisation and the social sufferings of those who are mad/mentally ill have been well documented in India (Goel et al., 2004; National Human Rights Commission of India, 1999). Josie and Su’s story (see chapter 5) provides a brutal close-up of inhuman treatment of those seen as mentally ill.<sup>31</sup>

Downplaying Alzheimer’s and emphasising the normal was a tactic to anchor disruption in the ‘normal’ difficulties of ageing and mitigate against the stigma of madness. Carers were not in denial and accepted the disease at this point. This was mostly clearly reflected in their use of language. In Hindi, chronic

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<sup>31</sup> How other families experienced stigma from their communities because of the conflation between dementia and mental illness will be detailed later as will be the institutional discriminations against people who have a mental illness.

diseases are generally referred to in the present tense and language plays a key role in how the sick role comes to colonise the entire identity of the person. “Mental *hai*, sugar *hai*, heart *hai*” (is mental, is diabetic, is a heart problem) was how illnesses were usually ascribed by other people onto the sick person. There was little use of progression or tense – it was not “*ho gaya:*” (it has happened) but “*hai*” (it is). The use of the present tense highlights the ontological shifts that occur in perception. People become indivisible from their illness and their former identities divorced from their present states. Normal is a distant shore on which identity is left stranded and people are now seen as demented, diabetic, and faulty hearts. Language becomes one way by which signs of illness become scripted onto and embodied within people. Language is a social symbol, providing information and cues about how sick people should be read and perceived within society (Goffman, 1963, 1986).

The word ‘problem’ was hardly ever used in the constitution of this new sick role. Rather ‘problem’ referred to things that could be fixed, and was applied to temporal conditions and specific body parts and processes (like leg pain, toothaches, and headaches). Carers often described their own health concerns as ‘problems,’ or applied the term to conditions where an *ilāj* could be sought to redress the problem.

However, in trying to preserve normality, families did not seek to bleach out the identity of the person with dementia just as in ‘seeing’ madness outsiders did not immediately seek to ostracise people with dementia. While the ‘gaze’ as an exercise in power, discipline and conformity was brought to bear on the person

with dementia, for carers, the gaze was also an entry-point into performance and pleasure (Foucault & Sheridan, 1977; Goffman, 1961). Disruptions were concealed in order to produce finished, polished images not just because it was preservation work but also because there was pleasure to be gained from beautification (Goffman, 1959, pp. 52-53). This 'discipline of normalisation' was productive, transformative and creative rather than repressive (Foucault, 1975, 2003, p.52). Families wanted their loved ones to look fresh and smart to outsiders, they enjoyed combing hair, dabbing powder, and selecting silk clothes. They spent money on clothes, cosmetics and soaps, cleaned mess, hid the 'dirty work' that went into producing this image, and sacrificed their own body-self to dirt and disorder. To view these solely as acts of conformity disregards the love in these acts of *seva*. Kumud Kaul, who cared for her mother, Mrs Hamdari, said, "So just before she is wearing her clothes I tell the girl, "Keep *nani's* clothes ready and nice," and so it's ironed and she'll get dressed. That is what I love."

### **Normality and Danger**

But asking outsiders to see normality was a risky approach. Ironically, the stakes hinged on the person with dementia behaving *too* normal. Claims of illness rested on the abnormality of the engagement and some anomaly had to be produced to substantiate such an assertion. To be *seen* to be normal was not to be normal. As time went by and my relationships with families deepened, certain bodily enactments of normality dropped off, and I began to see signs of disruption: urine bags, catheters, sweat, faded clothes, and mussed hair.

People with dementia were expected to be forgetful, a little vague, and eccentric. When they were not, carers could sometimes grow defensive. When I engaged with Radha's husband, Rajesh, we talked about his desire to return to Kerala, his wish to work, what he had eaten for lunch, his background and political leanings. In other words, Rajesh spoke normally. However, Radha found this conversation deeply troubling. She interpreted it as evidence for me to question the authenticity of her claims about Rajesh's dementia, and said defensively:

[Angry voice] Sometimes people don't understand. What do they think – that I am going to speak lies about my husband and say he isn't well? Sir sometimes speaks nicely. That's why nobody believes me. Nobody can believe that.

*Who says this?*

Some of the friends who come to visit. They don't believe me. I tell them, "Am I mad to say such things about my *a:dmī*: (husband)?"

When ears were tuned to hear senility and illness and instead heard the articulate speech of the elder, carer's characters were questioned. Carers were now seen as mad and their identity was under scrutiny. Radha's angry testimony – "Am I mad to say such things about my *a:dmī*: ?" – illustrates that people did view her askance because Rajesh did not always behave unusually. Importantly, this judgement applied only in the early stages of the illness; later, as diminished mobility, incontinence and lost speech became more visible, such questions were no longer relevant. But in the interim, which could be as long as ten years, families walked a tightrope between normal/ill and ageing/madness.

They sought to anchor the person with dementia's identity in the normal ageing body rather than in the *pa:gaal's* body, but staked their own claims to care in illness and ageing.

Preserving too much normality was a hazard carers skirted not just with outsiders but also with family members. Some family members were not entirely convinced about the dementia despite diagnosis and medication, but were hesitant about airing their doubts. In the Chopra family, for example, a familial narrative of diagnosis and care was initially presented to me – the proverbial story of strangeness, crisis, diagnosis, acceptance, *seva*, care and familial cohesion. In my first interview with K.L. Chopra, his wife Meera, their two daughters-in-law, and a distant older aunt were co-contributors to this unified tale. Even the local postman arrived midway to nod sagely as Chopra enthusiastically spoke about his 'settled' (i.e. married and gainfully employed) children who did so much *seva* for him and Meera. Three months later, time and the May sun had wilted nearly everyone's research fervour and only Chopra and his elder daughter-in-law Rubina were present for our interview. The tale of the good family stayed consistent – all the adult children were settled and performed the appropriate amount of *seva*. However, when I went upstairs to Rubina's flat for lunch, I found myself briefly alone with her. She hurriedly spoke:

There is nothing wrong with mummy. She knows everything – who's coming, who's going, what is hers, where it is, who has what – she knows everything. *Baas* it is just that daddy gives her so many medicines that she has become like this. And her younger son is not good. *See*, you sat

there for one hour and he came in once but he never sat down or offered you a cup of tea. He won't sit and talk. And his wife is busy in her job all the time (emphasis added).

In Rubina's secret narrative, Meera was not 'mental,' i.e., she had neither dementia nor mental illness. Rather, her problems were attributed to medication and modernity. Too many drugs, a working daughter-in-law, and a bad son; Cohen's (1998) work echoes again as the good family suddenly reveals its bad side. All one had to do, according to Rubina, was to *see* it. Meera's familiarity with her surrounds and her son's inhospitality were to be seen as signs of a bad family and not of mental deviance.

Other families had similar doubters; Sita Aggarwal's son showed me 20 years of his father's medical history, with multiple confirmed diagnoses of Alzheimer's disease, but still quietly questioned his father's dementia. Shivbaksh thought that 82 year old Helen's problems could be because of dementia but also attributed it to hormones and menopause. After Su died, Josie wondered whether he had Alzheimer's disease or a vitamin deficiency. Within these families, Cohen's (1998) 'bad' families resonated; there were squabbles and tensions with extended relatives and immediate kin. Running alongside was the undercurrent of hope, the desire for the dementia diagnosis to be replaced by some other condition for which there was hope for a cure. Even in cases where the person with dementia had died, carers still sought an alternative aetiology so that they could offer hope to other families.

Thus sight and seeing functioned as a contrary tactic – a way to acknowledge normality but also sickness and madness. In giving outsiders the opportunity to see for themselves, families risked much, and therefore sought to overlay their own perceptions of sight and family politics on the external's gaze. As Radha Menon put it, "You have to care for him, bring him tea, tell him, "Drink it, eat your food"... you just have to give him everything. [But] there are no problems – you can *see* it, can't you?"

### **Internal and External Stigma**

The project of the normal was about avoiding the stigma of madness. It eventually failed because as the disease progressed, performing normality became increasingly difficult and sequestration was commonplace. This was a two-way process where families and carers endured but also imposed exile on themselves and their relationships with their moral worlds. Stigma became internally and externally enforced, linked to space, bodily function and fear of social censorship.

In the Tandon household, isolation stemmed from diminished function. Tandon and Sheila led cloistered lives reinforced by the geography of their household: they lived on the first floor in a corner plot, up a winding staircase, behind high concrete walls. All their doors and windows had grills. Unless they permitted entry through an imposing black gate, which was locked from the inside, it was physically impossible to get to them. As Sheila's dementia progressed, her world shrank to her bathroom and bedroom. She spent her days being lifted from her bed to her wheelchair and back again. Tandon's life had also shrunk as he grew

increasingly preoccupied with the minutiae of his wife's body. He said repeatedly that he was alone. Although they once had good relations in their local community, attending marriages and social functions, few friends and neighbours now came to visit. Tandon was philosophical:

They feel sympathetic. They know me for the last 10 years and she was in the good books of the colony. Initially they used to come and inquire about her but now they have stopped because she can't respond to them. So how can they even begin to talk to her?

In Tandon's world, stigma was not so much a damaging marker as a social distance. The layout of the house, Sheila's lack of responsiveness, and Tandon's focus on her, made them difficult to access. They and their neighbours grew increasingly apathetic and disengaged from each other. Tandon himself admitted, "You will go to people's homes who will respond to you; why will you go where no one will respond to you?" In contrast, the Khan family actively sought to withdraw Omar from their community. They feared that as illness undid him, his reputation as a respected and well-known figure would be spoilt. Shafia explained this failed attempt:

We didn't like him going out because we didn't want outsiders to mock him. We thought it was better that people did not know of his illness but he would go out. The children would catch him and bring him home, "Aunty he was here, aunty he was there." Everyone soon came to know that he was sick, that he had some problem. He was always wandering out without any shoes.

In public spaces, the Tandons and the Khans used a set of defensive and protective practices (Goffman, 1959) to maintain the image of the person with dementia and the image of the family. By curtailing Omar's movement, the Khan family sought to preserve a virtual identity of who he was versus the social reality of who he had become. Tandon, through his social and spatial disengagement from his neighbours, sought a similar end. These were not attempts to 'hide' the truth; Omar's wanderings and Sheila's decline were freely known in their communities and had long disrupted the veneer of normalcy. Instead these were a kind of 'strategic' secret (Goffman, 1959), a way to disguise the depths of change and disorder within the household and to obfuscate the capacities of particular family members. Information was held back because of its potential to stigmatise and discredit the household. But in attempting to manage a family image and individual's identities, families found themselves increasingly isolated through their own internalised stigmas.

To understand the anxiety driving these practices, it is necessary to examine the stakes associated with 'seeing.' In the Khan's case, Omar's physical degeneration was also the decline of the family's social status. This affected their material and social capital. Omar's dementia and his loss of earning capacity put increasing pressure on the family budget, and they grew poorer and less able to draw on prior relationships to bolster their income. Former influential friends neither visited nor provided money; Shafia had approached an old contact for aid and in turn received Rs 1,000 per month for a year. Her son worked as a low-level manager in a telemarketing firm, her older daughters had married and moved elsewhere, and her youngest daughters had yet to be settled. Their precarious

finances had led to Shafia opening a tailoring shop beneath her flat to bring in extra income. Coupled with Omar's illness, these monetary woes affected the Khan's capacity to broker marriages with more affluent families and to make the necessary 'gifts' for these successful negotiations. Their income was not enough to overcome the stigma of dementia, here associated with symptoms such as wandering and wearing no shoes.

Those seen to be caring for an ageing (as opposed to sick) family member garnered significant social support. Suneeta Sadhwani (41 years) was the sole carer for her father Hari Prasad (74 years), and she tearfully described how nice people were in her neighbourhood. She related how people assisted her when Hari wandered away for the first time:

Once when I didn't know that he [father] was forgetting the way, we were coming home and I realised I had forgotten to buy a *dal*. So I said to him, "Papa, I've forgotten to buy that *dal*, can you please go and pick it up? In the meantime, I'll carry on home." He went there to the shop, he got the *dal*, but he was so late getting home. An hour had passed and I said to myself, "It doesn't take an hour to buy *dal*, the market is in front." I called up our ration *wallah's* shop and I said, "Uncle, this is what's happened...Papa hasn't come home yet. What the *chakkar* (confusion) is I don't understand." He said, "*Beta* you don't worry, I'll send my assistant out on the scooter to look for him." I also went downstairs to search and there was his assistant coming on his scooter...Now the lane you came down, on the opposite side, someone had left him there. Maybe it's

because of God that I get so much cooperation, I don't know, but people are very nice.

Suneeta's ability to gain sympathy and kindness from her community was based on a combination of neighbourhood density, time and Hari's symptoms. They had lived in their west Delhi colony for many decades and were well-known. Suneeta had taught in the local school and still gave tuition classes to supplement their income. Their second-floor flat was small and in the middle of the block in a densely packed suburb. Buildings were squashed together and the inside roads were narrow and apartments sprang up on either side. Since the Sadhwanis did not have a car, public transport was their only option; the main road from where buses, auto-rickshaws and trains were available, was a three minute walk away. To get to public transport, the local market, banks and the post office, one had to walk through the inner lanes of the colony, visible to neighbours from their windows and verandas. Because their income was low (see Chapter 4) and they could not afford to hire a full-time servant to run their errands, Suneeta and Hari walked to as many places as they could. They were a common sight, and their comings and goings were readily noticed.

Hari was a quiet, still man who rarely left his home on his own. He got lost easily and aware of his forgetfulness, he relied heavily on Suneeta to mediate his relations with the outside world. In public, he was neither aggressive nor repetitive, and had never been violent. He moved softly and hardly spoke; his communication techniques were restricted to folding his hands and saying *Namaste* or shaking hands. In being able to fulfil these decorum cues and not

being publicly disruptive, Suneeta was able to explain his dementia as the forgetfulness of old age. Till date, no major disruptions had occurred outside their home. Those that transpired within (occasions of disinhibition or incontinence) were managed and hidden from view. As there was no servant or attendant within the home, only Suneeta was aware of these disruptions and cleaned the mess. Thus by their geographic location in the middle of a dense suburb, the time they had lived there, Suneeta's affiliation with the local children, her lack of immediate familial support (her mother was dead, she was unmarried and had no siblings), their physical presence on the streets, and the mildness of Hari's symptoms, father and daughter wove themselves into the public space of the colony. They were seen as objects of sympathy, and were willingly helped by others.

Conversely, those families who were perceived within their communities as caring for a mentally ill or mad family member did experience stigma. The Singhs had long felt the bite of social exclusion. As Harinder Singh's dementia advanced, his family's life had shrunk. Jaspreet, his wife, cared for him while their daughter, Gurneet, managed the housework. The Singhs' son, Ajit, was in his late twenties and of an age and readiness to settle into marriage and children. He was a shy, burly man, who worked in a managerial role in a factory. Usually the family would not have had more than the usual difficulties of taste and compatibility in finding him a bride. However with Harinder's illness this was not to be. As Jaspreet explained:

Three to four girls we've approached don't want to marry my son because of his [father's] illness. What the parents are thinking is, "How

will our daughter go into that house and manage such a sick person?"

This is why they refuse; it's not like the daughters are refusing to marry my son.

Jaspreet makes two distinctions in this statement: (1) that stigma is based on its perceived link to the labour that will be demanded from the potential daughter-in-law, and the polluting effects of this work, rather than the concern that the disease has a genetic basis and (2) that stigma functions as a social net, enveloping not just the 'marked' person but also those associated through ties of kinship and love.

Pollution and contagion are inherent risks for carers who perform bodywork. Risk functions metaphorically and instrumentally for cleaning, and reaffirming order requires an engagement with disorder and dirt. Those who perform such work operate at the boundaries of containment, risking social propriety, and exposing their own bodies and selves in ambiguous ways (Twigg, 2000). Faeces, urine, smells and spillages are solids and fluids which cross body boundaries and carer's bodies may often be perceived as contaminated. Matter under fingernails, stains on clothes, lingering odours – these are bodily experiences of dirt – and outsiders may feel disgust at seeing such disorder. It threatens the purity and boundedness of their bodies. Pollution and dirt were lived realities in the Singhs' home. Harinder was incontinent and the family struggled with his diarrhoea but did not use diapers. Marrying into such a household would render ambiguous the social purity of the bride's identity. This does not refer to gender-specific notions of impurity (associated with menstruation or birth) but

to the impurities affiliated with those who police the boundary between contagion and boundedness.

When I returned to the Singh's home for our second interview, Gurneet – Ajit's sister – had recently quit her job as a school teacher to help her mother run the household. Gurneet was angered by the reaction of outsiders towards their home and at Ajit's difficulty in finding a bride. Alongside her mother and brother, she was part of the family stronghold, and again a common narrative of *seva* and care emerged, punctuated by a lament for the absence of external social support. But as we sat talking in their living room, I noticed Harinder repeatedly attempted to stroke his daughter's leg. Every time he laid his hand on her leg, she stiffened and quietly removed it, placing his hand on his armrest. He would gradually move it back, she would return it – this continued throughout our discussion. She neither complained nor changed her seat nor just held her father's hand. In this small act of body distancing, Gurneet's anger at the rejection of other people differed with her own tactics of distancing her father.

The time-sensitive and spatial nature of disgust explains this mismatch (see previous chapter) (Isaksen, 2002). For carers like Gurneet, experiencing the stigma of living within a sequestered household, and being angry at other families' unwillingness to send their daughters here, did not preclude her simultaneous resistance to being touched by the source of the stigma, her father. It may be hypothesised that this was because of her feelings of disgust or her resistance to being touched per se, or fear that such touching was

sexualised. But she never discussed such sentiments and so this remains conjecture.

Theoretically, disgust is linked to stigma (Miller, 1997). Within the household, there are dirty spaces (e.g. the bathroom) and clean spaces (e.g. the kitchen and living room). In transgressing the uses of these spaces, disorderly bodies upset the order of the household and the onus lies with other family members to contain the person. Carers may experience feelings of disgust in doing such work. Their touch may be defined through acts of hygiene, discipline and love in cleaning, bathing and feeding. Caring for a disordered body can entail controlling how that body is touched, and in turn, how one lets that body touch oneself. Touching dirt, faeces and urine may be acceptable in a bathing space but not in a living room space. Gurneet may have accepted touching and cleaning her father's faeces and urine in the bathroom, but she could not bear his touch in their living room. In such a way she resented the external stigma from outsiders against her family. But inside, she sought to distance herself bodily from her father.

### **Loneliness and Space**

The experiences of the Singhs are neither acute nor extraordinary. But they were deeply felt and highlight that stigma can often be experienced as small slights which when compiled can create suffering in everyday life. Other families experienced similar acts of exclusion; Tara, who had dementia, was dismissed from her local park by the other middle-class ladies of her colony, Josie was asked if Su was "still hanging on" by extended relatives, and Parvati's

dinner guests ignored her mother Meenakshi. There were reports from ARDSI volunteers in Delhi, Kolkata and Kerala of intense family conflict, dissolved marriages and isolated carers.

This is not to imply that families did not resist stigma. Josie refused further dealings with her relatives, saying she didn't want the kind of compassion they offered, Radha told outsiders that Rajesh's problem was none of their business, and Nina frequently told outsiders to "get lost." Said Nina indignantly, "*Hāī bechara, Hāī bechara* (Oh poor thing, Oh poor thing) – what *bechara*? You've made him like that. This is nonsense! Here I am in control, I can tell people to get lost!"

Moreover, being judged and stigmatised neither precluded families from stigmatising others nor automatically dispelled their long held values. The usual dislikes of class stratified beliefs. After Tara was dismissed by her peers, her daughter Bhageshwari would send her to the park in the evening with the maid for company. For Bhageshwari the maid was a category rather than a person – "She doesn't understand that this is a maid and this is somebody" – and sending Tara with the maid was acceptable because Tara was unable to differentiate between maids and people, unlike Bhageshwari who would not have sought social companionship with her maid. Similarly Josie, when I showed her photographs of children from the Kamini slum, muttered "So many children" in reference to the size of poorer families, and Shivbaksh explained that part of the resentment he felt towards his children was because they wouldn't seek his advice when they sought to marry their daughters. Through these vignettes it

can be seen that families were not just victims or martyrs, but people with agency, who were also contradictory, classist, and conservative. In short, they were like everybody else – all too human.

Unlike other people, many carers were lonely and did experience suffering because of the stigma associated with mental illness. Suffering was ongoing, mired in domesticities and anchored in everyday illnesses and loss. It was experienced because of stigma which was both internalised and externalised, simultaneously directed to, by and within families. Ajit the rejected groom, Tandon behind his walls, Tara who was dismissed by her neighbours, and Shafia and Omar who struggled over community engagement, are tales of everyday suffering. Social death may be the end point of stigma, but the journey towards it happens with the severance of small and large ties concomitantly with exclusion from public spaces. Though none of these families were ever socially dead, they did experience increasing loneliness and isolation within themselves and as a family unit.

Loneliness is often equated with anomie, exclusion, and marginalisation. In the gerontology literature, loneliness has been linked to life expectancy, quality of life, and measures of ‘successful’ ageing (Routasalo, Savikko, Tilvis, Strandberg & Pitkälä, 2006; Scharf, Phillipson & Smith, 2005; Victor, Scambler, Bond & Bowling, 2000). Urban landscapes are seen to be inhabited by an increasingly alienated population influenced by the totalities of capitalism and individualism (Salerno, 2003). Loneliness is often premised on the notion of social disconnect, including psychological (and sometimes physical) distance between family and

friends. But loneliness can happen *in situ*, i.e., within familial relations and domestic places, and indeed may sometimes be sought. For this, we need another kind of language, what Coleman (2009) calls, “being alone together.”

Coleman focuses on homosexuality and desire in an urban restaurant/bar in Delhi. He describes the environment as predominantly where people, unknown to each other, could be alone together, survey and watch each other but refrain from any kind of deeper engagement or solidarity politics. These are heterogeneous, anonymous spaces where social solitude is the given norm. People go to places be alone together. A movie theatre or holiday retreats are similar examples. These are predominantly social yet solitary spaces (Coleman, 2009).

In trying to extrapolate these connections to my study, let me start with difference: domestic homes are not spaces where unidentified people go to be alone together. They are private areas, different from the anonymity of public urban spaces. These are private social spaces, most often spaces of solidarity and cohesion. People are bound together through characteristics like kinship, love and culture. They may eat, sleep, relax and live together. In spaces of solidarity, there are family narratives of *seva* and care. This is the space where children become ‘settled,’ where the good family lives, and normality can be seen.

But the home is also a space for secret stories, hidden gestures and complex, thick connections. Homes contain within them spaces of solitude where people

may be strange and unknowable to each other. Specifically, as the dementia progresses, relationships change and people, once familiar, may come to seem foreign. This refers not just to the relationships people with dementia share with their families but also to how bonds between other family members may be rescripted and rendered strange. Violence, pollution, shifting power relations, new regimes of discipline and pleasure, money and medication, may all herald such change. People on the inner may suddenly find themselves on the outer; a powerful father may be undone by his dementia, a mother may be unable to cook, just as a suitable groom is suddenly an unsuitable husband.

Changing relationships can also signal a loss of power and prestige. In choosing to resist or sequester the family to avoid stigma, loneliness could be the end result. Nina might have exercised agency when she told people to “get lost,” but she also endured loss of friendship and support. Similarly Tandon, in choosing to live in his walled house, was secluded not only from the potentially stigmatising gaze of his community but also from the friendships and neighbourliness within his colony.

It is important to emphasise that loneliness was neither linked to intergenerational conflict nor abandonment of close kinship networks. Carers like Tandon, Nina and Josie all maintained relationships with their children, even though they lived apart. All loved their children. But in being the primary carer, there were tacit realisations that solitude and loneliness were part of the experience. These carers did not separate themselves from their families, but the nature of care work made them lonely and emotionally distanced from their

families and children. Hence Nina only asked her son (who lived nearby) for help when she grew 'fed up,' just as Tandon conceded, "Now if I only thought that my children have no time for me then, how can I expect to be a hopeful type?"

Taking the decision to live in solitude was also done by members within the home against each other. Yet these were silent rebellions and therefore safe. In solitude and lonely spaces, where few could hear and anonymity was assured, unmentionable things could be said without affecting relations within the home. Solitary spaces offered family members a space for their own voice without risking familial cohesion. In solitude, people could be unknowable (Rajesh's dementia), say the unspeakable (Rubina's doubts), do the unthinkable (Gurneet's actions), and still be alone together.

### **Institutional Discriminations**

In this section I will examine particular institutional practices in law, finance and healthcare. Thus far I have illustrated how individual relations and social processes combine to create the project to preserve the normal, how stigma is internalised and externalised, and how public and private spaces offer solitude and loneliness. All of these mobilisations of stigma and its travels occur within an established cultural context which is bolstered by institutional practices. Culture and institutions work in tandem to reinforce existing inequities. When dementia is conflated with mental illness, it also accrues the discriminations associated with the latter. When it associated with ageing, then a different set of protective practices are brought to bear which can simultaneously discriminate

against families but also requires them to be the greatest champions of the person with dementia. In earlier work (see Brijnath, 2008, Appendix 5.5), I documented this irony through an analysis of mental health and ageing legislation and policy. In both areas, whether consciously or not, care was privatised with the responsibility largely on the family. This affected the family's financial, physical and mental health (see Chapter 5), which in turn impacted on their capacity to care. Till date there is neither a specific policy on dementia care in India nor sufficient provisions for specific treatment and management practices.

That said, law and policies have had a tarnished history in India, not so much because of their formulations – which have been largely democratic and inclusive – but because of their implementation (or lack thereof), which has resulted in undemocratic, exclusivist practices. Corruption, bribery, police abuse, incompetent and inefficient bureaucracies are just some of the more widely known practices that appropriate and undermine the more noble ambitions of law. Much has been written on the relationship between democracy and these practices (see Bardhan, 1997; Baxi, 1985, 1993; Krishnan, 2003).

Specifically with dementia care, if there were a policy, what would it look like in practice in India? Would it be like *The Senior Citizen's Act* (2008), which I criticised because of its mandate that families must care for their elderly or risk criminal proceedings? This Act was criticised by some key service providers and dismissed by others:

In our society it is most unlikely that parents will go to a court of law to demand services from their children. But I am very unhappy with the way the document has progressed from the drafting stage to the final pieces. The government has really washed its hands from the whole business of care and has put the whole burden on the family. Except for a few tax incentives it puts every responsibility on the family. Fine, now the family may be responsible for care, but 10 years from now there will be no family for most of the people – where will they go? (*Dr Bose, Sarkari doctor*).

The implementation roles haven't been done as yet by the state. The Delhi government hasn't done it and if they haven't, then what hope for the rest of the county? Delhi is a role model (*Inspector Tyagi, Delhi Police*).

Key service providers highlighted that in India, like elsewhere, the implementation of policies and laws differ significantly from their theoretical ambitions and never wholly undo what has become standard practice over time. This applies equally to 'inclusive' and 'punitive' legislation. But if the word of law and policy are not the dominant mechanisms of control, then what circulates in practice is an *ad hoc* adherence to notions of rights and care, contingent on environments of deprivation and plenty, and individual notions of greed and altruism.

Institutional representatives such as doctors, police and financiers, cared, stigmatised and discriminated against people with dementia and their families according to their own personal politics and assumptions. These varied according to their own status in relation to families class, gender, and income levels (among other factors). The Bhagat's bank, for example, honoured all of Karamjit's cheques even though, by Nina's own admission, his signature had become "very, very shaky." As Nina explained, she used their considerable wealth as leverage against the bank: "I told the bank, 'The day you dishonour his cheque I will close my account. If he writes a cheque, you ring me up to confirm it and it has to be allowed, otherwise I will change my account.'"

While a determined Nina was able to mobilise financial capital, many others who lacked such substantial wealth, could not. ARDSI-DC frequently counselled that following diagnosis, families should immediately organise their finances. This included obtaining a power of attorney, writing wills, and property transfers. Those who did not do this could experience difficulty later in accessing accounts. If there was contestation between family members over property, then legal proceedings could go on for decades with no end in sight. India currently has the largest case backlog in the world, with nearly 30 million cases pending (Lal, 28 June 2008). Property is a particularly sensitive issue with numerous stories of usurpation and illegal land grabs. The *Mritak Sangh* or Association of the Dead is a north Indian pressure group which campaigns for people who have been declared dead (but are still alive) and have had their property seized (Fathers, 19 July 1999).

The elderly are seen as especially vulnerable to having their property seized by their children; the tactic of declaring elderly parents insane, then legally taking over their property, has occasionally been used in India (Shah, Veedon & Vasi, 1995). Shivbaksh described his youngest son as a *nikāmmā*: (useless, good for nothing) because he had illegally taken *qabza*: (possession) of the back rooms of Shivbaksh's house. The most common advice dispensed by Inspector Tyagi and the Delhi Police was that older people should retain property in their name. The motives behind *The Senior Citizen's Act* (2008) were to protect older people and their assets. One of the architects of the legislation, a major player in a large Indian NGO, admitted: "You cannot legislate for love and there will always be sceptics. But the thing is we will have to be very prudent and pragmatic because this involves property, this involves money transfers between generations."

Given that law and money could combine to discriminate against the elderly and usurp their rights, property and sanity, any discussion of finances had to be carefully broached. Families where children cared for a wealthy elderly parent were especially sensitive for any financial discussions were framed by this backdrop of property theft and stolen rights. When asked about finances, Nayantara said her father was comfortable, Bhageshwari maintained her mother Tara should enjoy her money, and Vandhana insightfully pointed out the power dynamics at stake if her in-laws were to be financially dependent on her: "They are not dependent, they are financially independent ... So that is a lot because if you're financially also dependent on someone, then it aggravates the situation and in that case I also have an upper hand."

A medical opinion is required for families to be able to seize property by declaring their elderly relative legally insane. The doctor has to deliver a diagnosis of 'mentally incompetent.' If seen as mentally ill, then people with dementia can be placed in asylums which are spaces so horrific that even the government wants to shut them down. Without belabouring the point, Josie and Su's story from Chapter 5 should again haunt us here.

Few age care homes in India will admit people if they are not physically and mentally competent, and many have the right to expel residents if their care becomes too burdensome (Lamb, 2005, 2009). Hospitals cannot house people with dementia because they are long-term patients. Even if this were possible, there is little awareness amongst staff to the needs of families and people with dementia. Nandini realised this when her father, S.T. Pillai, was admitted to hospital to have his pacemaker put in. Ensnared within the medical institution, with its systemic and cultural paradigms (see Chapter 4), she unsuccessfully tried to communicate with the doctors about her father's dementia. She warned that post-surgery, he would be agitated and confused and needed to be handled appropriately. However, insufficient attention was given to her concerns and S.T. was viewed by hospital staff as mentally ill. Nandini describes how a surgeon spoke to them in the intensive care unit:

Once the agitation was subsiding, the morning round doctor came. And he stopped and looked at him – I was standing by the bedside – “Oh you're a psychotic patient, you are a psychotic man, we've got a psychotic man here.” The first time I heard the word 'psychotic' being used and that too, to my father. I didn't say a word. I was just trying to

assimilate the word that he used and the emotion that it generates and the diction and his expression when he was using that word.

Health worker's attitudes towards people with dementia, and more broadly those with a mental illness, need further explication. With few exceptions (see Jain & Jadhav, 2008; Vibha, Saddichha & Kumar, 2008), little has been written in India on this. Rather the focus has mainly been on cultural beliefs and community attitudes to mental health issues. But as Nandini's experience indicates, lack of awareness and insensitive handling of patients and their families colours their interactions and future relationships with health services. This has direct implications for the appropriateness and usability of a service and may also be a contributing factor as to why there is under-utilisation of even the limited existing mental health services.

In summation, an overview of law, finance and healthcare underscores that in India: (1) stigma and discrimination against people with dementia occur largely because they are seen as mentally ill, (2) institutional forces and social processes create a culture in which stigma can travel, (3) the degree of discrimination is linked to perceived differences in power status (influenced by class, gender etc.), and (4) in practice, institutional representatives are more likely to behave according to the differences in status rather than the policies unless families are able to advocate otherwise (which requires them to be literate, loud, and willing take a risk).

There are power relations at stake which are woven into the institutional and social fabrics of everyday life. Such ties are difficult to unravel because they provide families' the moral and existential frameworks through which to view the world. The challenge of change is its uncertainty and possibility that as power is reshuffled, families may be left worse off than before. This is not to suggest that change is impossible or unattainable – as the stories of carers and families show – but it highlights that it needs to be incremental and gradual. As Parker and Aggleton put it:

To untie the threads of stigmatisation and discrimination that bind those who are subjected to it, is to call into question the very structures of equality and inequality in any social setting...[and] to call this structure into question is to call into question the most basic principles of social life (2003, p.18).

## **Conclusion**

In this chapter I have described the moral and social geography of stigma in individual relations, social processes and institutional settings. I have shown how it is internalised and externalised, linked to suffering and loneliness, informed a project to preserve the normal, and worked in tandem with institutional forces in law, finance and healthcare. Stigma operated differently in each of these moral worlds. In the public spaces of the institution and legislative processes, discrimination was dependent on institutional representatives and the capacity of families to mobilise their financial and cultural capitals. In social processes, pollution, labour and the perceived link to mental illness affected family's ability to broker successful relations and

marriages. Some families used strategies such as inviting outsiders into the private spaces of their home to 'see' normality within their families and in people with dementia. However, as was demonstrated, this strategy was not without risk.

In each of these moral worlds, stigma flowed along existing inequities of power by class, gender, and health status (to name a few). Each moral world also necessitated different tactics to manage stigma. Even within the same moral world, different families used different tactics such as resistance and isolation. Stigma may be a force of cruelty and ill-treatment, but is also subtle and accumulative. The careless remarks of a surgeon may not be as cutting as being excluded by friends from the local park. Similarly what is at stake in social processes may not be as great as what is risked in private spheres. The suffering and loneliness from stigma happens over time and space. While families may have solidarity in how they respond to stigma, they may also experience solitude in their private homes, where they might whisper their doubts.

Till now, much of the analysis in this thesis has centred on care and families relationships in their moral worlds, between each other and their communities. People with dementia have made occasional appearances but their voices have hitherto remained unheard. The complexity of voice and bodies remains unresolved. The next chapter will focus on redressing this gap through an examination of how voice is reframed by illness, how people with dementia partake and resist social processes through speech, and the sadness of eventual loss of voice and self in death.





*Kha:mosh!* The Hindi word for ‘silence,’ in all its dramatic intensity, resounds throughout Bollywood cinematic conflict and symbolises the power and voice of the speaker to command silence from his/her detractors. It is the trademark for ageing Bollywood star turned politician, Shatrughan Sinha, who uses the word to silence his opponents in electoral victories. In film, *Kha:mosh!* is used in multiple settings, from ageing *thakurs* and land grabs, to angry daughters who battle against conservative fathers. The words flowing on from *Kha:mosh!* are heavy in their portent, heralding the detractors’ fates until such time as God, true love, revenge or other forces intercede. The word and its context are critical ingredients in the melodrama of Bollywood films. They signal moral conflict, the battle between good and evil, emotional hyperbole, complex kin relations, and the epic nature of the story (Ganti, 2004).

Following this early scene from the film *Karan-Arjun* (1995), Durjan Singh makes good his promise, and swiftly dispenses with the *thakur* and his grandsons, leaving the widow alone in her grief. The widow then pleads with the Goddess *Kali* to intercede and deliver justice. The murdered boys are reincarnated. They grow up separated from each other and their mother but are reunited 20 years later. They then proceed to take revenge on the ageless Durjan Singh, reclaim their birthrights, and live happily ever after. All this is spiced with appropriate song and dance by the brothers and their bosomy beloveds, and at different junctures by divine intervention from *Kali* herself.

Such Bollywood fantasies are *masa:la:* productions, i.e., rather than conforming to particular genres or storylines, they incorporate romance, drama, action, comedy, and tragedy into three (or more) hours. The linearity of the story is unimportant; there are frequent interruptions for songs, sub-plots, and audience intermissions. Lalitha Gopalan (2002) has characterised Bollywood films as a 'cinema of interruptions,' wherein the film structure celebrates spatial and temporal discontinuities. Reality and authenticity can also readily be dispensed with; Bollywood film-makers do not especially focus on facts, instead preferring to offer audiences fantasy, and opportunities for imagination and escapism (Ganti, 2004).

In this chapter, I take the key elements of a Bollywood *masa:la:* to analyse the voices of people with dementia. In the place of story and plot logic, there will be romance, comedy, tragedy and action. Poetry and dance will occur in the noisy spaces of the dementia day care centre and in family's homes. The reader will be taken on a flight of fancy, but is asked neither to hear nor attribute any voice with insight into some deeper 'truth.' These are representations, ambiguous and open to interpretation, incomplete and complex. More is revealed in this chapter about my choices and agenda than those of people with dementia. Voice is also not to be taken as a measure of cognition or memory, typically associated as key indicators of personhood. Instead voice is to be heard as a means of engagement and embodiment of topics such as work, marriage, pleasure, affection and death. These vary by gender and environment. Act 1 of the story will focus on unravelling them.

Like all worthy *masa:las*, there will be an intermission in this chapter, a space to catch one's breath, before moving into Act 2, which will focus on the tragedies of the narrative. The journey of silence will be described – how carers cope when people with dementia advance to the end stages of the disease, how they die, and what happens when death finally arrives. Dying is framed by social scripts and political economies; the last section will explain this link between capital and culture.

Some may find it disconcerting that this chapter deliberately does not focus on memory, selfhood or illness, or on how aware people were of being ill or dying. These were inappropriate questions, as I quickly learned: this risked revealing the diagnosis to the person with dementia and upsetting the family. As was highlighted in chapter 3, people with dementia were largely unaware of their diagnosis because they were never told about it. Perhaps, if like in the West, people were aware of their prognosis, then such questions might have been answered more dutifully and sympathetically. But as it stood, my timid attempts to capture some kind of awareness of memory loss from the person experiencing dementia were slapped down swiftly. I completely failed at this task. But it was through this failure that I learned that a predetermined focus on a set of issues does not facilitate listening to what people really want to say. And so, I begin this chapter with a brief discussion on selfhood, experience, and how I learned to listen.

## ACT I

### **Scene 1: Failures of the anthropologist**

The person-centred approach to care has stemmed from efforts by dementia researchers to move away from a medicalised approach to a more personalised social model. In the early 1990s, researchers believed that as the dementia progressed, the self disintegrated until there was nothing left, i.e., a person with dementia became a non-person (Fontana & Smith, 1989; Kitwood & Bredin, 1992). More recent scholarship challenges such a viewpoint, documenting the discursive praxis in which people with dementia engaged with others to maintain a sense of identity (Beard & Fox, 2008; Kitwood, 1997; Small, Geldart, Gutman & Scott, 1998). A key advocate of the latter perspective was the late Tom Kitwood (1997), who argued that neuropathologies and malignant social psychology denied the self of people with dementia and enhanced their suffering. Infantilism, denial, abuse and disregard undermined people's sense of self, excluded them from social life, and sped their decline. Kitwood's solution was to focus on the person, build meaningful relationships, and deliver care and treatment in line with the values and beliefs of the person. He believed that such a person-centred approach could promote quality of life and improve health. There has been mounting evidence from western countries to support such a claim (see Brooker, 2007; Bryden, 2005; Nolan, Davies, Brown, Keady & Nolan, 2004).

But Kitwood's approach has also been criticised. The assumption that the self is social, and human interaction is essential to construct a sense of self and reality,

has been challenged. Davis (2004, pp.377-378) points out that dementia may entail an erosion of selfhood and loss of individual agency which no amount of social interaction can ameliorate. He advocates for greater honesty in acknowledging the violence of the disease and the suffering it creates for people, their families and health workers, rather than sanitising the dying process through a notion of unimpeachable personhood. However Bartlett and O'Connor (2007) point out that the person-centred approach fails to account for the broader socio-political context and loss of citizenship that comes with dementia, relies on others to construct a sense of self for people with dementia, and does not sufficiently account for power in caregiving relationships.

Kontos (2006; 2007), while sceptical of Kitwood's model, also problematises Davis' notion of selfhood which is premised on cognition and memory. The notion that the self is located only in the mind has its genesis in Western philosophy's Cartesian mind/body split. Yet as Kontos shows, selfhood also rests in the body and is expressed primordially and socio-culturally. Primordial practices refer to body practices about which one does not have to think in order to perform. A keen seamstress might 'automatically' know how to use the needle and thread or a typist might 'naturally' know where the symbols on the keyboard are. Socio-cultural practices refer to knowledge and appropriate performances of rites and rituals (e.g. saying grace before eating or covering one's head in a temple). Understanding how selfhood is embodied, argues Kontos, must be incorporated into Kitwood's model for there to be truly person-centred care.

In trying to apply all these points in my interactions with people experiencing dementia, the immediate result was often disaster. Despite absorbing the criticisms of the person-centred approach, I hadn't quite understood the point of lived experience and embodiment. In my own self, there was a mind/body split. Ideas around embodiment and person-centred care were stored in some academic corner of my brain while my interactions were transpiring at the level of the body and voice. I was seeking (rather foolishly) a linear interaction: first, somehow establish 'where' people with dementia were in cognition, age, function and memory, and then, somehow work to build a relationship.

The first step in this enterprise was to try and determine whether my participants with dementia were mild, moderate or advanced, had difficulty in recalling short or long-term memories, and the extent of their cognitive impairment. I thought I would subtly ask a series of questions, my own version of the Mini-Mental State Examination (Folstein, Folstein & McHugh, 1975), as it were. These questions included asking the person with dementia their age, the time of day, location, what they had eaten for lunch, who was the prime minister, and how many children they had. In a vague sort of way, I thought from these banal questions some kernel of knowledge would blossom and the key to personhood would suddenly appear. If I was unsure about just what I was doing, my participants were even more befuddled. Those who could still speak rarely did and often looked quizzical; their faces would settle into polite masks of half-smiles with confusion in their eyes as I asked them strange questions like, "Did you enjoy your lunch today?" There were two notable exceptions – Meera Chopra and Helen Meena Chand – who grew angry with my

approach. When I asked Meera Chopra (80) her age, she indignantly replied, “What kind of a question is that to ask someone of my age!” When I valiantly pushed on, asking her the time, she grew even more irritated: “What sorts of questions are these?”

Similarly, Helen Meena Chand, whom I initially assumed could neither walk nor manage daily affairs, stunned me when she proved both mobile and capable of passing on messages. I had gone to her home to give her husband, Shivbaksh, the refill script from the Cornwall OPD. When I arrived the front door was wide open and despite repeatedly ringing the bell there was no response. When I began to call out, Helen eventually answered and I followed her voice to her bedroom. Tucked into bed, with the pungent smell of urine permeating the room, she said in a croaky, thin voice, “He’s not at home. He’s gone out. I don’t know when he will return.” I was reluctant to hand the refill script over to Helen. What if she forgot about it or misplaced it or tore it up? I knew how much these scripts cost in time, effort, money, and personal dignity. But with no signs of Shivbaksh returning and my next appointment fast approaching, I gave the script to Helen. Immediately I regretted it. As I attempted to coax it back from her, she became annoyed and suspicious. Her voice grew firm and solid, her speech rapid and incisive. “Why give me something only to then ask for it back? Why do you want his script anyway? Why should you be the one to put it somewhere else, somewhere safe? What is wrong with leaving the script with me?” I was feeling increasingly stupid and desperate when Shivbaksh suddenly returned. I explained that I had annoyed Helen and he laughed and took the script from her. She cursed me in Haryanvi and Shivbaksh rebuked her in Hindi,

“Arre she is doing *seva* for us, working for us, and you are giving her *ga:li*: like this?” Helen remained furious, crossed her arms and ignored us both.

Helen’s anger at me was justified, as was Meera’s irritation. My initial approach was placing them under a psychological microscope. Through some accumulation of facts on age, memory and cognition, I was trying to map their every thought and idea to magically unlock the person within. I was operating more as an omniscient witchdoctor than an anthropologist, and being made to feel idiotic was no more than I deserved. Despite reading Nita Kumar’s (1992, p.73) counsel that just because people are objects of study does not make them simpler, easier, more static or accessible, I blithely made all of these assumptions in my dealings with people with dementia. A most malignant social psychology was at play and though now I may claim to feel embarrassed, at the time change in my attitude and behaviour was more because of my frustrations, bewilderment and failures. People did not fit into neat clinical categories, there was always ambiguity. Who was Helen? Did she have dementia? At what stage? I remember my field supervisor, Deepak Mehta, counselling, “Pay attention to voice, listen to what people have to say,” and recommending to me that I read the anthropologist Robert Desjarlais. But in those early days, even listening was hard, because of the novelty and terror of the field. I had to come to terms with the fact that despite knowing the geographic, linguistic and social cues of the city, I did not know my field at all. The anthropologist who is familiar *with* her field does not immediately become familiar *in* her field. I had to learn to live with uncertainty and being overly deterministic was my initial response to cover my anxieties.

There was no fixed event that marked a turning point in my approach. Eventually I just threw up my hands and gave up trying to establish who the person was or how old they thought they were. I just began to be with them. Time, space and personhood were pushed aside. In its place emerged a phenomenological understanding. This change was driven by lived experience, intellectually and bodily. In the early January days of fieldwork, when I was busy pigeon-holing people and the field roared in my ears, the dust made my fingers prune and my feet crack and peel relentlessly. By the end of April, at once more and less familiar with the world, the rising heat, dust and chaos of the city had browned me, straightened my hair, and strengthened my limbs.

At the same time, my dealings with people with dementia grew more fluid, and touching became the most common way to engage. I often found myself holding hands with people, stroking their hair and rubbing their backs. With women, blowing kisses and hugs were permissible; with men such behaviours were inappropriate. People responded positively to shows of affection and these were some of my sweetest encounters in the field. We danced, sang and talked to each other. These experiences were shaped by the slow loss of language and function among my participants and a different attuning of my listening and observation skills. Thus through my body and experience, I learned what Merleau-Ponty wrote long ago:

The real is a closely woven fabric. It does not await our judgement before incorporating the most surprising phenomena, or before rejecting the most plausible figments of our imagination ... The world is not an object such that I have in my possession the laws of its making; it is the natural

setting of, and field for, all my thoughts and all my explicit perceptions (1945 [2007], pp.136-137).

### **Interruption: The Dance**

Cut to a scene in the dementia day care centre in Kochi, Kerala. Chanchala (80 years), small, thin and dark with a near shorn head, wears a vermillion blouse and white cotton sari. She is sitting down and as I walk past her, she stretches her hand towards me. I take it and we wander over to another set of chairs. She does not sit down; instead she holds both of my hands and I gently swing them from side to side. She follows my movements, still holding onto my hands, and we are swinging our hands together. Then I gently shake my hips from side to side and Chanchala follows me. Now we are dancing to silent music. A few staff members notice and giggle. Eventually I stop and when I lead Chanchala to her seat she sits down. I blow her a kiss and she raises her hand to her lips, kisses it, then cups my cheek and my chin with that hand and looks into my eyes. Whether a connection is made or Chanchala is naturally affectionate to everyone remains unclear. Later in the ARDSI bus, she will not tolerate my back to her. She repeatedly touches me on my shoulder and when I turn to face her, she blows kisses. If I focus on anyone else, she touches my shoulder and demands attention and affection.

### **Scene 2: Men at Work**

Robert Desjarlais (1997), in his work with homeless people in Boston, wrote about the difficulties of representation when narrative and experience were

disrupted and disjointed. Trying to develop a cohesive story, “tying things together through time,” rests on novelty, continuity, transformation, plot and movement. But for those who struggle, whose days are defined by contingency, illness, medication and marginalisation, such characteristics do not apply. In its place, according to Desjarlais, a critical phenomenology is necessary, one which ties together how people think, feel and experience things and the processes by which they come to pass (1997, p.25). Such a phenomenology is political because it is concerned not only with the modalities of experience but also with how the forces of politics, economics and culture come to shape these experiences. Given that “experience is the medium through which people engage with things that matter most to them, both individually and collectively” (Kleinman & Fitz-Henry, 2007, p.54), it is necessary to understand this dialectic between and within people, in the complex but ordinary routines of everyday life.

In my sample, in Delhi, people with dementia led boring lives. Their days consisted of routines defined by others: prayer times, bathing time, mealtimes, siestas, evening walks, and bed. In between there were many hours in which no activities were undertaken and people sat in chairs or lay in their beds. Carers often used this time to do paid work, housework or rest. Depending on the mood, capacity, and interest of carers and people with dementia, sometimes activities like peeling vegetables (n=3), reading and writing (n=4), watching TV (n=3) or listening to music (n=5) were undertaken. With the exception of Nina who tried to fill Karamjit’s days with as many activities as possible, most carers

were too preoccupied with the basic activities of daily living to pay much attention to anything else.

This left people with dementia with few opportunities for pleasure or occupation. Boredom created too much time which was spent by slowly waking up and get dressed, protracting prayers, and lying down. Many felt depressed and oscillated from being withdrawn and quiet to aggressive and repetitious. Rajesh Menon (71) was depressed and bored because he could not work:

Actually after retirement I was offered a job. But these people (his family) they did not allow.

*Would you like to work?*

Yes, I can spend time – not for money. I can spend time.

*Occupy yourself?*

Yes. I can spend time. Engage.

For Rajesh, time was a commodity in surplus. He wanted to spend it to occupy his mind in a way that was meaningful to him. He had been an accounts officer and worked all his life to provide for his family. Having retired over a decade ago and following his dementia diagnosis, his life had profoundly changed. His wife Radha cared for him and they lived with their daughter, son-in-law and two grandchildren in a small flat in west Delhi. While Radha's days were full with caring for Rajesh and her grandchildren, Rajesh's routine was relatively empty. He was depressed and disengaged, spending much of his time reading the paper, watching TV or napping. He rarely left his home, had few friends visit, and constantly hankered for his 'native place' in Kerala.

Rajesh was not the only man who saw work as a means of engagement and greater self-esteem. There were many other men with dementia whose careers were imprinted in their bodies and central to their identity. Ex-military man, Kaalathinnu, was crisp and contained in his movements. He never slouched in his seat, his shirt was ironed, his clothes unstained, and he was focused on order and discipline. Similarly Francis and Santosh were men at work in the ARDSI dementia day care centre in Kochi. Francis, a former clerk of the High Court, enjoyed his days at the 'department' and officiously signed all newspapers, while Santosh, an erstwhile salesman for a powder company, still touted his 'product' in the day care centre.

Even those who disliked work could not escape it. Moses (79), despite retiring, still spent his days 'at work' as an 'assistant' at the day care centre, and was constantly trying to get leave. A sheaf of letters had been written to the day care manager asking for a holiday. His letters were mostly a jumble of his name and former occupation; often he was his own referee. Intrigued by his request, I approached him at the end of the day:

*I've read your application for leave*

[Remains silent, listening]

*I think it is a good idea. Take holiday tomorrow* [Tomorrow is Sunday and the day care centre is closed]

[Nods]

*Yes, now is a good time [to take leave]. We are not so busy*

Yes, it can be adjusted later

*Yes no problem. Is that ok with you Moses?*

Yes [walks away].

Globally, while there may be many kinds of masculinity, income-generating work has tended to be a critical component of hegemonic masculinities (Connell, 1995; Fitzsimons, 2002). In the subcontinent, in dominant and subaltern forms of masculinity, men are perceived as the primary breadwinners (Jackson, 1999). Employment is a source of identity and power within the public sphere and the household, offering men the respect of their peers and power and control over their wives and children. Paid work is also a means by which male dominance over the public sphere is retained, and has been linked to nationalist discourses (Chatterjee, 1990; Gupta, 2002). Whereas a hegemonic feminine identity can be achieved through caring, childbearing, and/or paid work, for men, loss of employment signals loss of power and self. Unemployment is a point of 'crisis,' signalling transformations in gender roles and relations (Haque & Kusakabe, 2005; Radhakrishnan, 2005). For these men with dementia, work was written into their bodies. Their desire to be 'at work,' sign papers, sell products, move authoritatively and even apply for leave, were attempts to hold onto power, pass time in a meaningful way, and to anchor themselves in what was familiar in a changing world. Being at work mitigated the losses associated with ageing, retirement, diminished bodily function, lessened status within the home, and the slow removal of personhood as a result of these changes.

In addition to work, men also sought to anchor their identities in the intimacies of personal relations and pleasure. In the ARDSI dementia respite care centre in Guruvayoor, Kerala, shaving was a public but intimate activity, which most male residents enjoyed. In the afternoon, a male staff member would arrive on the porch with a brush, mug, lather and razor. The residents would lie in their chairs dozing as he would shave each of them in turn. In a gesture of extreme trust, they would lay their heads back, keep their eyes closed, and leave their jugulars exposed. For them this was an act of great pleasure. Most would rest their arms on their stomach. Even noisy, disruptive residents were quiet during their shave.

For some, the personal achievements of others also became sources of pleasure. In the Bhagat's home, Karamjit took my hand and guided me around, pointing to each cross-stitched framed picture. I did not know until then that Nina had sewn all of these pictures, and Karamjit wanted to ensure that I noted that down. Up until that point I knew Nina was engaged in a struggle to preserve Karamjit's identity, but I now realised that his identity was inextricably fused to hers. Just as Nina had said, "I think that if a man loses his identity he is lost. What has he got left if I am not known as Nina Bhagat?" so too Karamjit took pride in his wife's accomplishments, showing them off to visitors in their home.



**Figure 16: An afternoon shave**

Experiences like shaving or showing off a spouses' accomplishments speak to Marriott's (1976, p.111) famous observation of 'dividual' selves in the sub-continent. According to Marriott, persons in South Asia are not so much individual, self-contained units (as conceived in Western philosophy) but are dividual or divisible. They absorb heterogeneous and material influences and simultaneously put out their own body substance-codes. In this way, people are absorbing and incorporating each other into their notion of self, exchanging and circulating substance codes. From this standpoint, we can interpret the above encounters – shaving, working, taking pride in a life-partner's achievements – as intimate exchanges of bodily substance codes within a particular cultural and economic milieu. In this way people reproduce within themselves elements of each other in a common social context.

### **Interruption: The Poem**

Meenakshi's daughter Parvati said, "Yesterday she asked me, 'Where are we going?' and, I replied, 'Home, sweet home' and that line – 'Mid pleasures and palaces though we may roam.' I just said it and then she just said the rest of it."

Mid pleasures and palaces though we may roam,  
Be it ever so humble, there's no place like home;  
A charm from the sky seems to hallow us there,  
Which, seek through the world, is ne'er met with elsewhere.  
Home, home, sweet, sweet home!  
There's no place like home, oh, there's no place like home!  
- *Home, Sweet Home*, John Howard Payne (1823)

### **Scene 3: Bride and Prejudice**

Women with dementia also struggled with loss, but their foci were on domesticity, beauty, poetry and children. As their lives grew increasingly uncertain, efforts were centred on preserving and building relations in the home. Women often harassed their daughters and husbands to let them cook, care for their children, and socialise with visitors by serving them tea. Notions of femininity and the power of women within the home framed these practices. Mrs Hamdari had been the matriarch of her family for many years. But as her dementia progressed, her duties and caring responsibilities were transferred to her daughters. The loss of power and occupation associated with this transfer agitated Mrs Hamdari, and she resisted these changes. Said her younger daughter Nayantara:

She is a very caring person and she can't help her [motherly] nature, so it was very difficult, very difficult. She has gone through not feeling in command, not handling the house or herself but slowly, slowly this is

becoming less of an issue. Initially there was lots and lots of aggression and a lot of fighting about wanting to cook. She used to be a fantastic cook but now we don't let her cook. When my younger sister was here from America, she got the flu and five times in the night, she [mother] woke up and went to check on her. She was very concerned.

Veena Das has argued that Indian women experience their bodies as both object and subject, in that gender is scripted onto the body and its images, as well as played out within everyday relations in public and private spaces (1988, p.193). Mrs Hamdari's attempts to cook, care for her daughter, and socialise can be understood as an embodiment and enactment of gender scripts which also play out in everyday kin relations. Home is central to this dynamic not least because for elderly Indian women, home can sometimes be an uncertain location. Compared to their male peers, widows in north India tend to be economically and politically marginalised, experience greater levels of neglect and abuse, poorer health and higher mortality (see Agarwal, 1998; Chen & Dreze, 1995). Given that elderly women have an increased likelihood of having their property stolen from them and being forced to retreat elsewhere, home is a space literally representing the stakes of power, emotions, and economics. For women in my sample, home occupied a strong place in their mind. Helen Chand and Meera Chopra rarely left their homes even to see doctors. In contrast Lakshmi Kumari continuously hankered after her home in Pakistan, and Meenakshi Ranjarajan harassed her daughter to take her to her childhood home in Kerala.

While home represented security and domesticity, it was not just aligned with traditional notions of family and care. The home was also a space for beauty and consumption. This duality is an extension of the representation of urban Indian women in popular culture; just as women are presented in the nexus of tradition and modernity, so too are their homes. Independence, glamour and consumption lie on one side, conservative family values and middle-class nationalism on the other (Thapan, 2001). Though much of the literature has tended to examine this dynamic in the lives of younger and middle-aged women, even elderly women occupy this juncture (Deshpande, 1998; Dube, 1988; Narayan, 1997; Thapan, 2000). As the dementia loosened her inhibitions, Gauri (75), widowed with adult children and grandchildren, had become increasingly obsessed with finding a suitable husband. To her, a husband represented income for her dreams of a wealthy home, which included cars, bungalows and many servants:

How do I seem to you? Am I beautiful? Will I get a boy?

*Yes, you seem very beautiful and good to me. Of course you will get a boy, why not?*

Best, best, doctor or engineer, nothing else.

To secure a suitable husband, Gauri sought to trade her beauty for wealth. Her notion of beauty centred on her fair skin. This was a running joke in the ARDSI day care centre in Kerala, where many of the attendants were darker skinned. The bus driver of ARDSI's van would tease Gauri by asking her what her name meant: "It means brightness," she replied. "No, it means darkness," he teased. "Arre sala (oh bastard), it means whiteness, you're the black one," she retorted.

Gauri's association between whiteness and beauty is a common link in India, which has been increasingly capitalised on by multinational cosmetic companies through their skin whitening products, Bollywood stars, and online matrimonial agencies (Osuri, 2008). In India, beauty is whiteness, tied to hetero-normative patriarchal orders and higher classes and castes. Bollywood has played a key role in disseminating this image in India and transnationally, a strategy that has colonial roots, invokes traditional notions of femininity, and reinforces existing power relations (Reddy, 2006). In a middle-class Indian zeitgeist, whiteness represents a safe and readily marketable form of beauty which women can apply to or mobilise from their bodies to lever themselves into higher socio-economic positions. In a private moment, in her afternoon repose, Gauri quietly tells of a life hard-lived, of days spent cleaning, scrubbing, studying and raising children. "My parents said I had to try to do everything otherwise I would make nothing of myself." Gauri's tactics can thus be seen as an effort to accrue more status and power within the wider context of patriarchal inequities and politico economic marginalisation.

## INTERMISSION



**Figure 17: An afternoon nap**

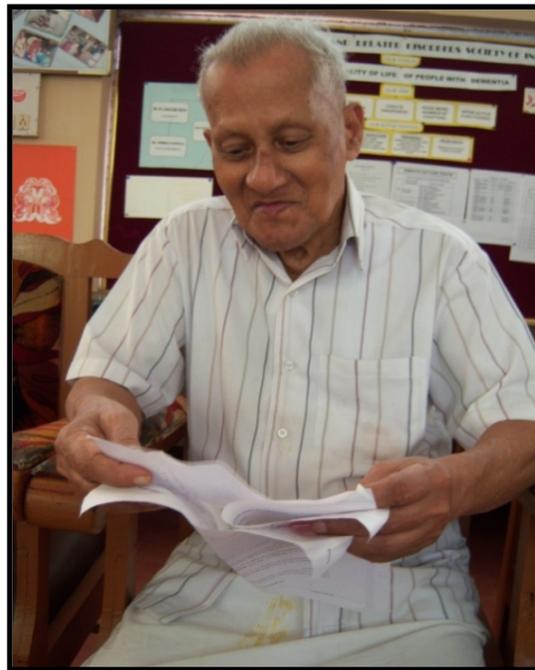


**Figure 18: Beautiful Gauri**

A person's body dies but not their spirit, not their life.  
I am a spirit, I am not a body.  
Once this body is worn out I will discard it.  
But I am limitless, just like God is limitless.  
I will keep coming back.  
Now in this life I have had it the best – I have been a man.  
In my next life I could come back as a bird, a tiger, a snake,  
I have attained *mukti*; the body is such a thing.  
- Kundan Lal Chopra



**Figure 19: Playing carom**



**Figure 20: Men at work**

## ACT II

### Scene 1: “It’s easy to let go now”

With time, people with dementia began to lose function. They forgot how to walk, talk, swallow, turn, go to the toilet, and eventually consistently failed to recognise their own family members. To manage these degenerations, carers’ efforts increasingly centred on diet, exercise, and medication. Though families incurred significant costs for such interventions, nevertheless they were sought, and no one considered palliative care. Families were disinclined to withdraw the feeding tube or not using the ventilator. The inextricable link between carer’s sense of self, the need to try all forms of an *ilāj*, and to give the greatest amount of *seva*, made the moral stakes too risky for such decisions.

In India, palliative care services are relatively new (less than 20 years old), underfunded, and closely tied to cancer and HIV/AIDS. Such services tend to be concentrated in major cities (thereby making them inaccessible to many in rural areas) and there is little public awareness of them (Seamark et al., 2000). Though practices around preparing for death have existed in India, these have tended to focus on spiritual aspects such as renunciation and asceticism rather than pain relief and medication. There is also a tendency amongst doctors to intervene therapeutically in incurable cases rather than palliate, because of financial incentives from pharmaceutical companies to prescribe their drugs (Mazza & Lipman, 2003). The intersections between medicinal drugs, the doctor-patient relationship, pharma-economies, and families’ quest for an *ilāj* have been discussed in Chapters 4 and 5. Here I focus on how people with dementia attempted to sidestep these (iatrogenic) effects through death. For

example, Rajesh Menon spent all his time harassing his wife Radha to return to their 'native place' in Kerala. When asked why, Rajesh replied:

I like Trivandrum. I want to be in Trivandrum. I want to be (sic) peaceful death there.

*You want to be peaceful there?*

Peaceful death in Trivandrum.

Like Rajesh, Helen also wanted to die. When I visited her home for my second interview with Shivbaksh, I asked her how she was. "I am ready to go up," she responded. Talking about wanting to die and planning for death have been noted in other studies on ageing in India. Sarah Lamb (2000), in her work with elderly Mangaldihi villagers in West Bengal, found that it was common for older people to plan and discuss their death, and Lawrence Cohen (1998) describes how those who were *marnevālā* (about to die) were regarded by Varanasi residents as people who had lost their authority and were doing *bakbak* (prattle; chatter). Similarly in my study, though people with dementia expressed a desire to die, their carers often dismissed such talk and concentrated their efforts on preserving life. This did not mean denial or lack of preparation for death. Indeed, because death was inevitable, many strived to fulfil the wishes of their ill loved one. Radha did take Rajesh back to Kerala for short breaks; Shivbaksh gave Helen all the *bi:ris* she wanted to smoke; and Lakshmi Kumari's family took her to visit her hometown in Pakistan.

Fighting to the end was part of *seva* even though, as Josie pointed out, "It's easy to let go now." Families caring for people who were in the late stages of

dementia underwent their own emotional metamorphosis as their loved one declined. They tried to limit their emotional attachments towards their loved ones and avoided thinking about the end, while stoically accepting the inevitable. Shafia had been married for over 25 years to Omar, and had spent the last seven years caring for him. With Omar on a feeding tube, ill and near-death more than once, Shafia knew it was a matter of time. Even as she feared the financial stressors of widowhood, she prepared herself for Omar's death:

Comfort and consolation – you have to be ready. This is the way it is for us. This is the way it is for everyone because life and death are in God's hands and there is nothing we can do. This is our fate and it rests with Allah. When a man is in his condition, when he can't stand, how long is he going to live with this illness? He can't eat, he drools, his *hāth-pair* don't work. You have to endure this; you have to prepare yourself.

**Interruption: Journal entry, 28<sup>th</sup> August 2008**

When I called Shivbaksh this morning, after days of trying, I was surprised by the disorientation, grief and loneliness in his voice. "How is Helen?" I ask.

She has gone to her *shmasha:n* (cremation).

[Gasps] *She's dead?*

Yes.

*Can I come visit you tomorrow?*

Yes come.

*What time?*

Come anytime, I just sit at home alone these days.

## **Scene 2: “My heart is cut on the inside, my heart weeps”**

During my time in Delhi three people died – Surinder Dharam Singh (58), Helen Meena Chand (82), and Gautam Mukherjee (88). A year before I interviewed Namita Sood, her mother had died, aged 83. Their voices were now silent. In this section, I describe the last days before these deaths. These were some of the most emotional and labour intense days of caring for families, as the forces of medicine, capitalism and culture came to bear on them.

People with dementia tended to spend their last days in the hospital. They were often admitted for fevers, pneumonias, hip fractures and blood infections. Very few died in their homes and often these deaths were sudden. Gautam Mukherjee had a high fever for two days and died in his sleep before his scheduled admission to hospital the following morning. In contrast, Helen Meena Chand had a fall, fractured her hip, and was admitted to hospital. There she contracted an infection, experienced a loss of appetite, lapses in consciousness, and eventually began to excrete and vomit blood. In her final two days, she went on the ventilator, and 25 days after her admission, she died alone in the early hours of the morning.

In comparing these two cases, there is a need to actively avoid the easy conflation of ‘good’ and ‘bad’ death. Such an approach risks elevating specific cultural scripts around dying to universal categories, often at the expense of other cultural ideas around dying. Work comparing Anglophone countries (like USA, Britain and Australia) and Asian nations (like Japan) found that though

choice, place, timing and personhood were common features of a 'good' death, their interpretations and applications were quite different (See Table 4).

**Table 4: Comparing cultural scripts of death in Anglophone and Asian countries**

	Anglophone countries	Asian countries
Choice	Patient in consultation with family decides when and how to die	Patient and families strongly follow the advice of physicians. Also strong emphasis on god as decision-maker, e.g. 'it's in God's hands now'
Place	Strong preference for death to occur at home surrounded by family	Death usually occurs in hospitals, surrounded by family
Timing	Person should die when the situation is hopeless and there is no longer any point to prolonging life	Person should die when they are old and have lived a full life. There should be efforts made to prolong the life of younger people, even if the situation is hopeless.
Personhood	The person should be aware and in control of their faculties, i.e., they should not be a 'vegetable'	Focus is on the relationship between the person and the social world even beyond death

*Adapted from Long (2004, pp.913-928).*

In applying the findings from Table 4, it can be seen that Gautam Mukherjee's death was not necessarily 'good' just because he died at home and Helen's was not 'bad' because it occurred in a hospital. If not for his sudden passing, Gautam too would have been in hospital. Being in hospital did not negate 'goodness,' and other families described positive interactions with hospital staff that helped to facilitate 'good' deaths. Nursing staff telephoned the Sood family at 4am to come and say goodbye to their mother. Namita recalled:

When we went into the room she opened her eyes and she smiled such a beautiful smile. We said her prayers and to the last strains of the *Gayatri-Mantra*, she slipped away. When we brought her back home and washed her, no rigor mortis set in; when you saw her face, it was a smile; it was a really beautiful smile. She [grew up] in a Sikh orphanage and she died around 4 - 4:15am. The Sikhs say this is *ammrit-vela*: [ambrosial period] – it is the most beautiful time to go.

Through Namita's story, a 'good' death is socially constructed: her mother was alert and smiling, she was surrounded by her family, her favourite prayers were recited, and she died at an auspicious time. The 'good' death was even embodied, as there was no rigor mortis, and Mrs Sood had a smile on her face in death. By now it should be evident that few practices in India strictly obey boundaries of caste, class, religion and gender. The Soods, who were Hindu, borrowed from Sikh precepts to comfort themselves, reflecting the cross-pollination, amalgamation and re-interpretations of ideas and customs as they circulate amongst different communities.

Hindu ideals around dying in India, particularly for men, see the body as a sacrifice to be made on the funeral pyre. Death is to happen in old age, following a life replete with children and grandchildren. In the days leading up to death, the dying man is meant to forgo food and consume only water in order to weaken his body, so that the 'vital breath' may leave it more easily, and to purge himself of faecal matter to purify himself. Then, having set his affairs in order and surrounding himself with his family, the man not so much dies as

relinquishes life and his body (Parry, 1981). Those whose intention to sacrifice themselves through death have not been established (e.g. children or those who meet violent and unnatural ends), or who are unfit sacrifices because of their sins, or whose death is already seen as an offering to the gods (e.g. ascetics), are not permitted to be cremated; instead they are to be immersed (in water or earth) (Das, 1976).

When viewed from this standpoint, even deaths like Helen's, which may seem 'bad,' have 'good' elements: she had lived a full life with children, grandchildren and great-grandchildren, her body was purified leading up to her death, and she set her affairs in order before dying. Shivbaksh recalled that prior to going onto the ventilator, she recognised him, sat up and put her arms around him. Even 'bad' deaths have redeeming features, just as 'good' deaths have negative elements which people choose not to dwell on. To definitively categorise deaths as 'good' or 'bad' bleaches out their ambiguities and glosses over the embedded moralities in the cultural scripts surrounding dying in India.

With death, some families observed traditional funeral rites according to their religion, while others opted for a more pragmatic line. Shilpi Mukherjee electrically cremated Gautam and did not await the arrival of her sons from overseas to fulfil any last rites; Shivbaksh observed all the Hindu ceremonial funeral rites for Helen. Even here the reasons for such practices were motivated by cosmic and earthly concerns: Namita Sood's mother had wanted a no-fuss electrical cremation but at the time of her death, electricity shortages in Delhi were so acute that there was no guarantee the body would be fully burnt.

Rather than risk a half-burnt body being dumped somewhere, Mrs Sood's daughters observed all the rites and burnt their mother's body with wood.

Irrespective of attitudes towards funeral rites, photos of the deceased assumed a central role in families' homes. Enlarged, laminated portrait pictures of the deceased were placed on living room mantle pieces or on prayer altars in bedrooms. Sometimes lights and garlands were placed around these photos and the sacred *tikka* might be applied to the portrait's forehead. The photos tended to show the person a few years prior to their death, with the exceptions of Su and Gautam whose pictures showed much younger, stronger, more virile versions of themselves. Commemorating deceased family members through photos is customary across Indian society, and is a way to "extend lineage continuity beyond the lives and transient memories of living family members" (Lamb, 2000. p.177). The photo functions spatially and temporally to link the deceased elder to future generations, who will venerate them. Photos allow an imagined connection to be made between the divine and everyday worlds through the elder who has attained *mukti* (release) but continues to be remembered within the bonds of kinship and family (Lamb, 2000).

Death also brought more immediate emotional and geographic changes to carers' lives. Soon after Gautam's death, Shilpi Mukherjee's sons began to make preparations to take their widowed mother back to the US to live with them. Josie's daughter came to live with her for six months, and Namita Sood and her sister returned to work. For Namita, who found the caring experience very positive – "It was seven years of picnic for us" – the picnic was now over. And

while these carers grieved, they all acknowledged that they had prepared themselves for this moment. With one exception – Shivbaksh Chand.

Shivbaksh had felt the cut of change most deeply. All through the months when Helen was alive, he was jocular, loud, irascible and cheeky. He had filled their home with the noises of cooking, television, and visitors. When I first met him in February he had on a white full-sleeved *kurta:-pajama*. But as the days grew warmer and Helen became frailer, on each subsequent occasion, Shivbaksh seemed to wear less and less. In our last meeting, he had on a white vest and shorts, and had lost weight. Whereas before he would hold forth on his sofa and punctuate his speech with explosive hand gestures, now he had retreated to a corner near his front door with a newspaper. Gone was the wild waving of his arms. The disciplinary ties in his life had also loosened; he admitted to drinking to excess and when his mind was totally *kharāb* (ruined), to smoking. There was neither talk of his dementia nor of visits to the OPDs. He rarely went to meet his friends at the local dispensary across his street. Instead he was quiet, contemplative, sadly awaiting his own death: “It could happen anytime and everyone has to go. A human being is born alone and must die alone. It is my time to die, I’ve lived my life.”



**Figure 21: Helen Meena Chand, 1926-2008**

### **Scene 3: The Political Economy of Dying and Donation**

Though there has been a large amount of work written on funeral rites and customs in India (see Das, 1976; Das, 1998; Madan, 2004; Mines, 1989; Orenstein, 1357; Parry, 1981, 1985; Schmalz, 1999), little has been published on the political economy of dying and dementia. Sharon Kaufman (2006), based on her work in American hospitals, illustrates the difficulties in decision-making when dementia is accorded the value 'near-death' and the disputes that arise when hospital staff and family members disagree over that value. Kaufman makes the point that decisions to prolong or end life are moral choices which result from medical categorizations, institutional imperatives, and deliberations about value.

In India, when people die within institutional settings (like hospitals), medical interventions and the value of life are also linked to capital. Medical interventions are bound to ideas of *seva* and families' efforts to resist dying are

part of the dying process. This applies even to those for whom there is little hope. Often people who were terminally ill are put on ventilators to prolong their life. P.K. Singh, a volunteer at ARDSI in Delhi, describes the last days of his wife who had Alzheimer's disease:

I had to put my wife in the hospital because of an emergency. She got high fever and an infection in her lung. There they said, "We'll have to put her on a ventilator." Putting her on a ventilator had two implications. Firstly it is very expensive. It is about Rs 11,000 - Rs 12,000 a day. And the second thing is, once you put it on, then you cannot take it off. It is a life support system. There is also some legal issue and you can't take it off. It has to be there until the patient is brain dead. Then the doctors decide that they can remove it.

Class is implicit in such a paradigm, for only those who can afford to pay for ventilators and life-prolonging treatments are able to avail themselves of these options. This goes to the politics and value of unequal lives, and fits within a larger issue of health service delivery in inequitable settings. Das and Hammer (2004) note that private providers in Delhi tend to over-medicate and/or perform unnecessary procedures for cash incentives, while public providers are more likely to under-treat or insufficiently treat patients (who are typically poor). Specifically with elderly patients who are dying, the cultural reluctance to end life (even in terminal cases like P.K.'s wife), determine medical interventions (procedures, drugs and technologies such as the ventilator), as do politico-economic forces such as money, access, and the values assigned to the lives of the rich and poor.

Nowhere perhaps are these disparities more evident or contrary than in organ donation. In death, Namita Sood and Josie Dharam Singh attempted to donate Mrs Sood's and Su's body respectively. But these efforts failed due to the misalignment of medical categorisations, institutional imperatives and deliberations about value. Before I explicate these links, a brief detour into the values around organ donation is necessary.

Donation has an ambiguous value in India for two reasons: (1) it evokes a tri-partite social relationship between donor, recipient and the nation-state and (2) has a murky association with organ trafficking. On the one hand, organ donation can be seen as an act of 'ethopolitics,' what Nikolas Rose (2001, p.18) characterises as the ways in which the moral precepts of a good person come to be conflated with the requirements of good government. Public appeals to donate eyes, organs, or blood as the gift of sight or of life or sustenance, draw on discourses of class, nation and immortality. The most famous Indian advertisement for eye donation in the 1990s featured the newly crowned Miss World, Aishwarya Rai, offering to "Leave my eyes when I die and have someone see again, to look at our world through *my* eyes long after I'm gone" (emphasis added). Since then many celebrities, film stars, cricketers, and politicians have pledged their organs after their death. Popular slogans and advertisements to boost organ donation – "Life...Pass it on!" "Organ donation, the gift that lives on" – suggests a vision of immortality, as one's life is never truly gone but merely transferred into another body. Much like the photos of the deceased in families' homes imagine a link between the divine and the everyday, so too organs are

mobilised as new kinds of commemorative objects. Photos may occupy prime position in a living room, but organs live in the body.

Additionally organ donation is mobilised to venerate the nation and its institutions through the donation of blood and bodies from its citizenry. Mass drives for blood donation have been tied to politically commemorative events such as the death anniversaries of assassinated politicians and ideas of national integration (Copeman, 2004, 2009). Cadaver donation is marketed as an ascetic practice to further the knowledge of medical institutions (Copeman, 2006). Thus through blood and body parts, complex social continuities are imaged between deceased and recipient, and between donors and the nation-state.

But the principles of this new biomorality are undermined by a reality of low organ donation, surpluses of organ trafficking, and stories of desperation, coercion and exploitation of the poor while the elite purchase and use such body parts. In this new biosocial enterprise, as the relationship between India's poorer and wealthier citizens are literally re-embodied, "Whatever the relationship, if any, between buyer and seller, the dominant vision of biosociality has shifted from the utopian...into a dual economy of sacrifice and substance" (Cohen, 2001, p.20).

Within this uncertain terrain of values, Namita and Josie's efforts at ethopolitics also encountered institutional bureaucracies and poor resources. Because Mrs Sood died outside of business hours, the organ banks could not be contacted to

harvest her body. As she had died in August, the Sood family could not delay her cremation for risk of putrefaction in the heat. Namita explains:

Those organ fellows were terrible because you couldn't get in touch with them. Otherwise she [would have] donated her brain and the rest of her organs. They should have a 24hour service because it doesn't come from higher on that you're going to die in office hours.

Josie tried to be more organised in her approach to donation but still failed. On final admission to the hospital, Su had pneumonia and could no longer swallow. Realising that the end was near, Josie initiated conversations between herself, ARDSI, and Dr Yashaswini to try and donate Su's organs. Yashaswini advised shifting Su to her hospital because of the difficulties associated with moving deceased persons (apparently ambulances cannot transport deceased persons and private taxis charge considerably more to do so). Also she cautioned Josie about the condition that Su's body would be in when it was returned to her: dissections and organ retrievals often led many families to reject the body post-harvesting. These procedures left Josie unsure about whether to donate as she described the doctors as, "All ready with their knives."

But a few days later when Su died, Josie took the decision to donate his body. The Autopsy Unit then refused to accept his body, claiming that because Su had Alzheimer's disease, nothing could be harvested. Then the Organ Donation Unit from the same hospital said that Su's eyes could be used and that they were on their way; 45 minutes later the same call and message were relayed to the family. The family waited for nearly four hours but nobody arrived. Repeat calls

were made to Yashaswini who did not answer her phone. Kavita from ARDSI-DC who had counselled Josie over the years advised, "Let it be Josie, let him go in dignity," and finally, in the August heat, Josie cremated her beloved Su.

In these two cases, the incongruities between medical category, institution and values are visible. In the Indian context, values around organ donation are imbued with sacrifice and substance, tapping into wider socio-economic inequities, which leave them as ambiguous acts. Medical categorisations view organ donation as a transference, i.e., from one body into another, rather than a research enterprise or object of study. So Su's body, because of the dementia, was seen as an unsuitable donor and his gift of life was rejected. Bureaucratic bungling and institutional inefficiencies also left the Sood family unable to donate even when they chose to. If these are people's experiences, it comes as little surprise that rates of organ donation remain so low. What remains unanswered is the comparative speed of the process if the resources of an illegal black market economy were brought to bear. What if these organs were being sold (rather than donated)? Would then the limitations of age and infirmity supersede the brute force of lucre? Would donation have been more successful as commodity? Would a free gift of life been more respected if it were not quite so philanthropically given? These are questions beyond the scope of this thesis but do require further investigation. In the interim, the failed attempts of these families at donation were painful endings to a highly emotional experience. As Josie said, "I was devastated by the fact that his body could not be donated to science, because that would have been his last wishes."

## Conclusion

The key elements of a Bollywood *masala*: have been used to structure this chapter. In place of plot logic, singular themes and gritty realities, there have multiple narratives, interruptions, numerous threads and fantastic stories. Yet even as the threads began to unravel for people with dementia, there was still space for relations and affections. The poetry, dance, and exchanges described in this chapter highlight that the deeper human intimacies are still very much present and people with dementia respond to them. On one level, it is unseemly that a research finding even be written to characterise interactions with people with dementia. Affections, respect and a willingness to listen should be humane and axiomatic to any given interaction. But as was also highlighted, humanity is not always in surplus in the difficult tasks of caring and dying. As people prepare for their loved one's death, a different set of interventions comes to bear on the dying process.

As described, families' emotional preparations for the death of their loved one were shaped by cultural scripts associated with dying and the political economy of dying and donation. Therapeutic interventions were linked to *seva* and capitalism and highlight the marked difference between Indian and Western notions of a 'good' death. As Josie's and the Sood's cases on organ donation illustrate, there is a new biopolitics transpiring on people's bodies, drawing on the old inequities of poverty, class, age, and illness to script new pains of loss and hurt. Further research is required into this area in conjunction with an examination of the intersections of global economies, nationalism and bioethics in organ donation (and trafficking) in India.

In caring for people with dementia and in preparing for and dealing with death, *seva*, relationality, and reciprocity have been explicitly explored in numerous contexts ranging from families' homes to the OPDs and institutions of government. But love has only been alluded to, even though it is implicit within the care-giving process, influencing relations, power-plays and attempts to secure better treatments and even cures. Love was in the sweetness of sugar in Chapter 6 and in the longing for home, partnership and identity explored here. Karamjit who showed off Nina's cross-stitch, big-hearted Shivbaksh who supplied Helen with her *bi:ri:s*, and devoted Namita and her mother, are all tales of love and loss. There are few happy endings in dementia care, but happily, I found pockets of deep love and commitment. It is to documenting these intimacies that I now turn.



## CONCLUSION

### “THIS IS THE TIME FOR ROMANCE”

Valentine’s Day occurred in the early days of my fieldwork. When I was growing up in Delhi, typically schoolboys and girls would exchange a few misty cards and college students would grow flirtatious over their Pepsi® on Valentine’s Day. By 2008, things had changed significantly and cupid’s arrow had struck the psyche of all classes. In the morning my maid wished me a happy Valentine’s Day; a friend text-messaged felicitations for “a beautiful and romantic day;” more messages followed from various companies encouraging me to buy their products to find true love. A typical message read: “WILL U MEET UR VALENTINE. Get valentine day forecast from Expert astrologer. Dial 55181, Rs. 6.99 pr.mm.” When I mentioned these messages to a staff member at ARDSI, he was contemptuous:

Do you know the price of a single red rose today is Rs.80?

*How much is it normally?*

About Rs.2 each. And there has been a guard put on the garden of the Vice-Chancellor at St. Stephen’s [college] because all the students are coming and plucking the flowers! It is madness!

I was astonished at this commercialisation of love. It is not that Delhi is a loveless city – indeed most of its parks are filled with couples behind suspiciously rustling foliage. But Delhi is more grasping and less melodic than cities like Mumbai or Kolkata. For all its claims to ‘modernisation’ and

'development,' gender inequities, gender-based violence, poverty, class politics and conservative values are still *du jour* in Delhi. On Valentine's Day, news stations covered stories of Hindu fundamentalist groups looting card shops and beating up couples. Within this context of money, sex and violence, love seemed an emotion too soft and too easily appropriated by the forces of capitalism and lust.

Not so, as I was to discover. One afternoon, as I sat with Josie in her hallway, a single overhead light glowing and the rest of the house in darkness, she said, "This is the time for romance." Outside the sky had gone a mossy, earthy green, the signs of an ominous storm to come. When the storm comes, the wind will peel paint flecks from the walls, water will seep under the doors, and time will seem to stop.

This disease has made everything so much more. We're not like every other couple, husband here, wife there. He is totally dependent on me and I treasure every moment. It is such a joy to look after him because I know I've only got him for another few years. See the sexual side of my life is gone. It's gone because of the disease and because of age. Our relationship has been transformed and he is now like my child. But I love to meet and talk to people. Especially to men – older men I prefer. Just to have a great conversation, for them to say, "Hey, you're a great person to talk to." I can't stand pity and all this *becharre* ('poor me') stuff. I say, "Look everyone has a job and this is my job and I am doing it. That's it." But I treasure these moments, these flashes. He calls me 'lovely' and the

other day, after months, when we were in church, he took my hand and said, "You're so cute." I felt like a young bride all over again.

To discover the love that existed between people with dementia and their spouses was one of the most joyous findings of my ethnographic journey. It was unexpected, for there are few happy endings with Alzheimer's disease. Death is inevitable and for many, this brings release and marks a huge life change after many years of caring. Perhaps because of the tragedies of the story and the intensity and intimacies of caring, carers and people with dementia shared a deep love. From Tandon who spent his days eternally hopeful and searching for a cure for Sheila, to Nina who struggled to maintain Karamjit's function and identity, Shivbaksh who cooked incessantly for Helen, and the hungry oceanographer who yelled across his living room to his wife, "Darling, what's for lunch?" – there were stories of love and devotion.

Academia has not been rigorous about love. Love is taboo. Much has been written about affect, relationality, reciprocity, cohesion and exchange; about the substantive processes of love (e.g. family planning, blood and kinship, childcare, eldercare, domesticity); and the commoditisation of love in an era of late-capitalism (e.g. sex work, transnational caregiving, reproductive tourism). Almost nothing has been written academically about the romance of love. Yet it is one of the key lubricants of human relations, driving people to form kinship networks and connect with each other.

To write about love is to risk romanticising one's work, the field, and its players. But anthropology is a discipline that speaks most to falling in love. One learns to love one's topic, to be passionate, to be immersed in a 'field,' an alien space the anthropologist endeavours to make familiar. Anthropology is much like migration – terrifying to begin with but eventually a site where a 'home' can be built. To be in love, anthropologically speaking, need neither preclude a critical gaze on our participants' lives nor the wider political context which shapes their identities and actions. Both views are necessary to capture the complexity of the topic and to do better justice to what we have been privy to. And so in this final chapter, as all the threads are woven together, I write first *of love* and then with love, of the analysis of the key themes that have defined this thesis.

### **“Any Sadness of Mine He Endeavoured to Make Sweet”**

The couples in this sample were of a generation that married young and usually through arrangements brokered by their families. Four couples had not even met their prospective spouse until the actual marriage itself. Helen and Shivbaksh were married off as children, when she was 10 and he, 15 years old. The duties of work and childcare had governed most lives and many couples described long periods of separation – husbands who were stationed in military zones, out on the ocean, in tea gardens or at far-flung government posts, while wives lived elsewhere raising their children.

Love throughout most of these couples' lives would have been akin to what Margaret Trawick (1990b) described in south Indian Tamil families. Love or

*anpu*, according to Trawick, was articulated through living rather than speaking, and encompassed numerous features such as *adakkam* (containment), *parakkam* (habit), *kodumai* (cruelty), *elimai* (simplicity) and *adimai* (servitude). Mothers were meant to be contained in their affections for their children and spouses restrained in the affections they showed each other. Too much love was believed to hurt both giver and receiver and threaten family unity. Love was seen to grow over time and included cruelty towards one's children with the intent of hardening them to the struggles of life and teaching them to appreciate the sweetness of success. Simplicity of living and service towards others, through processes such as preparing and serving food, were also aspects of *anpu*.

With retirement and illness, as the dementia progressed and institutional and social barriers hardened, couples found their relationships significantly changing. Some of the features of love as described by Trawick held true in my sample, but other aspects like containment and simplicity did not. Distal forces – like globalisation, transnationalism and urbanisation over time – and immediate factors – such as the nature of the illness and changes in family structure – contributed to these altered understandings of love.

While carers were contained in their displays of affection towards their loved one, they did not curtail themselves in describing their affections. Also notions of simplicity were quickly displaced by the complexities of *seva* and the details of carework. Days were spent focusing more and more on the minutiae of bodies and function, and *seva* and duty increasingly came to the fore. Spouses

tended to invoke the reciprocity of long years of marriage for their current caregiving:

Whatever I can do, I do. He is my husband ... as long as he is alive till then is my duty. All these years he has kept me happy, so the least I can do is this" (*Radha Menon, 62*).

Now it doesn't matter to him how we keep him but in my heart it matters because I have always lived well with him. That's why we desire that he experience no difficulties because of us. We only want the best of the best for him (*Shafia Khan, 54*).

Family and wider social relations were also changed by dementia. As described in the preceding chapters, people's lives tended to shrink in the public space that they occupied; there were fewer outings and lives eventually contracted onto beds and bathrooms. Adult children were often overseas, inter-state, lived elsewhere in the city, or were preoccupied with their own lives. Spouses were left alone to care, and for many these were years of introspection and loneliness. Some people, like Tandon, literally began to mobilise their solitude – through the physical spaces of their houses and outside walls – to keep visitors at bay.

The shifting of power dynamics and tighter disciplinary routines governing daily life also required carers to assume responsibility for tasks that were once beyond their purview. Women juggled finances, tax returns and administrative matters outside the home, while men had to focus on household chores and run

an establishment. As their scope of responsibilities expanded, carers often found themselves experiencing an emotional distance from the rest of their extended family and friends who could not wholly empathise with their experiences. The combination of increasing emotional distance from family and friends, contracting of activities within the public sphere, notions of reciprocity and *seva*, and greater awareness of the chores the person with dementia used to perform, strengthened the bonds between carers and people with dementia.

Said Nina:

We'll have our 50<sup>th</sup> anniversary this year. And we've had our ins and outs, seven year itches and all that. First it was husband-wife. You have to do this, I have to do this. You have your duty, I have my duty. You are together, be together. But now it is a comradeship, it is a friendship; it is as I would call it love. It's not sex but love. Pure, simple love. I think that if a man loses his identity he is lost. What has he got left if I am not known as Nina Bhagat?

Women were more open about their feelings for their spouses than male carers. Six women explicitly mentioned how strongly they felt for their husbands and the love that they shared. For some, love was also tied to power and control because despite the difficulties of caring, they attained greater authority over their own and their husband's lives through such work. As Nina put it, "Tomorrow if he is not there, the family will say, 'Why are you doing this? Why are you doing that?' But now, nobody can question me." Others, like Sita Aggarwal who cared for her husband in her son's home, enjoyed little

autonomy, bound as she was by the limitations of her husband's late-stage dementia and her dependence on her son for a roof over their heads.

Only two men in my sample were the primary carers for their wives – Shivbaksh and Govind Ballabh Tandon – the others shared this task with their daughters or daughters-in-law. For these two men, love was an emotion not readily admitted. Tandon said it was personal and Shivbaksh associated love with lust and passion, believing it to be something that occurred during one's youth. At 87 years, Shivbaksh believed that such amorous feelings were over for him and so when I bluntly asked him whether he loved Helen, he replied, "What love? What is love? In old age there is no love. This is duty, this is obligation, and there is no love between us." He gave me this answer in early May 2008. By the end of June, Helen was dead and when I went for my final visit in August, I asked him again, "Did you love Helen?" His answer:

Love comes in old age. I cared for her, I did *seva* for her, I did everything.

Love was going to happen under these circumstances. Now she is gone and I am alone.

### **"Now I am the Mother. Earlier she was the Mother"**

I always tell her, "We were your babies, now you've become my baby. I don't have two daughters, now I have three daughters, you are my daughter" (*Kumud Kaul*).

Dementia also inversed the traditional parent-child dyad, with children caring for their parents, likening such work to the childcare their parents had provided them. Both Kumud and Nayantara, in separate interviews, stated that they felt

that they were now mother to their mother, Mrs Hamdari. The same analogy held true for many other women caring for an elderly parent (but not for daughters-in-law who cared for in-laws with dementia). While understandings of *seva* informed these relationships, the mother-child paradigm enhanced the love, power and intensity of this dynamic. Unlike the containment of the traditional mother-child bond, in these cases, daughters showered affection on their mothers.

Love was displayed through gestures rather than speech. In the words of Deborah Hoffmann from *Complaints of a Dutiful Daughter* (1994), “The content didn’t matter; it was the feeling.” Children would stroke their mothers’ hair, kiss their cheeks, apply make-up and ensure they were well-presented. Watching TV together, lying down together, and holding hands were instances of love and exchange. Just as food played a critical role in fostering love between spouses, feeding and eating also created feelings of love between parents and children. Kumud and Nayantara would often take their parents out to lunch at their local club:

At least three to four times in a month, we make it a point to take them out. She feels very happy. Initially there is a lot of reluctance [laughs] and she’ll go on saying, “What shall I wear, I have no clothes.” And we sit at the dining table wherever we go; Nayantara sits with daddy and I sit with mummy or one of us sits [with the other], so both of us are there to look after them. Always, always.

Children's indulgence of their parents was underpinned by the knowledge that death was the end result. Restraining one's love was unnecessary because the person with dementia had already endured the hardships and sweetness of life.

Bhageshwari said:

The one thing that wears me down is that I know my mom is not going to survive for a very long time. Everyone has a dark spot in their lives, this is mine. I know she is not going to live for very long. It brings me down very badly. Everything else I can take in my stride. It's ok as long as I can see that smile on her face. It's not the pressure of doing [things] for her, it's not a pressure. As long as I see that she is feeling ok, it's fine. Some people find caring for parents a hindrance but for me, if she is around me, there is a sense of calm within me.

The reversal in parent-child relations also signalled the re-distribution of power as children came to have greater control over their parent's lives. They would prevent them from cooking, working, eating particular foods, and made them participate in various therapeutic regimes. Though spouses also enacted similar processes on the person with dementia, in the child-parent relationship there was an extra factor at play – sibling rivalry. This was not explicitly stated amongst participants of any family, but rivalries existed and determined carer hierarchies and therefore who exercised the most power and responsibility. Adult children sometimes grumbled about having to undertake particular aspects of care which their siblings did not. However, such complaints never turned into personal attacks on their siblings, and these rivalries were without verbal rancour. Nandini, who cared for her father and younger brother (who

was also unwell) said, “He may forget about me, but this guy [her brother] he’ll never forget.”

Similarly, Hemant Talwar and Savitri, his wife, were the main carers for his father. When I first met Hemant, wary though he was of the tape recorder, he was emphatic I note that people with dementia have a routine ‘set’ in their brains which should not be disrupted. This routine was paramount, he argued, and this was the reason why he did not take his father to visit Hemant’s brother in neighbouring Gurgaon. Similarly, one of Parvati’s brothers resided in Delhi nearby to her, but only cared for their mother when his sister went on holidays. Parvati said, “She made it clear initially that she would prefer to stay with me.”

With illness and age, in an urban landscape, in a time of social and economic transformation, and greater dialogue between India and the rest of the world, notions of love also shift. Previous adages of love as contained, habitual, simple, cruel and servile no longer apply. Love is linked to power and framed by age, illness and loss. Its manifestations are gendered and shaped by a history of reciprocity and exchange of bodily substance codes. Love is tragic and pleasurable, less spoken off, and more an emotion that is displayed. Whether in the couples of this study, the parent-child relations, or in the young Delhi romantics on Valentine’s Day, love is neither as contained nor as simple as it used to be. But cruelty, habituation and *seva* still hold and in earlier chapters I have described instances of violence and hurt. Love is also closely related to *seva* and includes the range and depth of families’ commitment and love for each other. Love has been implicit in this thesis and I now make a more explicit

analysis of the links between love and the key themes that have flowed throughout this work: *seva*; the political economy of care; access, citizenship and rights; class and power, agency and disruption; and gender.

## **Key Themes**

Little events, ordinary things, smashed and reconstituted.

Imbued with new meaning.

Suddenly they become the bleached bones of a story.

- Arundhati Roy, *The God of Small Things* (1997, p.32).

Elderly couples shared deep feelings of love for each other. They were bound to each other through the intimacies of care work, power, duty, and affections. **Seva** is a culturally-specific term that encapsulates this work, leaving enough room for intergenerational care as well as carework by spouses. Defined as the intellectual, emotional and physical care of elders based on respect, with such care likened to a form of divine worship, *seva* is a complex cultural category which flows across many practices (Vatuk, 1990). It is explicitly linked to power and discipline in everyday domesticities governing cooking, feeding and eating alongside other activities such as doctor-shopping, the pursuit of an *ilāj*, and bearing the costs associated with caring. *Seva* flows across kin networks and not just between immediate relations. Children, grandchildren, in-laws, extended relatives and fictive kin like attendants, neighbours and friends give and receive *seva* from each other. The elegance of *seva* lies in its intricacies, in how it can hold people together, invoke reciprocity and shared-memory, cultural ideas of love, duty and devotion, while still leaving space to explore the negativities of

care work – the coercion, abuse and surveillance – that transpires within the home.

*Seva* also feeds into the institutions of medicine, law and property, which in turn determine how care should be given and the incentives and admonishments associated with deviating from these standards. In this **political economy of care**, the second major theme of the thesis, the dialectic between the institutions of the state and cultural understandings like *seva* mutually reinforce the family's role in caring. Doctors' prescriptions to relatives to care as the remedy to the dementia diagnosis, the Senior Citizen's Act (2007) which has punitive measures for family members who do not care, and police counsel to the elderly to hold onto their property lest family members stop caring for them, are direct examples of how the state has firmly located the burden and costs of care entirely on the family.

There is also a historically-shaped link between consumption and carer's identities. A 'good' carer is one who will spend money in search of a cure and leave no option untried in biomedicine, traditional and transcendental medicines. To do *seva*, motivated families to endure dominant-subordinate relations in the clinic, incur expenses like medicines and diapers, hire attendants, and strive to give pleasures, large and small, to the person with dementia. The journeys that carers took to try and give their loved one solace and comfort; Nina's trip to Europe for Karamjit's stem cell treatment, Radha and Rajesh's journeys to Kerala, Lakshmi Kumari and her family's return to Pakistan – are such examples.

But corralling the costs of care within the domestic sphere leaves families vulnerable to mercenaries, and stories like Josie's and Su's resonate here. Their narrative reminds us that families' search for help can have exorbitant monetary and emotional costs, and highlights the need for policy makers and doctors to rethink seriously how care and treatment is conceived and delivered. In the world's most unequal democracy, disparities in healthcare delivery, access to services, and treatment by health professionals are more acute and deeply saddening. The question of **access, citizenship and rights** repeats itself throughout this work, with no easy answers. The lack of follow-up of medications for the person with dementia by doctors, ARDSI-DC's privileging of its relationships with its funders over the families, families' exploitation of their attendants, the vulnerability of elderly women in their homes, and failed cases of organ donation, all point to a system in crisis where people are largely left to self-educate and fend for themselves. One may hope with economic development and greater investment in the health sector this may change. But that more money will somehow translate into a better health system for people is questionable. The process will take too long. If past history is any indicator, then corruption, bureaucracy and bribery are likely to way-lay some of these funds. However there is always hope, and comfort may be taken in two small facts: (1) India has a thriving civil society and political freedom wherein critics and activism are vociferous, and (2) the Government is responsive to these voices and has taken steps towards caring for the elderly through additional funding of geriatric services, greater investment in professional training and research for the aged care sector, and the establishment of a National Institute of Ageing (Government of India, 2007).

In terms of the overall health system, rather than focusing only on capital and investment, substantive changes also need to be argued from a rights-based perspective. Injections of funds will not necessarily change the attitudes and approach of providers to people. Class hierarchies are deeply embedded in the social fabric and a western individual-centred approach to human rights and patient rights will not work effectively in India. Instead what is needed is a culture shift that is joined both to the relative political freedoms that Indian citizens enjoy and to the notions of love and *seva* that frame relations. Building on such cultural foundations need not necessitate a static view of culture. As has been shown throughout this thesis, culture in India is far from sticky and unchanging. The way forward is perhaps, as Kleinman (2007; 2008, 2009) advocates, greater integration of the medical humanities with biomedicine, a focus on the art as well as the technicalities of care. Caregiving is a moral practice, inextricably bound with being human, realising another's suffering and one's own agency in alleviating or augmenting that suffering. It is too important a task for health professionals, especially doctors, to shirk. The capacity to care is the underlying premise of social justice and development. And Sen (1999) reminds us development needs to be a process whereby the real freedoms people enjoy is expanded through the removal of unfreedoms like poverty, tyranny and social deprivation. Otherwise, as Pranab Bardhan (2010) evocatively argues, India is an awakening giant with feet of clay.

In analysing these wider **flows of capital (social, fiscal, and knowledge)** that determine health-seeking praxes, I have tried not to be over-deterministic in all my conclusions. The health system in India is an intricate maze shaped by rural-

urban, public-private divides, medical pluralism, doctor shopping, faith in the power of medicine to cure all ills, and a pharma-economy wherein doctors receive kickbacks for poly-pharmaceutical practices. But alongside the negatives, there are positives associated with this paradigm, such as families' sense of hope in proactively searching for a cure, doctors compensating for meagre salaries and long hours, and the benefit that some medicines can actually ameliorate distressing symptoms of the disease. The counsel of our anthropological ancestor, Marcel Mauss, is salient here:

It is a good thing possibly that there exist means of expenditure and exchange other than economic ones ... I believe that we must become, in proportion as we would develop our wealth, something more than better financiers, accountants and administrators. The mere pursuit of individual ends is harmful to the ends and peace of the whole, to the rhythm of its work and pleasures, and hence in the end to the individual (1923 [1966], p.59).

The role of **class** has also been highlighted, but alongside macro-level understandings of poverty and class conflict micro-pockets of **power, agency and disruption** have been built in. Class has been critical, defining the relations between rich and poor, whether as attendants, potentially trafficked organs, or sources of *seva*. In the urban landscape which has formed the backdrop of this thesis, class relations have been bound to wider issues around law and order, property, healthcare consumption, and palliative care practices. Class informs how people construct their realities and live in Delhi. The murder rates which influence people's sense of safety in the city, property wars within families, the

flow of money, and light-fingered attendants serve to create an environment where to be ageing in a city such as Delhi is to experience greater levels of unease and insecurity. Yet as has also been shown, the police, NGOs, communities and attendants also rallied around families to love and support them. When Suneeta's father got lost, a stranger dropped him home; when Shilpi could not care for Gautam and all their children were overseas, Sandra Anu their attendant called Gautam *papa-ji* and did the work; and even after Mrs Sood died, Namita continued to pay for the education of her mother's attendant.

**Gender** has also played its part, structuring the world-view of people with dementia and their carers. Whether the men at work or the women who sing, dance, and raise their children, voice is gendered and capable of agency and relationality. Care-giving is feminised, and I have demonstrated the roles of women, as wives, daughters and daughters-in-law, in undertaking the tasks of daily living. I have tried to show too how men cope with care-work. Though gender influences care-giving practices (e.g. medication administration), both men and women are resilient, active agents in their local worlds. They have numerous responsibilities in a late stage of life and some of these tasks disrupt traditional gender roles and norms. For women, love is very important in how they perceive their roles and explain the transformations that occur in their identities and marital relations. For men, such emotions are less readily admitted but deeply felt.

## Last Words

So where to from here? Ten months and ten days after I begin, I end. I find myself on a plane, returning to Delhi from Kerala to fly away from India. My body and hair is full of coconuts. I have had the famous *Āyurvedic* massage in Kerala. Two women strip me down to nothing and slather me with oil. They touch my head, back, neck, shoulders, breasts, arms, stomach, buttocks, legs, feet and toes. They see every part of me, implore me to relax, to be less 'tight,' but I cannot comply. At the end of my stay in India, I am stark naked and being touched. I have seen and touched so many bodies here. People naked or semi-clothed, dignified and maligned, old bodies and young ones, and yet the matter-of-factness I apply to their bodies I am unable to apply to mine. Perhaps these will be my lessons. That the casualness with which we analyse and evaluate others, in anthropology and the clinic, does not apply to our own lives. That the rhetoric of care and 'expertise' belies an amorphous reality wherein there are few experts, and learning by trial and error is commonplace. That love, power, and *seva* are more intense and complex processes than can be absorbed in the term 'care.' That in an era of globalisation, money and transnationalism, Cohen's (1998) bad family is there but gone, the social ties of Lamb's (2000) Mangaldihi villagers holds but doesn't. That dialogue between India and abroad is occurring at all levels and the conversations are more ambiguous and less certain. I find myself listening incessantly, throughout my last months in Delhi, to a song by an American rock group:

I pack my case  
I check my face  
I look a little bit older

I look a little bit colder  
With one deep breath  
With one big step  
I move a little bit closer  
I move a little bit closer

For reasons unknown  
I caught my stride  
I flew and flied  
I know that if destiny's kind  
I've got the rest of my life  
But my heart, it don't beat  
It don't beat the way it used to  
And my eyes, they don't see you no more  
And my lips, they don't kiss  
They don't kiss the way they used to  
And my eyes don't recognize you no more  
For reasons unknown  
For reasons unknown.

- *For Reasons Unknown*  
by The Killers (2006)



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## APPENDIX 1: ETHICS ACCEPTANCE LETTER



Standing Committee on Ethics in Research Involving Humans (SCERH)  
Research Office

Prof Lenore Manderson  
School of Psychology, Psychiatry & Psychological Medicine  
Faculty of Medicine Nursing & Health Sciences  
Clayton Campus

19 July 2007

**CF07/2018 - 2007/0623 / 2007000623: Understanding dementia care in India**

Dear Researchers,

The Standing Committee on Ethics in Research (SCERH) approved the above project at meeting C4/2007 on 17 July 2007.

### Terms of approval

1. This project is approved for five years from the date of this letter and this approval is only valid whilst you hold a position at Monash University.
2. It is the responsibility of the Chief Investigator to ensure that all information that is pending (such as permission letters from organisations) is forwarded to SCERH, if not done already. Research cannot begin at any organisation until SCERH receives a letter of permission from that organisation. You will then receive a letter from SCERH confirming that we have received a letter from each organisation.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by SCERH.
4. You should notify SCERH immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project:** Changes to any aspect of the project require the submission of a Request for Amendment form to SCERH and must not begin without written approval from SCERH. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. Please provide the Committee with an Annual Report determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. SCERH should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by SCERH at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

All forms can be accessed at our website [www.monash.edu.au/research/ethics/human/index.html](http://www.monash.edu.au/research/ethics/human/index.html)

We wish you well with your research.

A handwritten signature in blue ink, appearing to read "S. Houssami".

Dr Souheir Houssami  
Executive Officer, Human Research Ethics (on behalf of SCERH)

Cc: Ms Bianca Brijnath

## **APPENDIX 2: INTERVIEW GUIDE**

### **Families – First Interview**

- What was the person like before the dementia?
- How have they changed? When did you start to notice these changes? What made you think something was wrong? Tell me about what you initially did? Then what happened?
- Tell me about when you first decided to go to the doctor for the dementia? Tell me about how the person got diagnosed with dementia? What did the doctor tell you? How did you feel about hearing this information?
- How did other people around you react? What about the person with dementia? What do you think about these reactions at the time? How do you feel about them now?
- How has your understanding of dementia changed since after the diagnosis?
- How did you hear about the Alzheimer's and Related Disorders Society (ARDSI)? What sort of support do they give you? How has that helped?

### **Families – Follow-up Interviews**

- From the moment they wake up to the time they go to sleep, tell me about a typical day for the person with dementia? What do you find especially difficult?
- Tell me more about ... feeding/bathing/toileting etc. What do you do to manage it? How do others in your family react to these types of situations? How do you respond to these reactions?
- What sort of changes have you made to adjust to the dementia? How do you

think this has affected you and your family?

- Does anyone else help you in caring? What do they do? How does that help?
- What do you do for fun? Tell me about some of your experiences of caring which makes you feel good/smile? Tell me about good days with the person with dementia?

### **Key Service Providers**

- How and when did you hear about dementia?
- Tell me about when you first met a person with dementia? (If healthcare professional – can you tell me about the process of diagnosis?) How did the family and/or person with dementia respond?
- What are the key issues that families report to you? Then what do you do?
- If health professional/healer: what sorts of medications do you usually prescribe? Why? Do you know what other health practitioners families with a person with dementia have seen prior to seeing you? Do you think families seek alternative treatments? What sorts? What do you think about that? What are the present shortcomings in the health/care system? How do you think the medical community perceives dementia?
- How do you think the public perceives dementia? What do they think of the families? How does this affect some of the families you see?
- What do you think needs to be done in your profession to improve things?
- What sort of things need to be done more broadly to improve support to people with dementia and their families?



24<sup>th</sup> May 2007

Explanatory Statement – **Carers for a Person with Dementia**

**Title:** Understanding dementia care in India

**IMPORTANT NOTE:** Distress, due to recent life events may occur (unawares to the researcher) and if so, please discontinue reading about the following research.

**This information sheet is for you to keep.**

***Who am I?***

My name is Bianca Brijnath and I am conducting a research project as part of my PhD studies at Monash University in Melbourne, Australia. This means that I will be writing a thesis which is the equivalent of a 300 page book. My supervisors are Professor Lenore Manderson from the School of Psychology, Psychiatry and Psychological Medicine at Monash University and also Dr. Deepak Mehta from Delhi School of Sociology in India. I have received funding from Monash University and Alzheimer's Australia to support this work.

***What is my study about?***

As you would know from discussions with the Alzheimer's and Related Disorders Society of India or with other members in your household, my study is about families' day-to-day experiences of caring for a person with age-related dementia. I am interested in learning from you about how you manage care work, how your life has changed as a result of caring and who helps you to care. The results of the study are expected to provide evidence of what sorts of help is available and what needs to be improved in order to provide better support to families.

***Can you participate?***

If you are between the ages of 16 – 75 and currently have or have had full or partial responsibility for caring for a person who has been clinically diagnosed with dementia, I would like to invite you to participate in my research.

***What does the research involve?***

If you agree, you will be asked to participate in an interview where I will ask specific questions about your daily experiences of caring for your family member with dementia, what help (if any) that you receive, and what you think should be done to help families caring for a person with dementia.

***How much time will the research take?***

The interview will occur at a time and place that is convenient for you and will take approximately one hour. With your permission I would like to record our conversation so that I have all the information and do not miss out on important things you say.

A special note for full-time carers: If caring for your family member with dementia has been mainly your responsibility, I would like to talk more with you to get a better understanding of your experiences. This will involve two more interviews with me after every 3 to 4 months.

***What if you decide to participate but then change your mind?***

Your participation in this study is completely voluntary. If you do not want to participate or withdraw from the study, you can do so at any time before December 2008. All unprocessed information that you previously provided will also be destroyed.

***How will your privacy be protected?***

I will not use your name, or that of anyone you mention, in any discussions of the research or in

### APPENDIX 3: EXPLANATORY STATEMENT AND CONSENT FORMS (ENGLISH)

any reports that come out of the project. I will also remove or disguise information which might identify you. No one else will have access to the audio tapes. My supervisor may see the written transcripts, but only after I have removed all identifying information. In accordance with University regulations the tape and transcript will be kept on University premises in a locked cupboard/filing cabinet for 5 years. You should be aware that I can only protect your confidentiality within the limits of the law.

#### ***How will you know the study results?***

Upon request, I will be happy to provide you with a summary of the findings at the end of the project. Please note that I will use your data in a totally de-identified and anonymous form in all documents and for teaching purposes.

#### ***Distress and Inconvenience***

Talking about experiences of caring for a family member with dementia can sometimes be difficult and upsetting. If any at stage you wish to avoid answering questions which you feel to be too personal or intrusive or you feel that you cannot continue please tell me. If you think you need some extra help and support, let me know and I can help you contact the Alzheimer's and Related Disorders Society of India on <phone number to be inserted>. Alternatively, if you would like help from elsewhere, I can help you to find a counsellor to talk with.

#### ***Complaints***

If you have a complaint concerning the manner in which this research <project number here> is being conducted, please contact:

The Alzheimer's and Related Disorders Society of India, Guruvayur Road, P. B. No. 53 Kunnamkulam - 680 503 Kerala Tel: 04885 – 223801 Fax: 04885 – 222347 office@alzheimer-india.org	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans (SCERH) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au
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Thank you for your time.  
<insert signature>

Bianca Brijnath  
PhD Candidate  
School of Psychology, Psychiatry and Psychological Medicine  
Faculty of Medicine, Nursing and Health Sciences  
Monash University  
Tel: <insert local mobile number>  
Email: [bianca.brijnath@med.monash.edu.au](mailto:bianca.brijnath@med.monash.edu.au)



Consent Form – **Carers for a Person with Dementia**

Title: ***Understanding dementia care in India***

**NOTE:** This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have understood the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that:

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| 1. I agree to be interviewed by the researcher                          | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. I agree to allow the interview to be audio-taped                     | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. I agree to make myself available for a further interview if required | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

I understand that my participation is voluntary and that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project.

I understand that any data from the interview for use in reports or published findings will not contain names or identifying characteristics.

**Participant's name**

**Signature**

**Date**



Consent Form – **Parental Consent Form for Young People Between 16-17 years**

Title: ***Understanding dementia care in India***

**NOTE:** This consent form will remain with the Monash University researcher for their records

I agree that my child/guardian may take part in the above Monash University research project.

The project has been explained to my child/guardian and to me, and I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that I am willing to allow my child/guardian to:

- Be interviewed by the researcher  Yes  No
- Have the interview audio-taped  Yes  No

Child's name:

Child's Age:

Parent's / Guardian's Name:

Parent's / Guardian's relationship to participant:

Parent's / Guardian's Signature

Date

### APPENDIX 3: EXPLANATORY STATEMENT AND CONSENT FORMS (ENGLISH)



#### Protocol to Minimise Interview Distress for a Person with Dementia

Your family member who has dementia has approached either the researcher or you and has asked to be interviewed. In order to ensure everyone's safety please read and complete the following steps with the researcher:

1. I agree to have visible contact of the interview
2. I have informed the researcher of the early signs of distress. Please note here the early signs of distress:

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3. I agree to stop the interview if these signs become present
4. The researcher can request my presence if she feels < *insert person with dementia's name* > is becoming distressed
5. The researcher can assist me to relocate < *insert person with dementia's name* > to a space that they are comfortable in
6. The researcher can assist me in calming < *insert person with dementia's name* > down.

I agree that < *insert person with dementia's name* > may take part in the above Monash University research project.

The project has been explained to him/her and to me, and I have read the Explanatory Statement, which I will keep for my records. I understand that agreeing to let < *insert person with dementia's name* > take part means that I am agreeing to:

- Abide by the *Protocol to Minimise Interview Distress for a Person with Dementia*  Yes  No
- Allow < *insert person with dementia's name* > to be interviewed by the researcher  Yes  No
- Have the interview audio-taped  Yes  No

Carer's Name:

Carer's relationship to participant:

Carer's Signature:

Date:



24<sup>th</sup> May 2007

Invitation to participate in a research study into  
**Understanding Dementia Care in India**

To:  
<insert title and address of key service provider>

Dear Sir/Madam,

My name is Bianca Brijnath and I am conducting a research project on 'Understanding Dementia Care in India' as part of my PhD studies at Monash University in Melbourne, Australia. I am supervised by Professor Lenore Manderson from the School of Psychology, Psychiatry and Psychological Medicine at Monash University and also by Dr. Deepak Mehta from Delhi School of Sociology in India. I have received funding from Monash University and <Alzheimer's Australia (pending)> to support this work.

I have identified you either through a public domain (websites, newspaper) or by another key service provider as being an expert in dementia care in India and would like to invite you to participate in my study. I am interested in your opinion about the experiences of caring for a person with age-related dementia, the kinds of support that families need and the barriers encountered in obtaining this help. The results of the study are expected to contribute towards the evidence-base for developing initiatives to better support carers and people with dementia.

If you agree, I will interview you at a time and place that is convenient for you. The interview is expected to take approximately one hour and with your permission I would like to record our conversation so that I have all the information and do not miss out on important things you say. Upon request, I will be happy to provide you with a summary of the overall findings at the end of the project. Your data will be used in academic publications, conferences and for teaching purposes.

It is your choice about whether you wish to be identified fully, partially or not at all. If you wish to be fully or partially identified in the research I will request you to sign a Consent Form and also provide you with a copy of the interview transcript for any additional comments. If you do not wish to sign a Consent Form or do not wish to be identified I will take all necessary steps to protect your privacy. This means that I will not use your name, or that of anyone you mention, in any discussions of the research or in any reports that come out of the project. I will also remove or disguise information which might identify you. No one else will have access to the audio tapes. My supervisors may see the written transcripts, but only after I have removed all identifying information. In accordance with Monash University regulations the tape and transcript will be kept on University premises in a locked cupboard/filing cabinet for 5 years. You should be aware that I can only protect your confidentiality within the limits of the law.

Your participation in this study is completely voluntary. If you do not want to participate or wish to withdraw from the study, you can do so at any time before December 2008. All unprocessed information that you previously provided will also be destroyed. You do not have to answer any questions which you feel to be too personal or intrusive or if you feel that you cannot continue please tell me. If you think you need some

### APPENDIX 3: EXPLANATORY STATEMENT AND CONSENT FORMS (ENGLISH)

extra help and support, please let me know and I can help you contact the Alzheimer's and Related Disorders Society of India on <phone number to be inserted>. Alternatively, if you would like help from elsewhere, I can help you to find a counsellor to talk with.

If you are unhappy or if you have a complaint concerning the manner in which this research <project number here> is being conducted, please contact:

<p>The Alzheimer's and Related Disorders Society of India, Guruvayur Road, P. B. No. 53 Kunnamkulam - 680 503 Kerala</p> <p>Tel: 04885 – 223801 Fax: 04885 – 222347 office@alzheimer-india.org</p>	<p>Human Ethics Officer Standing Committee on Ethics in Research Involving Humans (SCERH) Building 3e Room 111 Research Office Monash University VIC 3800</p> <p>Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au</p>
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I hope that you will consider participating in my research and I look forward to meeting with you.

Thank you in advance for your time.

With regards,

<insert signature>

Bianca Brijnath  
PhD Candidate  
School of Psychology, Psychiatry and Psychological Medicine  
Faculty of Medicine, Nursing and Health Sciences  
Monash University

Tel: <insert local mobile number>

Email: [bianca.brijnath@med.monash.edu.au](mailto:bianca.brijnath@med.monash.edu.au)

**This information is for you to keep.**



Consent Form – **Key Service Providers for a Person with Dementia or their Carers**

Title: ***Understanding dementia care in India***

**NOTE:** This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have understood the Explanatory Letter, which I will keep for my records. I understand that agreeing to take part means that:

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| 4. I agree to be interviewed by the researcher                    | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. I agree to allow the interview to be audio-taped               | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. I agree to be identified either partially or fully in the data | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

I understand that in choosing to be fully or partially identified I will be given a transcript of the data concerning me for my approval before it is included in the write up of the research.

I understand that my participation is voluntary and that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project.

Participant's name:

Signature:

Date:



व्याख्यात्मक विवरण - डिमेन्शिया ( याददाश्त खोना ) से पीड़ित व्यक्ति के देखभालकर्ता के लिए

**शीर्षक** - भारत में डिमेन्शिया से पीड़ित व्यक्ति की देखभाल को समझना

**महत्वपूर्ण नोट** : जीवन की ताजा घटनाओं के कारण दुःख हो सकता है ( जिसके बारे में शोधकर्ता अवगत नहीं है ) और यदि ऐसा है तो निम्नलिखित शोध को पढ़ना बंद कर दें

यह सूचना शीट आपके पास रखने के लिए है।

**मैं कौन हूँ ?**

मेरा नाम बियान्का ब्रिजनाथ है और आस्ट्रेलिया के मेलबोर्न स्थित मोनाश यूनिवर्सिटी में पीएच डी के एक अंग के बतौर मैं एक शोध परियोजना चला रहा हूँ। इसका मतलब यह है कि मैं एक थीसिस ( शोध प्रबंध ) लिखूंगा, जो 300 पृष्ठों की एक पुस्तक के बराबर होगी। मोनाश यूनिवर्सिटी में स्कूल ऑफ साइकोलॉजी, साइकियाट्री एंड साइकोलॉजिकल मेडिसिन के प्रोफेसर लेनोर मॅडरसन के साथ-साथ भारत में दिल्ली यूनिवर्सिटी के डा. दीपक मेहता भी मेरे सुपरवाइजर ( पर्यवेक्षक ) हैं। इस कार्य के लिए मैंने मोनाश यूनिवर्सिटी और आस्ट्रेलियन फेडरल गवर्नमेंट से वित्तीय सहायता प्राप्त की है।

**मेरा अध्ययन किस बारे में है ?**

जैसाकि आप अल्जीमर्स एंड रिलेटेड डिस्ऑर्डर्स सोसायटी ऑफ इंडिया या आपके परिवार के साथ चर्चा से जानते होंगे, मेरा अध्ययन आयु से जुड़े डिमेन्शिया से पीड़ित व्यक्ति की देखभाल संबंधी परिवारों के रोजाना के अनुभवों के बारे में है। मेरी यह जानने में दिलचस्पी है कि आप देखभाल का कार्य कैसे करते हैं, देखभाल के परिणामस्वरूप आपका जीवन किस तरह बदल गया है और देखभाल में आपकी मदद कौन करता है। इस अध्ययन के नतीजों से यह प्रमाण मिलने की आशा है कि किस तरह की मदद उपलब्ध है और परिवारों को बेहतर समर्थन देने के लिए क्या सुधार किए जाने चाहिए।

**क्या आप भाग ले सकते हैं ?**

यदि आपकी आयु 16-75 वर्ष के बीच है और वर्तमान में या इससे पहले किसी ऐसे व्यक्ति की देखभाल की पूरी या आंशिक जिम्मेदारी निभाई है, जो नैदानिक जांच में डिमेन्शिया से पीड़ित पाया गया हो तो मैं अपने शोध में भाग लेने के लिए आपको आमंत्रित करता हूँ।

**शोध में क्या करना होगा ?**

यदि आप सहमत हैं तो आपसे एक साक्षात्कार में भाग लेने को कहा जाएगा, जिसमें मैं आपसे डिमेन्शिया से पीड़ित आपके परिवार के सदस्य की देखभाल संबंधी आपके दैनिक अनुभवों के बारे में विशेष सवाल पूछूंगा, आप क्या मदद ( यदि कोई हो ) पाते हैं, और डिमेन्शिया से पीड़ित व्यक्ति की देखभाल करने वाले परिवारों की मदद के लिए आपके अनुसार क्या किया जाना चाहिए।

**इस शोध में कितना समय लगेगा ?**

यह साक्षात्कार ऐसे समय पर किया जाएगा, जो आपके लिए सुविधाजनक हो और इसमें लगभग एक घंटा लगेगा। हमारी बातचीत को मैं रिकॉर्ड करना चाहूंगा ताकि मेरे पास सारी सूचनाएं रहें और आपके द्वारा कही गई कोई भी महत्वपूर्ण बात छूट न जाए।

पूर्णकालिक देखभालकर्ताओं के लिए एक विशेष नोट : यदि डिमेन्शिया से पीड़ित आपके परिवार के सदस्य की देखभाल की जिम्मेदारी मुख्यतः आपकी है तो मैं आपके अनुभवों को बेहतर ढंग से समझने के लिए आपके साथ अधिक बातचीत करना चाहूंगा। दो अतिरिक्त साक्षात्कार प्रत्येक 3 से 4 महीने बाद करने होंगे।

**यदि आप भाग लेने का फैसला करते हैं, लेकिन उसके बाद फैसला बदल देते हैं तो क्या होगा ?**

इस अध्ययन में भागीदारी पूरी तरह से स्वैच्छिक है। यदि आप भाग नहीं लेना चाहते हैं या इस अध्ययन से हटना चाहते हैं तो आप दिसंबर, 2008 से पहले कभी भी यह कर सकते हैं। आपके द्वारा पहले दी गई जिन सूचनाओं को प्रोसेस ( जांच ) नहीं किया गया है, उन्हें नष्ट कर दिया जाएगा।

## APPENDIX 4: EXPLANATORY STATEMENT AND CONSENT FORMS (HINDI)

### आपकी प्राइवैसी ( निजता ) की रक्षा कैसे की जाएगी ?

मैं आपके नाम, या जिस किसी का आप जिक्र करेंगे, उसके नाम का इस्तेमाल शोध की किसी चर्चा या परियोजना के बारे में निकलने वाली रिपोर्ट्स में नहीं करूंगा। मैं उस सूचना को भी हटा या छिपा दूंगा, जिससे आपकी पहचान की जा सकती है। किसी अन्य व्यक्ति की ऑडियो टेप्स तक पहुंच नहीं होगी। मेरा सुपरवाइजर लिखित ट्रांसक्रिप्ट (प्रतिलिपि) को देख सकता है, लेकिन पहचान संबंधी सभी सूचना हटाने के बाद ही उसे देख सकेगा। यूनिवर्सिटी के विनियमों के अनुसार टेप और ट्रांसक्रिप्ट 5 वर्ष तक यूनिवर्सिटी के परिसर में तालाबंद कपबोर्ड/फाइलिंग कैबिनेट में रखे जाएंगे। आपको मालूम होगा कि मैं कानून की सीमाओं के भीतर ही आपकी गोपनीयता की रक्षा कर सकता हूँ।

### अध्ययन के नतीजों के बारे में आप कैसे जानेंगे ?

यह परियोजना पूरी होने के बाद आपके अनुरोध पर निष्कर्षों का सारांश आपको देने में मुझे खुशी होगी। कृपया ध्यान दें कि मैं आपसे जुड़े डाटा का इस्तेमाल सभी दस्तावेजों में पूरी तरह से वि-पहचानीकृत (डि-आइडेन्टिफाइड) और गुमनाम तरीके से तथा अध्यापन के उद्देश्यों से करूंगा।

### कष्ट और असुविधा

डिमेन्शिया से पीड़ित व्यक्ति के परिवार के किसी सदस्य के देखभाल के अनुभवों के बारे में बातचीत कभी-कभी कठिन और तकलीफदेह बन सकती है। यदि किसी चरण में आप उन सवालों के जवाब टालना चाहें, जिनके बारे में आप महसूस करें कि आप जवाब देना जारी नहीं रख सकते तो कृपया मुझे बताएं। यदि आप सोचें कि आपको अतिरिक्त मदद और समर्थन की जरूरत है तो मुझे बताएं और मैं फोन नंबर- +91-1126167202 पर अल्जीमर्स एंड रिलेटेड डिसऑर्डर्स सोसायटी ऑफ इंडिया से संपर्क करने में आपकी मदद कर सकता हूँ। वैकल्पिक रूप से, यदि आप अन्य जगह से मदद चाहें तो वहां बातचीत करने के लिए मैं एक काउंसलर (परामर्शदाता) पाने में आपकी मदद कर सकता हूँ।

### शिकायतें

यदि इस शोध सी एफ ओ 7/2018 - 2007/623/ 2007000623 के संचालन के तरीके को लेकर आपकी कोई शिकायत हो तो कृपया निम्नांकित पते पर संपर्क करें :

द अल्जीमर्स एंड रिलेटेड डिसऑर्डर्स सोसायटी ऑफ इंडिया - देहली चैप्टर 163, कैलाश हिल्स नई दिल्ली-110065 टेलीफोन : +91 1126167202 फैक्स : 04885 - 222347 ईमेल : ardsidc@hotmail.com	ह्यूमन इथिक्स ऑफिसर स्टैंडिंग कमेटी ऑन इथिक्स इन रिसर्च इनवोल्विंग ह्यूमन्स (एससीईआरएच) बिल्डिंग 3 ई रूम 111 रिसर्च ऑफिस मोनाश यूनिवर्सिटी वीआईसी 3800 टेलीफोन : +61 39905 2052 फैक्स : 61 39905 1420 ईमेल : scerh@adm.monash.edu.au
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समय देने के लिए आपको धन्यवाद।

बियान्का ब्रिजनाथ

पीएच डी प्रत्याशी

स्कूल ऑफ साइकोलॉजी, साइकियाट्री एंड साइकोलॉजिकल मेडिसिन

फैकल्टी ऑफ मेडिसिन, नर्सिंग एंड हैल्थ साइंसेज

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सहमति फॉर्म - डिमेन्शिया से पीड़ित व्यक्ति के देखभालकर्ता

शीर्षक: भारत में डिमेन्शिया से पीड़ित व्यक्ति की देखभाल को समझना

नोट : यह सहमति फॉर्म मोनाश यूनिवर्सिटी के पास अपने रिकॉर्ड्स के लिए रहेगा।

मैं ऊपर बताई गई मोनाश यूनिवर्सिटी की शोध परियोजना में भाग लेने को सहमत हूँ। इस परियोजना के बारे में मुझे बताया गया है, और मैंने व्याख्यात्मक विवरण को समझ लिया है, जिसे मैं अपने पास रिकॉर्ड के लिए रखूंगा। मैं समझता हूँ कि भाग लेने को सहमत होने का मतलब है कि :

1. मैं शोधकर्ता द्वारा साक्षात्कार लेने के बारे में सहमत हूँ।  हां  नहीं
2. मैं साक्षात्कार को ऑडियो-टैप किए जाने की इजाजत देने पर सहमत हूँ।  हां  नहीं
3. यदि जरूरी हुआ तो एक अगले साक्षात्कार के लिए मैं उपलब्ध रहने के लिए सहमत हूँ।  हां  नहीं

मैं समझता हूँ कि मेरी भागीदारी स्वैच्छिक है, तथा मैं यह चयन कर सकता हूँ कि परियोजना के किसी भाग में आंशिक या पूरी तरह से भाग न लूं और मैं परियोजना के किसी चरण में अपने आपको हटा सकता हूँ।

मैं समझता हूँ कि साक्षात्कार के किसी भी डाटा का इस्तेमाल रिपोर्ट्स या प्रकाशित निष्कर्षों में नाम या पहचानात्मक लक्षण के तौर पर नहीं किया जाएगा।

भाग लेने वाले का नाम

हस्ताक्षर

तारीख

## APPENDIX 4: EXPLANATORY STATEMENT AND CONSENT FORMS (HINDI)



सहमति फॉर्म - 16-17 वर्ष की आयु के बीच के युवा लोगों के अभिभावकों की सहमति

नोट : यह सहमति फॉर्म मोनाश यूनिवर्सिटी के पास अपने रिकॉर्ड्स के लिए रहेगा।

नोट : यह सहमति फॉर्म मोनाश यूनिवर्सिटी के पास अपने रिकॉर्ड्स के लिए रहेगा।

मैं सहमत हूँ कि मेरा बच्चा/ संरक्षक मोनाश यूनिवर्सिटी की ऊपर बताई गई शोध परियोजना में भाग ले सकता है।

इस परियोजना के बारे में मेरे बच्चे/संरक्षक व मुझको बताया गया है, और मैंने व्याख्यात्मक विवरण को पढ़ लिया है, जिसे मैं अपने पास रिकॉर्ड के लिए रखूंगा। मैं समझता हूँ कि इसमें भाग लेने का मतलब यह है कि मैं अपने बच्चे/संरक्षक को इसकी इजाजत देने का इच्छुक हूँ :

- |  |                              |                               |
|--|------------------------------|-------------------------------|
| ▪ शोधकर्ता द्वारा साक्षात्कार लेने के बारे में | <input type="checkbox"/> हां | <input type="checkbox"/> नहीं |
| ▪ साक्षात्कार का ऑडियो टेप करने के बारे में    | <input type="checkbox"/> हां | <input type="checkbox"/> नहीं |

बच्चे का नाम :

बच्चे की आयु :

अभिभावक / संरक्षक का नाम :

अभिभावक / संरक्षक का भाग लेने वाले के साथ संबंध :

अभिभावक / संरक्षक के हस्ताक्षर

तारीख :

## APPENDIX 4: EXPLANATORY STATEMENT AND CONSENT FORMS (HINDI)



### डिमेन्शिया से पीड़ित व्यक्ति के बारे में साक्षात्कार के दौरान कष्ट कम करने का प्रोटोकॉल

डिमेन्शिया से पीड़ित आपके परिवार के सदस्य ने शोधकर्ता या आपसे बातचीत की है और आपको साक्षात्कार देने को कहा है। प्रत्येक की सुरक्षा सुनिश्चित करने के लिए कृपया शोधकर्ता के साथ निम्नलिखित चरणों को पढ़ें और उन्हें पूरा करें :

1. मैं साक्षात्कार के बारे में प्रत्यक्ष संपर्क करने के लिए सहमत हूँ।
2. मैंने कष्ट के प्रारंभिक चिन्हों के बारे में शोधकर्ता को सूचित कर दिया है। कृपया कष्ट के प्रारंभिक चिन्हों के बारे में यहां नोट करें :

- 
3. यदि ये चिन्ह मौजूद होते हैं तो मैं साक्षात्कार बंद करने पर सहमत हूँ।
  4. शोधकर्ता मेरी मौजूदगी के लिए अनुरोध कर सकता है, यदि वह महसूस करता है कि .....कष्टकारी होता जा रहा है।
  5. शोधकर्ता मुझे किसी ऐसे दूसरे स्थान ..... के बारे में सहायता कर सकता है, जो उनके लिए सुविधाजनक हो।
  6. शोधकर्ता मुझे ..... सांत्वना देकर शांत कराने में सहायता दे सकता है।

मैं सहमत हूँ कि ..... मोनाश यूनिवर्सिटी की शोध परियोजना में भाग ले सकता है।

इस परियोजना के बारे में उसे और मुझे बता दिया गया है, और मैंने व्याख्यात्मक विवरण पढ़ लिया है, जो मैं रिकॉर्ड के लिए अपने पास रखूंगा। मैं समझता हूँ कि <यहां डिमेन्शिया से पीड़ित व्यक्ति का नाम लिखें> को भाग लेने के लिए सहमत होने का मतलब है कि मैं इन बातों के प्रति सहमत हूँ :

- डिमेन्शिया से पीड़ित व्यक्ति के बारे में साक्षात्कार के दौरान कष्ट कम करने के प्रोटोकॉल का पालन करूंगा।  हां  नहीं
- शोधकर्ता द्वारा ..... का साक्षात्कार करने की इजाजत देता हूँ।  हां  नहीं
- साक्षात्कार का ऑडियो-टैप किया जाए।  हां  नहीं

देखभालकर्ता का नाम :

देखभालकर्ता का भाग लेने वाले के साथ संबंध:

देखभालकर्ता के हस्ताक्षर :

तारीख :



भारत में डिमेन्शिया पीड़ित व्यक्ति की देखभाल को समझने के लिए  
एक शोध अध्ययन में भाग लेने संबंधी आमंत्रण

सेवा में :

प्रिय महोदय/ महोदया,

मेरा नाम बियान्का ब्रिजनाथ है और मैं आस्ट्रेलिया के मेलबोर्न स्थित मोनाश यूनिवर्सिटी में पीएच डी अध्ययन के अंग के बतौर में भारत में डिमेन्शिया से पीड़ित व्यक्ति की देखभाल पर एक शोध परियोजना चला रहा हूँ। मोनाश यूनिवर्सिटी में स्कूल ऑफ साइकोलॉजी, साइकियाट्री एंड साइकोलॉजिकल मेडिसिन के प्रोफेसर लेनोर् मैडरसन के साथ-साथ भारत में दिल्ली यूनिवर्सिटी के डा. दीपक मेहता भी मेरा सुपरवाइजिंग कर रहे हैं। इस कार्य के लिए मैंने मोनाश यूनिवर्सिटी और आस्ट्रेलियन फेडरल गवर्नमेंट से वित्तीय सहायता प्राप्त की है।

मैंने एक सार्वजनिक क्षेत्र (वेबसाइट, समाचार पत्र) या अन्य प्रमुख सेवाप्रदाता के माध्यम से भारत में डिमेन्शिया से पीड़ित व्यक्ति की देखभाल के बारे में एक विशेषज्ञ के रूप में आपकी निशानदेही की है। मैं आपको अपने अध्ययन में भाग लेने के लिए आमंत्रित करता हूँ। आयु से जुड़े डिमेन्शिया से पीड़ित व्यक्ति की देखभाल, उनके परिवारों को जिस तरह की मदद की जरूरत है, और यह मदद पाने में आने वाली अड़चनों के बारे में आपके विचारों को जानने में मेरी दिलचस्पी है। इस अध्ययन के नतीजों से आशा है कि देखभालकर्ताओं और डिमेन्शिया से पीड़ित व्यक्ति को बेहतर समर्थन दिलाने के लिए प्रमाण-आधारित पहलें विकसित करने की दिशा में योगदान मिलेगा।

यदि आप सहमत होते हैं तो मैं एक ऐसे समय और स्थान पर आपसे साक्षात्कार करूंगा, जो आपके लिए सुविधाजनक है। इस साक्षात्कार में लगभग एक घंटा लगेगा और आपकी इजाजत से मैं हमारी बातचीत को रिकॉर्ड करना चाहूंगा ताकि मेरे पास सारी सूचनाएं रहें और आप जो कहेंगे, उनमें से कोई बात छूट न जाए। इस परियोजना के पूरी होने पर समग्र निष्कर्षों का सारांश आपके अनुरोध पर देने में मुझे खुशी होगी। आपके डाटा का इस्तेमाल प्रकाशनों, सम्मेलनों में और अध्यापन के उद्देश्यों से किया जाएगा।

यह आपकी पसंद पर निर्भर करेगा कि आपकी पहचान- पूरी, आंशिक या बिल्कुल नहीं दी जाए। यदि आप शोध में पूरी तरह या आंशिक रूप से पहचान देना चाहते हैं तो मैं आपसे एक सहमति फॉर्म पर हस्ताक्षर करने का अनुरोध करूंगा, और किसी भी अतिरिक्त टिप्पणी के लिए साक्षात्कार की प्रतिलिपि भी दूंगा। यदि आप सहमति फॉर्म पर हस्ताक्षर नहीं करना चाहते या पहचान नहीं देना चाहते तो मैं आपकी प्राइवसी की रक्षा के लिए सभी जरूरी कदम उठाऊंगा। इसका मतलब है कि मैं आपके नाम, या जिस किसी का आप जिक्र करेंगे, उसके नाम का इस्तेमाल शोध की किसी चर्चा या परियोजना के बारे में निकलने वाली रिपोर्ट्स में नहीं करूंगा। मैं उस सूचना को भी हटा या छिपा दूंगा, जिससे आपकी पहचान की जा सकती है। किसी अन्य व्यक्ति की ऑडियो टेप्स तक पहुंच नहीं होगी। मेरा सुपरवाइजर लिखित ट्रांसक्रिप्ट (प्रतिलिपि) को देख सकता है, लेकिन पहचान संबंधी सभी सूचना हटाने के बाद ही उसे देख सकेगा। यूनिवर्सिटी के विनियमों के अनुसार टेप और ट्रांसक्रिप्ट 5 वर्ष तक यूनिवर्सिटी के परिसर में तालाबंद कपबोर्ड/ फाइलिंग कैबिनेट में रखे जाएंगे। आपका मालूम होगा कि मैं कानून की सीमाओं के भीतर ही आपकी गोपनीयता की रक्षा कर सकता हूँ।

इस अध्ययन में भागीदारी पूरी तरह से स्वैच्छिक है। यदि आप भाग नहीं लेना चाहते हैं या इस अध्ययन से हटना चाहते हैं तो आप दिसंबर, 2008 से पहले कभी भी यह कर सकते हैं। आपके द्वारा पहले दी गई जिन सूचनाओं को प्रोसेस (जांच) नहीं किया गया है, उन्हें नष्ट कर दिया जाएगा। आपको किसी ऐसे सवाल का जवाब नहीं देना पड़ेगा, जिसके बारे में आप महसूस करते हैं कि वह अत्यंत निजी सवाल है या अतिक्रमणकारी है या यदि आप महसूस करते हैं कि आप सवालों के जवाब देना जारी नहीं रख सकते तो कृपया मुझे बताएं। यदि आप सोचें कि आपको अतिरिक्त मदद और समर्थन की जरूरत है तो मुझे बताएं और मैं फोन नंबर- +91-1126167202 पर अलजीमर्स एंड रिलेटेड डिसऑर्डर्स सोसायटी ऑफ इंडिया से संपर्क करने में आपकी मदद कर सकता हूँ। वैकल्पिक रूप से, यदि आप अन्य जगह से मदद चाहें तो वहां बातचीत करने के लिए मैं एक काउंसलर (परामर्शदाता) पाने में आपकी मदद कर सकता हूँ।

यदि आप नाखुश है या इस शोध सी एफ ओ 7/2018 - 2007/623/ 2007000623 के संचालन के तरीके को लेकर आपकी कोई शिकायत हो तो कृपया निम्नांकित पते पर संपर्क करें :

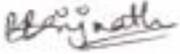
## APPENDIX 4: EXPLANATORY STATEMENT AND CONSENT FORMS (HINDI)

<p>द अल्जीमर्स एंड रिलेटेड डिसऑर्डर्स सोसायटी ऑफ इंडिया - देहली चैप्टर 163, कैलाश हिल्स नई दिल्ली-110065</p> <p>टेलीफोन : +91 1126167202 फैक्स : 04885 - 222347 ईमेल : ardsidc@hotmail.com</p>	<p>ह्युमन इथिक्स ऑफिसर स्टैंडिंग कमेटी ऑन इथिक्स इन रिसर्च इनवोल्विंग ह्यूमन्स (एससीईआरएच) बिल्डिंग 3 ई रूम 111 रिसर्च ऑफिस मोनाश यूनिवर्सिटी वीआईसी 3800</p> <p>टेलीफोन : +61 39905 2052 फैक्स : +61 39905 1420 ईमेल : scerh@adm.monash.edu.au</p>
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मुझे आशा है कि आप मेरे शोध में भाग लेने पर विचार करेंगे और मुझे आपसे भेंट का इंतजार रहेगा।

समय देने के लिए आपको धन्यवाद।

आदर सहित,



बियान्का ब्रिजनाथ  
पीएच डी प्रत्याशी  
स्कूल ऑफ साइकोलॉजी, साइकियाट्री एंड साइकोलॉजिकल मेडिसिन  
फैकल्टी ऑफ मेडिसिन, नर्सिंग एंड हेल्थ साइंसेज  
मोनाश यूनिवर्सिटी

टेलीफोन : +91 9990295958

ईमेल : bianca.brijnath@med.monash.edu.au

यह सूचना आपके रखने के लिए है।

## APPENDIX 4: EXPLANATORY STATEMENT AND CONSENT FORMS (HINDI)



सहमति फॉर्म - डिमेन्शिया से पीड़ित व्यक्ति या उनके देखभालकर्ताओं के प्रमुख सेवा-प्रदाता

शीर्षक : भारत में डिमेन्शिया से पीड़ित व्यक्ति की देखभाल को समझना

नोट : यह सहमति फॉर्म मोनाश यूनिवर्सिटी के शोधकर्ता के पास उसके रिकॉर्ड के लिए रहेगा।

मैं ऊपर बताई गई मोनाश यूनिवर्सिटी की शोध परियोजना में भाग लेने पर सहमत हूँ। इस परियोजना के बारे में मुझे बताया गया है और मैंने व्याख्यात्मक पत्र को समझ लिया है, जिसे मैं अपने पास रिकॉर्ड के लिए रखूंगा। मैं समझता हूँ कि इसमें भाग लेने के लिए सहमत होने का मतलब है कि :

1. मैं शोधकर्ता द्वारा साक्षात्कार लेने के बारे में सहमत हूँ।  हां  नहीं
2. मैं साक्षात्कार को ऑडियो-टैप किए जाने की इजाजत देने पर सहमत हूँ।  हां  नहीं
3. डाटा में मेरी आंशिक या पूरी तरह से निशानदेही किए जाने के बारे में सहमत हूँ।  हां  नहीं

मैं समझता हूँ कि पूरी तरह से या आंशिक निशानदेही के चयन की स्थिति में इस शोध पर लेख में मेरे से संबंधित डाटा शामिल करने से पहले उसकी (ट्रांसक्रिप्ट) प्रतिलिपि मेरी अनुमति के लिए मुझे दी जाएगी।

मैं समझता हूँ कि मेरी भागीदारी स्वैच्छिक है तथा परियोजना के किसी भी चरण में मैं आंशिक या पूरी तरह से भाग न लेने का चयन कर सकता हूँ, और इस परियोजना के किसी भी चरण में हट सकता हूँ।

भाग लेने वाले का नाम :

हस्ताक्षर :

तारीख :

## APPENDIX 5: LIST OF PAPERS PUBLISHED

Note: Only those publications relevant to the thesis topic have been included.

- 5.1 BRIJNATH, B. & Manderson, L. (2008). Discipline in chaos: Foucault, dementia and ageing in India. *Culture, Medicine and Psychiatry*, 32(4), 607-626.
- 5.2 Czymoniewicz-Klippel, M., BRIJNATH, B. & Crockett, B. (2010). Ethics and the promotion of inclusiveness within qualitative research: Case examples from Asia and the Pacific. *Qualitative Inquiry*, 16(6),
- 5.3 BRIJNATH, B. (2009). Familial bonds and boarding passes: Understanding caregiving in a transnational context. *Identities: Global Studies in Culture and Power*, 16(1), 83-101.
- 5.4a BRIJNATH, B. (In press, accepted 28 January 2010). Use of the MMSE to diagnose dementia in Delhi. *Dementia: The International Journal of Social Research and Practice*.
- 5.4b BRIJNATH, B. (In press, accepted 25 February 2010). Fluidity and the MMSE in India. *Transcultural Psychiatry*.
- 5.5 BRIJNATH, B. (2008). The legislative and political contexts surrounding dementia care in India. *Ageing and Society*, 28(7), 913-934.

# Discipline in Chaos: Foucault, Dementia and Aging in India

Bianca Brijnath · Lenore Manderson

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**Abstract** In India, care work for people in late-stage dementia is primarily conducted in the home. Using source material from urban India and drawing on Foucauldian theory, we illustrate the significance of three power/knowledge scripts in this context: social and cultural notions of acceptable, public bodies; medicalized forms of care; and the cultural contexts of the individual caregivers. The caregiver is the embodiment of these discourses and is charged with the task of mapping discipline onto inherently undisciplinable bodies. A tension exists between the caregiver's struggle to contain the unruliness of the person with dementia and, simultaneously, to act as a broker between the world of the care-recipient and the social world. We conclude that although the caregiver is the starting point for the exercise of discipline, the three power/knowledge scripts that inform care work are as much about surveying, routinizing and mobilizing caregivers' bodies as they are about disciplining the bodies of people with dementia.

**Keywords** India · Body · Dementia · Discipline · Power/knowledge

## Introduction

*There is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations.*

—Foucault (1979, p. 27)

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# Ethics and the Promotion of Inclusiveness Within Qualitative Research: Case Examples From Asia and the Pacific

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<http://qix.sagepub.com>  


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## Abstract

Qualitative researchers are often confronted by ethical challenges when making research decisions because current guidelines and principles guiding research ethics do not wholly cover the concerns that can arise in complex social research situations. In this article, the authors explore this dilemma in relation to our experiences of conducting sensitive qualitative research with vulnerable groups in developing countries of Asia and the Pacific. With a focus on informed consent, the authors offer three case examples to explicate the difficulties faced in matching ethics theory with proforma approval requirements, which may limit the application of more expansive approaches to research design. To conclude, the authors put forth recommendations for modifications to the ethics system as a whole to promote greater collaboration and inclusion of qualitative researchers to the review and practice of research ethics in Australia.

## Keywords

human research ethics, qualitative research, informed consent

In Australia, as in other nations, Human Research Ethics Committees (HRECs) continue to draw upon the traditional audit approach to ethics review that emerged from the biomedical community and which is steeped in Western cultural values (Christians, 2005). Yet when conducting qualitative research, which is more “ethically charged and unpredictable from the outset” (Howe & Dougherty, 1993, p. 19), the more open-ended and intimate nature of the data gathering process necessitates that researchers as well as HRECs be flexible and accommodating in their practices (Connolly & Reid, 2007). This is particularly true in cross-cultural settings where the history of research ethics has been linked to colonization and neocolonial discourses and the failure of people to treat each other with respect (Smith, 2005).

Alternate paradigms (e.g., feminist, indigenous) that build on an ethics of care, of reciprocity, integrity, and personal conduct have had greater success in creating sustainable relationships with participants and negotiating multiple identities and shifting power relations (Denzin, 1997; Gilligan, 1983; Oakley, 1981; Taylor et al., 1994). Yet over recent decades the ethics review process has become increasingly regulatory and bureaucratic in responding to the concerns that science poses to humanity (Fitzgerald, 2004; Haggerty, 2004) and in managing the perceived uncertainty of research encounters within the context of

late or postmodernity (Miller & Boulton, 2007). Correspondingly, qualitative researchers are nowadays implicitly encouraged to apply certain mainstream ethical procedures to their own research practice, to strive for a particular “gold standard” of evidence that addresses neither what constitutes evidence nor the overall purpose of the research study (Lincoln, 2005). Such an approach risks exacerbating potential harm to participants and researchers, as the latter must design their studies based on the pragmatics of project time lines and budget constraints and not necessarily an ethics of care (Johnson, 2008; Pascoe & Radel, 2008; Viète, 2004).

This article explores the authors’ experiences of developing and then implementing contextually and institutionally acceptable, inclusive, ethical approaches while conducting their respective qualitative research in Cambodia, India, and Papua New Guinea (PNG). Focus is given to issues regarding the involvement of vulnerable persons (i.e., children,

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## **Familial Bonds and Boarding Passes: Understanding Caregiving in a Transnational Context**

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*In January 2007 a first generation Indian migrant with Australian citizenship travelled to the United States from Australia to provide care for her Indian grandmother with severe dementia. She did so because her grandmother's primary carer, the Indian migrant's maternal aunt, had to escort her Filipina maid of over ten years back to the Philippines, after the maid had suffered an aneurism and had recovered enough to express her desire to return home. The multiple narratives embedded in these few lines illustrate that in the daily lives of transnational families and caregivers, gender, generation, migration, access, and homeland come together in a myriad of ways that complicate understandings of traditional caregiving and raise the question: whose 'story' do we focus on? Using an expanded framework of global care chains as articulated by Nicola Yeates and Loretta Baldassar's work on caregiving in transnational families, I explore through this personal 'case-study' how each link within the chain maps to the other and the power dynamics that contextualise these links. Building on Yeates' work, I argue for the recognition of temporality in transnational caregiving and conclude with a call for further research and theorising on caregiving that takes account of the transformations and transactions that occur within families in a global context.*

*Key Words:* Caregiving, dementia, gender, migration, South Asia, transnational

*After an interminably long flight, I was finally there—Charlotte, North Carolina. Delayed flights, rain, cold, time zones, hemispheres, countries, and oceans, all had been crossed to meet a woman who was unrecognisable even to herself. A stranger made not met, and one who was continually unmade and remade by those around her day after day.*

*So why was I in the USA? A frantic phone call at lunchtime three days ago with no other response to give but 'yes.' Flight Centre®, United Airlines®, Qantas®, Air New Zealand®, the gauntlet run. Acquiescence was non-negotiable, built on a foundation of empathy, obligation, duty, and guilt. There were memories of a mother and a grandmother shared by everyone in the family but the very topic of conversation herself. She shared nothing now but the (dys)functioning of her body. And Kriti<sup>1</sup> had shared in that the most, the longest and the best. Yes, she'd had help from*

# Use of the MMSE to diagnose dementia in Delhi

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## ABSTRACT

Diagnostic tools are created and administered within specific political, cultural and clinical contexts that problematise their supposed universality. This paper, drawing on interviews and participant observation undertaken in 2008 in New Delhi India, examines how clinical environments influence the interpretations and use of the Mini Mental State Examination (MMSE), a popular screening instrument for dementia. Findings indicate that while doctors recognize the limitations of the MMSE in theory, its continued use in practice is because of time shortages and competing work demands. Yet misdiagnosis or even false-positive screening has implications for service delivery and quality of care and further research is necessary into how diagnoses are made, which account for cultural and structural variance.

Key words: Culture, Dementia, Diagnosis, Delhi, Mini-Mental State Examination (MMSE)

# Screening for Dementia: Fluidity and the MMSE in India

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## **ABSTRACT**

The Mini Mental State Examination (MMSE) is a popular screening instrument for dementia and drawing on ethnographic data from India, three vignettes are presented to examine how the MMSE is operationalised by interviewers and respondents. Using the concept of 'fluidity' from Science and Technology Studies, it will be demonstrated that the MMSE is fluid and changes according to individual norms, institutional resources, and cultural settings. In some environments, the scores are discounted in order to count; in others the scale is perceived as an invitation to talk; and finally, it can also operate as an entry-point to seek treatment for other psychological concerns.

Key words: Cultures of screening, Dementia, India, Mini-Mental State Examination (MMSE), Fluidity

# The legislative and political contexts surrounding dementia care in India

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## **ABSTRACT**

Currently there is no specific policy on dementia care in India. Rather, the responsibility for care for people with dementia is not clearly articulated and formal care services straddle mental health and aged care. The result is that much care is placed upon individual families. This paper critically reviews Indian legislative and policy documents on this field of care, namely, the *Mental Health Act 1987*, the National Mental Health Programme, the National Policy on Older Persons and the *Senior Citizen's Act 2007*. The invisibility of dementia care in public policy translates into the absence of adequate treatment facilities and mental health staff, and leaves informal care-giving unsupported. This gap is replicated in mental health and dementia-care research and literature in India, with little being known about how family carers respond to the experiences of care-giving, manage the stigma, and access support. As India, like other middle-income and low-income countries, is experiencing an increase in its older population, more research is needed to develop the epidemiological, medical and anthropological understanding of ageing, dementia and care. This knowledge is vital to understanding the cultural context of the disease and must also be incorporated into public health policy if there is to be effective management of the rising need for personal care.

**KEY WORDS** – India, dementia, care, policy, mental health, ageing.

## **Introduction**

Mental and behavioural disorders account for 12.5 per cent of the global burden of disease. At any one time, about 10 per cent of the world population suffers from a mental illness, and more than 25 per cent are affected by mental and behavioural disorders at some point in their lives (World Health Organisation (WHO) 2001). Notwithstanding the methodological limitations of the measure ‘Disability Adjusted Life Years’ (DALYs), by 2020 it is expected that mental and behavioural disorders will contribute about 15 per cent of the total DALYs lost through disease and injuries

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