

Examining the determinants of health and long-term care for older adults in India through a socio-ecological model – A qualitative assessment

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ABSTRACT

Background: Ageing is associated with multiple long-term health problems and requires medication management, support with activities of daily living, and attention to psychological needs. This study aimed at exploring the enablers and barriers and psychosocial determinants of long-term care. **Methods:** A qualitative study, using semi-structured interviews and thematic analysis, was carried out from February to June 2018. One-on-one in-depth interviews were carried out with 28 participants, including care recipients ($n = 12$), caregivers ($n = 12$), and primary-care physicians ($n = 4$) at the Community Health Centre in the state of Jammu and Kashmir of India. **Results:** Attention from family members, leisure activities, faith in the healthcare provider, and a positive attitude towards life were found to be enablers of long-term care. Resource constraints and alienation from the community were barriers. Incorporating the psychosocial needs of care recipients and problems faced by family caregivers is essential in providing good quality care to individuals with chronic illness. **Conclusion:** The lack of a targeted, nationwide policy has resulted in considerable variability in long-term care services across the country. There is an urgent need to make long-term care an integral part of the Indian health system utilizing a holistic framework to address the health needs of older adults and implementing it through an equitable community-based comprehensive primary health and community-based model.

Keywords: Care-at-home, chronic illness, India, long-term care

Introduction

Long-term care (LTC) refers to the continuum of health and social care services required by individuals with chronic ailments and those with functional limitations and in need of assistance with activities of daily living (ADL).^[1] There is a global shortfall of more than 13 million LTC workers, and 8.2 million in Asia, which translates to more than 65% of the older adult population in this

region lacking LTC services.^[2] While global calls to action detailing the need for LTC have been made, strong national policies for LTC are absent for almost half of the world's population.^[3]

Primary-care physicians (PCPs) have a vital role in LTC. They serve as gatekeepers to the healthcare system and often enjoy significant trust and standing among their communities, especially in rural areas.^[4] For individuals with chronic disease who require LTC, PCPs are favourably situated to routinely monitor and modulate lifestyle to promote better health, manage medication, and also end-stage care. In addition, they often serve as the point of contact after episodes of ill-health requiring advanced facility care and hence can be instrumental in ensuring appropriate post-discharge care and recovery.

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The mortality and morbidity associated with noncommunicable diseases (NCDs) in India increased by 61.8% and 20%, respectively, between 1990 and 2016.^[5] Increasing urbanization, population ageing, and declining fertility are expected to further shift the epidemiological burden towards NCDs, and fewer LTC caregivers, presenting a unique set of challenges to the Indian health system. The National Program for Healthcare of the Elderly (NPHCE), the National Program for the Prevention Cancer, Diabetes, Cardiovascular Diseases, and Stroke, the National Cancer Control Program, and the National Program for Palliative Care are some initiatives in place to address aging and health in India. However, the lack of a single policy targeted towards LTC needs means that the public healthcare response is often disjointed and nonuniform across the country.

The union territory of Jammu and Kashmir (J&K) has close to three million adults above 60, with nearly a third reporting poor health. Cardiovascular disease, bone disorders, Vitamin D deficiency, oral, and mental problems are among the major reported health concerns, and chronic disease is significantly correlated with socioeconomic status.^[6–12] Nearly three quarters of older adults live with their children and 36% require ADL assistance. Less than 1% of the population has health insurance, and healthcare expenditure is high. Literature on this region is limited and mainly includes small-scale quantitative studies, which do not encompass the detailed perspectives of the population being studied. This qualitative research study was undertaken to explore factors affecting the LTC of the chronically ill in Jammu district, fill gaps in knowledge, and obtain in-depth information from caregivers and healthcare providers.

Materials and Methods

Study design

The study followed a qualitative, exploratory, cross-sectional design conducted in a rural community in J&K. Determinants of LTC summarized from a review of various WHO reports,^[13] and scientific literature published on LTC in India^[1] were used to set up *a priori* areas of inquiry to inform the research.^[14] Three separate semistructured in-depth interview guides with open-ended questions were developed for care recipients, family caregivers, and PCPs. The guide was planned using a funnelling technique, starting with an introductory question to ease the respondent into the interview, followed by questions about general health and daily routine. While the interview guide evolved through the course of the study, the aforementioned sections were common to all three questionnaires to ensure dependability in the data.

Study setting, selection, and description of participants

The study was conducted from February to June 2018. The study site, Ranbir Singh Pura (R. S. Pura), is a rural area of the Jammu district, which lies in the southwestern part of J&K. Older adults with chronic illness who require long-term care with assistance needed in performing at least one ADL, their family caregivers, and PCPs treating chronic patients at the out-patient department

of the Community Health Centre in R. S. Pura were chosen purposively interviewed. Care recipients and family caregiver interviews were conducted at the same time in their homes through prior appointments. Interviews with care recipients and families lasted 30–40 min. Physicians were similarly interviewed at the CHC, and these interviews were 20–30 min long.

Ethics

The Institutional Ethics Committee provided ethical approval for this study. Informed consent was obtained for participation in the study and for audio recording of the interviews. Some participants provided only verbal consent and others declined audio recording, in which case the researcher wrote down the responses as obtained.

Data analysis

Audio interviews were transcribed verbatim and written notes were entered clearly, in Microsoft Excel. All interview transcripts were made uniform to facilitate analysis. Respondent anonymity was ensured through a coding procedure; ‘Pt’ for the care recipient, ‘Fl’ for the caregiver, and ‘Dr’ for PCPs. In addition to the qualitative responses, demographic and health details of each care recipient were collected to place the data in context.

Thematic analysis was carried out by the researchers using grounded theory. The interview transcripts were analysed iteratively with an inductive approach to identify patterns in the data. Codes were assigned using the constant comparative method, which involved comparing pieces of the text for similarity in the construct represented by them.^[15] This allowed the analysis to evolve as novel themes arose.^[16] Subsequently, the transcripts were analysed independently by the other authors as a means of triangulation to ensure credibility in the emerging findings. The codes were then aggregated into patterns or basic themes, which when clustered resulted in organizing themes. Finally, these were combined and categorized into the global themes, which had been determined *a priori*.^[14] It should be noted that determining the global themes in advance allowed the responses to be better aligned with the research question and did not influence the initial coding process of the interview transcripts.^[17] Creating thematic networks of this kind allows for a high level of rigor in qualitative research by providing a hierarchical structure to themes that emerge from the text. The exploratory model was created in this way to be meaningful in context to the study objectives.

Results

Characteristics of study participants

Twenty-eight in-depth interviews (IDIs) were conducted comprising 12 care recipients, 12 caregivers, and 4 doctors. Care recipients ranged in age from 31 to 89, with a large number being above 60. Eight of these were females and four were males. Ten out of twelve family caregivers interviewed were female in the age range of 30–60 years and listed homemaker as their primary occupation. Diabetes and high blood pressure were among the most common chronic diseases among the interviewees, as shown

in Table 1. Nine out of the twelve long-term care recipients were found to be capable of carrying out 4–5 ADL independently. Two were completely independent in their ADLs, whereas none of the care recipients were found to be capable of carrying out only two or less ADLs. Incontinence was the most frequent concern.

T1: Health awareness – Most care recipients were unaware of their morbidity and medication. These were usually known to the family caregiver. Two caregivers noted that they had not disclosed the care recipients’ condition to them, to avoid distress and panic.

‘I am fine. Nothing has happened to me, just little weakness, and difficulty in walking’ – Pt A

(The caregivers informed the researcher that the care recipient had kidney failure)

T2: Healthcare utilization – Immobility and other sequelae of ill health, and health system issues such as long waiting times and facility staff behaviour, were common causes for underutilization of available healthcare. Three care recipients only visited a healthcare facility when they experienced an episode of ill health. Out of 12, 5 care recipients preferred private healthcare.

‘My legs don’t work so how will I go and get my medicine’ – Pt F

‘Government Doctors do not have time; I could not even turn on my side. I was laying on a stretcher in hospital for 2 days and no one asked’ – Pt I

T3: Family – Dependence on the caregiver was high with some caregivers unable to pursue any other activities.

‘She needs me all the time, so I had to quit college. My father and brother have to work, so I have to take all her care. I’m like her mother now, she talks to me only’ – Fl A

Physicians stressed that women were the primary caregivers, well acquainted with the care recipient’s pain and other limitations.

‘It’s the lady of the house. Be it mother, daughter but lady who helps and comforts them’ – Dr C

T4: Resources – Out of pocket expenditure on healthcare was about an average INR 2000–3000 per month. None of

the respondents were enrolled in government health schemes. No participant mentioned receiving any kind of support from nongovernmental organizations. Ambulance services, diagnostics, and medicines at the CHC were inadequate, and families relied on private providers. A large number of respondents mentioned financial burden and two reported being in debt.

‘I do not get any help from God or government. I have taken loan for her treatment, and everything is on mortgage. I just somehow manage and live every month’ – Fl E

‘Most of the patient’s family lose everything, in fact they take huge loans for their treatment, and we don’t have many schemes to support them also’ Dr D

T5: Community – Eight out of twelve care recipients were unable to leave their homes due to a lack of mobility. Five were unwilling to leave their home, believing that they were discriminated against due to their health, leading to a circular pattern of feeling isolated and attributing it to ill health.

‘No one comes to our house, nor do they call us in any function, earlier they used to come but not now. I alone take care of everyone’ – Fl B

On the other hand, seven care recipients mentioned that although they had mobility problems, they appreciated the company and experienced better moods when they had visitors.

‘Yes, I have friends and they come and meet me every day as I am unable to go outside’ – Pt B

Seven out of twelve caregivers agreed that the care recipients were stigmatized for their illness and felt marginalized, by friends, community, and sometimes physicians as well.

T6: Perception about Life – Attitude was found to have a sizeable impact on everyday activities and also affected family dynamics. Lack of acceptance, stress, and a hopeless attitude towards recovery or improvement in quality of life were important determinants of health state.

‘I just pray that God pick me up, I don’t want to live anymore’ – Pt E

Conversations with family unrelated to health had a positive impact on emotional health, as did spiritual and religious activities. Leisure activities such as music, television, reading the newspaper, and sitting outdoors helped maintain a positive outlook. Food also improved mood.

‘I like listening to radio every morning and News everyday’ – Pt F

Depression and an irritable personality were cited as effects of chronic illness. It was also mentioned that illness in one member had a negative impact on the health of the entire family.

‘When a patient is unwell, the whole family gets unwell. The atmosphere is such a way that how will anyone get well in it’ – Dr A

Table 1: Chronic conditions among interviewees

Chronic disease	Care recipients
Diabetes and blood pressure	3
Diabetes	1
Blood pressure	2
Rheumatoid arthritis	1
Paraplegia	1
Chronic heart disease	2
Tumour	1
Kidney failure	1
Total	12

T7: Doctor-patient relationship – Contextual knowledge and ability to communicate in the native language was an asset, which led to greater trust in the doctor–patient relationship and improved treatment compliance.

‘You have to make them comfortable when they come, initially they are a little hesitant but then u ask slowly they tell. They only go to doctors whom they are comfortable’ – Dr B

This was found to be true for both regular care seekers and out-patient visits. Doctors often worked beyond their duty hours and responded to all emergency calls. They cited material limitations of the health facility and high caseload as barriers to delivering a standard of care they believed ideal. Several doctors reported providing aid to families that were unable to afford services like diagnostics and medication.

‘We try to allot them free medicines and tests and inform them about government schemes’ – Dr A

Discussion

All older adults interviewed for this study received informal care at home, mostly by a female caregiver. Financial constraints affected healthcare utilization and many families experienced catastrophic expenditures. Similarly, a high ratio of patients to PCPs disallowed the latter from devoting suitable amounts of time to each patient, which led to a lack of faith in the public healthcare system. Community interaction and leisure activities were intertwined with psychosocial wellbeing. These relationships between the determinants allow them to be grouped into enablers and barriers in the LTC of chronically ill individuals, as displayed in Figure 1.

The findings correspond to previous evaluations of morbidity in Jammu and Kashmir.^[8,12,18] Caregiver duties encompassed the continuum of care, including healthcare decision-making with some care recipients being uninformed of their health condition, in the interest of mental health. This has been seen in other

communities where care at home by the family is preferred for chronically ill or older adults rather than care institutions.^[19] Lack of caregiver wellbeing was also seen due to the absence of systemic LTC support^[20] and the lack of social care, which was also echoed in PCP perspectives. Parallels were seen in relation to the barriers to care-seeking, fears, and negative perceptions about life among older adults under LTC.^[21,22]

Health policy in India and LTC

While LTC is not new in the Indian health policy environment, it has not received a dedicated focus. It has been a peripheral component in NCD programs, including the National Multisectoral Action Plan for Prevention and Control of Common Noncommunicable Diseases.^[23] The absence of a concrete plan of action for LTC is also conspicuous in policies related to the welfare of older adults. The NPHCE focuses mainly on institutional healthcare and lacks a concrete community-oriented publicly funded LTC system, which is counterintuitive since ageing-in-place is preferable from both a health and wellbeing perspective and suitable to the Indian cultural context. The National Policy for Older People also does not point towards a significant state responsibility in LTC and instead focuses on NGO and civil society support to the care provided by families, similar to the Maintenance and Welfare Act of 2007, which does not emphasize the role of the government in ensuring a system of publicly LTC.^[2] The lack of a dedicated policy for LTC burdens families and contributes to a high variability in the quality of care.^[24] The low policy priority accorded to LTC in low- and middle-income countries like India is also reflected in the quantum of research in this area, compared to other health conditions that receive greater attention both from the health system and international research agendas.^[25]

Future of LTC in India and the importance of primary-care physicians

PCPs have an essential role to play in the LTC continuum. In addition to often being the first point of contact with the

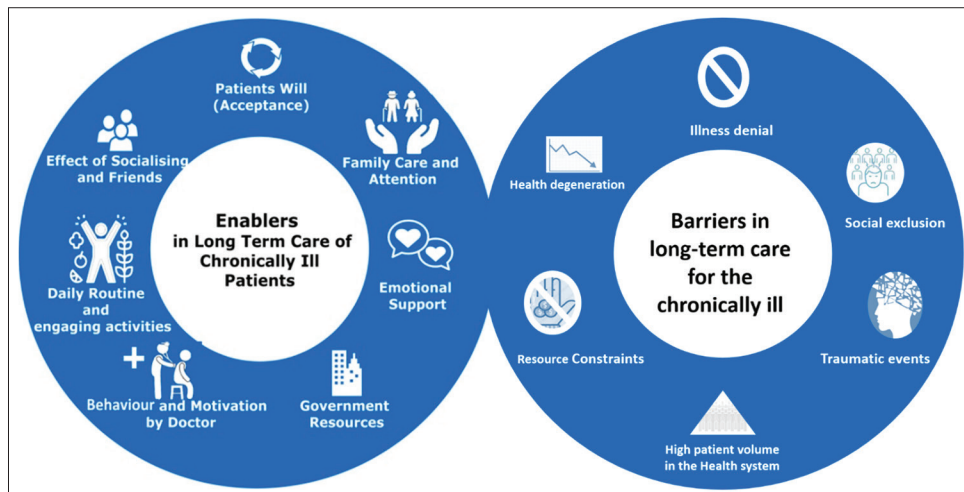


Figure 1: Enablers and barriers of long-term care

health system, the stewardship of LTC in the community rests with them. PCPs are uniquely qualified since their awareness of communities allows them to understand a patient's medical condition and care needs in relation to the social determinants of their health. Therefore, it would be pragmatic to expand the training of PCPs to include existing models in LTC, thereby empowering them to coordinate the care of individuals with chronic disease through teams of allied healthcare professionals and social care workers.^[4,26,27] In order to create a concrete and appropriate LTC policy, it is essential to focus on primary care. The National Health Policy, 2017 also highlights the need to include within the primary care package, geriatric, palliative, and rehabilitative services, all of which are components of LTC.^[28] In order to build an integrated continuum of care for LTC, it will be essential to strengthen primary care with an enhanced focus on NCD prevention, curative services, lifestyle management, and palliative care. It is also necessary to reprioritise primary care in medical education and incentivise medical graduates to pursue a family medicine speciality.

An existing initiative that can be used as a template for the creation of a LTC policy is the *Rashtriya Bal Swasthya Karyakram* (RBSK), which takes a comprehensive and systematic approach towards identifying and managing developmental issues in children.^[29] Similar to the RBSK, the policy should have networks of healthcare workers from the community to higher levels tasked with comprehensive screening of chronic conditions and disability, especially among older adult populations, to identify those in need of LTC.

The expansion of LTC at the national level should scale up from existing models of community-based care in the country. The Neighbourhood Network in Palliative Care in the state of Kerala includes several desired components such as care at home, caregiver support, financial aid from the community and civil society involvement, and a holistic care package including medical and social care for chronic patients.^[30]

Strengths and Limitations

The findings of this study focused on a small population with limited ethnic and cultural diversity. Even so, the findings show parallels in terms of stakeholder perspectives, systemic gaps, and drivers of care-seeking behaviour, across a range of health conditions among older adults and geographical contexts in India, thus providing the study transferability and dependability.

Conclusion

This study enhances the understanding of the contextual and systemic determinants of LTC in a rural community in India. Special attention is paid to nonmedical needs and their importance in enhancing quality of life. Going forward, two items will be of utmost importance; working towards policy action to make LTC a cornerstone of chronic disease management in the country, with a greater role for primary care, and reshaping

relationships between caregivers, care recipients and the health system to make LTC more patient-centred and holistic.

Key take-home message

Individuals with chronic ailments often require LTC. This is mainly delivered informally by family members. There are systemic gaps in the care continuum such as a shortage of doctors and a lack of allied health and social care resources. There is a need for the recognition of the social determinants of health in LTC and intersectoral action to streamline LTC services in India.

Novelty of this manuscript

This manuscript is the first to feature perspectives from a variety of stakeholders in a rural community in J&K, including care recipients, family caregivers, and healthcare providers. These perspectives have led to the emergence of individual, community, and provider factors which function as enablers and barriers to the successful provision of LTC to older adults and individuals with chronic ailments. By generating a panoramic view of the determinants of LTC at the community level, this study provides a way forward to address the lacunae that have led to a disjointed experience of LTC throughout India.

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Conflicts of interest

There are no conflicts of interest.

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