Understanding the Experiences, Challenges, and Needs of Dementia Caregivers in the Indian Subcontinent

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ABSTRACT

In the realm of dementia care-giving within India, the caregivers often resemble hidden patients, bearing the weight of an often-overlooked role. However, there remains a dearth of comprehensive data regarding the emotional and physical challenges caregivers face in the Indian subcontinent. We present a qualitative study that delves into the realities of being a dementia caregiver in India, investigating caregivers' experiences and examining the impact of several challenges on their daily lives. Through in-depth interviews, we engaged with four primary caregivers of individuals with dementia, delving into how care-giving shapes their social interactions, mental equilibrium, and emotional states. The findings highlight the importance of having an emotional outlet, a support system, and accessible resources for enhancing caregivers' quality of life. Drawing from these insights, we propose a set of design implications that can guide future endeavors focused on enhancing the overall well-being of dementia caregivers in India. This research effectively bridges a substantial knowledge gap, extending support and understanding to this vital cohort of individuals who stand at the forefront of dementia care.

CCS CONCEPTS

• **Human-centered computing → Empirical studies in accessibility**; *Empirical studies in HCI*.

KEYWORDS

Dementia Caregivers, Social Isolation, Disability Studies, Qualitative Research, India

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1 INTRODUCTION

In India, the number of individuals above the age of 60 suffering from dementia exceeds 8.8 million [4]. Dementia is considered a "hidden problem" as there is a prevalent tendency to mistake symptoms of dementia as mere signs of normal aging, especially in India [2]. The lack of knowledge, awareness, and acceptance of dementia frequently leads to delayed or no diagnoses in patients [2]. This misconception contributes to a dearth of support and understanding for both patients and caregivers, who are responsible for the care of dementia patients who may not possess professional care-giving expertise. While there is a growing body of literature addressing the experiences of caregivers of persons with dementia (PwD) globally [1, 5, 6, 9, 11, 12], there is a dearth of recent research focusing on the experiences, needs, and challenges of caregivers of PwD in India. In this work, we conducted semi-structured interviews with dementia caregivers to understand the experiences, challenges, and needs of caregivers of PwD and the perception of dementia in the Indian subcontinent. While there remains a general lack of awareness regarding its impact on PwD and their caregivers in India, societal stigmas and misconceptions prevail, which result in complete ignorance about dementia or a general reluctance to acknowledge the seriousness of the disease. Dementia is often trivialized and even the subject of jokes. Caregivers often experience disappointment and a sense of abandonment from friends and relatives who fail to understand the impact of the disease or provide support. Due to the prevailing taboo and lack of understanding and support, many individuals hesitate to disclose that a family member is grappling with dementia, which prohibited us from recruiting participants for our interviews. Most caregivers find themselves alone and isolated in their journey of fighting dementia. They feel compelled to forge their own path, seeking new approaches and strategies. In this research, we understand the challenges faced, explore strategies and coping mechanisms employed by caregivers, and identify potential opportunities for future interventions to support caregivers and improve their emotional and mental well-being. By shedding light on these important aspects, this research contributes to a better understanding of the caregiver experience of PwD in India.

2 INTERVIEWS

The interviews aimed to gain a comprehensive understanding of the experiences of dementia caregivers in India. Below, we describe the details of the interviews, including participant information, methodology, and the topics explored.

2.1 Participants

We recruited four participants (two males and two females, aged 24 to 54 years old with an average of 37 years old) who met the following inclusion criteria: the participant must (1) provide care for individuals who have a confirmed clinical diagnosis of any dementia type; (2) be an Indian residing in India and the primary caregiver

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for at least one year; and (3) be a family member living with the PwD and must be 18 years or above. All the participants currently reside in different cities in Maharashtra, India. However, they came from various socio-economic and educational backgrounds. Among the caregivers interviewed, one is an entrepreneur, one is a homemaker, one is a student, and one is a working professional. These participants provide care for four PwD, *i.e.,* three males and one female with different types of dementia.

2.2 Method

All four semi-structured interviews were conducted over the telephone or via video calls, and before the interviews, participants provided voluntary verbal consent. Initially, we collected demographic information regarding both the caregiver and the PwD. Subsequently, participants were invited to share their perspectives on the societal perception and mindset surrounding dementia in India, as well as their own experiences and challenges as caregivers. We also explored the strategies, if any, that caregivers employed for efficient care-giving and maintaining their emotional well-being. Additionally, we examined the availability, accessibility, and usefulness of resources to support caregivers in their care-giving role. The interviews were conducted in either English or Hindi, with the Hindi interviews being translated into English while ensuring the accuracy of context and meaning in participants' responses. Following transcription, the data were coded (see the complete codebook in Appendix A), and a thematic analysis approach was employed to identify and categorize common themes or categories, which provided relevant insights for the study.

3 INTERVIEW RESULTS

3.1 Perception Towards Caregivers Of PwD

Our interview results reveal that people in India often consider it their moral responsibility and obligation to prioritize their loved one's care at home, especially towards an elderly family member. This may be associated with strong family ties and cultural beliefs [2]. In India, the role of the primary caregiver is often taken up by the non-working member of the family or the member that can spend most of their time at home. The female members of the family (*e.g.,* wife, daughter, sister, daughter-in-law) are expected to take up the role of primary caregivers from the beginning. This results in a higher burden and stress to the females [2, 7, 8]. In exceptional circumstances, the male members are expected to shoulder the care-giving responsibilities.

Caregivers often feel that society expects them to be experts in care-giving. Caregivers are expected to learn or already possess the required skills and knowledge for care-giving in a short time. Caregivers are often blamed and reprimanded for any perceived inconvenience caused to the patient or others due to the patient's behavior. Additionally, any perceived shortcomings or failure in their role may cause guilt, shame, and regret to the caregiver as well as be looked down upon by society. Caregivers emphasized the importance of raising awareness about dementia and stressed the need for compassionate and mindful interactions within society. However, they expressed concerns about certain individuals engaging in moral policing and offering unsolicited and thoughtless guidance or suggestions. Such actions can be discouraging for caregivers and potentially cause harm.

3.2 Strategies for Enhanced Care-giving and Caregivers' Well-being

Most caregivers highlighted the importance and benefits of having more than one caregiver in the family to look after the dementia patient. In larger families, distributing care-giving responsibilities and working together reduces the burden on the primary caregiver. Sharing care-giving responsibilities is beneficial practically and emotionally, as well as helps build a support system within the family. In addition, caregivers mentioned that engaging the PwD in activities may be highly beneficial. Patients may benefit from participating in hobbies, games, or other stimulating activities as these engagements help maintain their cognitive and emotional well-being. When caregivers spend quality time with patients during these activities, it strengthens their bond and creates meaningful experiences, thereby providing them with a sense of fulfillment and satisfaction in their role.

To cope with the challenges like changes in lifestyle, social isolation, emotional and health issues, caregivers mentioned that they invest their energy and resources into activities that bring them emotional satisfaction. Caregivers highlighted the importance of allocating some time to prioritize self-care and engage in activities they enjoy or find solace in. In the Indian context, caregiving duties, typically shouldered by female caregivers, frequently confine them to indoor settings. This self-care not only helps maintain their mental well-being but also enables them to provide better care to the dementia patients they support.

3.3 Challenges

3.3.1 Coping with Changes in Lifestyle. Caring for a family member with dementia significantly impacts the lifestyle of the entire family, particularly the caregivers. Initially, caregivers face various challenges due to patient behavior, societal stigmas, sudden responsibilities, etc. They resist changing their lifestyle but eventually accept their situation, feeling they have no choice but to live with it. This mindset leads to a lack of proactive measures or solutions to address the challenges, which may lead them to adopt an avoidance attitude as a coping mechanism to negative emotions. For instance, some caregivers mentioned avoiding social gatherings and events to avoid inconsiderate questions, reminders of their loved one's condition, or triggers for difficult emotions. Over time, caregivers learn to adapt and find ways to manage their situation. They develop individualized strategies to protect their emotional well-being and maintain balance in their daily lives. However, long-term reliance on avoidance can exacerbate mental health issues and contribute to social isolation and loneliness. The primary caregivers often take a backseat and let go of their own needs and desires to ensure constant and efficient care for the patient. The journey of dementia care-giving can be isolating, as the responsibilities and focus on the patient limit caregivers' ability to engage in social activities and maintain social connections. The lack of support and understanding from family, relatives, or friends, as well as the need to forego personal pursuits and social activities to fulfill their care-giving duties, further contribute to their isolation.

3.3.2 Impact on Caregivers' Health. Due to the significant changes in caregivers' lifestyles, they often get overwhelmed or overburdened. Prolonged stress and negative feelings or emotions may lead to negative cascading effects like health problems and significantly impact other areas of their personal and professional lives. Research has suggested that there may be a correlation between a caregiver's mental and physical health, and primary caregivers often may suffer from poor immunity [3, 10].

3.3.3 Lack of Availability, Access, and Awareness about Resources. Better access to resources may be directly associated with ease in care-giving and better mental well-being of the caregivers. Financial resources and educational backgrounds play a significant role in caregivers' ability to cope with the challenges of dementia. Ensuring that information, support, and other required resources are accessible to all caregivers, regardless of socioeconomic background, can help them navigate the care-giving journey more effectively. Caregivers expressed frustration with the lack of technology and resources available to support them in their care-giving journey. They mentioned that, though information on dementia and care-giving strategies are available on the internet, the resources are often generic. Caregivers are either already aware of those strategies, or the information may not be as relevant or helpful. There is a dearth of step-by-step guidelines tailored to each patient's needs and a lack of comprehensive resources. Caregivers believe that technology can provide guidance and support, but currently, it falls short of meeting their specific needs. Moreover, during the interviews, caregivers expressed a lack of awareness about various tools and devices available in the market specifically designed for dementia patients. This lack of awareness prevented caregivers from effectively utilizing these tools to support their care-giving efforts. Many caregivers, especially those new to the role and without prior experience with dementia patients, emphasized that knowledge about these resources would have been extremely valuable to them. They suggested that healthcare professionals could be crucial in introducing caregivers to these tools and devices.

3.3.4 Collaboration with Healthcare Professionals. Healthcare professionals play a significant role in connecting caregivers with support groups and facilitating collaboration. However, the support and guidance provided by healthcare professionals vary. Caregivers value professionals who educate them about the care-giving journey and introduce them to communities or resources that can assist them. They express a need for early guidance and training in dementia care and emphasize the importance of comprehensive and tailored instructions. Caregivers stress the need for sustained support and assistance in managing the daily complexities of dementia care.

In India, seeking mental therapy or professional support for caregivers is seen as a sign of weakness. This perception particularly affects male caregivers, who feel societal pressure to project strength and self-reliance. This discouraged caregivers from seeking professional support or therapy. Some caregivers believe that seeking therapy for themselves, though helpful, may not be sustainable in the long term. They find more value in emotional connection and venting their feelings to friends, relatives, or fellow caregivers, rather than talking to healthcare professionals.

4 DESIGN IMPLICATIONS FOR FUTURE WORK

4.1 Building Community and Support Groups

Caregivers emphasized the pressing need for dedicated communities or support groups tailored explicitly to the requirements of dementia caregivers. Within the Indian context, the prevailing caregiver communities often lack a targeted focus on dementia care. Furthermore, in instances where specialized dementia caregiver communities do potentially exist, they remain relatively obscure and less acknowledged, in sharp contrast to the well-recognized, accessible, and utilized resources prevalent in Western nations. Communities can provide unparalleled emotional support essential for caregivers' mental well-being. Connecting with other caregivers facing similar challenges provides genuine understanding, effective support, and a sense of belonging, reassuring caregivers that they are not alone in their journey. Support groups or communities offer a valuable platform for caregivers to learn from other's experiences, share frustrations, and exchange coping strategies. Loneliness and isolation can be alleviated by establishing spaces where caregivers can connect, share, and find solace.

Online moderated caregiver communities or support groups may also be pivotal in providing emotional support and addressing social isolation and information challenges caregivers face. Moderation is necessary to ensure the accuracy and reliability of shared information. By verifying information and preventing the spread of misinformation, these communities become a trusted and consolidated source of support. Caregivers emphasized the importance of healthcare professionals in introducing them to these online communities and facilitating access to valuable resources. The involvement of healthcare professionals also contributes to the visibility and quality of data within these communities.

4.2 Spreading Awareness

Raising awareness about dementia symptoms, caregiver struggles, and combating stigma is essential. Caregivers have observed a positive shift in attitude from people around them when they understand the disease's severity, impact, and challenges on both the patient and the family. Increased awareness leads to a more compassionate and understanding society towards patients and caregivers. Caregivers stress the importance of being vocal about dementia and utilizing technology and media to promote awareness.

4.3 Tools that help in Anticipation and Planning

Caregivers and family members of PwD feel frustrated by the uncertainty and lack of anticipation in their care-giving journey. They emphasize the importance of planning and maintaining routines for dementia patients. Technology can be crucial in tracking and monitoring the patient's health and behaviors, helping caregivers anticipate and address potential challenges. The ability to predict and plan beforehand reduces vulnerability to negative emotions.

4.4 Leveraging Technology and Social Media Applications

Caregivers are willing to actively use a mobile application or platform that provides consolidated information and effective caregiving strategies for dementia. While resources and support groups exist on platforms like *Reddit*, they are not widely known or utilized by Indian caregivers. Instead, platforms like *WhatsApp*, *Facebook*, *Instagram*, are more popular in India. Hence, integrating widely used channels would enhance awareness and reach the targeted audience.

5 CONCLUSION AND FUTURE WORK

Caring for PwD presents unique challenges for caregivers, necessitating a comprehensive understanding of the condition and complex care-giving techniques. In the Indian subcontinent, where awareness about dementia is still limited, caregivers face significant obstacles. This study highlights the importance of caregivers having outlets such as engaging in hobbies, participating in support groups, or connecting with others to maintain emotional and mental well-being.

As an ongoing research, our interviews were conducted with a limited sample size of four participants. To enhance the depth of our study and gather more comprehensive insights, we plan to expand the number of participants in future interviews. While the current participants were exclusively from the state of Maharashtra, we recognize the importance of including individuals from diverse states to capture variations in cultures, traditions, and values. We aim to conduct interviews with healthcare professionals to obtain a well-rounded understanding of our study from multiple perspectives. Additionally, we also expand identified design implications by exploring technologies that enhance caregivers' quality of life through facilitating planning, anticipating future needs, fostering communities, and providing tailored information and support.

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A APPENDIX: REFINED THEMES AND CODES

Following are the themes or categories and the corresponding codes used for thematic analysis of the interview transcriptions.

A.1 Challenges

- Lack of Awareness: Challenges arising from insufficient knowledge and awareness among caregivers, family members, or society regarding dementia and its impact on care quality and caregiver well-being.
- Lack of Resources: Challenges stemming from limited access to financial, tool/device, time, or healthcare resources.
- Knowledge Gaps: Indications of insufficient or lacking information or data pertaining to care-giving and dementia.
- Emotional Struggles: Observations highlighting emotional or mental challenges experienced by caregivers or family members of PwD.
- Health Concerns: Records of health issues or changes in the health condition of PwD or caregivers/family members due to their care-giving responsibilities.
- Social Isolation: Mentions of caregivers or family members feeling isolated, lonely, or lacking support.
- Challenges Related to PwD Behavior: Difficulties faced by caregivers and family members due to the changing behavior or deteriorating condition of PwD.

- Cascading Effects: Instances where one event leads to subsequent challenges, resulting in an avalanche effect or snowballing difficulties.

A.2 Adaptation and Coping

- Lifestyle Changes: Observations regarding the adjustments in lifestyle and the associated challenges for caregivers or family members.
- Sensemaking: Attempts to comprehend the situation and create a road map for future care-giving.
- Coping Mechanisms: Strategies and approaches employed by caregivers to cope with challenges and adapt to changes.
- Learning: Utilizing previous experiences or patterns to track, monitor, respond, and learn from care-giving situations.
- Strategies: Adoption or recommendation of specific strategies or tips for effective care-giving and emotional well-being.
- Planning: Examining caregivers' prioritization and organization on a daily basis, and their perceptions of the importance or need for better day-to-day planning.

A.3 Design Implications for future work

- Support Systems: Mentioned existing, lacking, or required support networks beneficial for caregivers in providing effective care or ensuring their well-being.
- Helpful Features: Features or functionalities that could aid caregivers in their care-giving responsibilities according to the participants.
- Design Opportunities: Potential areas identified from the interviews where future interventions or improvements can be developed based on the insights gained.

A.4 Context

- Societal Perception: Notable observations regarding societal attitudes and perceptions toward dementia, PwD, caregivers, or family members, specifically within the Indian context.
- Cultural Context: Insights specific to the Indian cultural and social context.

A.5 Participant and Role Details

- Role and Responsibilities: Information about the roles and responsibilities of caregivers and family members, including task distribution or function allocation if applicable.
- Demographics: Background information about the caregiver and the PwD to understand their profile and context.