Why does institutionalised care not appeal to Indian families? Legislative and social answers from urban India

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ABSTRACT
In India, although notions of ageing and care are changing, there is a continued preference among families for home-based care of elderly relatives. The legislative policies and cultural practices that shape this preference will be examined in this paper with specific reference to aged-care facilities and the 2007 *Maintenance and Welfare of Parents and Senior Citizens Act*. Using qualitative data from a study on dementia care in urban India it will be shown how the Act and old-age homes are understood and experienced by Indian families and key service providers. In juxtaposing policy and practice it will be argued that while notions of care are being redefined by processes like migration and urbanisation, the preference for home care remains, indicating that existing services need to be re-oriented and expanded to support families in providing this care.

KEY WORDS – India, dementia, home care, institutional care, legislation.

Introduction

Like many other parts of the world India is also undergoing a demographic transition with a projected increase in the numbers of older people. According to the 2001 Census (Census of India 2006), the number of Indians aged above 60 years will more than double from 71 million people in 2001 to 173 million people in 2026. Improved public health, lower mortality and reduced fertility are key factors driving such change (Prakash 1999).

With ageing comes increased prevalence of age-related diseases such as cardiovascular disease, diabetes, arthritis, Alzheimer's and other dementias (hereafter dementia). In 2001, 1.5 million people in India were estimated to have dementia, the third highest number in the world. By 2040, this figure is expected to jump by 346 per cent (Ferri *et al.* 2005). Dementia has a heavy burden of care and when combined with other co-morbidities requires

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complex multi-sectoral responses. This has a significant impact on government, health systems, and individual families' resources. Given future projections of ageing and age-related diseases in India, there is need to identify prevailing values and beliefs of elder care in order to develop culturally appropriate and affordable models for the longer term. The aim of this paper is to describe how families and key service providers perceive and negotiate institutional care settings in India and how the socio-legal frameworks of care, particularly the 2007 *Maintenance and Welfare of Parents and Senior Citizens Act* (hereafter *Senior Citizens Act, 2007*; Ministry of Social Justice and Empowerment 2007), shape this understanding.

Currently in India there remains a preference for elder care to occur within the family setting. Cultural concepts of care and joint family structures have constructed elder care as critical to family functioning and family cohesion. Such cultural practices are augmented by a legal environment which seeks to locate the primary responsibility of care on families and both reward and penalise families when they do/do not fulfil these responsibilities. A notable example is the *Senior Citizens Act, 2007* which gives tax relief to families who care for elderly relatives but applies penalties, including monetary fines and a maximum prison sentence of three months, to those families which avoid their responsibilities.

Unsurprisingly within such contexts many Indians view institutions such as old-age homes, hospice care or other long-term facilities with deep ambivalence. Only about 2.73 per cent of elder care in India occurs in institutionalised or formal settings (Jamuna 2003). Even in western nations, like Australia and the United States of America (USA), the majority of care occurs within the home with only 6.7 and 7.4 per cent, respectively, of such care transpiring in aged-care facilities (Australian Bureau of Statistics 2003; Federal Interagency Forum on Aging-related Statistics 2006).

However, as forces like rapid economic development, migration, urbanisation and changing family structures deepen their effects on Indian society, care arrangements and the preference for home-based care will change. Already a host of aged-care facilities dot the urban landscape and the Indian government has taken steps through policy and legislation to define its role in elder care as an auxiliary, not primary, source of support. However, if well conceived, effective long-term responses to elder care in India are to be developed, critical engagement with changing social patterns and contemporary and traditional care paradigms are necessary. In this article I begin by describing forms of care (traditional and contemporary) and the legislation around ageing in India, specifically referencing the *Senior Citizens Act, 2007*. Then, drawing on qualitative in-depth interviews, families' perceptions of and experiences with care facilities are explicated within the wider legal context, specifically focusing on the *Senior Citizens Act, 2007*.

Study findings are then related to the wider literature and form the basis for future directions in research to develop culturally appropriate models for elder care in India.

Forms of care

Elder care in India (like other forms of care) was traditionally organised under the joint family system. Multiple generations lived within a single household sharing income and resources (at least in theory). Men usually managed social and economic matters while women ran household and other general affairs (Bhat and Dhruvarajan 2001; Prakash 1999). Older people had a social expectation of care from their children based on inter-generational reciprocation and the importance of doing *seva* (Lamb 2000; Vatuk 1990). *Seva*, literally 'service', is a layered concept encompassing the intellectual, emotional and physical care of elders by their younger family members. The concept is based on respect, with such care seen as a form of divine worship (Vatuk 1990).

With migration, urbanisation, consumerism and the changing role of women in contemporary Indian society, family dynamics and by extension forms of elder care have also changed (Patel and Prince 2001; Varghese and Patel 2004). Migration, whether in-country or overseas, tends to create more nuclear family units and often older family members are left behind. In some parts of India, the trend is so common that a shorthand has developed for it: PICA – Parents in India, Children Abroad (Prince, Livingston and Katona 2007; Prince and Trebilco 2005). Women's roles have also changed and with many now in full-time paid employment, they have reduced availability to care. Added to this denser urban living, higher costs of living and increased consumerism leave many families overall less likely to meet the medical, social, financial and psychological needs of their elderly relatives (Patel and Prince 2001). Consequently, many scholars make the point that older people are neither as securely positioned in their family's hierarchy nor as revered as past generations were (Dharmalingam 1994; Jamuna 2003; Kumar 1996; Mahajan 2006).

Concomitantly in India there has been a burgeoning commercial aged-care sector distinguished from the 'typical' aged-care home by its explicit user-pays model (Liebig 2003). Paid facilities encompass a range beginning with basic services (like food and shelter) at Rs. 3,000 (£41)[1] per month to luxury accommodation with *Āyurvedic* spas and on-site pharmacies at Rs. 25,000 (£348) per month (HelpAge India 2009; Lamb 2009).

In contrast, free homes, which have long been in India and become the typical image of institutional care, are spaces for poor older adults

abandoned by their families because of conflict or abject poverty. These places are free of cost and are predominantly managed by state governments, non-government organisations (NGOs), charities (*e.g.* Cheshire Home) and religious groups (*e.g.* ashrams). Food, shelter and other basic amenities are provided to such residents but little else (Liebig 2003). Both types of homes tend to only admit people who are physically and mentally competent and in the event of severe or debilitating illness requiring high care, residents are referred to hospitals, or families are requested either to provide a private attendant to allow the person to stay or to take the person home (Lamb 2005). Although in principle, people with dementia are excluded from old-age homes, in practice this is not always the case, particularly if symptoms begin to manifest long after admission into the facility. Moreover, if symptoms are not viewed as signs of illness but as the irascibilities of normal ageing, then this exclusion is even less likely to occur (Brijnath in press).

Despite the rapid growth of age-care homes across India, there is stigma associated with living in such a facility; such sites are interpreted as a symbols of social degeneration, where aged relatives are 'dumped', and love and *seva* commercialised (Bhat and Dhruvarajan 2001; Jamuna 2003; Kalavar and Jamuna 2008). Residents of homes are viewed as abandoned by their families and often referred to as 'inmates' by facility staff (Lamb 2005, 2009). In describing the discourses circulating on old-age homes in India, Sarah Lamb (2005: 80) notes 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'. In short despite the spread of aged-care centres across the Indian landscape these institutions are viewed with scepticism and unease.

The stereotype of life in old-age homes as intrinsically public, communal and routinised is a near universal one (Bond 2007). Though such homes do exist in India and abroad, significant work has been undertaken to increase quality of life and bolster social engagement, autonomy and privacy (Åberg 2008; Oswald *et al.* 2007; Cannuscio, Block and Kawachi 2003). Varied models of aged-care living (*e.g.* assisted living, community and home-based care, low- and high-care nursing facilities) have been developed in the West (Bond 2007); some of these models are presently being applied in India as well (see Dias *et al.* 2008; HelpAge India 2010; Prince *et al.* 2009).

In the West, the growth of aged care has not only been viewed as the weakening of family ties but also as a societal preoccupation with youthfulness which un/consciously isolates those who are visibly different from this image (Hazan 1994; Hochschild 1978). Often moving to a home signals the last stages of people's lives, a step undertaken when the demands of care become too heavy to be met within the home (Banerjee *et al.* 2003;

Eaker, Vierkant and Mickel 2002). While the move itself is not stigmatised, the loss of function that accompanies ageing, illness and dying is stigmatised (Featherstone and Hepworth 1991; Lawton 1998; Lloyd 2000). Thus the decision to enter institutional care is not easily taken, particularly when family members decide to admit an elderly relative (Caron, Ducharme and Griffith 2006).

Moreover, moving into a home can have negative effects; a systematic review of dementia research undertaken in the USA, Europe, Australia and Canada found institutionalisation to be disadvantageous to people with dementia, their carers and national budgets (Luppa *et al.* 2008). People with dementia tend to deteriorate faster in aged facilities, their carers' experience anxiety about their decision to institutionalise, and governments worry about the burgeoning costs of such care. Consequently, policies in nearly all countries (developed and developing) are oriented for care to occur within the home for as long as possible and to be undertaken by unpaid carers with secondary support from governments, NGOs and paid attendants (Luppa *et al.* 2008). To this end initiatives such as home-care attendants, meals-on-wheels, financial aid and respite care are available to varying degrees and there is consensus that such services need to be expanded to enable people to age 'in place' for as long as possible and/or until death (Cutchin 2003; Johansson, Jospehsson and Lilja 2009; Milligan 2009).

Policy context on aged care in India

In India, there is a dearth of policy and legislation explicitly referring to aged care. In the two most visible documents on this topic – the Indian National Policy on Older Persons and the *Senior Citizens Act, 2007* – the Government unequivocally sets out roles and responsibilities in elder care: families take the lead in care-giving with some secondary support from government and NGOs. The point is made that '(it) is neither feasible nor desirable for the State alone to attain the objectives of the National Policy. Individuals, families, communities and institutions of civil society have to join hands as partners' (Government of India 1999: 6).

Included in the supplementary support initiatives from government is a measure of tax relief to children who live with their elderly parents; promotion of intergenerational relations and discouragement of anti-ageist imagery in media and school curricula; and greater interaction between schools and elderly people in the community (Government of India 1999; McCabe 2006). Additionally, the central government's Ministry of Social Justice and Empowerment is seeking to implement 'An Integrated Programme for Older Persons' by partnering with NGOs and other

organisations to set up aged-care homes, dementia-specific facilities, medical mobile units, physiotherapy clinics and the like (Ministry of Social Justice and Empowerment 2008).

The recently passed *Senior Citizens Act, 2007* is intended to address the housing and care requirements of the elderly and to protect their economic wellbeing. While the unfortunate tactic of declaring elderly parents insane, then legally taking over their property, has occasionally been used in India (Shah, Veedon and Vasi 1995), the Act was developed more in response to changing patterns of migration (rural to urban and India to abroad), increased urbanisation, the trend towards nuclear-family living, and the reduced availability of women to care than the usurpation of property.

Comprising seven chapters and 32 sections, the Act stipulates that foremost children must care for their parents. In the absence of family, the Government should ensure beds are available in care facilities for senior citizens. A broad definition is taken of parent–child relations; a child may include biological, adoptive and step-kin alongside those who might potentially inherit property. An elderly person is anyone above 60 years of age (Ministry of Social Justice and Empowerment 2007: 1.1–1.2). Elderly parents may apply to their children directly or via an authorised person for funds for food, shelter, clothing and medical treatment. Children are legally obligated to supply such funds: 'the obligation of the children or relative, as the case may be, to maintain a senior citizen extends to the needs of such citizens so that senior citizens may lead a normal life' (Ministry of Social Justice and Empowerment 2007: 4.2).

Should families avoid their responsibilities, redress may be sought via a Tribunal which can authorise families to pay up to Rs. 10,000 (£139) per month as maintenance. Those carers who fail to comply may incur a fine of Rs. 5000 (£69) or a jail term of three months or both. The Act applies to Indian citizens within and outside India and should children be residing overseas, they may be served with legal summons by the Tribunal through the Central Government of India. The Act stipulates no role for either police or legal representatives because the intent is on reconciliation not litigation. The Act has been ratified by 11 state governments.

However, there are numerous problems with the Act. Firstly, it does not sufficiently account for the needs of those elderly people incapacitated by illnesses (like dementia) and unable to self-advocate; the burnout and fatigue that carers experience in doing care work; and the financial difficulties experienced by poor families who might be unable to maintain their elderly relatives. The punitive measures which seek to locate care responsibilities on families without adequate support do not positively engage with the changes that Indian society is undergoing and fail to meet the growing needs of those caring for frail elderly relatives (Brijnath 2008).

In excluding police, where responsibility lies for enforcing the punitive measures of the Act is not identified. How Tribunals have been set up, what uptake there has been of the Ministry's scheme, and how individual families have responded to the Act, remains to be seen.

Requiring further clarification is how the legislation applies to Indian migrants who have rescinded their Indian citizenship to become citizens elsewhere but still have elderly parents in India. Also needing explication is how cases where both children and parents may be over 60 years of age should be managed. How reasonable it is to expect the young-old to care for the very-old or for working family members to care for three generations – their parents, grandparents and their own children – needs to be dealt with in the Act.

Methods

Qualitative methods were used to ascertain how families and key service providers perceive and negotiate institutional care and the current socio-legal frameworks of care. Qualitative research does not seek to identify the generalisability of results across a population, but identifies the range of views held within the community (Mays and Pope 2000). The research design is flexible and iterative and sample sizes are often small, typically determined by theoretical saturation, *i.e.* when no more new themes, categories and explanations emerge, then data collection ceases (Marshall 1996).

Results for this article come from a larger critical ethnography which examined the lived experiences of families caring for people with dementia in India. Critical ethnographies focus on relationships, language, social encounters in local and global settings and show how culture, economics and political forces shape these interactions (Herzfeld 1987; Marcus 1995). The data gathered comprised a triangulation of in-depth interviews (N = 74) with families and key service providers, observational data (more than 250 hours) in home, hospital and community settings, and discourse analysis of policy documents and Indian cultural material related to ageing (*see* Brijnath 2008; Brijnath and Manderson 2008). Data collection and triangulation was undertaken by the author and then cross-checked against the peer-review literature. For qualitative studies, where smaller sample sizes are used (compared to quantitative methods), such data triangulation techniques ensure the trustworthiness of the data collected (Angen 2000; Whittemore, Chase and Mandle 2001). Collecting data through such multiple methods enabled refinement of the theoretical constructs, yielded new information and allowed for a constant comparison,

an iterative approach which made it easier to determine when theoretical saturation had occurred (Auerbach and Silverstein 2003).

Sample

Data were gathered over ten months in 2008 and the sample included families caring for a relative with dementia, NGO workers, government officials and clinicians. Families were recruited mainly in Delhi and from the membership database of a national Indian NGO which specifically dealt with the health and care needs of people with dementia. Carers comprised three men and 17 women who were primary care-givers to their family member with dementia (12 men with dementia; eight women with dementia; mean age 76.05 years). Primary carers were on average 52.65 years old and were spouses (N = 10), daughters (N = 6) and daughters-in-law (N = 4) of the person with dementia. No sons or son-in-laws were primary carers. The sample was relatively cross-sectional: there were 17 Hindu families and one family each who were Christian, Muslim and Sikh. Families were predominantly middle class (N = 15); the rest were affluent and none were poor or experienced serious economic deprivation. All persons with dementia received a formal clinical diagnosis from clinicians in large government hospitals in Delhi. These interviews were supplemented by an additional seven interviews with families caring for a person with dementia in Kerala to cross-check for differences in experiences and perceptions of care. None were reported.

Key service providers (KSPs) were defined as individuals formally providing direct health, care or social support to people with dementia and their families and comprised clinicians, volunteers, policy makers, police and attendants. Some KSPs had dual responsibilities such as a medical practice and working for an NGO or government department. For example, ten KSPs had a clinical qualification, and six of these were also members of the NGO from where families were recruited. Twelve KSPs were men, nine women, and men tended to have more authority than women (*e.g.* of ten clinicians, seven were men and three women).

Procedures

Multiple in-depth interviews were undertaken in Delhi with 20 families caring for a person with dementia. Twenty-one single interviews with KSPs were undertaken in Delhi, Kolkata, Kochi, and Bangalore. Interviews focused on three major themes: (a) understandings and experiences of ageing, care and dementia; (b) identifying formal and informal support systems available, their use by carers and KSPs; and (c) identifying potential

enablers and barriers to accessing such support systems, with particular attention to the role of stigma in everyday life in terms of age, care and illness. On average each interview was one hour long but typically two to four hours were spent with each participant. During this time observation also occurred. Detailed field notes were written in English after each visit. All the interviews and observations were undertaken by the author. Interviews were conducted in either English or Hindi, then translated and transcribed to English. Randomly selected portions of interviews were cross-checked by bilingual colleagues to verify the accuracy of the translation. The names of participants have been changed to protect their privacy.

Analysis

Analytic techniques 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 and Bernard 2003). This occurred both during and after data collection to determine data saturation (Bowen 2008; Morse 1995). Identified themes were incorporated into NVivo for coding and analysis. Meta-themes were then created by linking data sets with cohorts or settings and re-examined in relation to the peer-reviewed literature to ensure credibility, believability and validity. Standard techniques for qualitative research have been used to ensure the rigour and reliability of the findings: (a) findings are presented in their context; (b) how conclusions are reached is clearly demonstrated; (c) findings are triangulated by comparing and contrasting within the data set and other study findings; and (d) there is a detailed description of methods for replication (Mays and Pope 2000; Whittemore, Chase and Mandle 2001; Tobin and Begley 2004).

Ethics

The study was approved by Monash University, a national Indian NGO (from whose membership database families were recruited) and the Indian Government. The study was explained to carers and KSPs, they were given the choice to be recorded, and told of their right to stop the study when they wanted. Informed consent was obtained from these participants. For people living with dementia a special set of procedures was employed. However, as this paper does not present data from this cohort detailed descriptions are not provided here (instead *see* Czymoniewicz-Klippel, Brijnath and Crockett 2010).

Results

Understandings of institutional care were influenced by four themes: (a) cultural meanings of care; (b) the health impact of caring and coping mechanisms of carers; (c) the legal and policy frameworks of elder care; and (d) perceptions, conditions and actual experiences in old-age homes. Each of these themes will be described.

Meanings of care

Families attached deep meaning to care, viewing it through prisms of love, duty and reciprocity. Despite changes in urban Indian society, families desired to care for their elderly relatives as much as possible. The concept of *seva* was repeatedly mentioned across generations and gender:

Have you ever seen this? Where a husband is doing *seva* for his wife? Wives do *seva* for their husbands because women are less than men . . . But with us, we were both equal. (Shivbaksh Chand, 85 years, carer to his wife with dementia)

From childhood I have always dreamt that I will take care of my parents . . . My elder daughter lives in New York and this year she was saying, 'Come see New York in the winter'. I was telling her, 'Till you were 18–19 it was my responsibility to look after you but now you have grown up, you look after yourself. They [parents] are my children; I have to look after them'. (Kumud Kaul, 60 years, carer to her elderly parents and mother with dementia)

Experiences such as Kumud's and Shivbaksh's highlight not only the meanings derived from caring and the importance of doing *seva* but also show how illness and migration reconfigure relations across generations and gender. In transnational families, like Kumud's, elder care is still central, to the extent that Kumud sacrifices visiting her daughter to take care of her parents. In Shivbaksh's case, despite wider gender inequalities, his wife's illness and the former tone of their marriage results in a reversal of power relations and him giving *seva* to her. Such commitment to care was widespread amongst the sample. This does not suggest that families experienced no hardship and that fatigue never occurred; indeed nearly all carers said that caring was tiring and sought different ways of obtaining reprieve.

Impact of caring

Many carers had their own health problems, such as heart problems, cataracts, hip pain, back pain, cancer and hyperthyroidism, which added to the strain they experienced. Many also grappled with financial concerns, loss of employment and family conflict. Such problems have been noted in Indian and international studies focused on dementia and care-giving.[2]

While many carers required considerable support they tended to seek relief through informal means rather than appealing to institutions or formal support mechanisms. Often they relied solely on household resources and activities which could easily be incorporated into daily life. For example, when seeking reprieve, carers tried to encourage people with dementia to undertake simple domestic chores such as peeling vegetables or folding clothes. Alternatively many said they would go walking, play games, watch TV, pray and listen to music when they wanted to relax and/or when they felt overwhelmed:

I go to church, I just love to go to church, I get a calm [*sic*]. But you know it doesn't solve your problems . . . the problems are there, you have to learn how to best solve them yourself. (Josie Dharam Singh, 52 years, caring for husband with dementia)

However most of these activities only ensured short-term breaks and carers' capacity to take longer breaks was mediated by age and income. Younger members caring for infirm elderly parents were more likely to go on short holidays and ask a sibling or extended family member to help with caring:

Eventually it does bring you down. I go for holidays but I won't leave the country for very long. I'll go for maximum a week; I won't go for more than that. My sister and I always make sure that one of us is always there in town. (Bhageshwari Srivastava, 41 years, carer to her mother with dementia)

Older people were less likely to leave their spouses but depending on income they sought to enrol either themselves or their spouse in structured recreational activities such as painting and music classes. Such pursuits were endorsed by KSPs among whom there was consensus that institutional care was detrimental to individual health and home care critical to family cohesion.

Although the difficulties associated with caring were considerable, the meanings attached to care and the informal pathways through which carers sought relief created the perception that care was seen to be the personal responsibility of families. A wider legislative and policy environment bolstered this perception and in conjunction with the meanings attached to care and the impact of care work, shaped understandings of old-age homes. The following section discusses this legislative environment before explicating perceptions and experiences with aged-care centres in India.

Legislative and policy frameworks

In contrast to carers who stated their strong commitment to home-based care of their elderly relatives, many KSPs including policy makers

did not espouse a positive outlook for future family structure. Rather they tended to view migration and phenomena such as PICA as signs of cultural and familial decline and not catalysts for new ways of organising care:

This great Indian culture, that we make such a song and dance about, it's being replaced by materialism and a negative set of attitudes. Today there are so many nuclear families. All these old people who have registered with us, where are their children? (KSP#13, Police officer)

For many KSPs the 'decline' of the Indian family meant that the government had to assume greater responsibility for elder care rather than take a secondary role. As one clinician (KSP#2) put it, 'Fine, now the family may be responsible for care but ten years from now there will be no family for most of the people – where will they go?'

Policy makers said it was in response to these concerns over the decline of the Indian family that they drafted the *Senior Citizens Act, 2007*. Supporters of the Act saw it as essential to empowering and protecting the rights of older people, necessary in light of changing cultural values and families' capacity to care. However they also recognised that legal mandates to care could not broker caring relationships:

Now with the law it is a legal right of the parents to get the maintenance so that has changed the whole approach to the maintenance. But the criticism to an extent is justified in that no matter what law you have, the quality of care will be determined by the society. (KSP#4, Senior government official and policy maker)

You cannot legislate for love and there will always be sceptics . . . Thou shalt love thy father and thy mother – how do you legislate for this? . . . But ultimately a society has to reconstruct itself and reconstructing a society is always a challenge. (KSP#6, Senior NGO worker and policy maker)

KSPs involved in the implementation of the Act and/or who worked directly with families and older people wondered at the practicality of the new law. Many thought the legislation was not implementable and that it was impossible to define appropriate levels of care as this varied according to families' circumstances. Many were critical of the punitive component of the Act. A police officer in the Delhi Police's Senior Citizen's Unit pointed out that though the Act clearly stipulated no role for police or lawyers, it did not identify who would arrest and imprison families which did not support their elderly relatives. It also did not outline mechanisms for how children who lived overseas would or should care for their elderly parents in India. One NGO worker (KSP#10) said, 'There are so many loopholes, I don't know how you will work it out. You look after your parents because you want to look after your parents not because law says so'.

Old-age homes

Cultural meanings of care, the impact of caring, the coping mechanisms of carers, and the broader legislative and policy environment helped reinforce not only that care should be personalised and confined to the home but also bolstered the social perception that old-age homes were sites where one 'abandoned' relatives. Old-age homes were spaces which symbolised an abrogation of familial responsibility. For many carers even questioning them about institutional care was seen to be questioning them about their morality, decency and commitment to their loved one.

So many of my friends have suggested rehabilitation but I said, 'Forget it', that as long as I am alive, my husband will stay with me. I have that much decency. (Radha Menon, 61 years, caring for husband who has dementia)

You said in Australia you have those very nice wards where they try to make them comfortable but basically they are cut off from their family. So actually it is like a pretty jail. And they know it, which is very hurting to them. (Nina Bhagat, 70 years, caring for her husband who has dementia)

There are old-age homes in Delhi which are pathetic, pathetic – I mean who would go to an old-age home? A person who has no children, a person who has been kicked out by their children . . . by definition a person who is in an old-age home is really upset psychologically and how can he be happy there? (KSP#5, Clinician, Private practice)

As can be seen from these comments concerns about institutionalisation were conflated with lack of self-integrity, abandonment, incarceration and causing psychological distress. Such views were shared by families and KSPs. As one NGO worker put it, 'Institutional care robs the person of everything' (KSP#12).

Such perceptions were further reinforced by the material conditions in old-age homes. Families' and KSPs' views about old-age homes reflected legitimate concerns about overcrowding, lack of privacy, poor quality care, authoritarian staff with minimal training, and limited access to health services. These findings were triangulated by observational data gathered when the author visited five homes across Delhi, ranging from free government and charity-administered facilities to upmarket commercial homes. In all cases, irrespective of infrastructure, an authoritarian institutional ethos prevailed. For example, at one home, in the midst of an information session about dementia, a resident deemed to be 'mental' was presented by staff to the session instructors in front of all the residents (about 40 people). It eventuated that the resident had been moved into the home a month earlier by his family and was depressed and having difficulty adjusting to his changed circumstance. However, the institution's staff were convinced that he was 'mental' and treated him as such. Similarly, in an expensive exclusive

facility, the owner of the home while touring the author around, indiscriminately entered residents' rooms, rifled through their personal belongings, dispensed advice and required that the residents address her as 'madam' when they responded even though many if not all were of the same social status as she was.

There is need for minimum standards and provider–client relations to be improved in the aged-care sector in India. Notably the *Senior Citizens Act, 2007* mandates for standards but only one KSP realised that fact. He said circumspectly: 'the Act wants that we should maintain some minimum standards and after we have regulation, probably these things will improve' (KSP#2, Clinician, Government hospital).

Unsurprisingly given the negative associations with aged-care homes and the conditions observed in these homes, few in the sample considered admitting their elderly relatives. There were only three cases where families actively sought entry because the behavioural symptoms associated with dementia had become unmanageable and/or the person with dementia had become extremely violent towards the carer. In the first case, the Kochar family wanted to admit 92-year-old Lakshmi into a respite centre for a few days while her paid attendant went on leave. Sarojini Kochar (69 years) could not cope, by herself, with her mother-in-law Lakshmi's incontinence, paranoia and aggression. Even with the assistance of the attendant there remained significant strain on the household. But the family was unable to find a suitable facility in Delhi and had to manage as was.

In the second case, Josie (52 years) sought to admit her husband Surinder (56 years) because he had turned violent and severely beaten her. Unable to find an aged-care facility in Delhi which would take him, she tried to re-locate Surinder to a facility in another state. However, this attempt failed and the family returned to Delhi where Surinder was admitted to a private psychiatric facility for six months while Josie recuperated. Josie recalled how the first admission attempt failed:

We didn't actually set a foot inside the centre, because he stood outside trembling like a leaf. Trembling like a leaf and just saying, 'No, no, no, no'. I think he felt that he was going to be imprisoned, because I think he sensed that he had beaten me. He just refused to go, and my daughter-in-law was there with my son. I wouldn't have been able to do it independently.

In the last case, the three Mukherjee brothers and their families were based in the USA when their elderly parents came to visit from India. During the trip, their father's aggression worsened to the point where it became too much for their mother to cope. Consequently, Mr Mukherjee senior was admitted into an aged-care centre in the USA. However, this was a short stay

as the family struggled with his institutionalisation. Pranab (40 years), the youngest son, recalled:

It was hard, after sitting there for 45 minutes to an hour, to explain that you were going and he wasn't. The staff would come and distract him, take him for a walk and we would slip away. We used to feel bad about it.

The family eventually decided that their parents should return to India where Mr Mukherjee could be cared for at home by two paid attendants. The family pooled their resources to support their parents and regularly sent medications, diapers and other care materials from the USA to India. Alongside this, they visited their parents on a rostered basis.

Such vignettes illustrate that where institutionalisation did occur, families experienced feelings of guilt and the centres were likened to prisons. This theme resonates with KSPs' reservations that institutionalisation robbed people of everything and Nina's statement that aged-care centres were jails. Thus a strong preference was expressed for care to remain within the family and for better support and more respite-care facilities to be made available.

Discussion and implications

Findings from this study show both how the strong preference in Indian families for elder care to occur within the home and how meanings of care, the impact of care, and the legal and social contexts of care-giving create negative perceptions of institutional care. Resonating with earlier studies (Lamb 2000; Vatuk 1990), traditional concepts such as *seva*, reciprocity, duty and love continue to exert strong influence on forms of care. Despite changes in migration and family structure (Patel and Prince 2001; Prince, Livingston and Katona 2007; Prince and Trebilco 2005), far from shirking responsibility adult children, whether in India or overseas, played a key role in supporting their parents. Unlike previous studies (Dharmalingam 1994; Jamuna 2003; Kumar 1996; Mahajan 2006) which argued that older people are more insecure in their families than ever before, this study shows how new modalities of care are being articulated. The voices of carers like Radha, Nina, Kumud and Shivbaksh reveal how cultural concepts like *seva* are being rescripted through the illness experience of conditions like dementia, and being applied across generations, gender and geographies.

Aligning with earlier work on old-age homes (Lamb 2005, 2009; Jamuna 2003; Kalavar and Jamuna 2008), findings show that the stigma against institutional care remains. The old-age home continues to be associated with the abandonment of relatives, family conflict and psychological distress. Potentially, these associations might change with greater migration,

urbanisation, changing roles of women and improvements in care facilities. But as it currently stands, the use of institutional care is a last and temporary resort. Through cases like the Kochars, Josie and Surinder, and the Mukherjee family, circuits of care emerge wherein assistance is sought when the demands are too onerous at home and fatigue has set in. But institutionalisation is for a finite period and families upon recuperating seek alternative arrangements via the use of paid attendants at home.

This is not to suggest that institutional care does not have an important role to play but emphasises that there is need for minimum standards to be mandated, implemented and monitored. Part of the stigma against old-age homes centres on legitimate concerns such as the prevailing authoritarian attitude among staff and limited resources in some homes. One of the most positive aspects of the *Senior Citizens Act, 2007* includes the introduction of minimum standards in old-age homes and the provision of sufficient health and care services to meet the needs of older people. Such interventions must include in their scope changing the authoritarian attitudes and practices in aged-care institutions.

The preference for home-based care and families' attempts to define new modalities of care raises questions about the current legislative and policy environment around elder care, especially the *Senior Citizens Act, 2007*. There remain a number of obstacles in the Act's design and implementation and there needs to be greater clarity in how families' capacity to maintain their elderly relatives is to be determined, the methods by which maintenance amounts are to be estimated, defining advocates on behalf of those older people unable to self-advocate, and identifying the enforcers of the punitive dimensions of the Act when it is deemed to have been transgressed. The exclusion of police restricts the ambit of this law as one critical source of community liaison, support and monitoring is not involved in implementation. At a more fundamental level is there a need to even apply punitive borders to determine the scope and responsibility of elder care-giving? Given the determination of many families to care, I would argue not. Instead perhaps amendments could be made to provide high-quality short-term respite care and in-home support services. Such an intervention would need to be piloted to gauge the effectiveness and uptake of respite care and such findings would have salience not just in India but also in other countries in the South and South-East Asia regions (*e.g.* Pakistan, Bangladesh, China and Indonesia) where demographic transitions and changing typologies of elder care and family structure are also being experienced.

Findings from this study are limited by the middle- and affluent-class base of this urban sample, the overlay of dementia on the experiences of people providing elder care, and the single data collector. On a hierarchy of

qualitative evidence this is a conceptual study (Daly *et al.* 2007) illustrating the views of a hitherto unexplored group and showing how illness re-scripts practices of care by class, culture and location. The results presented are not statistically generalisable and have limited applicability to rural settings where kinship patterns, access to health and care facilities, and the socio-economic status of households is very different to the urban Indian context. In terms of future research directions this limitation could be addressed by researching a broader sample of participants with diversity in class, location and health experiences. Circuits of transnational care also need to be explicated. While children might not be immediately available to care, they play a valuable role in financing, sourcing information, procuring supplies and providing emotional support. How money, materials and labour travel across time and space and the use of technology in this dynamic need to be analysed. This is not a comprehensive list but a starting point for research activities to be pursued to build an evidence-based culturally appropriate elder-care model for India.

To conclude, what emerges from this study is a socio-cultural (and legislative) preference for home care and therefore the need to target more resources in supporting families to continue caring at home. There is a need to do away with the punitive aspects of the *Senior Citizens Act, 2007* as it does not positively respond to changing family dynamics in India and instead adds to the rhetoric of the decline of the Indian family. As this study has shown, the Indian family far from 'declining' is merely adapting to changed circumstances. Contemporary care arrangements in India are not static but dynamic and constantly changing – responding to social forces like migration and urbanisation – and still retaining traditional notions of *seva* and love.

NOTES

1 As of 24 August 2010, £1 = 71.80 Indian rupees.
2 For studies on the impact of dementia care in India *see* Emmatty, Bhatti and Mukalel (2006), McCabe (2006), Patel and Prince (2001), Shaji *et al.* (2003), and internationally *see* Annerstedt *et al.* (2000), Braekhus *et al.* (1998), Brodaty and Green (2002) and Hux *et al.* (1998).

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