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Research Paper

Uncovering the Unspoken: Exploring the Emotional Landscape of Caregivers of Alzheimer's Patients

N Sindhu[1]*, Dr. Padmakumari[2]

ABSTRACT

The aim of this qualitative study was to gain deeper insight into the emotional experiences of informal caregivers of Alzheimer's disease who are in their fourth stage and beyond. Existing studies have shown that caregivers often experience negative emotions such as guilt, frustration, sadness, and isolation, with a particular focus on female caregivers in India. However, the role of these emotions on caregivers' well-being and cognition, as well as the role of gender in India, remains unclear. To address this gap, the study employed face-to-face and telephone interviews with informal caregivers of people with Alzheimer's. The researcher adopted a purposive sampling strategy, recruiting eight female caregivers and three male caregivers. The interviews, which lasted between 30 minutes and an hour, were recorded, transcribed, and analyzed using thematic analysis. The study's significant findings revolved around three main themes: "the complex terrain of caregiving," including the initial denial stage, the emotional struggles caregivers face, and the impact of caregiving on their social lives. The second theme was the "transformative journey of caregiving," which talks about how the caregivers found a balance between themselves and the caregiving roles and lastly, the "gendered nature of caregiving," which explored how gender roles and societal norms affect the caregiving experience. This research emphasizes the need to comprehend the multifaceted aspects of caregiving and the importance of specialized support systems to enhance caregivers' well-being. The study's findings provide valuable insights into caregiving dynamics, which can facilitate improving the quality of care for individuals with Alzheimer's in India.

Keywords: *Alzheimer's Disease, Caregiving, Emotional Experiences, Transformative Journey, Gender-Specific Interventions*

"Caregiving often calls us to lean into love we didn't know possible." - Tia Walker

A*lzheimer's disease* is a neurodegenerative disorder that progressively worsens and is one of the leading causes of dementia among the elderly across the globe (Kumar, 2022). According to government forecasts, approximately 194 million people in India will be above 65 by 2031. Due to an increasing population of the elderly in India in the near future, the risk of developing a chronic disease like Alzheimer's in society is increasing at an

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[1] MSc Psychology (Clinical), Department of Psychology, Christ (Deemed to be University), Bangalore, India.
[2] Professor at Department of Psychology, Christ (Deemed to be University), Bangalore, India.
*Corresponding Author

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alarming rate (Singh, 2021). The buildup of tau tangles and beta-amyloid plaques causes neurodegeneration, which deteriorates cognitive function and gives rise to AD symptoms (Tiwari et al., 2019). The disease gradually impairs cognitive functions, including memory, language, thinking, and reasoning. As the disease progresses through its seven stages, individuals may experience a loss of complete independent functioning. During the advanced stages, caregivers must provide higher levels of care to support those with Alzheimer's as they can no longer take care of themselves (DeTure & Dickson, 2019). Informal caregivers (hereafter referred to as caregivers), such as family members, friends, and neighbors, provide most of the care and are crucial once the individual enters the 4th stage of the disease (Schulz et al., 2020).

During this stage, individuals may experience a loss of independence and struggle with daily instrumental tasks, necessitating complete care. As a result, caregivers are crucial in managing the care of those with Alzheimer's disease (Clinical Stages of Alzheimer's, 2022; Brodaty & Donkin, 2009). In India, caring for family members tends to be divided along gender lines, with women often bearing the brunt of responsibilities (Prasad & Rani, 2007). This is primarily due to cultural norms that strongly emphasize women as caregivers within the family unit (Ugargol & Bailey, 2018). While there has been a recent increase in the number of men providing care for older adults with neurodegenerative conditions (Sharma et al., 2016), there is still a need for more research into the experiences of male caregivers in India. For those caring for loved ones with Alzheimer's, the role can be incredibly challenging as they grapple with difficult decisions about the best way to support both themselves and their family member (Bursch & Butcher, 2012). Providing informal care demands substantial effort, productive time, and financial resources from caregivers. The mental health of caregivers deteriorates due to caregiving fatigue. This is especially noticeable in women whose well-being has decreased over time. As a result, inadequate care may be provided to individuals who rely on them (Brinda et al., 2014; Gupta et al., 2012). According to Srivastava et al. (2016), women, who are typically the primary caregivers, are reported to be burdened more due to the "expectations" of caregiving. Therefore, extensive research has honed in on the emotional toll experienced by caregivers of individuals with Alzheimer's disease, with a particular focus on female caregivers and their susceptibility to "burnout and psychological distress" (Shaji et al., 2003). These emotional experiences can profoundly impact cognitive abilities, including attention, memory, and decision-making. When individuals are faced with intense emotions such as stress, anxiety, or sadness, their ability to concentrate and retain information may be compromised (Tyng et al., 2017). While there have been numerous studies on the emotional experiences of Alzheimer's caregivers, many of these studies have been restricted to specific regions and genders or only examined a single aspect of caregivers' emotions, such as positive or negative experiences.

Moreover, past research has yet to explore the impact of emotions on the cognitive capacities of caregivers. Hence, this study aims to further our understanding of the emotional experiences of informal carers of patients in the fourth stage of Alzheimer's disease by addressing essential objectives. By examining both male and female caregivers, the research explores the nuanced aspects of their experiences, highlighting potential overlaps and distinctiveness. It tries to thoroughly examine the intricate emotional factors at play, revealing how feelings can impact how caregivers view their mental abilities. In addition, this research aims to highlight the elements that influence how fulfilling or unpleasant the experience of providing care is. Finally, using a qualitative approach, this study highlights the need for a thorough understanding of carers' emotional landscapes in the particular context of Alzheimer's care in India. It provides insightful information to help design targeted support systems.

METHOD

Study Design

Using phenomenology, the researcher has tried to learn about the emotions the caregivers experience and their attitude toward it. It is a method to study the lived experiences of the caregivers of Alzheimer's (Ravitch & Carl, 2016). Face-to-face interviews enabled close interaction between the participants and the researcher (Rubin, 2005). For this study, the researcher used Moustakas' transcendental phenomenology which involves studying the lived experiences by bracketing the opinions or the ideas of the researcher.

Population and Recruitment

In the current study, a total of fourteen participants were interviewed, however only eleven were included (n=11), with eight female participants and three male participants. Table 1 below provides a breakdown of the demographic information for each participant. Participants were selected for this study using purposive sampling, a non-probability sampling technique that allows for selecting individuals based on the study's purpose. As Creswell (1998) recommended for phenomenological research, participants were selected based on their experiences with the phenomenon being studied. In this case, the participants were informal primary caregivers for individuals with Alzheimer's disease receiving in-home care. Qualitative research does not emphasize a specific sample size (Ravitch & Carl, 2016). However, the current sample size was determined based on data saturation, meaning that the researcher collected enough information to ensure that no new insights were gained. The inclusion and exclusion criteria for the study are mentioned below: *The inclusion and exclusion criteria for the study were clearly defined. The study included primary caregivers who were already working and within the age limit of 30-50 years. The participants were required to be fluent in English as it would be the primary mode of communication. The study focused on caregivers residing in metropolitan cities in India to ensure a diverse population was included. However, caregivers providing services in hospital settings, those already on medication, providing care for more than two individuals, or those who have taken/are taking therapy or affiliated with respite services were excluded from the study. The criteria were set to ensure that the study participants were appropriate for the research and would provide accurate results.*

Table 1 Participants demographics

Participants	Initials	Age	Sex	Marital Status	Urban/Rural setting	Care Recipient's Alzheimer's Stage
P1	S	48	Female	Married	Urban	Moderate
P2	JS	50	Female	Married	Urban	Stage 7
P3	V	30	Female	Married	Urban	Moderate
P8	PK	48	Female	Married	Urban	Stage 5
P6	KS	31	Female	Unmarried	Urban	Moderate
P5	MC	49	Female	Unmarried	Urban	Moderate
P4	G	50	Female	Married	Urban	Moderate
P7	V	50	Female	Married	Urban	Moderate
P9	BG	29	Male	Unmarried	Urban	Stage 4
P10	PK	30	Male	Unmarried	Urban	Moderate
P11	KS	49	Male	Married	Urban	Stage 7

Data Collection

The data collection process involved face-to-face interviews with participants. Prior to the main interview, a pilot interview was conducted. Informed consent forms and demographic details were collected from participants before the interview. Semi-structured interviews were conducted to gather in-depth information using open-ended questions about the participants' past and present experiences. Interviews were conducted either in person at participants' homes or through Zoom, based on their preferences. The main questions asked during the interviews can be found in Appendix A. Each interview lasted approximately 40-90 minutes, with participants giving oral and written consent for audio recording to allow for verbatim transcription and research purposes. The Descript app was used to transcribe the interviews.

Trustworthiness

The main goal of trustworthiness is to assess the procedures used during data analysis to ensure that results accurately reflect the values the caregivers were trying to convey **(Lietz et al., 2006)**. The proposed study used three techniques to ensure the validity of its conclusions. When a researcher is rooted in transcendental phenomenology, they are conscious of their prejudices and place them in a bracket without letting it influence their understanding of the lived-in experiences of the participants **(Creswell, 1998)**. While reflecting, the author was aware of their own opinions and those of their research participants. Throughout the interview process, the author kept a journal to allow for self-reflection. The information obtained from the interviews and journal articles were routinely discussed with the supervisor. This guaranteed that individual biases did not affect how the data was viewed, enabling unbiased analysis. Response validation is essential to guarantee that the information gathered accurately matches the intended message **(Long & Johnson, 2000)**. As a result, the researcher allowed participants to validate their meanings during and after each interview. Participants were allowed to ensure that their responses' meaning was correctly interpreted before the researcher started analysing. This aimed to create a precise and accurate explanation of the participant's experiences **(Long & Johnson, 2000).**

Ethical approval

The Christ (Deemed to be) University Institutional Review Board provided approval for the study. All participants provided verbal and written informed consent for using the data collected via interviews for the research purpose.

Data analysis

In order to ensure the precision of the information, each interview was recorded and transcribed offline before being thoroughly reviewed by a second evaluator against the original audio recordings. The data reached saturation after the eleventh participant as no new information was being gathered. Following **Braun and Clarke's (2006)** analysis method, the verified transcripts were meticulously read and subjected to a six-phase thematic analysis. Audio recordings were transcribed into verbatim scripts, and each transcript was anonymized and reread multiple times for accuracy. The researcher undertook line-by-line, manual coding. Transcripts were coded immediately; thus, subsequent recruitment and interviewing occurred alongside coding, which allowed for a constant comparison of participants and findings. Data were analyzed using inductive and deductive thematic analysis **(Braun & Clarke, 2006).** Furthermore, the researcher and supervisior met regularly throughout the analysis to ensure each stage remained focused on the research aim, and identified codes were discussed jointly to generate themes. The analysis identified three main themes: (1) The complex terrain of caregiving, (2) Caregiving as a Transformative Journey, and (3) Gendered experiences.

RESULTS AND DISCUSSION

The study tried to understand the emotional experiences of male and female caregivers of Alzheimer's who are in their fourth stage and beyond. Both male and female participants have had similar and unique experiences, considering the cultural context of India. The following findings and discussion will be based on the three themes that emerged from data analysis. The three key main themes are (1) The complex terrain of caregiving, (2) Caregiving as a Transformative Journey, and (3) Gendered experiences. Within each main theme, there are sub-themes that are unique to every participant.

Themes 1: The Complex terrain of Caregiving

This theme emphasizes how caregiving goes beyond a single emotional state and encompasses positive and challenging emotions. Caring for Alzheimer's patients is fundamentally complex and emotionally taxing. They frequently deal with behaviors and circumstances they are otherwise not used to (Brodaty & Donkin, 2009). These difficulties include wandering, anxiety, hostility, and the psychological burden of seeing their loved ones deteriorate and suffer (Sideman et al., 2022). The caregivers reported that the process is intense and characterized by complex difficulties. It relates to the various challenging and occasionally disruptive behaviors that caregivers of individuals with Alzheimer's frequently experience during their caregiving journey (Schulz, 2016). For the caregivers, these behaviors may be distressing and demanding. For example, some of the behavioral challenges mentioned by the caregivers are:

"So I had told the servant I will, um, um, come quickly, keep an eye. She called and she said, Didi, Mummy ne mujhe lock kar diya balcony mein. I started panicking because with her in the balcony, Amma won't be able to open the door to me. I didn't know what to do. Fortunately, Amma was inside somewhere in the bedroom. That was a nightmare for me"(P8, Personal Communication, 2023).

Caregivers reported how the whole caregiving process was very uncertain as they did not know what to expect next, even if they kept themselves all prepared. The unpredictable nature of Alzheimer's means that caregivers often live in a state of perpetual uncertainty. They never knew what to expect next in terms of their loved one's behavior or health:

"I go to the room. She's like, she has removed all her clothes. Everything is on the ground. She's on the bed and she's urinated everything early in the morning. Don't know when it has happened. That, that was the toughest thing which I've seen in anybody" (P2, Personal Communication, 2023).

Along with the uncertainty, the caregivers witnessed their loved ones' cognitive and functional deterioration. They often felt despair, frustration, and helplessness, which were worsened by the aggressive, wandering, and agitated behaviors displayed by the care recipients. Participants have mentioned various emotional challenges:

"It is scary because, uh, at least if it was a sudden death, we would've accepted it. But suffering daily, it's, it's not acceptable, because we are seeing him shrinking. Like, he was huge. We are seeing him struggle in front of our eyes now. That's really, sometimes it's too hurting"(P3, Personal Communication, 2023).

According to Kubler-Ross, denial reflects the initial difficulty caregivers may have in accepting the diagnosis and progression of Alzheimer's disease in their loved ones (Tyrrell, 2023). Caregivers found it difficult to accept the reality of the disease, which caused them to go through a phase of denial where they may minimize the severity of the ailment or cling to the hope that things will get better. Participants have discussed how this denial phase impacted their ability to provide appropriate care and support.

“After two and a half years, there was more of a problem, like, you know, uh, physical, mmm, started deteriorating. Like, uh, she didn't have control over her bowel movements. I couldn't accept it. I wouldn't believe it. I couldn't understand and because I have not seen anybody coming through this, the family, or I have not seen it (P2, Personal Communication, 2023).

Sometimes, caregivers reported putting the care recipient's needs before their own, sometimes to the detriment of their own physical, emotional, and social requirements. This also includes losing oneself during this process, as also mentioned by a participant:
“My life was revolving around her. I did not exist for myself because I was, I didn't, in my list of things to do in a day, I didn't even, I didn't have a place in the list actually. After everything was over, kuch time bacha toh mai hoon, nahi toh mai nahi hoon” (P8, Personal Communication, 2023).

Another interesting finding was that the male caregivers reported how the intense demands of caregiving, coupled with emotional exhaustion, sometimes lead to their own forgetfulness regarding tasks, appointments, or even self-care. This revealed the extent to which caregivers immerse themselves in their caregiving roles, often at the expense of their own well-being and cognitive functioning.

“So, I tend to forget small things. For example, uh, if I want to give water to my father, i will give it to my mother. Like, it'll not happen one time. It has happened like last 10 times. it tends to happen like, uh, when you are doing so much and you will tend to forget some small things” (P9, Personal Communication, 2023).

Theme 2: Caregiving as a Transformative Journey

The second global theme "Transformative Journey of Caregiving" emphasizes how caring for a loved one with Alzheimer's disease causes the caregivers themselves to undergo significant personal transformation and growth (Mishra et al., 2023). It captures the profound and multifaceted nature of caregiving. The caregivers' emotions in this situation affect how they regard themselves, their relationships, and their worldview. For example, as the caregivers went through this process of caregiving, they mentioned accepting the situation and the person. Often, this acceptance was described to be emotionally challenging for them.
“So many things happen. you feel very, very confused about what's really happening? How? What is this? Uh, I would say this is very shocking. I would say not in a positive sense, but how this life is. So you get how it is, ki after all, you have to accept it.These are the challenges as well, but you have to accept it” (P9, Personal Communication, 2023).

While providing care, the caregivers found fulfillment and meaning, which encouraged them to continue providing care despite emotional challenges. Some of the participants reported how they felt more calmer than before:

"I think I've become more calm and definitely brought in the anger. Everything is, you know, I can say almost. Personally, I can say no anger towards anything after seeing her if this is going to be the stage in life "(P2, Personal Communication, 2023).

In these situations, caregivers are aware that looking after themselves is not selfish but rather necessary for them to be able to care for their loved ones effectively. Equal importance to self, highlighted the caregivers understanding of the need to balance their needs and well-being and the caregiving obligations.

"And now I just think that I should be happy and she should be happy and we all have to be, you know, at some particular so that I mean I don't want, you know, to, so my, I mean, I have to keep myself also in proper frame of mind because if I am not well, then how will I be able to take care about these (P4, Personal Communication, 2023).

At the same time, they mentioned the importance of being fully present in their interactions with their care recipients. This shift allowed them to let go of overwhelming worries about the future progression of the disease and instead immerse themselves in the immediate experiences they share with their loved ones:
"So, today you can be anything you can, have you, you can have much, you can have anything finally you don't have anything that's what I realized. Now, my thing in life is anybody asks for help, just to help, just spend, move it on. Be happy as much as you can, you know, you don't know what comes (P2, Personal Communication, 2023).

Theme 3: Gendered experience in caregiving

While providing care to their loved ones, caregivers often go through a host of emotions, an emotional rollercoaster. Often, the experiences of males and females are pretty different (Hossain et al., 2019). There are certain aspects of caregiving that both male and female caregivers go through in general. This is irrespective of the domains of caregiving experiences.

"That was a big task for me because considering her age and her ailment and everything, it was very difficult. Initially, I could manage, uh, manage, uh, by just taking that time. She was not so bad. But, uh, slowly she progressed into all this and it was a very serious, uh, this, I couldn't leave her alone" (P7F, Personal Communication, 2023). He was not eating food and he was saying something else. He was taking the names of those who passed away. So, we could not handle it properly in four to five days, In these situations, sometimes we left like that, we can't do anything" (P10M, Personal Communication, 2023).

Regardless of gender, caregivers face a decrease in their usual social interactions due to the demands of their caregiving responsibilities. Caregivers emphasized how caring for a loved one can affect a caregiver's capacity to maintain connections, participate in social activities, and engage in social gatherings or events. They could, therefore, have less time and energy to devote to socializing with friends, family, and peers.

"I cut off from the social circle. Like I can't go anywhere else" (P7F, Personal Communication, 2023). I don't go, going to the college because I'll go, who will take care of her because all are going to the work and also so I stay with her home" (P9M, Personal Communication, 2023).

Similarly, certain aspects were gender specific. For example, this is a distinctive characteristic found among male caregivers. These caregivers frequently took a carefree outlook on life, which affected how they approached juggling their caregiving obligations with other elements of their lives. The carefree attitude of male carers stands out as a distinctive viewpoint that affects how they negotiate the difficulties of caregiving:
"Being my mother, uh, I could deal with her in a certain way. I could be firm with her. I can shout at her also if needed. I would be as carefree as possible in dealing with her, because I realized that she's not doing it purposefully. So, I used to resort to humor as the best way of relieving the, you know, the situation at a particular time" (P11M, Personal Communication, 2023).

Forgetfulness was another specific challenge that emerged from the unique demands and experiences of male caregivers.

"I remember I had to give her breakfast. I forgot that oats had to be boiled or cooked. So, I just mixed milk and the oats powder, put some sugar in it, and gave it to my mother. And, uh, she had it, she didn't say anything. And I realised, oh, this is not how it should be. It has to be cooked. But I was very sad that my mother actually did not even realize that it was not cooked" (P10M, Personal Communication, 2023).

Female caregivers frequently reported showing empathy for others and have had an awareness of their suffering. Recognizing the emotional needs and problems of the people they care about is another example of this empathy.

"It's not because she's my husband's mother. It's not because I have been with her for so many years. I'm not obliged. I would do this for any human being in her place" (P8F, Personal Communication, 2023).

Female caregivers also reported embracing aging/illness as a natural part of life and come to terms with it. This also shows how female caregivers go through the psychological journey of caregiving, highlighting their ability to face challenges with a sense of acceptance and commitment:
"So many things happen. you feel very, very confused about what's really happening? How? How? What is this? Uh, I would say this is very shocking. I would say not in a positive sense, but how this life is. So, you get how it is, ki after all, you have to accept it. These are the challenges as well, but you have to accept it" (P9, Personal Communication, 2023).

Table 2 Main themes, Sub-themes

Main Themes	Sub Themes
The complex terrain of caregiving	Adapting to Behavioral Challenges Emotional Struggles Denial Personal Sacrifice Basic forgetfulness

Main Themes	Sub Themes
Caregiving as a Transformative Journey	Acceptance of Reality Finding Meaning and Fulfillment Equal importance to self Embracing the Present and Helping Others
Gendered experiences in caregiving	Dealing with uncooperative behaviour Reduced Social Interactions Balancing Needs & Responsibilities Carefree Approach Forgetfulness Empathetic Acceptance

DISCUSSION

The complex terrain of caregiving

This study was undertaken to understand Indian metropolitan family caregivers' lived experiences of individuals with Alzheimer's. To meet this objective, the findings reflected how the caregivers experienced their emotions and the sacrifices they endured, the role of caregiving on the caregiver's cognition, and the transformative change that enabled the caregivers to provide quality care despite their difficulties. At the beginning of their caregiving journey, caregivers confront a profound sense of denial in response to the diagnosis of Alzheimer's. In line with previous research by (Smith et al., 2019), the participants share comparable feelings. The study found that this initial response acts as a psychological coping mechanism for caregivers in dealing with the emotional distress brought about by the diagnosis. The cultural norms in Indian society, as highlighted by Vliet and colleagues (2011), further explain how they make it challenging for caregivers to acknowledge their loved one's cognitive decline. The participants' narratives align with the existing literature, underlining the significance of this initial phase of adapting to behavioral changes like resistance from the care recipient, continence management, and others. This adjustment often becomes challenging while balancing the other roles that they have. Research on role theory has highlighted the crucial role that caregivers play in the well-being of care recipients (Gérain & Zech, 2019). It has been observed that in India, taking on the role of a caregiver is not considered a change in role. As a result, many Indian caregivers may not realize the importance of learning caregiving skills or taking care of themselves. After interviewing several caregivers, it was found that the most common motivation for caregiving was a sense of duty or obligation, followed by affection for the person with Alzheimer's. Some caregivers became caregivers because no one else was available to do so. These findings are consistent with other studies conducted on Indian caregivers (Pinquart & Sörensen, 2006). However, the multiple roles caregivers play can have unintended consequences, such as increased parental burnout and having no time for their loved ones apart from the individual with Alzheimer's (Gérain & Zech, 2019). As time progresses, the participants grapple with emotional struggles that extend beyond denial, reminiscent of the findings in Simpson and Acton (2013). The behavioral concerns, along with cognitive challenges posed by Alzheimer's, become increasingly pronounced. These challenges make it all the more difficult for caregivers to balance their needs and responsibilities with the demands of caregiving (Gottschalk et al., 2021). Both male and female caregivers reported facing reduced social interactions, especially at the initial time of the diagnosis. During caregiving, the caregivers in the study reported minimizing their presence from the outside world and stopped participating in social interactions outside the house. In the Indian context, cultural expectations regarding familial duty and societal norms often intensify these emotional struggles (Narayan et al., 2015). One way to understand this is through Bronfenbrenner's ecological system theory to understand the impact of community and societal norms on emotional struggles. This theory proposes that individuals are influenced by multiple layers of their environment, including the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. According to Chandran and colleagues (2016), at the macrosystem level, the cultural and societal norms and values of the larger society can influence the experiences of patients and caregivers. In the context of India, societal expectations and community-based care both significantly influence the experiences of caregivers. These dynamics can result in an emotional toll, leading to reduced social interactions. Collectivist norms and community culture significantly impact caregiving experiences (Ng & Indran, 2021). The caregivers reported going through a period of personal sacrifice without knowing how to balance the responsibilities and manage the uncertainty. They often mentioned not having time for themselves as the task of caregiving was considered to be very intense.

Caregiving as a Transformative Journey

As the caregiving processed from the initial stages, many participants described their journey through Alzheimer's caregiving as leading towards the acceptance of the challenging reality and the person they are providing care for. This transition, as Yuan et al. (2023) have observed, is a pivotal aspect of their transformative journey. Caregivers reported coming to terms with the unyielding nature of Alzheimer's disease and crafting coping mechanisms to navigate this challenging terrain over time. With time, caregivers recognized the profound significance of their contribution to the well-being of the care recipient. The caregivers attributed different reasons for their shift towards caregiving, such as not wanting to see their loved ones suffer, not feeling guilty after the death of the care recipient, encouragement from their family members, and other intrinsic factors. This new-found understanding often acted as a potent motivator, inspiring caregivers to provide care with dedication and empathy. In Indian society, where caregiving is often seen as an expression of love and duty, this aspect holds even greater significance (Schulz, 2016). As the caregiving journey unfolds, caregivers learn to accord equal importance to their well-being, heeding the wisdom documented by Duxbury et al. (2017). Both male and female caregivers come to appreciate the imperative nature of self-care in ensuring their ability to provide sustained, high-quality care to their loved ones. In the Indian context, where the concept of self-sacrifice for family is deeply ingrained, this shift towards self-care represents a notable transformation. Ultimately, the participants, regardless of gender, arrive at a juncture where they not only embrace the present but also extend their support to others confronting similar challenges. This transformation signifies a move from initial resistance to a deep sense of compassion and acceptance, reflecting the conclusions drawn in Armstrong et al.'s (2020) research.

Gendered Experiences in Caregiving

In addition to the above themes discussed, it's essential to delve into the gendered experiences of caregivers in Alzheimer's caregiving within the context of Indian society. Both male and female caregivers face commonalities in their experiences, such as physical exhaustion and dealing with uncooperative behavior from Alzheimer's patients, as discussed earlier. However, the current study has found some distinct gendered experiences as well.

Male caregivers tend to adopt a somewhat carefree approach to caregiving, possibly influenced by traditional gender roles and societal expectations. However, the same was not the case with the female caregivers. They reported asking the "head of the house" to decide on the care recipient. However, some caregivers did mention having the authority to do what they wished. These findings reveal the ingrained patriarchal structure in India in the context of caregiving (Sharma et al., 2016). It is noteworthy that male caregivers have reported a higher incidence of forgetfulness while providing care, despite the fact that they had the support of their wives while providing care, unlike female caregivers who provided care alone.

According to research by Tyng and his colleagues (2017), emotional experiences can significantly affect cognitive abilities such as attention, memory, and decision-making. For example, when an individual experiences intense emotions such as stress, anxiety, or sadness, their ability to concentrate and recall information may be compromised. One of the male caregivers even reported giving his mother uncooked oats due to his forgetfulness resulting from exhaustion. The study found that male caregivers in India do not typically reduce their work hours or social interactions when caring for someone with Alzheimer's. They viewed it as usual to continue their regular activities while providing care with little difficulty. On the other hand, female caregivers had to cut down on all their work outside the home to align with cultural norms. Throughout the caregiving journey, male caregivers often provided care without accepting the diagnosis until the fourth stage of the disease. In contrast, female caregivers showed higher levels of empathy and acceptance throughout the journey. They also reported being more involved by educating themselves about the disease. The findings show how, with time, they developed a deep emotional connection with the care recipient and better understood their needs.

However, female caregivers also reported experiencing a loss of self, with little time to devote to themselves. Skaff and Pearlin's (1992) study on role engulfment and the loss of self shows that Alzheimer's caregivers often experience identity loss. This phenomenon is more common among spouses and female caregivers. Those who experienced a more significant loss of self tended to have fewer social interactions and roles outside their caregiving responsibilities. These gendered experiences within Alzheimer's caregiving in India highlight the complex interplay between societal norms, gender roles, and individual coping mechanisms. While there are similarities, recognizing the distinct experiences of male and female caregivers is essential to understanding the multifaceted nature of Alzheimer's caregiving within the Indian cultural context.

Summary of New Findings

The findings in this study shed light on the complex and transformational path taken by family caregivers who care for people with Alzheimer's in the social and cultural context of Indian society. However, the study findings highlight several issues that are unique to Alzheimer’s disease in India. Firstly, as they accept the diagnosis, the caregivers initially struggle with a strong sense of denial; this psychological defense helps them deal with the subsequent emotional upheaval. This initial response is exacerbated by cultural conventions that make it difficult for caregivers to accept their loved one's cognitive deterioration.

In providing care, caregivers—especially women—face intense emotional challenges, frequently sacrificing their personal lives and feeling a loss of identity. Gender roles are crucial in this encounter, with male caregivers generally taking a more relaxed approach due to social expectations.

On the other hand, female caregivers demonstrate higher levels of acceptance and empathy. Balancing personal demands with caregiving obligations can be challenging, especially for female caregivers who provide round-the-clock care. Caregiver transformation occurs at the end of the caregiving journey, which takes people from initial denial to profound acceptance and a greater sense of purpose in their duties. Together, these results show the complicated nature of Alzheimer's caregiving in India, highlighting the emotional difficulties and transforming change that they go through. Thus, current descriptive findings can be used to guide other caregivers of individuals with Alzheimer's, including topics relating to symptom changes when approaching different stages and strategies to have a balance between self and other responsibilities

Implications

The results of this study have important implications. They first emphasize the need for more awareness and education regarding Alzheimer's disease and caregiving in India. Early phases of the journey are marked by a strong sense of denial and emotional problems for caregivers, highlighting the urgent need for support networks and early intervention. Second, it is essential to recognize the significance of gender dynamics in caregiving. To customize support and treatments to each gender's specific requirements, it is imperative to recognize these disparities. The unique obstacles that male and female caregivers in the Indian setting experience should be considered when designing caregiver support programs and initiatives. The research also highlights the possibility of community-based treatments and support groups to help caregivers on their transformative journey. This suggests that more community-based tools and interventions should be created and promoted to support caregivers during their difficult caregiving journey and raise the standard of care for individuals with Alzheimer's.

Limitations and Future Directions

It is important to note that this study has a few limitations that must be considered. Firstly, the sample size is relatively small, which means that the findings may not be applicable to all Indian metropolitan family caregivers. In future the researchers can include a larger sample for generalizing. Additionally, since caregiving experiences can change over time, a longitudinal approach could provide a more comprehensive understanding of these dynamics. Furthermore, cross-cultural studies across different regions of India have the potential to reveal regional variations and cultural norms challenges. Therefore, the study's findings can greatly support and expand earlier studies. the potential to reveal regional variations and cultural norms challenges.

CONCLUSION

This research highlights the complex nature of Alzheimer's caregiving among Indian metropolitan families. Caregivers initially grapple with denial, driven by societal standards, but eventually go through a transformational path of acceptance and awareness of the significance of their caregiving role. Despite differences in caring styles due to gender, both male and female caregivers place a high importance on self-care and interpersonal support, improving the quality of care given to people with Alzheimer's. However, there were significant differences found as well. This study underscores the necessity for tailored interventions that consider these challenges.

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