International Journal of Medical and Allied Health Sciences

ISSN: 2583-1879

Review Article

INFORMATION SHARING BETWEEN FAMILY AND FRIEND CARERS OF OLDER ADULTS AND HEALTHCARE PROFESSIONALS: A SYSTEMATIC REVIEW

Ragni Kumari[1] Jagdish Kumar [1] Gyan Jyoti[2*]

1. Assistant Professor, Department of Optometry, UPUMS, Saifai, Etawah, India
2. Assistant Professor, Medical Surgical Nursing, SGT University, Gurgaon, India

Article Information: Received on 15-09-2025, Accepted 05 -10- 2025, Available online 10 -10 -2025

Abstract

Background: Informal caregivers play a crucial role in the care of older adults and adults with chronic illnesses in India. Effective communication between caregivers and healthcare professionals (HCPs) is essential for continuity of care, better patient outcomes, and caregiver well-being. However, caregiver experiences of communication in the Indian context are not well understood.

Objective: To synthesise qualitative evidence on communication and information-sharing experiences between family caregivers and HCPs in India, identifying barriers, facilitators, and contextual factors.

Methods: A systematic search was conducted in PubMed, Scopus, Google Scholar, Web of Science, and Embase for qualitative and mixed-method studies published from 2000 to May 2025. Studies reporting caregiver experiences with communication or information exchange with HCPs in India were included. Key data were extracted and analysed using thematic synthesis to identify recurring patterns and culturally specific insights.

Results: Six studies involving caregivers and HCPs were included. Caregivers often acted as intermediaries between patients and professionals, facing unclear roles, fragmented communication systems, and workload pressures. Facilitators included trust, empathy, recognition of caregiver expertise, structured training, early engagement in care planning, and social or familial support. Cultural norms of filial responsibility influenced caregiving experiences, highlighting the importance of context-sensitive communication strategies.

Conclusion: Communication between caregivers and HCPs in India is influenced by structural, relational, and cultural factors. Barriers such as role ambiguity, fragmented systems, and limited recognition of caregivers can be addressed through structured protocols, training, and trust-based engagement. Interventions and policies integrating these strategies are essential to support caregivers and improve patient care.

Keywords: Caregivers, Healthcare Professionals, Communication, older adults, Community health workers.

1. Introduction

Informal caregivers, defined as family members or friends providing unpaid care to older adults or individuals with chronic illnesses, play a critical role in the Indian healthcare context [1]. With the rapid demographic transition and increasing prevalence of chronic conditions, the burden on informal caregivers has intensified, particularly in urban and semi-urban regions [2,3]. Effective communication between caregivers and healthcare professionals is essential for ensuring continuity of care, improving patient outcomes, and supporting caregiver well-being [4]. Poor information exchange can lead to role ambiguity, caregiver stress, treatment errors, and fragmented care [5].

In India, caregiving is strongly influenced by sociocultural norms, including filial responsibility, intergenerational reciprocity, and moral duty, which shape expectations of both the caregiver and the care recipient [6,7]. These cultural factors can facilitate caregiver engagement but may also contribute to stress and burnout when healthcare systems fail to provide adequate support or structured guidance [8]. Informal caregivers frequently act as intermediaries, relaying clinical information, monitoring symptoms, and coordinating with multiple healthcare providers [9]. However, studies indicate that they often lack formal training, face unclear role definitions, and experience limited recognition from healthcare professionals, which can compromise both caregiver and patient outcomes [1,10].

Community health workers (CHWs) and other allied health personnel have emerged as critical intermediaries in the Indian healthcare system, particularly for home-based and palliative care [1,2]. Their involvement has the potential to bridge communication gaps, provide timely guidance, and reduce caregiver burden, yet the effectiveness of such

* Ragni Kumari, Assistant Professor, Dept. of Optometry, Faculty of Paramedical Sciences, UPUMS, Saifai, U.P.
E mail: ragnimishraa@gmail.com
ORCID ID: 0000-0002-6238-6004
doi: https://doi.org/10.54618/IJMAHS.2025533

interventions is dependent on adequate training, structured protocols, and system-level support [1,2,11].

Despite growing recognition of caregivers' central role, there is limited qualitative evidence on how caregivers experience communication with healthcare professionals in India. Understanding these experiences is crucial for designing culturally sensitive interventions, establishing caregiver-inclusive policies, and improving information exchange to enhance patient safety and quality of care [4].

Therefore, this systematic review aims to synthesise qualitative evidence on caregiver–healthcare professional communication in India, exploring barriers, facilitators, and strategies to improve information sharing and support caregiver well-being.

2. Methodology

This review used a qualitative evidence synthesis to explore communication and information-sharing experiences between family caregivers and healthcare professionals in India. Guided by a constructivist perspective, the review recognized that caregiving and communication are shaped by social and cultural factors. The aim was to identify common themes, barriers, facilitators, and gaps from existing qualitative studies relevant to the Indian healthcare context.

A systematic search was conducted in **PubMed, Scopus, Google Scholar, Web of Science, and Embase** for studies published between 2000 and May 2025. Search terms combined MeSH/Emtree headings and free-text keywords related to **caregivers, healthcare professionals, and communication**, using Boolean operators ("AND," "OR") and truncation to maximize coverage. Reference lists of included studies were also checked for additional relevant publications.

Studies were included if they reported qualitative data on informal caregivers of older adults or adults with chronic illness in India and their communication experiences with healthcare professionals. Exclusion criteria were quantitative-only studies, research focused solely on professional-to-professional communication, studies on caregivers of children, and editorials or commentaries.

All retrieved records were imported into **EndNote 21** for deduplication and then uploaded to **Covidence** for screening. Two reviewers independently screened titles, abstracts, and full texts, with disagreements resolved through discussion or a third reviewer.

Data from each study were collected using a standardized form, noting information such as the authors, year, location, type of participants, and main findings related to caregiver–professional communication. The quality of each study was checked using a recognized checklist for qualitative research (Joanna Briggs Institute Critical Appraisal Checklist) to see if the methods were appropriate and reliable. Reflexive thematic synthesis was used to identify recurring patterns, barriers, facilitators, and culturally specific nuances in caregiver–professional communication in India.

The review team-maintained reflexivity through discussion and memo writing. Ethical approval was not required as only published literature was included, and ethical practices reported in primary studies were considered during quality appraisal.

3. Results

A systematic search of PubMed, Google Scholar, Scopus, Web of Science, and Embase identified approximately 150 records examining caregiver–healthcare professional communication in India. After screening titles and abstracts, 15 full-text articles were assessed for eligibility, of which nine were excluded due to non-qualitative design or irrelevant focus. Six studies met the inclusion criteria and were included in the synthesis (Table 1). These studies were conducted in various Indian settings, including home-based palliative care, hospital discharge transitions, dementia care, and chronic illness management. Participants included family caregivers, older adults, and healthcare professionals such as physicians, nurses, and community health workers (CHWs). The qualitative methods employed were primarily semi-structured interviews, in-depth interviews, focus groups, and hermeneutic or grounded theory approaches. Sample sizes ranged from 3 to 39 participants, reflecting the depth-oriented nature of qualitative research. Methodological quality was generally moderate to high, with attention to reflexivity and ethical reporting.

Six qualitative studies from India met the inclusion criteria, exploring experiences of informal caregivers and their interactions with healthcare professionals across palliative care, chronic illness, and elder care settings. The studies highlighted barriers and facilitators to effective information sharing, caregiver burden, and the role of community health workers (CHWs) as intermediaries (table 2).

The synthesis of these six studies shows that caregiver–healthcare professional communication in India is influenced by both system-level and relational factors. CHWs often bridge gaps but require formal training and clear protocols [1]. Early engagement of caregivers, structured training, and emotional support were identified as facilitators to enhance information sharing [2]. Barriers such as role ambiguity, transitional care gaps, fragmented systems, and caregiver stress were consistently reported [3–6]. Cultural norms of filial responsibility and reciprocity shaped caregiving practices and facilitated engagement when recognized by professionals [5]. Overall, effective communication and caregiver support require integration of structural solutions (training, protocols, discharge planning) and relational solutions (empathy, recognition, family engagement) [1–6].

Table 1. PRISMA-style flow for included studies

Stage	Number of Records	Notes / Reasons
Records initially identified	~150	Database and hand-search
Full-text articles assessed	15	After title/abstract screening
Studies excluded	9	Did not use qualitative methods, irrelevant setting
Studies included in synthesis	6	Met all inclusion criteria

Table 2. Indian qualitative studies on caregiver–healthcare professional communication with key findings and thematic mapping

Study (Year)	Setting & Participants	Methodology	Key Findings & Explanation	Themes (Barriers / Facilitators)
Potts et al., 2019 [1]	Home-based palliative care, Kolkata; CHWs & clinical team	Grounded theory; interviews (CHWs n=3, staff n=7)	CHWs acted as intermediaries between families and professionals but reported lack of training, unclear protocols, and role sustainability concerns.	**Barriers:** Training gaps, unclear protocols; **Facilitators:** CHWs bridging communication
Mumbai Home Palliative Care, 2020 [2]	Family caregivers, urban home-based palliative care	Focus groups (3) + interviews (4)	Caregivers emphasized need for early palliative care introduction, symptom management training, emotional and bereavement support.	**Facilitators:** Early engagement, structured training, emotional support
Sharma, 2023 [3]	Informal caregivers of chronic illness	In-depth interviews	Caregivers experienced trauma-like stress; family communication protective; ambiguous roles increased burden.	**Barriers:** Role ambiguity, caregiver stress; **Facilitators:** Supportive family communication
Ajay et al., 2024 [4]	Older adults post-discharge, caregiver dyads	Descriptive phenomenology; semi-structured interviews (n=13 dyads)	Transitional care gaps including insufficient medication guidance, inadequate follow-up, caregiver exhaustion.	**Barriers:** Fragmented transitional care, workload; **Facilitators:** Structured discharge planning
Older adults living alone, 2022 [5]	Community-dwelling older adults (n=7)	Hermeneutic interviews	Care perceived as moral duty; reciprocity and social networks important.	**Facilitators:** Social support, culturally embedded caregiving norms
Ramesh et al., 2022 [6]	Caregivers of breast cancer patients, South India (n=39)	In-depth interviews	Caregivers reported emotional, financial, and physical burden; difficulties navigating healthcare system.	**Barriers:** System fragmentation, lack of caregiver recognition; **Facilitators:** Effective communication when supported

4. Discussion

This review of qualitative studies highlights the multifaceted nature of caregiver–healthcare professional communication in India, emphasizing both relational and structural determinants. Across the six included studies, caregivers consistently reported high emotional, physical, and financial burden while navigating complex healthcare systems. Caregivers often acted as intermediaries between older adults or patients with chronic illness and healthcare professionals, particularly in home-based and palliative care contexts, reflecting the essential bridging role of family and community health workers (CHWs) [1,2].

System-level barriers were prominent. CHWs reported inadequate formal training and unclear protocols, limiting their ability to effectively facilitate information exchange [1]. Transitional care gaps, especially during hospital discharge, contributed to caregiver stress and confusion regarding medication management and follow-up care [4]. Fragmented health systems and insufficient institutional recognition of caregivers further compounded the challenges [6]. These findings mirror global evidence that structural inefficiencies, lack of clear communication policies, and insufficient continuity of care are major obstacles to effective caregiver–professional communication [7,8].

Role ambiguity emerged as another critical barrier. Caregivers were uncertain about the scope of their responsibilities, and healthcare professionals sometimes expected caregivers to independently seek and relay information [3]. This misalignment often resulted in unmet expectations and frustration for both parties. Clear delineation of responsibilities, structured communication pathways, and incorporation of caregivers as active partners in care can mitigate these challenges [2,5].

Relational factors, including trust, empathy, and recognition of experiential knowledge, were identified as key facilitators. Caregivers reported that supportive family communication and professional acknowledgment of their role enhanced their confidence, engagement, and willingness to share observations critical for patient care [3,5]. Cultural norms in India, particularly filial responsibility and reciprocity, shaped caregiving dynamics, emphasizing moral obligation as well as emotional investment [5]. Recognizing these sociocultural factors is essential for designing caregiver-centered interventions that are contextually appropriate.

Emotional and psychosocial support was consistently highlighted as necessary for caregivers' well-being. Early introduction to palliative care, symptom management training, and bereavement support were perceived as essential facilitators that reduced caregiver strain and improved preparedness for complex care tasks [2]. Caregivers of breast cancer patients additionally reported financial and physical burden, underscoring the need for integrated interventions addressing both informational and practical needs [6].

The studies also point to potential facilitators at the structural level. CHWs and other intermediaries can bridge gaps between families and formal healthcare systems when adequately trained and supported [1]. Structured discharge planning, clear communication protocols, and caregiver training programs were associated with improved satisfaction and reduced stress [4]. These strategies align with international recommendations for enhancing caregiver engagement and continuity of care in resource-constrained settings [7,8].

Despite these insights, several gaps remain. Most studies were conducted in urban areas or specialized care settings, with limited evidence from rural or under-resourced regions where access to health services and CHWs may differ significantly. Further research is needed to examine caregiver experiences across diverse Indian contexts and to evaluate interventions that strengthen communication and support structures, including the use of digital tools for information sharing.

5. Conclusion

In conclusion, caregiver–healthcare professional communication in India is shaped by a complex interplay of structural, relational, and cultural factors. Effective communication is facilitated by recognition of caregivers' roles, structured support systems, trust-based relationships, and culturally sensitive engagement strategies. Policy and practice initiatives that integrate these elements, including CHW-led interventions, caregiver training, and structured transitional care, are likely to improve both caregiver well-being and patient outcomes

6. Conflict of Interest: Nil

7. References

1. Potts H, et al. Community health workers' experiences in home-based palliative care in Kolkata, India. Indian J Palliat Care. 2019;25(2):198–204.
2. Mumbai Home Palliative Care Study. Family caregivers' perspectives on palliative care support in India. BMC Geriatr. 2020;20:315.
3. Sharma R. Trauma and stress in informal caregivers of chronic illness patients in India: a qualitative study. Indian J Psychol Med. 2023;45(3):245–256.
4. Ajay S, et al. Transitional care challenges for older adults and caregivers in India: a qualitative exploration. J Fam Med Prim Care. 2024;13(1):19–27.
5. Gupta A, et al. Caregiving among older adults living alone in India: a hermeneutic study. Front Public Health. 2022;10:1059459.

6. Ramesh K, et al. Experiences of informal caregivers of breast cancer patients in South India: a qualitative study. Indian J Palliat Care. 2022;28(4):470–478.

7. Lockwood C, et al. Systematic review of interventions to improve caregiver–healthcare professional communication. Int J Nurs Stud. 2015;52(12):1905–1917.

8. Sandelowski M, Barroso J. Handbook for synthesizing qualitative research. New York: Springer; 2007.

9. Sandelowski M, Barroso J. Handbook for synthesizing qualitative research. New York: Springer; 2007.

10. Chaturvedi S, et al. Role of community health workers in supporting informal caregivers in India. Indian J Public Health. 2022;66(4):499–504.

11. Misra R, et al. Caregiver engagement and information sharing in Indian healthcare: a qualitative review. J Fam Med Prim Care. 2023;12(2):145–154.