Original Article

Rural Elders – What are their felt needs and challenges faced by their Caregivers?

Johanna R.[1], Jenny Lalramilani[1], Roshni R.[1], Sharon Sophia S.[1], Laltlansangi[1], Bimi John J.[1], JoiceMuchahary[1], Yash Alok Dhotekar[1], Cherub Jane Irene W. [1], SheejahSelvamani[1], Cheruba Jonathan[1], Kusum V Moray[2], BhavyaBalasubramanya[3], Madhu Mohan [4], Vinod Abraham [5]

Abstract

Objective: To identify the needs of rural elders (≥ 60 yrs) and to assess the challenges faced by their caregivers in providing care for the elders, in rural Southern India

Methodology: The study was a community based cross-sectional study, conducted in a rural block in Tamil Nadu, India in 2016. First part of the study consisted of conducting four focussed group discussions (FGDs) with male and female elders and caregivers respectively. Based on the themes from the FGDs, a structured questionnaire for the quantitative study (part two of the study) was designed. We could interview 158 elders and 96 caregivers.

Results: The needs of the elders were found mainly to be in the areas of food, finances and emotional aspects. Study revealed 83 (52.5%) of the elders reported having to cook for themselves, 69 (43.6%) reported that they did not receive old age pension. The caregivers did not perceive taking care of elders as a burden.

Key words: Elders, Caregivers, Rural India, Needs

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INTRODUCTION

Currently, India has a population of about 1.34 billion[1]. The population is not only steadily growing, but also 'ageing'. The proportion of people aged above 60 years and above was 5.6% in 1961, and has increased to 8% in 2011 and is projected to be 19% by 2050[2]. These increase in numbers, complemented with weak public pension, inadequate social security system and changing household structures make planning and providing for the elders critical.[3]

Life expectancy at birth in India has increased from 37 years in 1950 to 68.3 years in 2015, due to better health care facilities.[2] Addressing the key issues like malnutrition, Infant Mortality Rate, poor sanitation, reproductive health and rural health, by the government of India, resulted in the surge of life expectancy.[4] Also, life expectancy at the age of 60 years in 2015, was higher for females (18 years) as compared to males (16 years).[5] This means that often, women outlive men in India.

With an ageing population, there arises a need to look at the various changes that we need to make at the national, community and the family

1: Third year medical students, Course: MBBS: Bachelors in Medicine and Surgery, Christian Medical College, Vellore, Tamil Nadu, India; **2:** Project Manager, WHO-KMC Project, St. John's Research Institute, Bangalore, Karnataka India; **3:** Assistant Professor in Community health, Christian Medical College, Vellore, Tamil Nadu, India; **4:** Post graduate student in Community health, Christian Medical College, Vellore, Tamil Nadu, India; **5:** Professor, Community Health, Christian Medical College, Vellore, Tamil Nadu, India; **Institutional Affiliation:** Christian Medical College, Bagayam, Vellore, Tamil Nadu, India 632002

Corresponding Author: Dr. Kusum V. Moray**,** Project Manager, WHO-KMC study**,** St. John's Research institute**,** Bangalore-560034 kukimoray@gmail.com

level. Legislations, policies and national programmes for the welfare of elders have been rolled out by the various ministries of government of India since 1990s[6]. Despite these initiatives, we have a long way to go in caring for our elders. The first step in caring for the elders would be to do need assessment.

The traditional practice of co-residency with children, especially male child, is still predominant in rural India; 75.4% of the elders stay with their children[7]. The care of the elders, hence to quite a large extent depends on the care rendered by their caregivers. Elders and their care givers need to balance independence and engagement to maintain dignity and a happy familial environment[8].

The 'caregiver' is an individual who is primarily responsible for the physical, emotional and financial care of the elders person. This study aimed at assessing felt needs of the elders and determining the challenges their caregivers faced in rendering care to the elders by identifying specific domain(s) which could be the focus in future interventions to make the life of elders better.

Objectives: To identify the needs of rural elders (≥ 60 yrs) and to assess the challenges faced by their caregivers in providing for the elders, in a rural community in Kaniyambadi block, Vellore district, Tamil Nadu, Southern India

METHODOLOGY

The study was a community based cross-sectional study, conducted in the service-area of the Community Health Department of Christian Medical College, Vellore. The CHAD (Community Health and Development) programme under the Community Health Department offers health care services mainly concentrating Maternal and child health, Non-communicable chronic disease management at the periphery. Mobile services are offered to the Kaniyambadi block, which comprises of 82 villages, with a population of 1.13 lakhs. Two of these villages: Mettuedayampatti and Sathumadurai were chosen for the study based on convenience of distance from research centre.

To assess the attitudes and priorities of the elders's needs and the challenges that the caregivers perceived, we conducted four focus group discussions (FGD). The FGDs were conducted with male and female elders and caregivers respectively. The community volunteer and the community health worker in both the villages were asked to notify the eligible members (elders ≥ 60 years and their caregivers); two days prior to the (FGD). A locally acceptable 'balwadi' centre (A centre that is a nodal point of the integrated child development scheme in India, which provides care to the under-five population at the village level) was chosen for conducting the FGD. The FGD participants included eligible individuals who willingly assembled in the balwadis at the set time. Three people from the investigator group had been allotted the roles of moderating, transcribing and constructing socio-grams respectively. The person who constructed the socio-gram also noted the non-verbal cues of the respondents.

The number of respondents who participated in the FGDs is as shown in Table 1. The respondents turning up at the site of the FGD at the set time implied their consent for participation. They were explained the need for the discussion and the way an FGD works.

Table 1: Distribution of the participants in the Focus group discussion

FGD group	Males ≥ 60yrs	Females ≥ 60yrs	Male caregivers	Female Caregivers
Number of respondents	5	9	5	7

We took their permission to record the discussion electronically. Each FGD lasted for about 30-40 minutes. The FGD was concluded when there was repetition of the opinions that came across from the group.

Six predominant themes emerged from the FGDs in the needs assessment of the elders, namely- needs from family and relationships, financial needs; medical needs, physical, emotional and social needs. The challenges perceived by the caregivers also fell into these broad themes. A structured questionnaire for the quantitative study was designed based on the above-mentioned themes from the FGDs.

A sample size of 150 was calculated using the prevalence of financial dependence among elders from a survey done in Himachal Pradesh and Uttarakhand, India[9].

In the two selected villages Mettuedayampatti and Sathumadurai (chosen by convenience), the households with at least one elders were approached, written informed consent obtained and the structured questionnaire was administered to one elders and one caregiver in each household. If there were more than one elder in a household, we chose the participant for study randomly. The participant was asked to identify who the primary caregiver to them was, and this individual was approached for the caregiver part of the study. The study was conducted in March 2016. The participants of the study were the residents of the

two villages, who were asked about their needs in the physical, social, financial and emotional domains. We identified their caregivers and interviewed them if they were present at the time of interview. We excluded those who could not respond to our questionnaire due to their physical or mental state. We could interview 158 elders and 96 caregivers; as only 96 caregivers were available at the time of the study (either elderstays alone or caregiver unavailable after 2 visits to the house).

The data from the focus group discussions were analysed by classifying the responses of the participants under meaningful themes (colour coded in a Microsoft excel workbook). Data from the quantitative part of the study was entered in Epidata version 3.1 software and analysed using Statistical package for social sciences (SPSS) Version 16. Mean and standard deviation were calculated for continuous variables and proportions for categorical variables. Pearson's Chi square test was used as a test of association. Odds ratios (OR) calculated to determine strength of the associations, if present. Sub-group analysis was done.

Flowchart of the methodology is presented in Figure 1.

RESULTS

The results of the study are presented in two sections, qualitative (the FGD) results and the quantitative (cross sectional study) results.

Section 1

Five themes emerged from the FGD analysis. The important findings are presented in Table 2. For the elders, there was an obvious need for company; family and relationships were a major area of contention. Finances were a major need; some of them did not get a pension, and among those who did, some said they had to give it away to their children. The pension per say, was said to be inadequate for a period of one month. Travelling to a health facility or a relative's house was a problem they attributed to very infrequent public transport. The private transport in the form of 'autos rickshaws' (a three-wheel motorized vehicle for hire) charged about two thirds their monthly pensions for a day's trip outside the village they resided in. Most elders cooked their own food or expressed neglect when it came to the family pot.

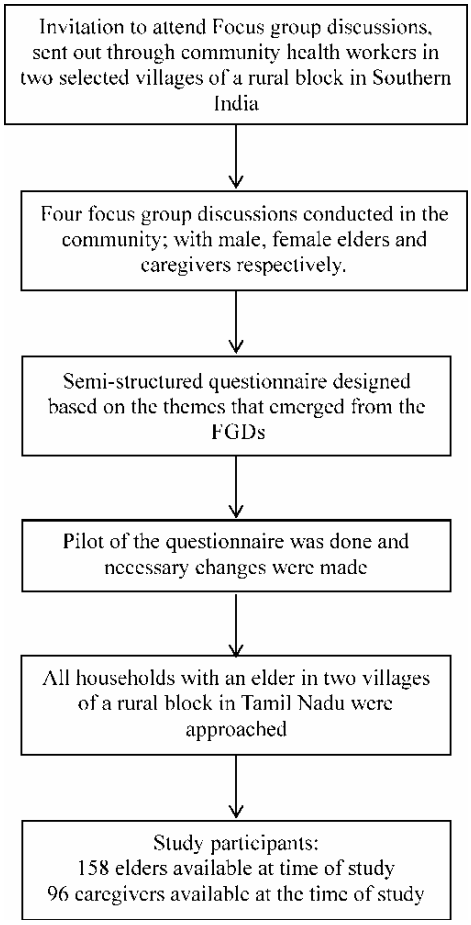

Figure 1: Methodology algorithm

Table 2: Themes and results of the focus group discussions (Qualitative study)

Themes identified in the FGDs	Elders (Male and Female)	Caregivers (Male and Female)
Family and Relationships	**Neglect** (Quote- "I wrote out my property in my son's name, gave dowry for my daughter and now they have neglected me" **Uninvolved in decision making** **Help in times of need** **Hesitancy to approach children** **Need for company** (Quote-"we need people for company and to help us. Even though I have three sons they don't do anything"	**Elders guide the young** **Their presence a sense of security** **Sense of obligation** (Quote- "Elders are our parents, they took care of us; we need to take care of them" **Relationships not very cordial between daughters-in law and their mothers-in-law** (Quote-"My mother-in-law complains about me to my husband. There are lot of fights. I am not considered a daughter ever"
Physical needs of elders	**Food, Clothing, Shelter** "I need someone to cook for me" "We get new clothes twice a year"	According to caregivers—physical needs of elders- **Food and clothing** "We buy them clothes for Pongal and 'Aadi' festivals" "We cook commonly for the whole family, we do not cook separately for elders" "I have to ask my mother-in-law what to cook every day; otherwise she doesn't like it. She doesn't eat many vegetables"
Social life of elders	Loneliness Neighbours keep them company Attend important family and village functions	Elders mostly stay at home When the caregivers need to go out, elders take care of the house They take the elders to attend close family functions only
Financial needs of elders	**Most get Old age pension**; but not enough for a month **"**We can't buy necessary items because it is expensive**"** Hesitancy to ask money from caregivers (Quote- "What can I ask my children? My son is very controlling.") Some work for a living "We need to work every day for our wages"	Elders manage their finances Money is an important need for the elders Pension is not enough Caregivers do not expect money from elders
Health care of Elders	"Go to hospital when I have fever, breathlessness and difficulty in walking" Transport to hospital is an issue "Only one bus from the village, that too at night" "Autos charge 150 to come to Vellore, travelling to the hospital is expensive"	"We take them to the hospital if there is any health problem" "They pay for their medical expenses" "My mother-in-law underwent surgery few months back; we paid for it"

Among the caregivers, there was a general feeling that they took good care of the elders. Yet, there were subtle implications that relationships among a few were strained and that finances were an issue.

Acceptance of "full-time old age homes" was found to be low among both the elders and the

caregivers. The elders felt that these homes were expensive, that they would be expected to work there. They believed they would be better off staying alone or with their children. The caregivers thought that as the elders had taken care of them when they were younger, it was now their duty to take care of the elders. It was deemed culturally in acceptable to leave care of the elders to an old age home.

As a part of transcribing the FGD, we noted down non-verbal cues. There were many emotions involved while the FGD went on. We could observe a sense of purpose and will to fight challenges in a few elders, while others expressed sadness and non-fulfilment of expectations. We recorded that one elders shed tears on talking about difference with family, and another had given up hope of support from hers. In general, the male elders had less to talk about as compared to the females. The sociograms recorded showed the direction of conversations that occurred during the FGD. And a major finding was that most of the participants directed their opinions to the moderator rather than among themselves.

Section 2 A

There were 158 elders and 96 caregivers interviewed from two villages (Mettuedayampatti and Sathumadurai) from Kaniyambadi block, Vellore district, Tamil Nadu. Among the elders, 98 (62%) were female and 60 (38%) male. Of the 158 elders, 73.4% (116) were aged between 60 and 70 years of age; 79 (50%) were widowed. Mean age was 68.39 years (SD 6.69 years) with range from (60 to 90 years). Of the 158 elders, 51 (32%) were employed in informal sectors. Modified Kuppuswamy scale was used for socio-economic assessment. According to the 2015 modification of the income, majority of the elders, 53.8% (n=85) belonged to the upper lower class. The results of the different needs of the elders are presented in Table 3.

Table 3: Needs of the elders

Physical needs		Frequency (n=158)	Percentage (%)
Number of meals a day	1	3	1.9
	2	29	18.4
	3	122	77.2
	>3	4	2.5
Possession of a Ration card	Yes	140	88.6
	No	18	11.4
Procurement of Clothing (Multiple answer)	Self	23	14.6
	Family	40	25.3
	Government	18	11.4
	More than one source	69	43.7
Ownership of current shelter	Self/ Spouse	95	60.1
	Son/ Daughter	46	29.1
	Other relatives	10	6.3
	Rented	2	1.3
	Government	5	3.2
Financial needs			
Sources of Income (Multiple answer)	Occupation	50	31.6
	Old age pension	69	43.7
	Retired pension	26	16.5
	From caregiver	71	44.9
Expenditure of Pension money	For Self	52	54.7
	For self and family	26	27.4
	Only family	17	17.9
Who is approached in time of financial needs	No one	20	12.7
	Son	102	64.6
	Daughter	15	9.5
	Relatives	4	2.5
	Friend/Neighbour	9	5.7
	Multiple sources	8	5.1
Family and Relationship needs			
Involvement in decision making	Always	74	47.4
	Sometime	31	19.9
	Never	51	32.7
Experienced hurtful behaviour	Never	93	59.6
	Sometimes	48	30.8
	Often	15	9.6
Feeling of loneliness	Yes	43	27.2
	No	71	44.9
	Sometimes	44	27.8
Social needs			
Spend time with neighbours	Yes	120	75.9
	No	38	24.1
Attendance to family, village functions	Do not attend	53	33.5
	Important ones only	77	48.7
	Attend all functions	28	17.7
Healthcare needs			
Need for Chronic care	Yes	77	49.0
	No	80	51.0
Healthcare sector sought	Government	45	28.7
	Private	70	44.6
	Alternative medicine	42	26.7
Healthcare expenditure footed by:	Self	81	51.3
	Relative	63	39.9
	Self and relative	11	7
	Friend/Neighbour	3	1.9
Transport to healthcare facility	By Foot	26	16.5
	Cycle	4	2.5
	Bus/ auto	68	43
	Vehicle owned by family	60	38

Section 2 B

Of the 96 caregivers interviewed, 67 (69.8%) were females and 29 (30.2%) male; Majority of the caregivers, 55 (57.3%) were employed. The results of the domain-wise views of the caregivers are presented in Table 4.

Table 4: Perceptions of the caregivers

Physical needs		Frequency	Percentage (%)
Separate meals prepared for the elders	Yes	7	8.4
	No	76	91.6
Satisfaction of elders with meals cooked	Satisfied	73	88.0
	Complaining	9	10.8
	Refuse to eat	1	1.2
Financial expectations from elders			
Caregivers who expect finances from elders	Give willingly	61	82.4
	Give reluctantly	2	2.7
	Do not give	11	14.9
Family and relationships			
Are the elders involved in decision making at home?	Make the final decision	34	35.4
	Ask the caregiver's opinion	9	9.4
	Share their opinion	33	34.4
Are the elders involved in household activities?	Yes	76	79.2
	No	20	20.8
Inconveniences to the caregiver due to elders			
Caregiver had to change occupation	Yes	10	10.4
	No	86	89.6
Caregiver could not participate in events	Yes	5	5.2
	No	91	94.8
Difference of opinion/Arguments with elders	Yes	19	19.8
	No	77	80.2

Note: Not all sections total to '96' (the number of caregivers interviewed) because, some questions are not applicable. For example; some caregivers lived close by and not in the same house as the elders, so when we asked if they cooked a separate meal for them, the answer was that the elders cooked for themselves.

Section 3: Bivariate analysis

The factors associated with elders feeling hurt and lonely were analysed. The results are presented in Tables 5 and 6. Female elders are more likely to feel lonely as compared to males.

Table 5: Associations between elders who feel hurt and factors

Determinants	Categories	Elders who felt hurt	Elders who did not feel hurt	Odds ratio (95% CI)	P value
Age	≥ 71 years	15	26	0.81 (0.39,1.68)	0.564
	≤ 70 years	48	67		
Gender	Female	44	52	1.83 (0.93,3.59)	0.079
	Male	19	41		
Occupation	Unemployed	44	64	1.05 (0.52,2.10)	0.892
	Employed	19	29		
Retired Pension	Receive	8	28	1.65 (0.67,4.07)	0.274
	Don't receive	55	75		
Old age Pension	Receive	31	37	0.68 (0.36,1.3)	0.244
	Don't receive	32	56		

Table 6: Factors associated with loneliness of the elders – living alone/ with family, presence of caregiver etc. should be checked as well

Determinants	Categories	Elders who felt lonely	Elders who did not feel lonely	Odds ratio (95% CI)	P value
Age	≥ 71 years	23	19	0.98 (0.48,1.99)	0.963
	≤ 70 years	64	52		
Gender	Female	61	37	2.16 (1.12,4.15)	**0.02**
	Male	26	34		
SES	Lower SES	71	51	1.89 (0.87,4.12)	0.106
	Higher SES	14	19		

DISCUSSION

The first part of the study, where we conducted a qualitative study, was an essential step in understanding the fibre of the needs of the elders in the local context. The focus group discussions, on coding and analysis, revealed that food, money, relationships and transport emerged areas of discontent among the elders in the rural block in Tamil Nadu, Southern India. The material needs of the elders were not sufficient for comfortable living and being dependent on others for the same, was a source of distress. Holm AL et al in their qualitative study showed that two themes evolved: Creating meaning to life and a struggle for being independent with the help of caregivers. The study also

found that most elders experienced sadness and pain when their caregivers did not understand the need of the elders to create meaning/ remain independent[10].

Rajan SI et al stated that despite there being new policies, the elders lived with low social status in financial deprivation, abandonment and humiliation[11]. Some of the quotes by the elders in our study were: "A thousand rupees in pension is not enough even to sustain a week's expenses", "What can I ask my children? My son is very controlling" and "We need to work every day for our wages" resonate the statement in the working report.

Present study found that there was a general agreement among the elders and the caregivers that sending away the elders to full time 'old-age' homes was deplorable. The elders had qualms of "there being several rules" or that "they will make us work" in the old age homes. The elders felt that they would be better off staying alone than in old-age homes. The caregivers felt that it was their responsibility to take care of the elders. "They took care of us when we were young, it is our turn now", they said. Institutional long-term care is virtually non-existent due to cultural and economic factors. In India, inter-generational relationships, caring, ill health and so on are considered private issues and generally kept within the confines of the family.

In the quantitative section, we asked the elders regarding their physical, financial, social and emotional needs. The elders/ their spouse were the owners of their current shelters in 60.1% (n=95) subject. This is agreement with the "State of the elders-2014" report by 'Help age India'; where it was found that 64.9% of the elders lived in their own houses[12]. The numbers may not be very dismal, but despite their ownership status, there may still be issues of inclusion. This can be seen in one of the quotes by a participant in our qualitative study: "They (son's family) live on our property and have thrown us out". Of the elders in our study, 31.6% worked for their living, despite being older than 60 years of age. This is higher than the 11.8% seen in the help age India report[12].

We found that 43.7% (n=69) received the government old age pension and 88.6% (n=140) possessed a ration card (which entitled them to receive food supplies from the public distribution system). In our study, we found that 54.7% (n=52) of the people who received pension spent it on self. In contrast, a study done by Jothi S et al in Puducherry, Tamil Nadu showed that around 85% of the elders spent the entire pension amount for their own use (health needs, travel, daily activities and social needs). In this study, as well as in ours, the elders were dissatisfied with the amount of money received as pension, it being insufficient[13].

Health care needs were sought from the private health sector by 44.6% of the elders as compared to 72% in the economic and health survey of elders in India in 2014. Among the participants, 49% (n=77) had chronic health care problems. Transport to the health care facility was an issue; 43% (n=68) had to take the irregular public transport. The expenses for healthcare had to be borne by self in 51.3% (n=81) of the elders, in contrast to 39.4% in the report on the elders by Help age India[12]. These stark differences may be due to the fact that, our study population was entirely from a rural set up in Southern India, whereas the report included elders (age has been taken as >54 years) living in urban as well as rural areas[12].

We tried to assess the psychological issues among elders, we found that female elders were twice as more likely to feel lonely. Overall, 27.2% (n=43) felt lonely among our elders study population.

We also interviewed caregivers, 85.1% of whom, accepted financial support from the elders. The decisions at home were taken at home based on the opinions of both the elders and the caregivers, according to 34.4% of the caregivers. The caregivers' inconveniences due to caring for the elders was listed by the caregivers as change in occupation (10.4%), non-participation in events (5.2%) and arguments/fights at home (19.8%). The qualitative study showed some of the caregivers listing reasons for why having an elders at home is good, such as: Guidance in running the household, help with caring for children and during pregnancy.

Limitations of the study: Our study was done over a period of two weeks, and we may not have been able to establish a good rapport with the elders. There were also situations where we could not interview the elders and their caregivers separately; this could have led to them giving less hurtful/more socially acceptable answers. Some of the elders and many of their caregivers were not present at the time of interview. This may have excluded caregivers and elders who had gone for work and their views on balancing work and family could have been missed by our study.

Over all, understanding the needs of the elders and the problems of the caregivers was a first step in trying to make the lives of both categories better.

As a part of sharing the findings of our study with the community, the investigators staged a play in the village where the study was conducted. The

theme was caring and inclusion of the elders. The play was received well by the residents of the village and was attended by people from all age groups.

CONCLUSIONS AND RECOMMENDATIONS

The needs of the elders were found to be in the areas of food, finances and emotional aspects [83 (52.5%) of the elders reported having to cook for themselves, 69 (43.6%) reported that they did not receive old age pension and only 7 (4%) were able to save money. Women felt lonelier 61 (63.5% of women) than men 26 (43.3% of men)]. The average medical expenses of the elders were found to be INR 343. The acceptance of "full-time old age homes" was found to be low among both the elders and the caregivers. The caregivers did not perceive taking care of elders as a burden. Of the caregivers, 10 (10.2%) had to change their occupations to take care of their elders and 19 (20%) reported having a difference of opinion with the elders.

Keeping the findings of our study in mind, we recommend setting up of day care centres in the community, where elders could be engaged actively throughout the day. Providing a mid-day meal for the elders would be a good initiative, considering the fact that food was found to be an important need. A call to the government to increase the amount given as old age pension and to increase the coverage of the scheme will help the elders in need.

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