Caregiving Patterns to Older Adults in India

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Introduction:

India has begun to feel the burden of an aging society. Aging individuals are now living longer with increasing life expectancy and availability of better health facilities but are also requiring more assistance or care to manage their day to day activities. Even though nearly a tenth of India's population comprises of older adults, it is impossible to draw an uniform picture of older adults across the country due to the varied and complex nature of the demographic transition in India with Indian States being at surprisingly diverse levels of economic development, cultural norms, and political contexts (Aliyar and Rajan, 2008). From gains in longevity of older adults, the altered needs and circumstances of the elderly as they age come forth. On account of higher life expectancy and the epidemiological transition that led to a move from infectious diseases to chronic diseases among the community, the care needs, especially healthcare needs of older adults have become more pronounced (SAGE, WHO, 2010). Traditionally, families have been the core source of social, economic, instrumental and emotional support for the elderly in India but modernization, migration of children and smaller family units reflect that this source is eroding (Bloom et al, 2010). It is widely accepted that adult children take on the primary responsibility of caring for older parents with acute needs.

The focus of this paper is to investigate the emerging patterns of caregiving to older adults in India on account of recent changes in their living arrangements. The study intends to estimate care provision through family, non-family (extended social support), formal (paid or institutional care) and informal caregivers (spouse, children, relatives, and nonrelatives) to older adults in India by family structures through their morbidity and disability experience. It is assumed that older adults living in family settings would have better access to family based informal care (unpaid) from caregivers in familial settings as opposed to older adults living alone who would have less access to family-based informal care and may depend more on formal (paid) and non-family caregiving (social support networks, community and religious networks). In India, since there is a lack of a formal social support scheme, older persons depend on filial piety and intergenerational support during their old age (Gupta and Pillai, 2002). From an economic point, India does have a tradition of providing pension to the retired elderly but this is available only to around 10% of the Indian population who had been part of the formal workforce. Home based care with family members as primary caregivers is still the first and often the only option for a majority of the elderly (Puri, 2004) and the most common type of living arrangement for the elderly in India is found to be living with married sons and their families (Prakash, 1999). The basic social structure in India has historically been the 'joint family, where extended family, including brothers with their spouses and children stay under one roof. This family structure has been the socio-economic backbone of the average Indian and has also looked after it's elders in their old age by giving them socio-economic and emotional support (Shah AM, 1998). However, this common family structure

is changing at a rapid pace. With an increase in mobility from rural areas to urban areas in recent times, the 'joint family' is breaking down into several scattered nuclear families. How the institutions of family and healthcare and family will adapt and cope with this demographic and health transition that challenge them is interesting to explore (Lee, 2003; Lloyd-Sherlock, 2010).

It is therefore important to understand who or what offers care and support to the older adults in all these 'care requiring' circumstances that older adults face. Women have been traditionally handling the 'caregiver' role in Indian families, more so in rural households (Prakash, 2001, 1999 & Jamuna D, 1997). As women continue to join the labour force, there is increasing strain on women and men and others in the family to care for older adults as well as the younger family members (Budlender, 2008; Sabates-Wheeler and Roelen, 2011). Such changes challenge the traditional forms of caregiving where care was sought from one's family and the family operated as a well-knit unit and this affects the older adults more as their care needs only increase with age. Additionally, the social networks of the elderly in India have often been ignored and studies have focused on the 'family' for too long. It is more likely that social support from the world beyond the family is an inevitable progression in the Indian context. In the absence of care from adult children, the expected primary caregivers, the extended family can sometimes take on the responsibility of caring for the elderly person. Also, as a coping mechanism it is seen that the elderly can develop new contacts and relationships with people living in and around them and invest considerable time and energy in maintaining this relationship (Sussman MB, 1976, p. 26).

Health and well-being have a significant impact on economic security, level of independence and social interaction of the elderly (Bloom et al, 2010). In India, as high as 55% of older adults rate their current health status as poor (BKPAI Report, 2012). There is also a high self-reported prevalence of chronic disease among the elderly in India (Situation Analysis of the Elderly in India: Report, 2011) which has been supported by other epidemiological studies too. Chronic non-communicable diseases (NCDs) are now the leading cause of morbidity and mortality in many low- and middle-income countries (LMICs) including India. The epidemiological transition is causing increased morbidity among the adults, more so among the elderly (SAGE, WHO, 2010). Chronic morbidity necessitates constant care and support for older adults and is hence an important need for older adults. There is a rise in NCDs, particularly cardiovascular, metabolic, and degenerative disorders, as well as communicable diseases (Ingle and Nath, 2008). The morbidity profile by age for India' clearly shows that the elderly experience a greater burden of illnesses compared to other age groups, across genders and residential location (NSSO, 2006). With modernization, older adults increasingly face barriers to good health status and 'care' from within the family due to family nuclearization and dependency (Gupta and Sankar, 2002; Rajan and Prasad, 2008). From a gender standpoint, more women are reporting poor health status as compared to males, and yet a far greater proportion of men are hospitalized as compared to females (87 versus 67 per 1,000 older adults) (Rajan and Sreerupa, 2008).

Disability is generally considered a good indicator of overall health status in older populations. It is thought to arise from the cumulative damage of the chronic disease processes that affect humans throughout life and that become manifest in older age (Fried L & Guralnik J, 1997; Pope AM & Tarlov AR, 1991). Physical disability in older adults has been viewed as a critically important public health issue. Several theoretical models have been put forth to explain different levels of physical disability (WHO, 1980, 2002). Everyday self-

maintenance activities (ADL and IADL) are considered prominent indicators of disability which require assistance (Albert, 2004). Impairment in everyday activities indicates cognitive and motor deficits to carry out work-a-day routine tasks. Age-related increase in disability implies that older people may not be receiving adequate social support due to the changing family structure. It is postulated that NCD-related disability will increase and contribute to a higher proportion of overall disability, in tune with the greying of the population for India (Kowal et al, 2010).

In India, around 8% of the elderly required assistance to carry out activities of daily living (ADLs) and around 5% of the elderly found it difficult to carry out any of the Instrumental ADLs (BKPAI Report, 2012). Across the world, it is established that most of the ADL/IADL assistance that older adults receive is from informal rather than formal sources and the informal caregivers are predominantly spouses and other kin (Spector et al, 2000). Also, from the BKPAI Report (2012) it is seen that with advancing age, assistance required for ADL and IADL tasks increased significantly. It is of immense interest to recognize assistance to older adults and identify caregivers for older adults. How do living arrangements of older adults influence the availability of assistance and actual receipt of care would be interesting to investigate.

The Specific Objectives of this Study are:

(i) To explore the 'care needs' of older adults living in familial settings in India and

(ii) To identify the care gap, caregivers and emerging caregiving patterns for older adults in varying living arrangements through their morbidity and disability experience

METHODS:

Sample: The study analyses the data from the United Nations Population Fund project on 'Building Knowledge Base on Population Ageing in India' (BKPAI, 2011), a cross-sectional survey of men and women over the age of 60 years and their spouses in 7 states of India. This long-term network study had two critical objectives: (i) research using large sample secondary data sources such as the NSS and NFHS, and (ii) collection of primary data to gain first-hand information about the country's elderly, including their socio-economic condition, living arrangements and overall health status.

It yielded a nationally representative sample of 9852 (N) older adult respondents aged 60 years or over and their spouses. Seven states were selected across India based on: (i) share of the elderly population and (ii) regional representation and included – Odisha, West Bengal, Maharashtra, Himachal Pradesh, Punjab, Tamil Nadu and Kerala. All these States had a higher proportion of the elderly compared to the other States.

Information on caregivers to older adults in the backdrop of changing family structures is the focus in this paper and this was understood through the responses to questions that ranged from assistance provided for ADL and IADL tasks, chronic morbidity management, illness and hospitalization.

Analytic Strategy:

Since the caregiver to older adults in different family structures is the interest here, responses to the questions on main caregiver/alternate caregiver such as who took the older

adult to hospital, who paid for treatment, who assists with ADL and IADL tasks, etc. were recoded according to the caregiver type into servant, spouse, any family and any relative or friend category. In order to obtain appropriate descriptive statistics, current living arrangements/family structures were cross-tabbed with the caregiver (servant, spouse, any family, any relative or friend). The servant as caregiver constituted the formal paid caregiver.

Data was analysed using statistical software – SPSS 20.0. Cross tabs were tabulated and tables prepared. Chi-Square test results were presented with significance being reported at a p-value of <0.001. Based on the emerging findings, logistic regression is being attempted.

Initial Results:

Older Adults and Sickness:

The sickness scenario for older adults in the BKPAI data was captured with respect to any ailment they had in the last 15 days preceding the date of interview. Older adults were asked about the care they received during sickness including who took them to the health centre and who paid for their treatment expenses. In the past 15 days preceding the survey, 11.5% of older males and 13.3% of older females had suffered from an ailment. More rural older adults (14.3%) reported sickness compared to urban older adults (10.4%) in the same time period and this was significant with a p-value of <0.001. Those older adults living alone/living with servant had reported higher sickness at 13.2% of the total. Age was significantly associated with sickness and 16.1% of older adults from the 80+ age group reported sickness.

For older males, the spouse accompanied them to the hospital most often (31.5%) while a combination of son/daughter/daughter-in-law/son-in-law/unmarried children and grandchildren under the category ‘any family’ accounted for 57.4% of those who took them to the hospital. ‘Any relative or friend’ accounted for 7.4% of those who took the older adult with the servant accompaniment being negligible. On the contrary, for older females, spouse accompaniment accounted for only 14.3% while ‘any family’ accompaniment accounting for as high as 75.7% and this was significantly associated. Probably a grim reminder that there aren’t enough spouses to care for their wives at advanced ages or a cultural practice of women caring more for men. Current living arrangements were significantly associated with those who accompanied the older adults to the hospital. It was seen that for those older adults living alone, 18.0% of them were accompanied by ‘none’ while 44.0% of them were taken to the health centre by ‘any family’ while for older adults living with children and others ‘any family’ constituted 73.1% of the accompanying persons. For older adults who lived with their spouse/lived with spouse and servant, the spouse accompanied them to the hospital the maximum (52.3%). Age group was also significantly associated with ‘who took them to the hospital’ with ‘any family’ member accompanying older adults at 57.7% for older adults in the 60-69 years age group, 73.4% for older adults in the 70-79 years age group and as high as 86.1% for older adults in the age group of 80+ years. Interestingly, spousal accompaniment went down from 30.7% for those in 60-69 years age group, followed by 16.6% for those in the 70-79 years age group to as low as 6.6% for older adults in the 80+ age group indicating probably that the spouse was not around to accompany them at advanced ages.

Regarding bearing the sickness expenses for older adults, the 'any family' category paid for 48.2% of the older males while the same category paid for 46.6% of the older females. These findings were similar for rural and urban elderly at 46.6% by 'any family' for older rural adults followed by 49.5% for rural older adults. For those older adults living alone/with servant, 41.4% of older adults self-bore the treatment expenses while 33.3% of older adults who lived with spouse/lived with spouse and servant self-bore the expenses and 31.2% of older adults who lived with children and others self-bored the expenses. For those older adults living with children and others, 48.9% of the older adults had their expenses borne by 'any family' and for those older adults living with spouse/living with spouse and servant, 40.7% of them had their expenses borne by 'any family'.

Significantly, by age group of older adults, 29% of older adults in the age group of 60-69 years self-financed their illness expenditure while this decreased to 19% in the 70-79 years age group and further to 11.5% in the 80+ years' age group. More spouses paid for the expenses in the 70-79 years age group (13.9%) compared to 8.7 and 8.2 respectively in the higher age groups. More family members (any family member) paid for the expenditures as the age of the older adult increased - from 49.2% for older adults in the 70-79 age group to 65.1% and 74.6% for the successive higher age groups.

Older adults and Hospitalization:

Morbidity requiring hospitalization brings forth the need for physical, emotional and financial support for older adults. With respect to the morbidity profile of older adults, it is seen that 12.1% of older adults in the age group of 80+ years were hospitalized in the past 1 year followed by 11.1% of older adults in the 70-79 years age group and 8.3% in the 60-69 years age group. More rural older adults (10.1%) were hospitalized compared to urban older adults (8.7%) in the preceding year. Significantly, for older males it was their spouses who took them to the hospital (31.5%) and 57.4% were taken to hospital by 'any family'. Significantly, for older women, only 14.3% were taken to the hospital by their spouses while 75.7% of them were taken to hospital by 'any family'. For those older adults living with their children and others, 73.1% of them were taken to hospital by 'any family' while 52.3% of older adults who lived with their spouse were taken to hospital by their spouse. Alarmingly, for older adults as they age, spouse accompaniment came down from 30.7% for older adults in the age group of 60-69 years followed by 16.6% in the age group of 70-79 years to 6.6% in the age group of 80+ years. At the same time, significantly, a higher proportion of older adults were accompanied by 'any family' member; it increased from 57.7% of older adults in the age group of 60-69 years to 73.4% of older adults in the age group of 70-79 years to 86.1% of them in the age group of 80+ years.

For financial support for hospitalization, it was seen that a higher proportion of older males 'self-financed' themselves at 35.08% while it was as low as 11.47% for older females. Of interest is that 68.21% of older females' hospitalization expenses were borne by 'any family' member compared to 47.3% of older men. Nearly a half (46.0%) of older adults who lived alone/with servant 'self-financed' themselves for hospitalization expenses while 64.0% of older adults who lived with children and others were supported by 'any family' member. 'Any relative or friend' supported and paid for 14% of older adults who lived alone/with servant. By age group, 74.6% of the 80+ age group were supported by 'any family' member and this support decreased with decreasing age. 13.9% of older adults in the age group of 60-69 years were supported by their spouses and this went down to 8.7% for older adults in the

age group of 70-79 years and lowest being for older adults in the age group of 80+ years at 8.2%.

Older Adults' Status in ADL and IADL tasks:

Data on functional status of older adults available from a contemporary survey that attempts to capture longitudinal data on aging in India (LASI Pilot Survey, 2010 which interviewed adults who were 45 years and older is presented below in comparison to the BKPAI (2011) data. There is not much difference between both datasets obtained with respect to ADLs except that in the LASI the respondents were 45 years and older but had surprisingly higher reported difficulty in ADLs.

From the BKPAI study sample, females in a higher proportion reported difficulty for 0-4 IADLs while men in a higher proportion reported difficulty for 4-8 IADLs. By caregivers who provided assistance to Older Adults for ADL tasks, the 'Any Family' category comprising of son/daughter/daughter-in-law/son-in-law/unmarried children was highest in proportion followed by Spouse, Relatives, Servant and Others. Even with caregiving assistance for IADL tasks. The 'any family' member category was the highest in proportion followed by spouse, relatives, others and servant. Also, the son / daughter-in-law combination were the main providers of ADL and IADL assistance to the older adults followed by spouse in the case of ADL assistance and son in the case of IADL assistance.

Table 1 (a): Caregivers who assist with Activities of Daily Living (ADL) tasks (in percentage)

	Caregiver	Bathing	Dressing	Toilet	Mobility	Continence	Feeding
	Spouse	18.4	17.8	19.1	18.4	19.1	20.4
Any Family	***Son***	15.4	14.1	17.2	25.4	17.6	16.4
	Daughter	15.2	14.4	11.8	13.2	10.5	15.1
	Son/Daughter-in-Law	38.3	42	40.9	32.5	37.9	35.5
	Relatives	7.4	3.7	4	4.1	5.5	2.6
	Servant	2.5	4.6	4	3.5	5.9	5.9
	Others	2.7	3.4	3	2.9	3.5	3.9

Table 1 (b): Caregivers who assist with Instrumental Activities of Daily Living (IADL) tasks

Caregiver	Use of Telephone	Shopping	Food Preparation	Housekeeping	Laundry	Transportation	Medication	Finances
Spouse	14.2	17.4	18	17.4	18.7	16.9	18.4	15.1
Son	18.4	15.5	15.6	17.7	15.6	15.5	16.2	17.8

Daughter	16.2	14.7	14.9	14	14.4	15.7	14.3	15.5
Son/Daughter in law	38.8	39.6	39.4	38.3	39.5	39.6	38.3	38.1
Relatives	7.4	7.6	7.1	7.9	7.2	8.3	7.8	8.3
Servant	1.9	2.5	2.4	2.7	2.5	2	2.7	2.7
Others	2.9	2.7	2.6	2.0	2.1	2	2.3	2.5

Older Adults and Difficulties with ADL and IADL in BKPAI data:

A majority of older adults did not report of any difficulty with ADLs (92.5%); hence around 8% of older adults had difficulty with 1 or more ADLs. It was seen that 6.2% of older women and 4.2% of older men had difficulty in 0-2 ADLs requiring partial + full assistance while 2.7% of older women and 1.7% of older men reported difficulty in 2+ ADLs requiring partial + full assistance. Further, 4.6% of older adults living alone/with servant had difficulty in 0-2 ADLs requiring partial+ full assistance while 5.8% of older adults living with children and others had the same requirement. These findings challenge the myth that older adults who lived with family would be less impaired in their ADL competencies as compared to those who live alone/with servant/spouse only, etc. As age advanced, it was seen that the 2.6% percentage of adults in the age group of 60-69 years had difficulty in 0-2 ADLs and 0.8% in 2+ ADLs. This increased to 16.5% in the age group of 80+ years for 0-2 ADLs and 9.6% in case of 2+ ADLs. The main caregiver for older adults in the 0-2 ADL difficulty group was the son/daughter/daughter-in-law group followed by 'others' accounting for 16.1% of the older adults. This 'others' group will be an interesting one to decipher. For Instrumental Activities of Daily Living (IADLs), it was noticed that 33.4% of older men and 39.8% of older women had difficulties in 0-4 IADLs and 66.6% of older men and 60.2% of older women had difficulties in 5-8 IADLs. Interestingly, more rural older adults had difficulty in 0-4 IADLs while more urban older adults had difficulty in 5-8 IADLs.
Those older adults who lived with children and others had the highest proportion for difficulty in 0-4 IADLs whereas those older adults who lived alone had the highest proportion for difficulty in 5-8 IADLs. The main caregiver for older adults with difficulty in 0-4 IADLs was the 'any family' member (57.5%) followed by Spouse (32.5%). For those with difficulty in 5-8 IADLs, main caregiver was reported as 'none' (71.0%) thus indicating care deficit for the elderly. As high as 90.4% of older adults had been suffering with difficulty in 0-4 IADLs since 5+ years indicating the chronic disability they may be facing. However, for those with difficulty in 5-8 IADLs, 22.6% of older adults had been facing this difficulty since less than a month. However, significant proportions of older adults were impaired in both ADL and IADL capabilities.

Chronic Morbidity among Older Adults and Care available:
As high as 64.5% of the sampled population was diagnosed with the presence of a chronic morbidity and the numbers were slightly more for older women compared to older men. Rural older adults had more incidence of chronic morbidity (65.8%) as compared to their urban counterparts (63.2%). Presence of chronic morbidity increased as age advanced – 59.25% of older adults in the age group of 60-69 years had a chronic condition while 71.8% of them in the age group of 70-79 years reported the same and it was highest at 79.0% in the 80+ years age group.

Interestingly, those living alone had less reported chronic morbidity as compared to those living with children and others while it was lowest for those living with spouse at 58.0%. In terms of longest duration of morbidity for each older adult, 51.9% of them had been ailing from a chronic morbidity for more than 5 years and hence a care burden or care gap was

evident in both rural (49.0%) and urban older adults (55.3%) as well as among older men (50.0%) and women (53.5%). Presence of longstanding chronic morbidity of more than 5 years was also highest among the 80+ years age group at 63.2% followed by 56.9% in the 70-79 years age group and dipping to 47.0% in the 60-69 years age group. Regarding taking the older adults to hospital, 31.5% of older men were accompanied by their spouse to the hospital whereas only 14.3% of older women reported being accompanied by their spouse. As high as 75.7% of older women were accompanied by 'any family' member to the hospital while 57.4% of older men were accompanied by 'any family' member. Around 8% of older adults were accompanied by 'any relative or friend' to the hospital.

Discussion:

While on the one hand we see that family structures and living arrangements of elderly people are changing in the background of the population ageing and demographic transition in India, It becomes evident that older adults have definite care requirements under varying situations and data points out that the caregiver keeps varying for different living arrangements and how the elderly actually cope in each situation is different. While it is seen that living alone has sometimes been more beneficial for older adults, in a disability situation, it might be contrary. It is important to note that the social interactions of older adults and the support they receive from non-co-residing adult children also indicates their dependency status and what they perceive of a give and take relationship with their children. Further analysis into effects of each type of living arrangement on the health and disability status of older adults would be necessary.

Although older adults still seem to be part and parcel of their families to a large extent and care provision is still high from the family end, changing living arrangements and family composition in tune with adult child migration for economic and other gains might reduce the availability of care and support to older adults from their families in the near future. It is also evident that the social support for older adults outside their household is still not a widely available and availed component for their care and assistance. Hence, there is need to devise formal strategies to address the care and assistance needs of older adults in India, especially the poorer and marginalized families which are unable to cater to the needs of the older adult.

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