6. 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. Although it might be argued that ARDSI had a vested interest in claiming stigma existed – to garner more funds to raise awareness of their organization – this does not present the complete picture. Many within ARDSI worried about the existence of stigma and these anxieties reflect the complex picture that emerges when stigma is examined in India. In my field notes I often noted the contradiction of 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 even 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. While stubbornness and anger in one's *buddhāpan*, or old age, may have been accepted with ageing, behaviour disruption, violence and disinhibition were more readily interpreted as signs of madness/mental illness and could become grounds for institutionalization. Categories such as 'ageing' and 'madness' constantly risked collapsing in on each other, separated only by the efforts of families and the NGO. 'It is important not to label people with Alzheimer's as mad; they are *ya:dda:sht ke mari:z* [the memory patients]', said P.K. Singh, an ARDSI volunteer, to the residents of a Delhi old age home.

The stigma experienced by families depended on how others perceived them and where they positioned themselves on the scale between ageing and madness. I describe these performative acts of positioning and illustrate how stigma is internalized 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 institutional practices. I explore how families exercise agency and choice in their responses and resistance to stigma as well as how families and people with dementia stigmatized others (and each other) for perceived 'defects' or marks. In mapping this 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 (1959, 1990), 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 (such as race, religion, nationality) – that a larger social group then uses as the basis to discredit and exclude them. 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 criticized for centring too much on individual attributes and characteristics, without attending to the structural factors that exclude and discriminate (Parker and Aggleton 2003). Albeit closely related, stigma and discrimination are not the same. The former is a deeply discrediting attribute, while the latter is a set of actions by which the stigmatized individual's life opportunities are reduced (Reidpath, Brijnath and Chan 2005). Discrimination and stigma tend to flow along established rivulets of power and inequality and institutions tend to discriminate against people not only on the basis of their stigmatized attributes but also by class, gender and race (Parker and Aggleton 2003). Therefore, 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 stigmatized.

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 marginalized through the institutional power of the state.

Link and Phelan's work has resonated with Arthur Kleinman's writing 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 stigmatized, he argues, is to experience social suffering – a term he, Lock and Das (1997: 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 that people and societies may inflict on each other to preserve an established order. Also emphasized is the role of state apparatus in creating suffering, stigma and social death. Kleinman's work in China shows that social death can mean the disintegration of the existence, value and perpetuity of the individual and the family (Lee et al. 2006; Yang and 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: 1528). Further, they argue, stigma threatens what matters most, occurs in an inter-subjective space between people and also in individual bodies whether consciously acknowledged or not. In other words, 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 mobilize bodies differently in public and private spaces. To understand these mobilizations, 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, residing in 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 older relative has psychosis, in front of med reps and other patients, it may be because the patient is seen to be mad. But it can also be explained through a range of other factors such as an authoritarian doctor-patient relationship, high patient demand and/or the pressure to multitask in order to manage heavy workloads. Similarly, prescriptions for antipsychotics may be offered not because the person has psychosis, but because a doctor receives kickbacks from pharmaceutical companies (see chapter 4). Indeed, things are never what they seem when praxis is contextualized by space; a point that Deleuze articulates well: '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 any paternal function. It is only here that things begin to get interesting' (1998: 77).

Preserving the Normal

Many families were engaged in a project to preserve the normal and avoid the indignities of stigma. 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. 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 early on 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 fifteen 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 away 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 stigmatize 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, explained: '*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].

Downplaying Alzheimer's and emphasizing the normal was a tactic to anchor disruption in the 'normal' difficulties of ageing and mitigate against the stigma of madness. It was not that carers were in denial; by this point

they had accepted the disease. This was mostly clearly reflected in their use of language. In Hindi, chronic diseases are generally referred to in the present tense and language plays a key role in how the sick role comes to colonize 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 functions as a social symbol, providing information and cues about how sick people should be read and perceived within society (Goffman 1963, 1986).

Interestingly, the word 'problem' was hardly ever used in the constitution of this new sick role. Rather, 'problem' referred to things that could be fixed, applied to temporal conditions and specific body parts and processes such as 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 ostracize 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 and Sheridan 1977; Goffman 1961). Disruptions were concealed in order to produce finished, polished images not just to preserve the image of the normal, but also because there was pleasure to be gained from beautification (Goffman 1959: 52–53). This 'discipline of normalization' was productive, transformative and creative, rather than repressive (Foucault 1975, 2003: 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 to dirt and disorder. To view these solely as acts of conformity disregards the love in these acts of *sevā*. For Kumud Kaul, who cared for her mother, Mrs Hamdari, love was a key factor in her striving for normalcy: '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, the carer's character came into question. The questions of integrity and madness were passed onto the carer and they would have to defend themselves against the sudden scrutiny. For example, 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 that carers faced 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, *sevā*, 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 *sevā* 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 remained consistent – all the adult children were settled and performed the appropriate amount of *sevā*. 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* [finished] 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 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 surroundings 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 twenty 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 eighty-two-year-old Helen's problems could be caused by dementia, but also attributed them 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 etiology so that they could offer hope to other families.

Thus sight and seeing functioned as a contrary tactic – a way of acknowledging 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 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

If the project of preserving 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 interactions 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 had once enjoyed 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 ten 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 all 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 of disguising the depths of change and disorder within the household and of obfuscating the capacities of particular family members. Information was held back because of its potential to stigmatize and discredit the household. But in attempting to manage a family image and individuals' identities, families found themselves increasingly isolated through their own internalized 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 the Khans grew poorer and less able to draw on prior relationships to bolster their income. Former influential friends no longer 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. These monetary woes, coupled with Omar's illness, affected the Khan family'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), the sole carer for her father, Hari Prasad (74), 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 realized 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 private tuition 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. As 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 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. As he was able to fulfil these decorum cues and was not publicly disruptive, Suneeta was able to explain

his dementia as the forgetfulness of old age. To date, no major disruptions had occurred outside their home. Those that transpired within, occasions of disinhibition or incontinence, were managed and hidden from view and as there was no servant or attendant within the home, only Suneeta was aware of these disruptions and cleaned the mess. Thus, due to 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 to be 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 have faced no 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 on any 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 body-work. 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, exposing their own bodies and selves in ambiguous ways (Twigg 2000). Faeces, urine, smells and spillages are solids and fluids that cross body boundaries and carers' 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 of their bodies. Pollution and dirt

were lived realities in the Singh 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 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 *sevā* 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 his 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 was at variance with her own tactics of distancing her father.

The time sensitive and spatial nature of disgust explains this mismatch (Isaksen 2002). For carers such as 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 that this was because of her feelings of disgust or her resistance to being touched per se or fear that such touching was sexualized. 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 were neither acute nor extraordinary. But they were deeply felt and highlight the fact 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 by distant relatives if Su was 'still hanging on'; and Parvati's dinner guests ignored her mother, Meenakshi. There were also 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'. Nina was indignant, '"Haī bechara, Haī 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 stigmatized did not preclude families from stigmatizing others nor did it automatically dispel their long-held 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, when I showed Josie photographs of children from the Kamini slum, she 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 carers 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.

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 that was both internalized and externalized, 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 – these are

all tales of everyday suffering. Social death may be the end point of stigma, but the journey towards it brings with it exclusion from public spaces and the severance of both small and large ties. Although 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 marginalization. In the gerontology literature, loneliness has been linked to life expectancy, quality of life and measures of 'successful' ageing (Routasalo et al. 2006; Scharf, Phillipson and Smith 2005; Victor et al. 2000). In the urban studies literature, 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 disconnection, including psychological and sometimes physical distance between family and friends. But loneliness can also 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 a place 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 to be alone together. Cinemas and holiday retreats are similar examples. These are predominantly social yet solitary spaces (Coleman 2009).

In trying to extrapolate the 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 such as kinship, love and culture. They may eat, sleep, relax and live together. In spaces of solidarity, there are family narratives of *sevā* and care. This is the space where children become 'settled', where the good family lives and where 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.

Thus changing relationships signaled a loss of power and prestige. Choosing to resist or sequester the family to avoid stigma could result in loneliness. 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 stigmatizing gaze of his community, but also from the friendships and neighbourliness within his colony.

It is important to emphasize that loneliness was neither linked to intergenerational conflict nor abandonment of close kinship networks. Carers such as Tandon, Nina and Josie all maintained relationships with their children, even though they lived apart. All loved their children. But there were tacit realizations that solitude and loneliness were part of the experience of being the primary carer. These carers did not separate themselves from their families, but the nature of carework 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?'

The decision to live in solitude was also made 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 a breakdown in 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

To date there is neither a specific policy on dementia care in India nor sufficient provisions for specific treatment and management practices. In my earlier work (see Brijnath 2008), through an analysis of mental health and ageing legislation and policy, I documented the way in which care was (un)wittingly privatized with the responsibility left largely with the family. In earlier chapters I have shown how this affected families' financial, physical and mental health and their capacity to care.

It was often brought home to me by key service providers that even if there was a policy on dementia care, its implementation would differ significantly from its theoretical ambitions and could never wholly undo what had become standard practice over time. Rather, key service providers emphasized that what would continue to circulate would be an *ad hoc* adherence to notions of rights and care, contingent on environments of deprivation and plenty and individual notions of greed and altruism. Thus, institutional representatives, such as doctors, police and financiers, cared, stigmatized 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 mobilize financial capital, many others who lacked such substantial wealth could not. ARDSI-DC frequently counselled that following diagnosis, families should immediately organize 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 2008).[1] Property is a particularly sensitive issue and there are numerous stories of usurpation and illegal land grabs. To put this in perspective, there is a group called the *Mritak Sangh*, or Association of the Dead, a north Indian pressure group that campaigns for people who have been declared dead but are still alive and have had their property seized (Fathers 1999).

Older people are seen as especially vulnerable to having their property seized by their children; the tactic of declaring ageing parents insane, then legally taking over their property, has occasionally been used in India (Shah, Veedon and 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 recently passed *Maintenance and Welfare of Parents and Senior Citizens Act* (2008) were to protect older people and their assets. The Act mandates

that children must care for their parents or risk a fine of Rs 5,000 and/or a jail term of three months. Care is interpreted to mean funds for food, shelter, clothing and medical treatment and parent-child relations may include biological, adoptive and step kin alongside those who might potentially inherit property. 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 aged and usurp their rights, property and sanity, any discussion of finances with families had to be carefully broached. Discussions about finances with families where children cared for a wealthy older parent were especially sensitive, for these 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 aged 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, spaces so horrific that even the government wants to shut them down. Without labouring the point, Josie and Su's story from earlier 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 care staff of the needs of families and people with dementia. Nandini realized this when her father, S.T. Pillai, was admitted to hospital to have his pacemaker fitted. Ensconced within the medical institution, with its systemic and cultural paradigms, 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 paid 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 workers' attitudes towards people with dementia and more broadly those with a mental illness, need further explication. With few exceptions (see Jain and Jadhav 2008; Vibha, Saddichha and 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-utilization of even the limited existing mental health services in India.

In summation, an overview of law, finance and healthcare underscores the fact 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.

Conclusion

By describing the moral and social geography of stigma in individual relations, social processes and institutional settings, I have shown how stigma is internalized and externalized. I have also illustrated how stigma is linked to suffering and loneliness, how it informed a project to preserve the normal and how it worked in tandem with institutional forces in law, finance and healthcare. Stigma operated in a different way 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 mobilize their financial and cultural capitals. In social processes, pollution, labour and the perceived link to mental illness affected the ability of families to broker successful relationships 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 alongside existing inequities of power by class, gender and health status. 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 feel solidarity in how they respond to stigma, they may also experience solitude in their private homes, where they might whisper their doubts.

In living with stigma, the power relations woven into the institutional and social fabrics of everyday life become visible. Such ties are difficult to unravel because they provide families with the moral and existential frameworks through which to view the world. In trying to respond to stigma and facilitate change there is always the 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 the fact that it needs to be incremental and gradual. As Parker and Aggleton explain: 'To untie the threads of stigmatization 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: 18).

Notes

1. To deal with the backlog of cases, since 2001 the Government of India has established over 1,700 'fast track' courts. To date these courts have cleared over 3 million cases. However due to budget cuts the central government announced that it would no longer fund the scheme from March 2011 onwards. As a result, over the past two years, in a number of states, 'fast track' courts have been discontinued (Biswas 2013).