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Exploring Elder Care in Different Settings in West Bengal: A Psycho-Social Study of Private Homes, Hospitals and Long-Term Care Facilities

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***Abstract*—**West Bengal, one of the most rapidly ageing states in India, has inadequate structure for elder care. Therefore, there is an urgent need to improve elder care which involves focusing on different care settings where the elderly exists, like - Homes, Hospitals and Long-Term Care facilities (e.g. - Old Age Homes, Hospices). The study explores various elder care settings, with the intention to develop an understanding about them, and thereby generate comprehensive information about the entire spectrum of elder care in Kolkata. Empirical data are collected from the elderly and their caregivers in different settings. The tools for data collection are narratives, in-depth interviews and focus group discussions, along with field observations. Mixed method design is adopted to analyze the complexities of elder care in different set ups. The major challenges of elder care in private Homes are: architecturally inadequate housing conditions, paucity of financial support and scarcity of skilled caregivers. While the key factors preventing the Hospital and Long-Term Care Facilities from providing elder care services are inadequate policies and set governmental standards for elder care for the hospitalized elderly in various departments of the Hospital and the elderly residing in different kinds of Long Term Care Facilities. The limitations in each care setting results in considerable neglect and abuse of the elderly. The major challenges in elder care in West Bengal are lack of continuum between different care settings/ peripheral location of private Homes within public health framework and inadequate state Palliative policy- including narcotic regulations. The study suggests remedial measures to improve the capacity to deliver elder care in different settings.

***Keywords*—**Elder care settings, family caregiver, home care, geriatric hospital care, long term care facility.

I. Introduction

AGEING marks the decline in physical, cognitive, emotional, social and economic status, leading to inimitable challenges not only for the elderly but also for their families, caregivers and the health care system. India ranks in 67th position in the 'Quality of Death Index', 2015, among the eighty countries selected for the assessment [1]. As per Government of India National Policy on Older Persons, 'senior citizens' is defined as a person who is 60 years old and above. About 64 per thousand elderly persons in rural India and 55 per thousand in urban areas suffer from one or more disabilities. The Quality of Life of the elderly is poor as is evident from the poor health profile. Elderly generally suffer from chronic diseases which require long term care. A series of studies point out that elderly in India are generally prone to cardio-vascular illness, stroke, circulatory diseases, cancer, arthritis, hypertension, osteoporosis, high blood pressure, kidney problems, vision problems, diabetes, chronic bronchitis, rheumatism, digestive disorders, Genito-urinary disorder, vision and hearing impairment, anemia, skin and vision [2]. They also suffer from multiple morbidities, which make elder care more challenging in different settings. India has 0.6% capacity to provide Palliative Care [3].

India has 8.6% of the global elderly population and has six lakh centenarians. It presently houses nearly 103.8 million persons who are above 60 years of age; with a sharp rise of 27.2 million from 2001 census record (Elderly in India Report, 2016). According to EIU, 2015 [1] estimate, 6% of the population of India are expected to be aged 65 and above by 2020. In India people aged 60 years and above are regarded as elderly [4]. Population aging generates many challenges and sparks concerns about the healthcare systems and the well-being of the elderly [5]. Rapid growth in elder population along with the development of urban culture in India has led to the emergence of multiple problems for the elderly in India. Besides, population ageing is not accompanied by commendable geriatric policies in India.

Geriatric care receives marginal attention in India resulting in vulnerability of the elderly with regard to the medical care in last days of their lives. Lack of institutional interest and limited standardized policy and protocols on end-of-life care of the elderly is a major challenge for elder care in India. Even the views of family members regarding end-of-life care of the elderly are unexplored in the Indian context. Therefore, there exists an urgent need to improve the elder care. Elder care is complicated because it is not limited to treating the disease alone [6], but also requires addressing the psycho-socio-economic issues of the patient and their family members to maintain the elderly patients' individual goals and independence, from a multi-specialty and multi-disciplinary care perspective. Further, elder care cannot be improved by focusing on any single setting for elder care. The elderly stays in different settings at different phases of their life/disease progression- like Homes, Hospitals, Long Term Care Facilities, etc.

Each of these settings has unique challenges in providing elder care. Therefore, these challenges faced by the elderly

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and their caregivers in each setting needs to be explored, in order to arrive at a consolidated picture. The findings may help us to provide recommendations on the entire spectrum of elder care.

Elder care issues receive marginal attention in India and most of the old people die at Homes and Hospitals. In the next three sections, Elder Care in three different settings are discussed, followed by the Consequences of providing Elder Care on Family Caregivers.

A. Elder Care at Homes

Government of India policies like- National Policy for Older Persons (1999), the National Policy for the Senior Citizens (2011) and the National Policy for the Health Care of the Elderly (2011) have recommended home as a care setting, they have failed to address inter-state differences in demographic features, basic infrastructure of elder care, political context and ideology, which have resulted in challenges in providing home care to the elderly facing. Besides, the homes work in isolation as they are not connected to Hospitals or Long-Term Care settings. Within the murky state of elder care in India, ageing and dying is allegedly difficult. The situation of ill elderly and their families at homes is more difficult, due to lack of adequate structure and provision for community based home care, except in the state of Kerala.

B. Elder Care in Hospitals

In India, outside Homes, Hospitals are important places for elder care. However, Hospitals in India face several challenges. Hospitals in India are situated within a rudimentarily developed public health system, wherein health delivery system at different levels—primary, secondary and tertiary--function fragmentarily. This seriously disrupts continuum of care for the elderly. Inadequate care provisions in the community push many to seek care at the tertiary level, i.e. hospitals and other types of acute care set-ups. This makes Hospitals over-burdened and limits their capacity to deliver elder care. This is particularly problematic in Public Hospitals where it is seen that only 50% of the beds are functional [7]. Besides, Indian Hospitals bear huge number of patients who compete for scarce resource [8]. This leads to yet another serious problem like 'bed-blocking' [9]. The hospitalized elderly with multiple co-morbidities often become bed blockers in Hospitals. Such elderly not only suffer from genuine health problems but also have a high dependency level in activities of daily living (ADL) which hamper their discharge to the community. Lack of community based rehabilitation program prevents such elderly to return to their homes from the Hospitals. Further, an audit of patients admitted in a Kerala-based Cancer Hospital found that patients seek hospitalization for pain and palliative care as later as 19 months after they were diagnosed of cancer, by which time the metastasis devastate their body and doctors are left with little option for treatment [10]. The existing medico-legal complexities further accentuate the issues of elder care in Indian Hospitals. The Position statements issued by Indian Society of Critical Care Medicine (ISCCM) and Indian Association for Palliative Care pertaining to end-of-life primarily focus on safeguarding the Physicians from legal complexities and therefore, do not adequately address different complexities during end-of-life and their findings are not supported by empirical research [11], [12]. Moreover, the ISCCM position papers pertain only to the elderly who have been admitted to the Intensive Care Units of the Hospital. Therefore, there is scope for addressing the issues of the elderly who are admitted in General and other Wards of the Hospital.

C. Elder Care in Long Term Care Facilities

There is lack of adequate structure and policy on Long Term Care Facilities. These facilities, like Old Age Homes, Hospices do not have standardized policies for elder care. Besides these structures often act in isolation and are not connected with other elder care facilities.

In a multicity (Bangalore, Chennai, Hyderabad, and Tiruvananthapuram) based study [13], on the relocation experience from Family Homes to Old Age Homes the following themes were found to be evident- challenges in interpersonal family relationships, conflicts in values and perceptions, particularly with regard to neglect and abandonment. In another study [14], the primary reasons for relocating from Family Homes to Old Age Homes were found to be nobody to take care, having no children, widow/widower hood. In a multi-city study (Bangalore, Chennai, Hydrabad and Tiruvananthapuram) on elderly women residing in Old Age Homes, the reasons for their relocation were found to be chiefly childlessness and widowhood. Older women in Old Age Homes reported higher degrees of psychological closeness and contact with daughters than sons.

The major health problems observed among the elderly in Old Age Homes were locomotive/joint and muscle disorders, hypertension, diabetes mellitus, respiratory disorders and hearing loss [14]. All inhabitants of old age homes were having one or more physical morbidity (ies). The chief mental health problem - among the elderly in Old Age Homes - was found to be Depression. The Old Age Home residents suffering from psychiatric illness had one or more associated physical morbidity (ies) [15].

Residents living in Old Age Homes had better Quality of Life - in terms of Health-related factors - than those staying at their Family Homes [16]. The prevalence of psychiatric illnesses was also found to be less among the elderly living in Old Age Homes (30%) tan those residing in Family Homes (38.3%).

D. Consequences of Providing Elder Care on the Family Caregivers

The positive and negative consequences of care giving vary widely across caregivers [17]. Since care giving is often provided in family settings, various factors influence the level of caregiver burden, such as care giving attitudes of family members, family structure, and residential location. The greater the number of care giving tasks performed by the care

giver, the greater the perceived burden [18]. Significant relationship has been found between caregiver's burden and their role conflict, role overload. Caregiver's gender, health, age, support staff also affects caregivers burden. It is found that both relationship quality and support staffs are negatively related to caregiver's burden while role overload and role conflict are positively related. The study also reports that female caregiver's Quality of Relationship with elderly care-recipients is poorer than males. They claim that in households where caregivers strongly adhere to Indian social norms of filial piety, women experience substantial increase in perceived caregiver burden and role overload. Cost and burden of informal caregiving are found to be high in rural Indian community. Various studies have revealed home care to be deeply gendered, with the bulk of care work done by women – mostly daughters and daughters-in-law [17]. Caregivers' stress and lack of dignity of dying at Private home have also been found [19].

Understanding the challenges faced by the elderly and their caregivers in each elder care settings are a prerequisite, to arriving at consolidated and comprehensive recommendations for geriatric care. There is lack of studies from India to explore elder care in different settings. Even the views of physicians and family members regarding elderly care are grossly unexplored in the Indian context. This, in turn, has led to poor provision for geriatric care at the policy level. The study attempts to fill the knowledge gap by conducting empirical research on the elderly in various settings in Kolkata (West Bengal) which might help to take evidence-based decision at the policy level.

E. Elder Care in West Bengal

West Bengal, in East India, is considered as one of the rapidly ageing states in India [20]. The expected lifespan in West Bengal is projected to remain higher (at 69 years, in 2006-2010) than the national average. The state has around 33 per cent of the total elderly population below poverty line [21]. The utilization of Hospital facilities is considerably low among the elderly in West Bengal. It was estimated that 4.3% of their respondents in West Bengal, aged above 50 years, did not receive any treatment when needed, thereby showing a fairly high unmet need for health care [22]. Although the exact reason for not seeking hospital care could not be ascertained from the reports, nevertheless it might be inferred that apprehension related to high out-of-pocket expenditure made many avoid hospitalization. In state-wise comparison West Bengal ranks highest in out-of-pocket expenditure on medicine and lowest in investment for long-term care. Poor health insurance coverage of elderly in the state (less than 1% in forms of public or private insurance schemes) explains the huge financial burden [23].

Additionally, it was found that in West Bengal, nearly two-thirds and one-third of sample population of 1173 people above 50 years of age, reported requiring assistance in ADL and IADL respectively, thereby making the state rank highest in disability as compared to five other states surveyed. West Bengal has the highest burden of acute morbidities among the elderly (26%) and nearly two-thirds of the respondents in the survey (66%) reported suffering from chronic ailments [24]. The elderly in West Bengal suffered from higher locomotor disability and psychological stress compared to the other six states in the study [25]. The survey to explore the status of elderly in West Bengal, revealed that 10.6% and 12.7% of the surveyed elderly (N=1275) in urban and rural areas of West Bengal respectively, required full/ partial assistance in at least one Activities of Daily Living (ADL) domain and indicated growing incidence of loss of ability for ADL at higher age. The survey also showed low functionality in Instrumental Activities of Daily Living (IADL) [24].

In a study conducted on 78 secondary hospitals of West Bengal, the state performed poor in the technical efficiency measure with only 26 of them, mostly located near Kolkata, found to be relatively efficient. Unavailability of doctors, inadequate availability and training facilities of the services of support-staff- like ward boys, *ayas* (semi-skilled nurses, helping the skilled nurses and the physicians) , infrastructure deficiencies in handling emergency cases were identified as greatest obstacles. These factors cumulatively make secondary hospitals situated in the rural districts operate as mere transit points for emergency cases before they are rushed to specialized hospitals in Kolkata [25]. Elderly abuse in West Bengal is considered to be higher than other states [26].

II. Objectives

The broad objective of the study is to focus on various elder care settings, in order to gather knowledge about the present care structures and their challenges in West Bengal, and thereby generate comprehensive information about the entire spectrum of care.

III. Method

A. Locale of the Study

Hospitals, Homes and Long-Term Care Facilities- like Old Age Homes, Hospices - in Kolkata.

B. Source of Data/ Sampling

Data will be collected from different elder care settings.

C. Respondents

Cognitively coherent elderly aged 60 years and above, at the time of commencement of the study, at different setups and Family caregivers of elderly, aged 18 years.

D. Data Collection and Procedure

Mixed method design was adopted to collect data. Narrative, Interviews Questionnaire and Focus Group Discussion methods will be used for data collection. Field observation method would be used to substantiate the findings. Data collection would involve both Qualitative and Quantitative methods.

IV. Results and Discussion

Findings from the field, though sparse, provide a gross

contradiction to a generalized opinion that Family homes provide last resort to elderly persons at the end of their lives. Home care is found to be deeply gendered and marked by conflict between elderly patients and their caregivers, which possibly gets accentuated as life draws towards an end putting the dying person amidst conflicts and abusive relationships.

A paucity of external support to empower family carers in attending to dying persons at homes make them stressed and anxious and finally results in aggressive and abusive behavior. This issue demands special attention in the context of West Bengal where domestic abuse of elderly is considerably higher than other states [26] Field investigation also suggests that most families find hard to accept death due to their lack of spiritual orientation. Innovative strategies for integrating spiritual care in palliation need to be devised to enable family carers in accepting death.

Very recently private agencies have come up to provide different care services for the elderly patients. However, available media coverage about these services suggests these providers are still in their infancy and have several limitations in their organizational strategies [26]. Firstly, the services are target oriented in providing narrow-fitted solutions to the medical problems for which they are hired. They hardly take into account 'whole person' concerns while addressing the distress of one who is dying. Second, these services despite being provided within home settings, minimally involve family members, thereby alienating them from the dying person. Such paid care services are not sustainable as they hardly empower and educate family caregivers. Moreover, there are no standards to evaluate the quality of services provided. Finally, a high cost of these services makes them beyond the reach of many urban poor. Since services provided by private healthcare agencies and NGOs are inadequate, hospitals still serve as a major place to receive many dying elderlies even though they might not be suitable to give palliative and end-of-life care.

Thus, even though family homes in the city are situated within a dense concentration of healthcare facilities, they are quite secluded. It receives minimal linkages and support. Huge amount of resources are being exhausted and tensions pile up within families, who strive to get the best care for their elderly dying member.

It is therefore suggested that improvement in home care for the elderly can be made possible by re-engineering the health care system. A resource-strapped country like India needs to integrate a multitude of services within a common public health framework for optimizing care and support for the dying elderly. A WHO- supported model for integrating palliative care into public health framework suggests a concerted effort of public policy, education, opioid availability and implementation of palliative care at all levels of the health system [27].

The family homes are not linked within a continuum of care. While the National Policy on Older Persons in 1999 and the more recently National Policy for Senior Citizens in 2011, have put emphasis on different community settings, it has treated each of the care settings in isolation to one another without considering their integration in the entire health system. Moreover, these care set-ups, particularly the hospitals (presently beyond the purview of this paper) themselves need to be capacitated to care for elderly while dying.

On the other hand, a practical framework prepared by WHO for guiding the developing countries in formalizing Long-Term Care (LTC) provides exiting and promising cases from different developing countries [28]. The report shows that countries like Costa Rica, Mexico, Ukraine, Lithuania, Sri Lanka, some parts of China, Republic of Korea and Thailand laid major thrust on residential homes to facilitate caregiving for chronic ailments. Many of these countries have a paucity of resources, and yet they are successful in strengthening LTC structures. Strategically these countries have linked homes with community resources to reduce the caregivers' burden in families and ease out financial pressure associated with care. While all countries have made an effort to capacitate family carers through awareness generation, few have gone to an extent of helping the over-stressed family members with home-making services and various types of respite facility by engaging NGOs and other voluntary activities. These cases are an important lesson for India. The paper referred to successful models, developed in developed as well as developing nations, to suggest an outline that would facilitate the family homes to respond adequately to the concern of dying elderly and their carers.

A. Capacity Building of Family Carers

Following the UK model of community-based care for the elderly [29], many existing elder care structures like Old Age Homes need to be re-created as 'intermediary care set-ups' to reduce high medical dependency of the patients on hospitals during their final days and help home carers when caring becomes difficult. Moreover, most countries abroad which have supported home care, have considered carers as an important resource — a feature that is missing in the state-run programs. The 'intermediary care set-ups' need to play an important role in facilitating knowledge and skill dissemination for home care. Such an initiative might make family home more sustainable.

B. Inputs for Home Modifications to Suit Elderly

In the course of field investigation, it was seen that many of the houses were architecturally inappropriate [30] to care for the elderly. The UNFPA survey also confirms that many elderlies reside in old and dilapidated housing structures in West Bengal. While home Modification Programs, along the lines of western countries [31], might not be possible, the 'intermediary care set-ups' may still provide technical support and orientation to the family carers.

C. Early Identification of Unmet Palliative Care Need

Another marked finding of the study is that elderly who receive home care are predominantly suffering from cancer. Most of them seem to be receiving palliation at the end stage—a feature that goes against the current practices of good cancer management. This data assumes greater importance because the state health department is the major provider of

the health care facilities to elderly patients covered in the sample (eight out of fourteen received treatments from Public hospitals). No government hospital has worked out a palliative program for home care through proper identification and 'need assessment'. Except a few home carers, most have accessed information in an erratic manner. If identifying palliative services is difficult, reaching those in need of help is equally difficult for NGOs dedicated to the cause. In short, home-based palliative care needs to be supported through proper organizational strategies and state support.

D. Empower Patients by Providing Healing Choices

Also, a number of families were found to use alternative medicines in addition to biomedicine and given the state's potential for alternative medicine; there is a need to free palliation of its dominant biomedical orientation. Home-based palliation is also impeded by stringent rules centering on the availability of morphine and other narcotic drugs in West Bengal. All the cancer patients covered in the study reported to be in pain. The study also reports frequent and emergency hospitalization among the sample households without any dedicated or familiar doctor on contact, except in one case. The 'intermediary care structures' need to be linked to the family homes for reducing emergency hospitalization. Hospital discharge planning too needs to take cognizance of home's capacity to address the needs of the dying.

Finally, the study raises critical concern about the home's potential for EoLC for the urban poor. Most of the families in the sample though poor, had no insurance or social support. EoLC in such homes need to be supported by proper service mix, involving both health and social services. The state has around thirty-three percent of the total elderly population below poverty line [21], and this suggests that many of them might need social security for the carers if family care is encouraged. It may be mentioned that major social security schemes for the elderly in West Bengal have been introduced fairly recently. In 2008, the Community Based Primary Health Care Services for urban population covering both Below Poverty level and Above Poverty level was commissioned.

A number of central government-supported programs and schemes like the National Program for Health Care of the Elderly (NPCHE), Old Age Pension (OAP), and mobile medical programs have not yet been fully operational with broad population coverage. Some schemes involving equal sharing by the center and the state government like the Indira Gandhi National Old Age Pension Scheme (IGNOAPS) provide a measly four hundred rupees - for people in the age group 60–79 years and Rs. 1,000 for people 80 years and above.

V. Conclusion

In conclusion, the study brings out few salient issues faced by the elderly and their family caregivers. Structurally, family homes in India are situated outside the public health framework and architecturally constrained to provide good care to the dying elderly. The study reveals a huge unmet need for home-based palliation. Finally, it questions the rhetoric of home care by suggesting that the mere presence of home carers or multi-generational co-residence does not assure good quality of dying, unless more state provisions for an integrated health delivery are available to help elderly and their carers.

The study concludes by identifying some of the barriers in care-giving to the elderly in Kolkata and suggests measures to integrate home, hospitals and Long-Term care facilities within a continuum of care.

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