

“It’s Not Just Care, It’s Our Life”: A Qualitative Study of Caregiving Relationships Between Young Adults with Mobility Disabilities and Their Parents in India

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Abstract: Caregiving relationships between young adults with mobility disabilities and their parents are often examined through the frameworks of burden, dependence, and/or role strain, overlooking the relational and emotional processes through which care is experienced by both parties. This qualitative study explores caregiving as a psychological and relational experience shaped by emotional reciprocity, negotiation, and shared meaning within the Indian sociocultural context. Using Interpretative Phenomenological Analysis (IPA), in-depth semi-structured interviews were conducted with six participants (three parent-child dyads). The analysis yielded five interconnected themes: caregiving as moral identity and relational interdependence; emotional withholding as a form of care and reciprocity; negotiated autonomy within close relationships; systemic inaccessibility as a shared burden; and the redefinition of normalcy through adaptation, companionship, and shared joy. Findings highlight caregiving as a co-constructed relationship rather than a unidirectional task, where autonomy, identity, and emotional well-being are continuously negotiated.

Keywords: caregiving relationships, mobility disability, family caregivers, young adults, interpretative phenomenological analysis

Family caregiving relationships have long been a focus of psychological inquiry and are most often examined through constructs such as caregiver burden, stress, coping, and mental health outcomes (del-Pino-Casado et al., 2021; Liu et al., 2020). This body of literature has been instrumental in highlighting the demands of caregiving and the risks it poses to caregiver well-being. However, by largely conceptualizing care as a set of instrumental tasks performed by one individual for another, this framework overlooks the relational, emotional, and developmental dimensions of caregiving. Such dimensions become especially salient within family contexts, where care is embedded in long-standing relationships, shared histories, and ongoing emotional bonds (Blinka et al., 2022; Zarzycki et al., 2022).

These relational dynamics are particularly pronounced in caregiving relationships between young adults with disabilities and their parents. Unlike caregiving in later life, these relationships unfold alongside the development of young adulthood, including identity formation, autonomy negotiation, and future planning (Bruhn & Rebach, 2014; Taylor et al., 2019). Parents often continue in caregiving roles well into their child’s adulthood, resulting in relationships that are simultaneously parental, practical, emotional, and

interdependent. Therefore, caregiving extends beyond physical assistance but encompasses emotional attunement, shared decision-making, and mutual adaptation. Emotions such as love, fear, guilt, trust, and obligation play a central role in shaping how care is provided, received, and negotiated over time (Bassola et al., 2020; Huo & Kim, 2022).

Emerging qualitative research has increasingly drawn attention to the emotional complexity of such caregiving relationships. Rather than being unidimensional, caregiving is often experienced as ambivalent and layered. Caregivers may describe closeness, fulfillment, and a sense of purpose alongside fatigue and frustration, while care-recipients may experience gratitude and safety alongside guilt, restraint, or a desire for greater independence (Huo & Kim, 2022; Zarzycki et al., 2022). These findings challenge dominant caregiver-centric narratives by emphasizing caregiving as a dyadic process in which both individuals actively shape the emotional climate of the relationship (Lyons et al., 2002). Despite this shift, much of the existing literature continues to privilege caregiver perspectives, often positioning care-recipients as passive dependents and underexplores their emotional and relational experiences (Jeyathevan et al., 2019; Kuharic et al., 2024).

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For young adults with mobility disabilities, caregiving relationships are often long-term and deeply embedded in everyday life. Assistance with activities of daily living, transportation, and access to education and/or healthcare require sustained parental involvement, reinforcing close interdependence within the family (Tough et al., 2019). While such involvement can foster emotional closeness and a sense of security, it can also complicate the processes related to self-definition, decision-making, and perceived independence. These tensions are often intensified in environments marked by limited physical accessibility and pervasive social stigma, where families must continually negotiate both care needs and external barriers (Green, 2007; Murphy et al., 2006).

Cultural context further shapes how caregiving relationships are understood and enacted (Pharr et al., 2014). In collectivist societies such as India, family caregiving is commonly framed as a moral obligation and an integral component of familial identity rather than a negotiable role (Chakravarti, 2008). Caregivers may internalize caregiving as an expression of duty or devotion, while expressions of emotional strain, resentment, or relational tension may be muted to preserve family harmony (Devassy et al., 2021). At the same time, inadequate accessibility, limited institutional support, and widespread stigma surrounding disability place additional pressures on families, situating caregiving within broader systems of structural constraint rather than solely within interpersonal relationships (Chakravarti, 2008; Devassy et al., 2021).

Despite growing global attention to family caregiving, notable gaps remain in the literature. Research has predominantly focused on caregiving for older adults or individuals with intellectual and developmental disabilities, with comparatively less attention given to young adults with physical or mobility disabilities (Jeyathevan et al., 2019; Roth et al., 2020). Moreover, many studies continue to examine caregiving outcomes at the individual level, rather than attending to the relational processes through which caregiving is emotionally negotiated by both caregivers and care-recipients (Lyons et al., 2002). These gaps are particularly pronounced in the Indian context, where culturally grounded psychological research centering on disabled young adults' experiences of caregiving remains limited.

Responding to these gaps, the present study explores caregiving relationships between young adults with mobility disabilities and their parent caregivers in India. It centers both caregiver and care-recipient perspectives to examine caregiving as a relational and emotionally negotiated experience by illuminating how caregiving relationships shape everyday life, identity, and well-being within specific cultural and structural contexts. The primary research question was: What are the nuanced aspects of personal relationships between young adults with mobility disabilities and their family caregivers (parents) beyond caregiving duties, and how do these relationships influence the overall experiences of both parties?

Method

Study Design

A qualitative, specifically the Interpretative Phenomenological Analysis (IPA) methodology, was used for its capacity to explore lived experiences in depth, offering insight into how individuals make sense of personal and relational phenomena (Smith, 2016; Pietkiewicz & Smith, 2014). IPA centers on the subjective experiences of participants, situating their meaning-making within broader relational and sociocultural contexts. It was suited to this study, which sought to amplify the often-marginalized voices of young adults with mobility disabilities and their caregiver parents in India. Through this approach, the study sought to interpret not just what caregiving relationships looked like, but how they were felt, navigated, strained, and sustained.

Participants

This study included six participants, with three dyads: a young adult with a mobility disability and their primary caregiver parent. Inclusion criteria for the care-recipients were: (a) between the age of 18-28, and (b) have a mobility disability that restricts overall body movement. Inclusion criteria for family caregivers were: (a) being the primary caregiver parent of the care-recipient, and (b) provided care for the care-recipient in most activities of daily living (ADLs). Purposive sampling was used to select participants who offer insight of their unique experience. Participants were recruited through personal contacts and

snowballing. Participant demographics are presented below.

Table 1. Caregiver-Care-Recipient Demographics

Dyad	Code (Caregiver-Care-recipient)	Age (Caregiver/Care-recipient)	Gender (Caregiver/Care-recipient)	Relationship	City of Residence
1.	AVP-AP	51/21	Female/Female	Mother-Daughter	Gurugram, Haryana /Hyderabad, Telangana*
2.	RM-KM	50/25	Female/Female	Mother-Daughter	New Delhi
3.	SK-SS	58/28	Male/Male	Father-Son	Gandhinagar, Gujarat

* This dyad divides time between two cities. While the family home is located in the first city, the caregiver and care-recipient spend significant time in the second city due to the care-recipient's employment. They regularly return to the first city for family time and extended stays, during which the care-recipient works remotely.

Dyad 1: AP & AVP

AP is a 21-year-old woman with Spinal Muscular Atrophy Type 2. AP is employed, holds a bachelor's degree, and lives with her family caregiver. Her functional status involves dependence on most ADLs, transportation, and access to health services. AP also receives secondary caregiver support. Her caregiver, AVP, is a 51-year-old woman and AP's mother. AVP is employed full-time, has a master's degree, and has been providing care for over 21 years. She offers medical, ADL, transportation, and emotional care, and also supports aging parents, highlighting her multi-generational caregiving role.

Dyad 2: KM & RM

KM is a 25-year-old woman with Arthrogryposis Multiplex Congenita, a congenital mobility condition. KM is employed, has a master's degree, and resides with her family. Her functional needs include ADLs, transportation, and moderate support for career and healthcare access. She does not receive external support services. Her caregiver, RM, is a 50-year-old woman and KM's mother. RM is employed full-time, holds a bachelor's degree, and has been KM's caregiver for 25 years. RM also supports aging parents.

Dyad 3: SS & SK

SS is a 28-year-old man diagnosed with Facioscapulohumeral Muscular Dystrophy, a progressive neuromuscular condition. SS is pursuing his doctoral degree and experiences functional limitations in mobility, emergency preparedness, and leisure/social participation. He lives with his parents and does not have additional external support services. SK is a 58-year-old man and SS's father. SK is retired, holds a master's degree, and has provided care for six years. His support includes medical assistance, financial management, emotional support, and ADLs.

Procedure

The study was approved by both authors' institutional review board. After obtaining informed consent, interviews were conducted individually with caregivers and care-recipients via a HIPAA-compliant Zoom platform. Data were collected using semi-structured interviews. The interview protocol was developed through an iterative process involving a review of relevant literature and ongoing reflexive engagement. Open-ended questions guided the interviews, with follow-up prompts to address topics that did not emerge organically. Each interview lasted approximately 60 minutes and was audio-recorded. To avoid distress and ensure accessibility of the interviews, participants were given the option to take breaks

Data Analysis

Interviews were transcribed verbatim, with identifiable information removed for analysis. Consistent with the idiographic and phenomenological orientation of IPA, each interview underwent an in-depth, case-by-case analysis (Smith, 2016). Data were analyzed using the seven-step IPA process (Charlick et al., 2016; Smith et al., 2009).

First, transcripts were listened to, read, and re-read to facilitate immersion in the data. Second, initial noting was conducted through detailed notes focusing on descriptive, linguistic, and conceptual elements. Third, emergent themes were developed by identifying meaningful patterns within sections. Fourth, connections across emergent themes were examined and organized into higher-order categories. This process was repeated for each transcript, with deliberate bracketing of earlier themes. Subsequently, patterns across cases were identified to highlight shared experiential qualities and points of divergence. Finally, interpretations were deepened through engagement with existing literature.

Reflexivity and Researcher Positionality

This topic holds deep personal significance for the first author beyond its academic dimensions. As a young adult living with a mobility disability who relies on her parents for daily support, she brings a lived understanding of the relational dynamics within caregiving. These experiences shaped how she approached the study, encouraging close attention to the emotional nuances and the layered meanings participants described in their caregiving relationships. Her epistemological orientation aligns with narrative and constructivist perspectives, which view knowledge as emerging through lived experience and meaning-making. During the IPA process, her experiences informed how she listened to participants' stories, sensitizing her to moments of vulnerability, ambivalence, and relational complexity. At the same time, she engaged in reflexive practice to remain attentive to how her positionality could shape interpretation and analytic decisions. As a disabled researcher, she occupies a space that blurs traditional boundaries between participant and scholar. This perspective allowed her to approach the research with both analytic rigor and relational sensitivity while remaining mindful that participants' experiences, though resonant, remain distinct from her own.

The second author is the first author's academic advisor. She has extensive research experience in the reciprocity and psychosocial adjustment of caregivers and their family members with disabilities. She offers a researcher's perspective, balancing the first author's stance. While this researcher does not share lived experience as a caregiver of a person with a disability. Awareness of this positional difference informed ongoing reflexivity throughout the study. Her additional training in qualitative methods and prior experience conducting research with community populations supported ethical and respectful engagement with participants. Throughout the analytic process, attention was given to critically examining assumptions and considering how the researcher's perspectives might shape interpretation, helping ensure that participants' perspectives remained central to the analysis. Credibility was enhanced through close engagement with the first author's in-depth discussion about participants' narratives and the inclusion of illustrative quotations to represent caregivers' perspectives.

Results

Results from the three dyads revealed five interconnected themes that illuminate caregiving as a relational and emotionally negotiated experience. These themes captured how caregiving relationships are shaped by love, responsibility, negotiation, structural constraints, and shared meaning across everyday life.

Theme 1: "It's Not a Burden, It's Who We Are" – Caregiving as Moral Identity and Relational Interdependence

Caregivers consistently described caregiving not as an obligation or burden but as an integral part of who they are as parents. Care was framed as an extension of love, moral responsibility, and personal identity. Parents emphasized gratitude and meaning rather than sacrifice, often drawing on cultural and spiritual language to articulate their role.

AVP shared: *"I'm the blessed and happiest mother to have her in my life... I couldn't imagine my life without her."*

Even when describing extensive physical and logistical care, caregivers emphasized attentiveness and presence rather than effort or strain. SK similarly stated:

“It’s not a challenge. It’s our pleasure to serve,” reframing caregiving as dignified service rather than hardship.

This framing fostered deep relational interdependence. Caregivers and care-recipients described relationships marked by transparency, mutual influence, and emotional closeness. AVP noted:

“We are very, very open to each other... I’m not shy to share my weak side.”

These dyads demonstrated that caregiving was not static but evolved into a reciprocal relationship where both individuals shaped each other’s growth and self-understanding.

Theme 2: “Holding Back, Holding On” – Emotional Withholding as a Form of Care and Reciprocity

Care-recipients frequently described consciously withholding emotions, frustrations, or needs to protect their caregivers from additional strain. This emotional restraint emerged as a form of reciprocal care, shaped by awareness of caregivers’ efforts and limitations. AP shared

“I never say anything to her even if I want certain things a different way... If I ever did, I would feel very guilty because I know she’s doing a lot.”

Others described modifying their routines to minimize perceived burden, such as staying out longer to avoid repeated caregiving demands or limiting requests for help. KM, similarly shared how she consciously structures her outings and interactions to reduce the burden on her caregivers, even when it means minimizing her own spontaneity or emotional needs:

I find it very weird when my non-disabled friends tell me that, you know, you have to just come out for one hour... I mean, that’s no point... I should be out for longer so that at least they [my parents] also get some time to do something.

These narratives revealed that care-recipients engaged in significant emotional labor, managing guilt and self-restraint to maintain relational harmony. Emotional withholding was not experienced as passivity but as an active strategy to preserve connection, reflecting a subtle yet powerful form of reciprocity within caregiving relationships.

Theme 3: “We Negotiate Everything” – Autonomy Within Close Relationships

Autonomy emerged as a negotiated, relational process rather than a fixed state. Caregivers expressed pride in their children’s independence while simultaneously experiencing fear related to safety, accessibility, and social vulnerability. Care-recipients, in turn, described balancing their desire for freedom with sensitivity to caregivers’ concerns. RM explained:

“My biggest fear is leaving her alone... I know how the world is.”

Despite this fear, she emphasized allowing her daughter to make important decisions related to education and daily life. Care-recipients described autonomy as something they actively worked toward through persuasion, compromise, and adaptability. SS stated:

“It’s about who convinces the other first... It’s like a 50-50 thing.”

These participants described creative compromises, such as caregivers staying physically nearby but not directly involved, allowing care-recipients a sense of independence while maintaining reassurance. These highlighted autonomy as relationally scaffolded, achieved through trust, negotiation, and emotional attunement rather than separation.

Theme 4: “The World Is the Problem, Not Us” – Systemic Inaccessibility as a Shared Burden

Across all dyads, participants emphasized that the most significant challenges in caregiving arose not from disability itself but from systemic barriers and social inaccessibility. Caregivers described frequent encounters with inaccessible infrastructure, bureaucratic indifference, and lack of disability awareness, which positioned them as constant advocates.

AP recounted having to argue with authorities when her daughter was assigned an inaccessible examination center despite disability accommodations.

“Unfortunately, even for her engineering entrance exam...despite applying in the “Physically Handicapped” category, the center was allocated on

the first floor without a lift. So I had to go to headquarters, as no one would pick up my calls or respond to emails, request them for the center on the ground floor. I had an argument with the person there. Because he thought, surprisingly, these people who sit in such places...he said physically handicapped means "ki aap ka haath kat gaya hai" (that your hand has been amputated)...I was like...[you don't know]...neurological conditions are also [physical disabilities]..., I had to tell him all these things and made my center changed. Sometimes you have to go beyond just simple explanation, because people don't understand it...like a fighting mood."

KM, shared:

"In India, accessibility is the biggest problem... at home we manage, but outside it becomes impossible."

These systemic failures restricted family activities, social participation, and emotional ease. Thus, caregiving extended beyond the private sphere into continuous negotiation with external systems. Both caregivers and care-recipients experienced frustration and fatigue related to these barriers, reinforcing a shared sense that caregiving strain was structurally produced rather than relationally driven.

Theme 5: "This Is Our Normal Now" – Shared Joy, Companionship, and Redefining Everyday Life

Despite challenges, participants described caregiving relationships as rich with companionship, humor, and shared joy. Families emphasized everyday moments, conversations, and rituals as central to their relationships. Caregiving was intertwined with friendship, intellectual exchange, and emotional safety.

AVP captured this in her reflections on the conversations she shared with her daughter, which spanned topics from movies and gender politics to social critique. For her, the most rewarding moments came not during major milestones, but in quiet, unhurried times where they simply lay next to each other and talked:

"When we both are lying down in the bed seeing each other and talking... any topic in the world... movies, society, women, mindset... that is the most rewarding moment for me."

Care-recipients similarly highlighted emotional acceptance, noting caregivers' unconditional support during moments of vulnerability, including identity disclosure. For AV, her relationship with her mother was also centered on emotional safety and acceptance. Whether it was her mother helping her wear a saree after returning from an international trip, or responding with compassion and openness when AV disclosed her sexuality, these moments became powerful reminders of trust and intimacy:

Despite suffering from jet lag. She had just returned from a foreign trip...she had had numerous sleepless nights, but the amount of effort and dedication she put in, to help me wear a saree, not a very disability friendly garment...Caregiving when it comes to just wearing a saree sounds very mundane...when it is compared to caregiving in the hospital which I have been to multiple times and when it comes to other basic things that are life-changing experiences. But, caregiving even for something as simple as wearing a saree is something that I love my mother for.

Other dyads similarly described joy not in grand gestures, but in the ordinary and the shared. RM spoke fondly of making jokes and memes with her daughter, even about disability, emphasizing a lighthearted dynamic that transformed potentially sensitive subjects into spaces of laughter and connection:

"We make jokes... even about disability... and chill. We don't feel like we have to avoid anything. Sometimes, she posts my memes on social media too."

Across the narratives, what emerged was not a singular definition of "normal", but a quiet, continuous process of redefining what life looks like under the conditions of care. Families spoke not of sudden transformations, but of gradual adjustments, silent compromises, and adaptive rhythms that reoriented their everyday lives.

Discussion

This study explored caregiving relationships between young adults with mobility disabilities and their parent caregivers in India, foregrounding caregiving as a psychological and relational experience rather than a unidirectional task. Through IPA, five interconnected themes revealed caregiving as emotionally reciprocal,

negotiated, and embedded within cultural and structural contexts. Collectively, the findings challenge dominant caregiving narratives that emphasize burden or dependency alone and instead position caregiving as a co-constructed relationship shaping identity, autonomy, and emotional well-being for both caregivers and care-recipients.

Across dyads, caregiving was framed as an extension of love, moral responsibility, and personal identity. Caregivers emphasized meaning, gratitude, and relational closeness rather than sacrifice, aligning with research in collectivist contexts where caregiving is understood as a moral duty and familial identity (Chakravarti, 2008; Devassy et al., 2021). However, this moral framing also obscured emotional strain, as caregivers often suppressed fatigue or ambivalence to preserve harmony and uphold ideals of selflessness (Tan-Ho et al., 2020).

Young adults actively engaged in emotional withholding, guilt management, and behavioral adjustment to minimize perceived burden on caregivers. This highlighted the emotional labor undertaken by care-recipients to maintain relational balance, challenging caregiver-centric models of care. Consistent with dyadic caregiving research, reciprocity was often enacted through silence, restraint, and accommodation rather than explicit exchange, underscoring caregiving as emotionally bidirectional even when practical care flowed primarily in one direction (Kuharic et al., 2024; Lyons et al., 2002).

Autonomy emerged not as an individual achievement but as a relationally negotiated process. Caregivers sought to support independence while grappling with concerns about safety, stigma, and inaccessibility. Care-recipients navigated these tensions through negotiation and adaptation, resonating with critiques of individualistic autonomy models and emphasizing agency as relationally situated (Green, 2007; Huo & Kim, 2022).

Notably, the most significant sources of strain stemmed from systemic barriers rather than the caregiving relationship itself. Inaccessible infrastructure, bureaucratic insensitivity, and limited disability awareness extended caregiving labor into ongoing advocacy, echoing research on structurally produced caregiving stress in low-resource contexts (Chakravarti,

2008; Liu et al., 2020). Participants resisted narratives framing caregiving relationships as inherently burdensome by locating strain within the external environment. Reforms that prioritize universal design, inclusive education, and accessibility legislation will not only ease caregiver strain but also expand opportunities for disabled youth (Ganjiwale et al., 2016; Gokhale, 2021).

Despite these challenges, caregiving relationships were marked by shared joy, companionship, and ongoing adaptation. Families redefined routines and expectations, articulating disability not as disruption but as part of everyday life. Joy and closeness coexisted with difficulty, reinforcing caregiving as an emotionally complex lived experience (Blinka et al., 2022; Zarzycki et al., 2022). Overall, the findings support a relational understanding of caregiving that integrates emotional reciprocity, negotiated autonomy, and cultural meaning. For psychological research and practice, this study underscores the need to move beyond individual-level models toward relational frameworks that situate caregiving within broader sociocultural contexts.

Limitations and Future Directions

Several limitations should be considered when interpreting the findings. The sample size was small and intentionally selected to align with the idiographic focus of the IPA approach. While this allowed for in-depth exploration of individual experiences, it limits generalizability. Additionally, participants were recruited through personal networks and snowballing, which may have resulted in a sample with relatively strong relational bonds or reflectivity.

The researcher's positionality as a disabled individual with caregiving experience likely facilitated rapport and depth of disclosure but may also have influenced interpretation despite reflexive practices. Interviews were conducted online, which enhanced accessibility but may have constrained non-verbal communication or emotional expression.

Future research could extend this work by examining caregiving relationships across a wider range of family structures, including siblings, extended kin, or non-familial caregiving. Temporal and follow-up studies, in particular, could deepen understanding of how caregiving

and care-receiving perspectives evolve over time. As young adults with disabilities develop greater autonomy, educational and vocational roles, and independent identities, relational dynamics with caregivers may shift in meaningful ways. At the same time, aging caregivers may renegotiate their sense of identity, attachment, expectations, and roles within the relationship. Examining these evolving dynamics across the lifespan could illuminate how caregiving relationships are sustained, redefined, or transformed as both parties move through different developmental and life stages. Caregiving across different cultural and socioeconomic contexts within India could also be explored. Finally, comparative cross-cultural studies may help clarify how caregiving relationships are shaped by differing cultural norms, policy environments, and support systems.

Conclusion

This study contributes to psychological understandings of caregiving by foregrounding caregiving relationships between young adults with mobility disabilities and their parent caregivers as emotionally reciprocal, negotiated, and culturally embedded experiences. Findings highlight caregiving as a relational process shaped by love, responsibility, negotiation, and shared meaning. It also challenges unidirectional models of care and emphasizes the emotional labor carried by all parties. In India, caregiving relationships are shaped not only by family dynamics but also the broader structural and cultural forces, including inaccessibility and moral expectations surrounding care. These findings underscore the need for relationally informed and culturally responsive approaches to caregiving. A shared emotional landscape can lead to more inclusive and effective interventions honoring the realities of disabled individuals and their families.

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