

A CASE STUDY ON BURDEN OF INFORMAL CAREGIVERS OF ELDERLY PEOPLE

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The existing evidence base shows that in India, about 272 million were poverty ridden. In addition, poverty increases the risk of elder neglect and abuse in economically under privileged families. However, limited database is available on the estimate of poverty-ridden elders in India (Sridhanya, 2013).

Gore (1992) estimated that about six per cent of the poor persons, that is, about 16.3 million persons were above the age of 60 years and poor. He also adds that a vast majority of the poor elderly persons were not receiving old-age pensions.

However, current official estimates of poverty among the elderly are not available, we can be sure that there are millions of elderly persons below the official poverty line.

a) Care for Elderly in India

The population of the elderly persons has been increasing over the years. By 2025, the world will have more elderly than young people and cross two billion mark by 2050.

While the western countries have a fairly well organised network of institutions for the care of the elderly, the growth and development of these facilities in India, which began as early as 1901, remains inadequate. In India, like many traditional societies, today faces a unique situation in providing care for its elderly as the existing old-age support structures in the form of family, kith and kin, are fast eroding and the elderly are ill equipped to cope alone with their lives in the face of infirmity and disability. The onus of caring for the elderly is therefore

now much more on the state than the family and will necessitate the creation of adequate institutional support.

Among female elderly, only 7.89 per cent were literates as against 24.82 per cent in overall female population. During last decade, there was many literacy programmes across the country and some of the states and hundreds of districts were declared as 100 per cent literate states and districts. However, in such places, we do not have reliable data on the literacy rate of elderly (Gokhale and Dave, 1994).

Therefore, an urgent need to examine the various aspects of this new and fast growing population to ensure the design of appropriate policy and programmes directed to meet the varied needs of this vulnerable and dependent group.

In Indian context, elderly people are cared by three institutions such as paid or unpaid old age homes, formal paid caregiving at home, or facilities, more importantly unpaid caregivers who contributes in caregiving. However, in the absence of available data their contribution has to be analysed.

b) Old Age Homes

According to statistics, there are 1018 old age homes in India. Of these, 427 homes provide care at no cost while 153 old age homes are on pay and stay basis, 146 homes have both free and as pay and stay facilities. In addition, detailed information is not available for 292 homes. In particular, 371 old age

homes across the country are available for the sick and 118 homes are exclusive for women. A majority of the old age homes are concentrated in the developed states including Gujarat (HelpAge India, 2002).

c) Formal caregivers

The term “caregiver” refers to anyone who routinely helps others who are limited by chronic conditions. “Formal caregivers” are volunteers or paid employees connected to the social service or health care systems.

Informal caregivers

Informal caregiving: This is a more inclusive term that refers to unpaid help provided by all nonprofessional providers of care, including family members, friends, neighbours, and/or members of a religious or other type of community. In addition to family members or significant others, friends, neighbours, or members of a faith community may provide informal caregiving (Schumacher, 2006).

The term “informal caregiver” refers to family members and friends, who provide nearly three-quarters of the care currently being provided to impaired older adults living in the community.

It is critical to understand why family caregivers care. Brodaty and Donkin (2009) have extensively discussed the existing literature base and identified several motivating reasons factored around family caregiving and their benefits to family caregivers. Some of such critical factors are sense of love, reciprocity, spiritual fulfilment, and a sense of duty, guilt, and social pressure and in some rare cases greed (Eisdorfer, 1991).

Caregiving roles: These can be classified into a hierarchy according to who takes on the majority of responsibilities versus only intermittent supportive assistance. Primary caregivers tend to provide most of the everyday aspects of care, whereas secondary caregivers help needed to fill the gaps (Cantor and Little, 1985; Sullivan, 2002; Tennstedt, 1989).

(Penning, 1990) identifies that among caregivers, who live with their care recipients, spouses account for the majority of primary caregivers, whereas adult children are more likely to be secondary caregivers. The range of the family caregiving role includes protective caregiving such as “keeping an eye on” an older adult who is currently independent but at risk, to full-time, around-the-clock care for a severely impaired family member. Health care providers may fail to assess the full scope of the family caregiving role if they associate family caregiving only with the performance of tasks (Vitaliano et al. 2003; Pinquart & Sorensen, 2003).

Methodology

The objective of this study is to gain a deep and thorough understanding of the experiences of the informal caregivers that providing caregiving to their elderly parents in the socio cultural context.

This study focuses on the subjective existential meaning of the phenomenon that occurs when family members care for aged parents with physical rather than cognitive decline. It also shed lights on insights regarding the cultural values relating to parental caregiving from the *Indian* perspective. Through phenomenological and family systems exploration, this study is concerned with understanding the experiences of a family members of eldercare in Pollachi, Tamil Nadu and is able to take a micro-view from the participant themselves in an effort to ease out causal factors that highlight the contemporary Indian social culture.

Case Study of Sheeba(name changed)-Caregiver

Sheeba is forty-five-year old woman and she has two children. In addition, she is the primary caregiver to her mother who is 78 years old. Sheeba’s mother owns a house and the family belongs to the middle – class. When Sheeba was 15 years old, her father died of heart

attack. Not having a breadwinner, the family survives by menial jobs. Fortunately, the family's own house (two storeys) has been saving them to a greater extent in both ways; providing roof over head and source of finance by renting out the part of house. Sheeba has completed her undergraduation and B.Ed degree with great many hurdles. But she has been given stretching hands such as free education up to schooling provided by religious institutions. Her education attainment is the only shield that brought her a decent school job where she studied, which paved the way to lead her life in a dignified way not only for her but also for the family. As a result, her sisters were able to complete; younger sister completed UG, and the younger sister completed her 8th std.

As the things were going well, the family met an unwanted turn; the youngest sister fell in love with someone and eloped. Meanwhile, the family got her Sheeba's first sister got married with insurmountable pain. Being the only breadwinner in the family, Sheeba's marriage was not a choice of matter. Adding more pain to Sheeba, her mother had been identified with cancer. Now, all sisters got married and Sheeba was the only breadwinner and caregiver to her mother. Her chance of getting married was gloomy. Considering Sheeba's future and prospects her mother insisted her to have a family life of her own. But , Sheeba was reluctant to marry since she was the only caregiver and ready to sacrifice her life. Suggestions from all corners, she was willing to marry if marriage would not limit her caregiving to mother.

Finally, at the age of thirty - eight, with so many hurdles all her life, sacrificing her life for the family, protecting the family at hard times she had a shoulder to cry on. Her husband was an administrative officer in a school. As a caregiver, she was now with multiple roles; mother of two, caregiver, and caring wife. Even though she was juggling with the roles, she had to constantly bear with the husband's anguish and complain that she was paying attention highly on caring her mother than he or his family. Inevitably, she

quit her job to play her role better. Sheeba convinced herself that mother was old and her mother's days were numbered and thereafter she could satisfy the needs of her own family at the highest. To make her financially better and spare time for time caregiving she started a crèche. Unexpectedly, add pain to Sheeba's life, her husband had deceased with a very rare type of cancer and he had been bed ridden for six months and died. During this period, she had to caregive both her mother and husband. His death brought excruciating pain to Sheeba. Being the only breadwinner of her family and as middle-aged women (45 years old), she had to take care of her two children with less money came in. As manna from heaven, the school where her husband worked offered a job, provided with free education for her children give her tremendous support to care her family includes her mother for whom she crucified herself.

Burden

Even after all sisters got married, Sheeba was not willing to marry because there was no one to look after her mother. Sheeba's sisters could have volunteered to take care of their mother. However, the youngest sister's husband was not in favour of his wife going to her parent family to take care of the ailing and aged mother. The other sister is fully preoccupied with her family needs and requirements. *Both the sisters as the case study shows, it is more a circumstantial problem to take care of the elderly persons person than reasons they attribute. Thus, the onus of caring the mother fell on the eldest daughter. Besides, not having a family of her own helps in looking after her mother. Even her marriage, normally a happy occasion, became a great burden because of caregiving. All her life, she has less privileged financially. This leads her to let her taking right strategies at difficult times. For instance, marrying someone who willing her caregiving, starting crèche, keeping aside the worries and getting back to jobs.*

Sheeba's views about her mother

Sheeba always consider her mother as a lovely and welcoming person who could bear all the pain whatever thrown at mother. By nature, Sheeba's mother was kind hearted and spared her whole life for her children. Her daily chores like getting up for prayer and taking care of personal hygiene was taken care by herself without troubling anyone in the family. Indeed, she is very considerate person and never forced her views on anyone. These personal attributes of her lead Sheeba's decision to take care of her mother, even ready to give up her own prospects.

Theme 1: The Emotional Bonding as the features of caregiving

“The emotional bonding refers to the attachment that care recipient and caregiver is having. During the discussion, the first thing that emerged was their helping behaviour was linked with attachment behaviour and dependency of the elder. The emotional bonding occupy the very significant procession in the field of psychology and healing sciences and has been extensively elaborated as “attachment theory” throughout various stages of life and several relationships.

What motivated you to take care of your mother by yourself? Have you ever been on the idea send your mother to old age home?

In this study, emotional bonding refers to basis on which they took to elderly persons caregiving and their personal conviction towards the vulnerable people in general and the informal caregiver in particular.

Caregivers views-what they say

The following depicts the conversation between the researcher and the caregiver:

Caregiver (Sheeba)

“Even If I see old people who are destitute on road, I like taking them to my home and care them.so how can I leave my

parents... no that is beyond me...even I discontented old age homes and those who are leaving their parents also...I never leave my lovable mother”

It is found that the respondent have a very strong attachment toward their elderly parents. It was understood that respondent felt it to be their prime responsibility to take care of their elderly parents they not only considered their moral responsibility but also accepted that by doing so, they got inner personal satisfaction. By repaying their debt within academic literature in the field of caregiving stems it position experiencing the external satisfaction because of bonding of love and sense of model application,(Gaffney .M.2006) ,Bourgeois.S Johnson.A.(2006), Carnevale F , Alexander E, Davis M, Rennick J Troini R(2006)., Fallon P (2006) Van den Berg B, Spauwen P. (2006) Hepworth D. (2005).

THEME-II Implications on caregiver (physical exhaustion)

Implications on caregiver refers to the ways by which caregiver was affected due to providing elderly persons caregiving services It was found that the caregiver had to perform multiple roles that included child care , going to work, fulfilling family responsibility apart from taking care of elderly parents. Since the caregiver had to perform such multiple roles, they expressed that quite often their roles clashed with each other leading to the development of self-satisfaction. Generally, caregiving affects people in variety of ways however, the degree of affection may vary from one caregiver to another as the following case studies that records the researchers, and caregivers focused queries. It involves multiple roles and several simple to complaint function relating to care .In your caregiving does multiple roles have any clash.

What are the difficulties you have faced in the course of caregiving?**Respondent- Sheeba**

“If you see my daily routine, I'm am housewife with of two kids. In addition, I'm the

daughter of the care recipient. I'm running my own nursery school to make both ends meet ... Many times due to some reason or other one-role clashes with other.when my husband complains, I use to convince myself by thinking that my mother will be for few days after that I can pay attention to my family. Unfortunately, my husband died recently which makes my life more miserable than it was before. So, I wallow in self-pity now for not making himself happy as he wished for. All the family members are close to my heart and what hurts me when I see that one role is getting neglected while fulfilling the other.

Since the caregiver had to perform such multiple roles, she expressed that quite often their roles clashed with each other, leading to the development of self-dissatisfaction. It was also found that the roles that the respondents had to perform, including caregiving, kept them busy for the entire day causing physical as well as mental fatigue.

THEME-III financial implication

In general, financial implication is rather burdensome as in most of the cases the caregiver parents have multiple health ailments more often the caregiver is doubly crushed. Discussions with the respondents revealed that providing caregiving services to the elderly parents was affecting them financially. Since in most of the cases the respondents parents had multiple health ailments depending on the type of health issues it was affecting the financial condition of the respondents accordingly.

What is the extend of financial difficulties you experience?

Respondent- Sheeba

Finance ...that is a big issue... I could not leave my mother ...I had to quit my job then I was looking for my husband's helping hand to meet medical bills ... If required we may use the money reserved for my kids . Parental care expenses like chemotherapy pushes me ...I am an educated woman...why can't I do something like starting a day care centre on my own

...then somehow I make myself comforting financially .

My husband became sick as he was affected by cancer he had been in bed for six months and died lately. I had to spend huge amount in connection with the events ...my pocket wasn't deep but my relatives, friends pitch in. ...So many helped ...how long others can support me financially... I am helpless now and this feeling dreads me always..."

Financial expenses for health care for elderly persons are very high. It is very difficult for the middle class family to bear such expenses more often. These expenses come all of the sudden and unplanned expenditure. Besides, financial strain on unplanned expenditure causes tremendous stress.

It was understood from the above case that since the respondents has the responsibility of taking care of their elderly parents it was affecting them financially in a big way, however, due to emotional bonding towards their parents they could not avoid spending every bit of their savings on their parents health care. Inadequate personal and or family income and lack of productive assets such as savings pension or retirement benefits which are handicap for older people in India (Raju, 2000). Substantial financial burden can arise the cost of drugs and primary care, while hospitalization can have a devastating financial impact. (Dror, Vanputten Rademarker, and Coren 2008).

THEME IV Burden

It is understood that in case the elderly parents had more than one child there is a passive resistance to accept and at times, denial amongst the children regarding accepting the responsibility of providing caregiving to their elderly parents. Since providing elderly persons care to fragile parents is a big responsibility, understanding this aspect every adult child had the tendency to avoid taking it and expected the other to take responsibility. Ultimately, the son, daughter, or daughter-in-law who was more sensitive and emotionally attached to the parents takes the responsibility.

Why the caregiving responsibility falls on you?

Respondent- Sheeba

We are three sisters. My father died when I was very young. Mother was the only breadwinner who struggled hard to get my second sister married as the third sister eloped. Latter, my second sister got married. Meanwhile, we came to know that my mother is deceased with cancer. As a result, I didn't want to marry because I had to look after my mother and I had a dilemma that whether I would get married? Because I had crossed 35. Because of this fear, I refused to marry. After compulsion from every side, I accepted for the marriage with the condition that my spouse should allow my mother with me.

It was my late marriage. As I was last to get married taking care of my mother (responsibility) was mine. No one shows much eagerness and comes up on their own to accept the responsibility of taking care of the elderly persons ... They consider it is as a burden ... they do not want any kind of disturbance in their personal family life. However, I cannot do that... I cannot be like them ... I simply cannot leave my mother in this condition when I know that she will not be able to take on their own... After all, she is my mother ... I cannot be so selfish being daughters, know my responsibilities and simply cannot run like my sisters... I have to follow my duty...so responsibility of taking care of my parent left to me others escape by saying that they are busy with the family.

It is understood that the responsibility of providing caregiving, most of the time, is taken up by that person who is more emotionally attached to their parents irrespective of his financial and/or physical capacity. When a spouse is not available to provide care, the responsibility typically falls to a daughter. In the absence of a daughter, a son may become the primary caregiver, although there is evidence to suggest that sons often pass along caregiving responsibilities to their wives.

Which family members become caregivers and the type of care they provide are also influenced by cultural factors (Montgomery and Kosloski, 2000). Intergenerational conflicts can occur with elderly parent and his/her son/daughter/daughter-in-law or between grandparents and grandchildren.

THEME V Social Isolation (alienation)

Caregivers commonly experience a loss of social contact with others. Social loneliness has to do with quantity of contacts: not having enough people or enough activity in one's life. Loss of social contact is a very common consequence of caregiving. This is particularly concerning as social support has been identified as protective against the strains of the role. Informal caregivers of elderly persons with dementia are described as leading constricted lives with diminishing social contacts and friends (Opie 1990).

Whether the caregiving process leads to social isolation?

Respondent- Sheeba

My second sister is not allowed to come here frequently. She visits yearly once and she will not stay here... My first sister and her husband also not want coming. However, they visit when there is an emergency. My mother's sister lives nearby and she is also sick. Often she comes here and enquires the things and goes. I cannot go everywhere and. I do limit myself going outside. If there is any gathering in my husband house, I go with great risk...

Case Study Conclusion

Case study of this research work show that the informal caregivers not only experienced lack of care related knowledge, not able to cope with cultural values, physical and psychosocial exhaustion but also experienced lack of support.

Quality of care, which is delivered by the informal caregiver, is reduced in the situations where the basic support, resources and

care related knowledge are not available for them. These issues not only lead to caregivers burden and stress but also deteriorate care recipients condition as well.

Therefore health providers, policy makers and other family members of the care recipients must work together in order to help the informal caregivers acquire more care related knowledge in terms of management strategies and sense of competence. Secondly, in terms of support for the caregivers need more on financial, physical and emotional support. Above all, successful ageing of care recipient is a key factor in reducing caregivers burden.

Finally, implementing caregiver centric programs to educate and support the family caregivers and linking them to more formal social resources are essential. The issue of how family caregivers experienced burden is complex and warrants further research.

Bibliography :

Brodaty, H and Donkin, M.H. (2009), 'Family Caregivers of People with Dementia' *Clinical Neuroscience*, Vol.11, and No. 2, pp. 217-228.

Cantor, M. H and Little, V. (1985), 'Aging and Social Care,' (2nd Ed.), *Handbook of Aging and the Social Sciences*, New York: Van Nostrand Reinhold, Evidence Level V. pp. 745-781.

Dror, D.M., Van Puttenrademaker, O and Koren, R. (2008), 'Cost of Illness: Evidence From a Study in Five resources-PO or Locations In India', *Indian journal of medical research* Vol. 127, pp. 347-361

Eisdorfer, C. (1991), 'Caregiving: an Emerging Risk Factor for Emotional and Physical Pathology', *Bull Menninger Clin*, Vol.55, No: 2, pp. 238-247.

Gokhale, S.D., & Dave, C. (1994), 'India'. J.I. Kosberg', (Eds.), *International Handbook of Services for the Elderly*.

Greenwood Press, Westport, C.T., pp. 188-1970.

Montgomery, R. J. V., & Kosloski, K. (2000), 'Family Caregiving: Change, Continuity, and Diversity',. Rubinstein, R & M. Lawton (Eds.)', *Alzheimer's Disease and related Dementias: Strategies in Care and Research*, pp. 143-171.

Opie A (1990), 'Caring for the Confused Elderly At Home: Report on Work in Progress', *Women's Studies Journal*, pp. 46-64.

Penning, M. J. (1990), 'Receipt of Assistance by Elderly People: Hierarchical Selection and Task Specificity', *Gerontologist*, Vol.30, pp. 220-227

Schumacher, K. L., Beck, C.A and Marren, J. M. (2006), 'American Journal of Nursing, 106 (8), 40-49. Evidence Level VI Sridhanya, 2013

Sullivan, M.T. (Feb 2002), 'Caregiver Strain Index (CSI). Try this: Best Practices In Nursing Care To Older Adults: John A Hartford Institute for Geriatric Nursing, College of Nursing, Issue 14, New York University

Tennstedt, S., & McKinlay, J. (1989), 'Informal Care for Frail Older Persons. M. Ory & K. Bond (Eds.), *Aging and Health Care*, London: Routledge, pp. 145-166

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003), 'Is Caregiving Hazardous to one's Physical Health? A Meta-Analysis, *Psychological Bulletin*, Vol.129, pp. 946-997. Evidence Level I.

Pinquart, Mand Sorensen, S. (2006), 'Helping Caregivers of Persons with Dementia: Which Interventions Work and How Large are Their Effects?', *International Psychogeriatrics*, Vol.18, No: 4, pp. 577-595. Do: 10.1017/S1041610206003462.

Gaffney .M.2006) ,Bourgeois.S Johnson.A.(2006), Carnevale F ,