# **Original Research Article**

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# Health problems and healthcare needs of elderly- community perspective from a rural setting in India

Arun N. Bhatt<sup>1</sup>\*, Marina Rajan Joseph<sup>1</sup>, Iby Ann Xavier<sup>1</sup>, Pinkutty Sagar<sup>1</sup>, Remadevi S.<sup>2</sup>, Sherin Susan Paul<sup>3</sup>

<sup>1</sup>Department of Community Medicine, MOSC Medical College, Kolenchery, Kerala, India

<sup>2</sup>School of Health Policy and Planning (Kerala University of Health Sciences), Thiruvananthapuram, Kerala, India <sup>3</sup>Department of Community Medicine, Pushpagiri Institute of Medical Sciences, Thiruvalla, Kerala, India

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\*Correspondence:

Dr. Arun N. Bhatt, E-mail: communitygeriatrics@gmail.com

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#### ABSTRACT

**Background:** Population is ageing in India. Health care and other needs associated with ageing have risen. The study objectives were to explore the concept of 'healthy ageing'; health problems of elderly; and felt needs in the care of elderly perceived by the community.

**Methods:** Total of five focus group discussions was conducted. Three Focus group discussions were conducted with family members of homebound elderly and one discussion each were conducted with primary health workers and residents of old age home to supplement the qualitative information gathered from the family members.

**Results:** The participant could make a long list of geriatric health problems. But, their knowledge and attitude towards them was grossly incorrect. All the problems were regarded as part and parcel of ageing for which help was not sought proactively. Mental health problems were regarded as 'behavioural' and 'psychological' problems. The health problems had its bad effect on family relationships. The perceived healthcare needs were mostly of palliative nature. Day care centres were proposed to improve social interaction of elderly. The community could not afford the level of services which they need. Home care visits by a health team were regarded highly useful.

**Conclusions:** Wide spectrum of barriers to healthcare access of elderly exists in the community. In this regard, a comprehensive community based geriatric health care program including health promotive, preventive, curative and palliative services needs to be formulated with a strong component of health education.

Keywords: Healthcare needs, Gerontology, Community geriatrics, Qualitative research

# **INTRODUCTION**

In India, the total number of the aged will surpass the population of under 14 by 2050.<sup>1</sup> The state of Kerala has the highest proportion of elderly (12.6%) in the country,<sup>2</sup> thereby putting an additional burden on the health care system of the state. In developed countries, various health promotion initiatives have reduced the health risk of the aged and thereby the healthcare costs.<sup>3</sup> In India however,

the complex health care needs of the elderly have not yet received sufficient attention despite the huge number of 100 million.<sup>4</sup> Various government programs targeting the geriatric population follow a vertical approach where the community needs and perceptions are often ignored. The primary objective of this study was to understand the various health problems in old age perceived by the community, attitude towards them and the felt needs in the care of elderly. This research would enable us to develop a pragmatic geriatric care program.

#### **METHODS**

#### Study setting

The study was conducted in a rural setting in central Kerala, the southernmost state in India. The study area which covers a population of 40,000 is the service area of Community Medicine department of a private medical college. There are six villages in three contiguous localities. The primary care service is delivered through a team of medical officer, junior public health nurses (JPHN), field assistants to JPHNs (FA), health inspector (HI) and community health volunteer (CHV). The department had been running various development and health projects in the service area for more than forty years. The study was conducted during May and June of 2015.

#### Study design

This was a qualitative research by Focus Group Discussion (FGD).

#### Selection and description of participants

Community Health Volunteers identified families with homebound elderly. The Family Members (FM) who were primary caregivers of these elderly were invited for FGD. Three FGDs were conducted in FM category, each in one of the villages of the three contiguous localities. There were 22 participants altogether in these three FGDs. One FGD with six participants each were conducted for Residents of an Old age Home (ROH) in the service area and JPHNs of the department.

#### Data collection

Principal investigator was the moderator in all the FGDs. Other investigators worked as scribe and observers. Scribe noted down the discussion verbatim with emotional cues. An audio recorder was used to ensure completeness of the script. There were no domineering or silent participants. The script was translated into English. Validation with back translation was done to ensure that the essence of discussion was preserved in the translation. The translations were done independently by members of study team.

#### Data analysis

The script were entered into Microsoft excel. Thematic analysis was done based on grounded theory approach. Inductive coding was done by investigators independently and then triangulated. The thematic framework got refined as recurring themes were identified. Themes were primarily developed from the FGDs of FM. Information gathered from JPHNs and ROH were used to contrast, corroborate and validate the former.

#### Ethics approval

Participation in the study was voluntary. Written informed consent was taken from the study participants. Audio recorder was used with permission of the study participants. Adequate privacy was ensured for the group during discussion. The confidentiality of the scripts is maintained. The Institutional Ethics Committee of MOSC Medical College granted ethics approval to conduct the study (approval no. 68/2015).

## RESULTS

#### Profile of participants

In FM category there were 22 participants, two FGDs with seven participants each and one FGD with eight participants. There was a single male member in this category. One participant was illiterate (4.5%), 10 (45.5%) had studied in middle or high school, 6 (27.3%) had studied up to intermediate and 5 (22.7%) were graduates. In the JPHN category all the six JPHNs of the department participated in the FGD and all were females. All of them were diploma holders in nursing. Among the six ROH participants in the FGD, three were males and three were females. Among them one participant was illiterate; two participants had studied up to primary school and rest three participants studied up to middle or high school.

#### Health problems of old age perceived by the community

#### Physical health

Family members gave a list of physical symptoms pertaining to old-age. Most emphasized symptom was 'aches'. Other symptoms listed were fatigue, loss of appetite, breathing difficulty, abdominal discomfort, acidity, constipation, loss of teeth, incontinence of bowel and bladder, postural instability, joint pains, paralysis of limbs, loss of taste, loss of vision and hard of hearing. Specific diseases named were only diabetes, hypertension and stroke. Family members had insight that physical health affected other dimensions of health. Some insightful comments were, "because of her back ache, my mother has lost even the pleasure of watching television", "she has become irritable because of hearing problem".

#### Mental health

Decreased sleep, failing memory and certain 'behavioral' and 'psychological' changes were thought to be inevitable attributes of old age. The 'behavioral' and 'psychological' attributes were named by different participants with others agreeing to them. The list is as followed- 'Childishness', 'adamancy', 'tantrums', 'irritability', 'short-temperedness', 'sadness', 'insecurity feeling', 'complaining', 'expecting to be pampered' and 'distrust'.

A plausible explanation for some of such attributes was given by the ROH group who attributed their short temperedness to cognitive impairment. One among them explained, "I get frustrated when I could not remember simple, important affairs of day-to-day life and when I could not grasp conversation". A few family members said that elderly have anxiety about death. One JPHN said that many elderly may be sexually active and may have related healthcare needs which they are afraid to discuss as the society considers sexuality in old age inappropriate.

#### Social health

Lack of personal income, dependency and loneliness were the major social problems identified by most of the participants. Participants observed that rarely, incidence of elderly abuse and neglect occur in the community. One family member narrated an incident of abandonment of an old demented lady in a taxi by her family. Another family member had seen his neighbor beating his elderly parents. JPHNs had rightly pointed out home bound elderly as a vulnerable group for abuse as "nobody else would come to know their plight".

All the FM participants opined that elderly enjoy company of grandchildren and that would make them active. JPHNs identified the dispute between the in-laws as a social issue that interfered with care giving. They also noticed that the youngsters get impatient with the slow pace of elderly. According to the family members, elderly get angry at youngsters for their disrespect. While majority had views that modern society shows disrespect towards elderly, some of the participants had contrasting opinion. Some family members and all JPHNs commented that disharmony usually sprouts when elderly expect a decision making role in family matters, a tradition that is slowly disappearing from Indian society. Mental health problems were misunderstood; affecting harmony in the family relationships. Some of the excerpts from the discussion which gave cues are as followed.

"She would narrate incidents from remote past, such good memory! Yet, sometimes she would enact forgetting, telling my husband that I did not give her food! I do not know why!"

"My mother-in-law when misplaced her pension money, suspect that other family members had stolen it".

"She would confirm what I say with neighbors for example today's day or date, because she does not trust me".

"Though I care for her, she complains to guests that I don't".

One participant expressed caregiver burn out, "I get angry at my mother. I know, it is wrong but, I cannot help it. I had been struggling to care her for a long time and now I am fed up! May be, I need some counseling". JPHNs had seen caregiver burn out in families of homebound elderly.

Some community members stigmatize old age. Two participants had experiences of neighbors avoiding them when they sought help to take their elderly parents to hospital at times of need. These neighbors attributed the old age sickness to sins in the family. One participant recalled her neighbor's comment with overwhelming emotions, "He could have been dead by now! Why are you over caring?"

Some family members thought that they should take a conscious extra effort to participate elderly in social functions. According to JPHNs, elderly feel socially responsible and would enjoy social participation recollecting the enthusiasm which even homebound elderly show in casting their vote in election.

ROH members were disappointed with their children for admission to old age home. One of them said, "We are disappointed of our children whom we brought up with much effort and expectations" and another participant said, "There is no love in today's society, many more old age homes will come up". JPHNs and family members unanimously condemned admitting parents to old age home as 'abandonment'. They preferred to take care of elderly parents at their own homes. The family members were gloomy about their own future in old age, they were afraid that the current young generation may not care for them when they get old.

#### Attitude towards old-age health problems

All the family members were proud about the care service they availed for the elderly. They proudly said-"We care them the best we can, we take them to hospital whenever they have complaints", "We don't leave them sick and unattended, we take them to hospital". However, sickness in old age was viewed as 'hopelessness' and 'part and parcel of ageing'. Health care seeking was considered for 'psychological satisfaction'. Family members stated 'lack of time' and 'health care costs' as the major barriers in caring for elderly. The common opinions regarding physical complaints of elderly were that they take minor symptoms seriously and unnecessarily demand for medications. One whole group of family members opined that "some elderly may act sick to attract attention". Family members and JPHNs opined that 'having someone to chat' would heal elderly. According to them, the best health status expected in old age was their independence in activities of daily living.

Manifestations of mental health problems were labeled as inevitable 'behavioral' and 'psychological' attributes of old age, for which healthcare seeking was not considered. They thought that these manifestations were 'purposeful' for 'attention seeking'. JPHNs and some family members attributed lack of income, dependency, lack of engagement in activities and loneliness as the causes for the 'psychological' and 'behavioral' problems.

One of the family member who was also an elderly commented that elderly are not cared enough, "in-fact, elderly are not reciprocated the care they had given for their children" to which another young family member in the group disagreed "if the elderly are not cared enough, how is it that they survive up to 80s and 90s?" The discussions also brought out attitudes which prevented participation of elderly in the family. Prominent comments were- "there are parents who would like children to do homework than 'waste time' talking to grandparents" and "old person will not be able to think logically and should not be involved in the social or family matters". A contrasting view expressed by a few family members was that, elderly have rich life experience and are good resource persons in social affairs. JPHNs identified physical disability and lack of family support as the barriers for social participation.

#### Current healthcare seeking practice and felt needs

The current practice among the participants in healthcare seeking was medical consultation when complaining of symptoms or when found 'sick'. JPHNs observed that health problems of elderly get ignored until it become serious. Many participants thought of starting exercise and diet control in old age, "I will start doing exercise once I become old to maintain health". Some participants discussed "encouragement to continue the daily routines" as the strategy to keep the elderly healthy and active. One participant explained, "My mother is not confident of standing on her own, I train her, I would make her stand up and let go and stand far for a few seconds".

Majority of the participants preferred modern medicine. Participants were not aware of a medical specialty for old-age. Some of the family members expressed the need for service of a home nurse at an affordable cost. All the family members found it difficult to take the homebound elderly to clinic. They hope for consultation and treatment service at their door step. JPHNs were of the opinion that routine house visits by health care team would be of great value. One participant expressed caregiver burn out and expressed her need for help. JPHNs mentioned that there was a need to provide counseling service to address caregiver burn out and family conflicts.

All participants opined that elderly people long for company of their contemporary friends. They discussed about the possibility of a facility were the elderly people can meet and socialize. They also discussed barriers of organizing such a facility in terms of transportation, availability of trained staff and funds. JPHNs suggested the formation of self-help elderly groups who would accompany and support each other for activities like hospital visits, shopping etc. Some participants identified physical structures in the house as a barrier in the care of elderly, "even if I get a wheel chair, the doors are small for it". One JPHN said that some elderly might benefit from aides like walking sticks and European style commode which is still not very popular in India.

ROH group discussed the difficulty they experience in social participation, "I am unable to fill up those forms in the bank, everyone is busy and there is nobody to help". They thought that institutions should take special measures to enable their participation. They suggested that old age homes should always be part of a hostel for youngsters. One of them explained, "We feel enthusiasm to live, seeing those young chaps busying themselves for work in the morning, seeing the vigor with which they walk!"

## DISCUSSION

The study results may represent concepts of females in the community as they dominated the discussions. However, their views are important as females play the role of caregiver in the family. The participants could draw a list of health problems of elderly with an insight that they affected other domains of health. Aspects of health promotion and disease prevention in old age were not conceived in the discussion. Old age was not recognized as continuum of life course. Lifestyle modifications were considered as intervention to be started in old age and the felt needs discussed were mostly palliative. The medical specialty of geriatrics was not known to the community.

As understood from the healthcare seeking behavior discussed, health problems of elderly may get ignored until they become severe. It is a well-known fact that ill health is passively accepted as part of ageing in the Indian communities and the attitude seemed to be the same in this community as well.<sup>5</sup> The discussion covered aspects of economic, infrastructural, knowledge and attitudinal barriers in caring for elderly. A previous study mentioned that immobility, inaccessibility, misconception and poverty lead to poor utilization of healthcare services.<sup>6</sup> Domiciliary visits which was a felt need, is a core strategy in National Program for Health Care of the Elderly.<sup>4</sup> Risky ideas intended for balance training was shared. Complications due to unskilled care by family members are largely preventable.<sup>7</sup> Caregiver burn out of the family members needs to be probed and addressed. A study reported from United States of America has shown that the care giving service contributions by family members were worth billions of dollars if to purchase.<sup>3</sup> Any program initiative for geriatric healthcare services should have a component for caregiver support like counseling and training.

The mental health problems affected harmony in family relationships. The mental health needs of elderly were not recognized. Manifestations of mental health problems were mislabeled. It was noticed in a study that a general lack of awareness has existed among the people regarding the common mental health disorders found in the geriatric population.9 A study reported in 2001 mentioned that dementia and depression were not recognized as health problems.<sup>10</sup> In the current study more than a decade later, it was ominous to find that the attitude had not changed. Some participants thought, elderly may act sick to attract attention which was a dangerous concept. In a nationwide survey among elderly, majority of the sick people reported good health whereas only a minority of healthy reported sickness.<sup>11</sup> This was because ill health was passively accepted as part of ageing. Sexual health care needs of the elderly came up in the discussion only once. Expression of sexual desires in old age was considered as taboo by the community. The concept that ageing and deterioration of sexual function being inexorably connected is a myth.<sup>12</sup> Sexual expressions by the elderly are indicator of good general health and physicians should actively explore sexual function of elderly patient.13

When the family refuses the role traditionally expected from the elderly, conflicts occur. Respect to elderly has great cultural importance in India.<sup>14</sup> In a study done in Karnataka, 52% elderly felt that old age has affected their role in the family and 35% felt that they were not consulted while making decisions.<sup>15</sup> Residents of old-age home were disappointed with their children for admission in old age home. Old age homes were condemned as a place for abandonment. The community preferred to provide care for the elderly in their own house. Culturally preferred co-residence is beneficial for psychological wellbeing of elderly.<sup>16</sup> In a study done in Karnataka, elderly preferred their own home to old-age home in spite of all the difficulties they experienced in the family.<sup>15</sup> Grandchildren were considered important relations of elderly in our study. This relationship has a great value as grandmothers minding grandchildren maintained higher executive function compared to those who do not.<sup>17</sup> JPHNs identified caregiver burn out, in-laws guarrel and disrespect of elderly by youngsters in the family as some of the reasons for conflicts in family. JPHNs identified home-bound elderly as a vulnerable group for abuse. Family members discussed instances of physical abuse and neglect. A study reported that elderly are prone for abuse in families and institutional settings.<sup>18</sup> Chronic verbal abuses could be the most common followed by financial abuse, physical abuse and neglect.<sup>18</sup> Old age health problems were stigmatized by some community members. Some community members may consider elderly as passive members of society. A study had shown that society considered elderly as mere recipients of social welfare schemes rather than active participants in the economy.<sup>19</sup> Concept of day care centres and Self Help Groups were suggested for social participation of elderly.

#### CONCLUSION

Community recognized many symptoms of old-age health problems but was unaware of specific health problems of old age. There was a tendency to trivialize health problems in old age. Mental health problems were misunderstood. Elderly suffer a number of social problems in the community including stigmatization and abuse. However old-age homes were condemned by the community. The felt needs were in general for palliative care services. Community has needs for caregiver support services and domiciliary visits for homebound elderly and day care centres to improve social participation. Structured health education is essential to raise awareness about health problems in old age and to impart concept of healthy ageing.

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