



Value- Integrating Home- Based Elderly Care In India: A Perceptual Study Of Stakeholders Of Elder-Care Organizations.

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INTRODUCTION

Ageing is a global phenomenon. Population ageing is irreversible and inevitable reality because of advancement of health and medical facilities and declining fertility. In 2010, an estimated 524 million people were aged 65 and above which is 8% of the world's population. By 2050 the number is expected to be triple to about 1.5 billion, representing 16 % of the world's population. Although more developed countries have the oldest population profiles, the majority number of older people and the most rapidly aging populations are in less developed countries. Between 2010 and 2050, the number of older people in less developed countries is projected to increase more than 250 percent, compared with a 71 percent increase in developed countries.

According to Census 2011, there are nearly 104 million elderly persons (aged 60 years or above) in India in which females are 53 million and males are 51 million. From 5.6% in 1961 the proportion has increased to 8.6% in 2011. For males it was marginally lower at 8.2%, while for females it was 9.0%. As regards rural and urban areas, 71% of elderly population resides in rural areas while 29 % is in urban areas. India has acquired the label of "an aging nation" with 7.7% of its population being more than 60 years olds (Ingle and Nath,2008). The current statistics for the elderly in India gives a prelude to a new set of medical, social and economic problems that could arise if a timely initiative in this direction is not taken by the programme managers and policy makers.

While increasing longevity is a positive thing, there are other negative factors like morbidities and disabilities that are associated with age. The elder persons in the society face a number of problems due to absence of assured and sufficient income to support themselves for their healthcare and other social securities.

Loss of a social role and recognition, and non-availability of opportunities for creative and effective use of free time are also becoming a matter of great concern for elderly persons.

The trend clearly reveals that ageing will emerge as major social challenge in the future; and vast resources will be required towards the support, service, care and treatment of the elderly persons.

According to the WHO report of 2015, that by 2030 more people than ever will be at the risk of developing ill health and chronic diseases accompanied by old age. With the rapidly increasing number of aged, the care of elderly has emerged as an important issue in India. Providing care for the aged has never been a problem in India where a value based joint family system was dominant. This joint family structure has always been the socioeconomic backbone of the average Indian individual (Shah, 1998). The institutionalized care, assisted living and old age homes started coming into the picture because of the change in the family structure from joint to nuclear. Although there is a change in family structure, people still do not prefer institutionalized care, assisted living or old age homes because of various societal stigmas attached to the same. A 2014 study by the Researchers of King George's Medical University, Lucknow which studied the reasons of people staying at old age home found out that misbehavior from family members was the major reason of leaving their homes and staying at old age homes. Earlier family structures were joint, they had many members in their families, they lived in traditional houses. Joint family, kinship and value system in the past ensured emotional help, physical security and social support to the elderly, but things have been changed with the changing time. Now, the traditional houses have been changed into multi-storied buildings, family structure has been changed from joint to nuclear, the children leave their elderly parents and go abroad, increasingly it becomes difficult for them to take care of their parents, which leaves the elderly people vulnerable and isolated.(Raju, 2002).

While health services are available in public and private health settings, the care of older persons remains a responsibility of the family. Families are resilient and can share the burden of providing for and caring for older family members. Ansari (2002) stated that even though the the family members provide better economic facilities like food, clothing, medical treatment , housing etc., they have less time and willingness to serve the elderly.

Over time, older people eventually lose the ability to survive independently due to increasingly restricted mobility, greater frailty, and a decline in physical health due to various acute or chronic disease or dementia. With the loss of independence, older persons must rely on others for basic Activities of Daily Living(ADL) and may require assistance by some form of long- term care.

A study from ICMR (2012) at the All India Institute of Medical Sciences revealed that 70 per cent of patients who died after receiving emergency care died in their home indicating the importance of developing home care services for older persons.

Health care refers to the quality of care and what factors can make health care better. The most important factor which makes health care is its need. But just the need of health care doesn't make it essential, the service quality, the care giver and care receiver relationship, the standard of the services, the staff and their competency makes health care a better option not only for patients but also for the elders who really need care at home and their own environment (Alodhayani, 2017).

The concern ageing was realized by Indian government and recently in April 2018, the government under the Ministry of Social Justice and Empowerment started the Integrated Scheme for the Older Persons which aims to improve the quality of life of the Senior Citizens by providing basic amenities like shelter, food, medical care and entertainment opportunities and by encouraging productive and active ageing through providing support for capacity building of State/ UT Governments/Non-Governmental Organizations (NGOs)/Panchayati Raj Institutions (PRIs) / local bodies and the community at large.

There is growing need for culturally sustainable models of home-based care (HBC) for older people but the need is complex. For example, there is no systematic welfare system built around elderly care, there is a changing family structure and there are social reasons (dependency and social images) for elderly's' and families use of elderly care service. Thus, there is a need to understand the mechanisms of provision of working and sustainable models of HBCs for the elders. We need a deeper insights of critical success factors as well as how to deal with challenges in managing elderly care. A deeper understanding of variations in the provided elderly care can provide insights on key components for successful designs and implementation of different models of elderly care in various contexts. Swedish models for elderly care have also great challenges but would have many valuable insights to offer India. Through cross national studies, lessons can be learnt on how collaboration amongst various stakeholders can be organized and coordinated, that can improve the HBC services for older people. In this paper, we discuss the findings of an inductive study based on exploratory in-depth interviews of managers and social entrepreneurs managing organizations providing home-based care (both medical and non-medical). Some of the care-giving organizations studied also specialize in Ageing care services. We arrive at a series of important findings that form the basis for developing an integrated value-based model of Home-based Care (HBC).

Materials and Methods

The study is purely qualitative . Cognitive interviews, In-depth Interviews, Case studies and Focus Groups were developed for data collection. Cognitive interview and in-depth interview schedule were developed by the team for stakeholders which was distinctive for each of the stakeholders group.Keeping in mind the following themes.

Understanding of Home based Care

Qualities of Care givers

Expectations of Service Buyers

Challenges in Home Based care,

There were six major types of stakeholders that have been covered in the study: The stakeholders of homebased care services for elderly people are categorized namely – Service Providers / Founders, CareGivers, Care Receivers, Doctors, Service Buyers and NGOs.

• **Table 1 – Sample Distribution of Stakeholders of Homebased Care Services**

	Vadodara (Urban)	Vadodara (Rural)	Ahmedabad	Mumbai	Pune (Urban)	Pune (Rural)	Varanasi	Kolkata	Total
Service Providers	4	0	0	6	0	0	3	2	15
Care Receivers	3	0	0	1	5	0	0	3	12
Care Givers	4	0	0	8	8	5	1	4	30
Service Buyers	2	0	0	1	0	0	0	1	4
Managers	2	0	2	9	0	0	3	2	18
Elderly People	1	2	0	1	4	5	2	2	17
Doctors	2	2	0	1	0	0	1	2	8
Total	18	4	2	27	17	10	10	16	105

As shown in above table 1, total 105 participants were interviewed by using cognitive interviews and in-depth interviews. It can be described that 22 interviews from Vadodara (Urban – 18, Rural – 4), 2 interviews from Ahmedabad, 27 interviews from Mumbai, 27 interviews from Pune (Urban – 17, Rural – 10) and 5 interviews were conducted in Kolkata.

RESULTS AND DISCUSSIONS

I. Understanding about Home Based Care

Service Providers understanding on Home Health care Service providers believe that when elderly people do not have their family members to take care of them or when they are bedridden and no one is there to help them for their routine activities such as, bathing, toiletries, medicines, walking and eating and drinking, homebased care services are preferred. Elderly people understood that they feel alone without family members and need someone to take care of them and talk to them. A service provider from Varanasi responded homebased care is a care of patient. Mostly homebased care services are preferred when families need someone medically trained to take care of elderly people. Service provider also mentioned that most of his staff are young female nurses who have completed their nursing courses from nearby cities. There was not found a need of social care from the service buyers or elderly people. According to the service provider, homebased care services are found less in demand in Varanasi due to the absence of circumstances when such need cultivates in the family. The perception of homebased care is generally positive amongst the stakeholders. Most of the stakeholders believe that home based care is a more appropriate alternative for care delivery (post-operative of palliative) as compared to the conventional model of old-age homes. For instance, Founder director of a renowned HBC organization in Mumbai which operates in joint-venture with a global HBC player, has raised concerns over the lack of adequate facilities either in the conventional care-giving models for the elders outside hospitals in absence of their filial relations, viz., the old-age homes or the day-care centers.

Elderly people understanding on Home Health care

One elder woman, who was partially blind, never heard about homebased care services in the city. She has two caregivers to take care of her in morning and night shifts for ten years. Both caregivers used to come to their house to do daily household chores such as, cleaning and dusting house and washing clothes.

II. Qualities of a caregiver

From the analysis of the interviews of service providers and elderly people, we identified various qualities of caregivers from their perspectives

Service Providers' Perspectives on Qualities of Caregivers(CG)

Service providers were asked about the qualities of caregivers for good homebased care services. It is derived that health of caregiver was found more important. It was stated that caregivers should be clean, hygienic and physically healthy so that they can take care of elderly people. Caregivers should have helping attitude and should cooperative to the needs of elderly people. Other qualities found from the perspectives of service providers were hard work and ready to do everything for elderly people and need to be adaptive to the habits and lifestyle of elderly people. When asked about the qualities of caretaker, a service provider from

Varanasi responded that a caretaker should be trained enough to understand the need of the elderly people. They should also need to strong enough to lift elderly people if needed and support them to walk or to exercise.

A cast and religion of a caregiver was found to be an important factor in homebased care. A service provider in Vadodara city stated that sometimes clients (elderly people) prefer the caregiver who is of the same caste. When the castes of both caregiver and an elderly match, the rapport established becomes easier and the client keeps caregiver longer period of time. It also helps caregiver to understand the beliefs, traditions and culture of family. In India, there exists stigmas and stereotypes about castes, economical status and religions. Elderly people sometimes do not prefer caregiver of lower caste.

Perspectives of Elderly People on Qualities of Caregivers(CG)

Elderly people were asked what qualities caregivers need to have to provide good homebased care services. It can be seen in above graph that faithfulness of caregiver and knowledge of elderly care is found most important from the perspectives of elderly people. It was also observed during the interviews of elderly people that trust was an important factor because of they have faced and heard caregivers stealing things from their home and misusing the property of their house. It was also reflected that compassion and feel of care were also preferred as an important characteristic among caregivers. It was also stated that caregiver need to be well-mannered and well-behaved.

From the analysis of both service providers and elderly we found out following adjectives that can be considered as the desired qualities of a caregiver: Passionate, Compassionate, Professional, Compliant to protocols, Situational Awareness, Sincerity, Technical skills, Sense of Hygiene, Dedicated, Caring, Patience, Trustworthy, Willingness to Learn, Good Communication skills, Empathy, Loving, Practical Wisdom

III. Role of a caregiver

All the stakeholders (Service providers, Elderly People, Caregivers, Doctors and Managers) were asked what according to them the roles of caregivers for homebased care services were.

Roles of caregivers from the perspectives of service providers were - Helping elderly people in their routine activities, taking care of regular medications of Elderly People, doing patient related work only rather than other household chores and helping elderly people to walk and exercise.

According to elderly people, cleaning and grooming of elderly is also a responsibility of a caregiver. According to Caregivers, giving medicines, grooming and helping elderly in bath and toiletries are also responsibilities of caregivers.

IV. Motivation of Founders to start a HBC organizations

There were two important observations that we made about the motivation behind starting a home-based care organization by their founders. Firstly, almost all the founders had some personal experience about the challenges faced in caring the older people (for example the post-operative care of an old parent, or relative, the lack of existence of adequate and appropriate services catering to the specific demands of the elder, etc). These personal experiences moved the founders and they became conscious of a pressing need for home based care in India.

Secondly, the lack of autonomy and financial freedom amongst certain elders, the career demands of the care-receiver's family members and the workforce being skewed towards hospitals made the situation even worse for the older people and the requirement of an affordable health care at home which is well organized and designed appropriately taking into consideration the specific needs of the older and their family members.

V. Expectationsof Family members or service buyer

Expectation from caregivers

The expectations towards caregivers from service buyers or families who preferred homebased care services for their parents or relatives were appropriate home-based care for their parents and trustworthiness were most expected from caregivers. Other expectations were such as verification of caregiver needs to be done by homebased care organization, Caregiver need to be adaptive to lifestyle of elderly people and should also be punctual.

Expectation from homebased care organizations

The expectation of family members from the homebased care organizations are: Hiring people who can do their job well, should not cheat the customer and have a keen eye on the caregiver and the services provided by them by regular feedback.

VI. Challenges faced in Home Based Care

From the analysis of the interviews of all the stakeholders we found out the following challenges in home based care:

High Cost:

Home based care services in general are not affordable and in spite of a large aged population, the services haven't yet reached the ones who really need it. The main reasons for the same are:

Increasing Real Estate Costs: According to the Co-Founder of a renowned HBC which is based in Mumbai and New Delhi, and which is a pioneer in India in the organized Home-based care space.

Second main reason is *Lack of Insurance Cover for Home Based Care*. In India, home-based care services are not covered by the medical insurance policies issued by all the insurance companies. This is because they mostly cover hospitalization expenses and not post-operative care back at home. This makes the elders' family who mostly pay for the HBC services, more sensitive to prices charged by the HBC service providers; and with increasing competition in the HBC space, the customers have also started demanding discounts.

Lack of Awareness of Home Based Care:

Awareness about Home Based care hasn't reached to many people especially the ones residing in rural areas of the country. This is also a reason that the cost of Home based care is high on the country. It was found from the conversations with people in Varanasi, doctors were also not aware about the existence of homebased care organizations in the city. It was believed that homebased care is something which is taken care by hospital staff in their free time.

Lack of skilled caregivers

One of the most important challenges identified by the stakeholders in organizing and managing the HBC services, consistently highlighted by all the interviewed stakeholders is the lack of skilled and reliable care workers. The lack of reliable workforce is primarily due to two reasons:

For workers who are trained in nursing, working in hospitals is a more attractive and prestigious career than working as a home-based care worker where they feel they are being treated more like a house-maid than a trained professional

For workers who are not trained as nurses, they lack adequate technical skills required to address the specific requirements of the old age people.

CONCLUSION

Ageing is a phenomenon that is prevalent in global context and especially in a developing nation like India. Ageing comes along with various problems for the elderly as well as their family members. These problems need proper care that has to be taken. Institutional care is an option that comes with many limitations that hinders the independence and mobility of the elderly.

Home based care is providing them all the services at home which is more convenient to the elderly and their family members. And so proper innovative and sustainable models of Home based care need to be created which is also value integrating and can curb the various limitations and challenges that are currently faced because of lack of awareness about organized home based care..

The existing models are so diverse, for instance in cities like Mumbai and Pune, there are proper organized set up for home based care services, in Vadodara, the services are very much unorganized. In Varanasi, people go there during their old age to attain 'Moksha', the services are philosophical and religious in nature. In Kolkata, it is mutual interdependence of people for caregiving services. In the rural areas, its value based and there are many stigmas that are attached to caregiving, the caregiving services are more of barter kind of system in the rural areas. Thus in a diverse country like India, the existing models are extremely based on the society, culture, religion and many more diverse factors.

This study helped in exploring the existing models of homebased care in India. India being socio culturally diverse it was understood that the development of any new model should be always keeping in mind this diversity and no system can be imposed because in a country like India any transplanted model would be deleted by the people.

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