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Understanding Caregiving Beyond Burden: Needs, Coping, Support, and Well-Being

Aruna Maruthi

Abstract: ***Family caregiving can involve substantial physical, emotional, social, and financial demands, and caregiver burden has consequently received considerable attention in research. While this focus is important, burden alone may not fully represent the caregiving experience. Caregivers differ in their needs, coping responses, available support and resources, and experiences of well-being, and difficult and positive aspects of caregiving may coexist. This narrative review examines caregiving through four interconnected dimensions: caregiver needs, coping, social support and resources, and caregiver well-being and life satisfaction. Relevant literature, with particular attention to Indian caregiving contexts, was reviewed to examine how these dimensions contribute to a broader understanding of caregiving beyond burden alone. The review suggests that recognising a caregiver's need is distinct from having the resources to meet that need, and that difficulty accessing appropriate support should not automatically be interpreted as inadequate coping. It also highlights that meaning, satisfaction, competence, connection, or personal growth may coexist with strain, but should neither be assumed nor prescribed as expected outcomes of caregiving. The review therefore emphasises the importance of understanding what is difficult for the individual caregiver, what is needed, what coping resources are already available, and what support is missing before considering intervention. A practical Caregiver Reflection and Support Guide is proposed to help caregivers identify these dimensions and consider personally relevant, evidence-informed responses. The paper advocates a need-responsive, culturally sensitive approach that acknowledges caregiver burden without allowing burden alone to define the caregiving experience.***

Keywords: caregiving; caregiver needs; coping; social support; caregiver well-being; positive aspects of caregiving; caregiver support

1.Introduction

Caregiving is a complex human experience that can influence the physical, emotional, psychological, and social well-being of the caregiver. Research has extensively documented caregiver burden, stress, fatigue, emotional distress, and the challenges associated with prolonged caregiving responsibilities. These concerns are important and cannot be minimized. However, viewing caregiving primarily through the lens of burden may not fully represent the diversity of caregivers' experiences (Lillekroken et al., 2024; Quinn & Toms, 2019).

Caregivers differ in the demands they face, the resources available to them, the support they receive, the ways in which they cope, and the meaning they attach to their caregiving role. The same caregiving responsibility may therefore be experienced differently by different individuals and may even be experienced differently by the same caregiver at different stages of the caregiving journey. Difficulty and positive experience need not be mutually exclusive. A caregiver may experience exhaustion, worry, or strain while simultaneously experiencing affection, responsibility, connection, satisfaction, competence, or a sense of meaning (Kong et al., 2026; Mishra et al., 2023; Quinn & Toms, 2019).

An important aspect of understanding caregiving is therefore the recognition of caregiver needs. The presence of a need does not automatically indicate poor coping. Rather, recognising one's needs and responding appropriately to them may itself form part of adaptive coping. A caregiver who recognises exhaustion and seeks respite, identifies a lack of information and seeks guidance, or acknowledges emotional distress and seeks psychological support is actively responding to the demands of caregiving (Creado et al., 2006; Lillekroken et al., 2024).

However, recognising a need and having the resources to address it are different matters. A caregiver may recognise the need for respite but have no family member or service available to provide it. Similarly, financial, healthcare, social, or practical difficulties cannot be adequately addressed through psychological coping strategies alone. It is therefore important to examine coping together with the personal, familial, social, and practical resources available to the caregiver (Lillekroken et al., 2024).

Coping may also involve the way in which caregivers understand and appraise their experience. Where appropriate, broadening awareness beyond burden alone may enable caregivers to recognise aspects of caregiving that are otherwise overshadowed by stress, such as personal strengths, contribution, connection, competence, purpose, or meaning. Such an approach does not suggest that caregivers should deny hardship or be encouraged to "think positively" in circumstances of genuine deprivation. Rather, it acknowledges the possibility that burden may be one dimension of caregiving without necessarily constituting the whole experience (Mishra et al., 2023; Quinn & Toms, 2019).

This distinction is particularly important when considering caregiver support. Intervention should arise from an identified need rather than from the assumption that every caregiver requires psychological intervention. Different needs require different responses. Practical difficulties may require practical assistance; exhaustion may require respite or redistribution of caregiving responsibilities; lack of information may require education; psychological distress may require appropriate psychological support; and, where relevant, difficulties in appraisal or meaning-making may benefit from interventions that encourage broader awareness and adaptive coping (Lillekroken et al., 2024).

Against this background, the present article examines caregiving through four closely related areas: the effects of

caregiving on caregivers' physical, emotional, and psychological well-being; the coping strategies used by caregivers, including recognition of needs and appraisal of the caregiving experience; the availability and role of social and other support resources; and their relationship with caregivers' overall well-being and life satisfaction. Through an examination of existing literature, the article seeks to identify areas of unmet caregiver need and consider practical, culturally sensitive, and evidence-informed approaches to caregiver support.

The purpose is not to replace the concept of caregiver burden with an exclusively positive interpretation of caregiving. Rather, it is to develop a more balanced understanding in which difficulties are acknowledged, needs are identified, available resources are considered, and the possibility of meaning, connection, competence, and well-being is not overlooked.

Rationale / Need for the Study

Family caregivers perform an essential role in supporting individuals who are ill, ageing, disabled, or otherwise dependent on assistance. While caregiving may arise from affection, responsibility, family relationships, cultural expectations, or personal choice, its demands can affect caregivers' physical, emotional, psychological, social, and everyday functioning. Understanding caregiver well-being therefore requires attention not only to the responsibilities involved in caregiving, but also to the needs caregivers experience, the ways in which they cope, and the personal, familial, social, and practical resources available to them (Lillekroken et al., 2024).

Research from India indicates that caregivers may experience unmet needs related to information, practical assistance, respite, emotional well-being, social participation, training, financial resources, and access to appropriate services. These needs are not uniform. Caregiving circumstances differ according to the condition and dependency of the care recipient, duration and intensity of care, family circumstances, available support, socioeconomic resources, and the caregiver's own physical and psychological condition. Consequently, caregiver support cannot be based solely on the assumption that all caregivers experience the same difficulties or require the same response (Lillekroken et al., 2024).

Coping forms an important part of this experience. It may involve managing practical demands, seeking assistance, mobilising social support, regulating emotional responses, and recognising and responding to one's own needs. Recognising a need for respite, information, assistance, or psychological support may itself be an important step towards adaptive coping. However, the ability to recognise a need does not guarantee that an appropriate resource is available. The interaction between caregiver needs, coping strategies, and accessible support therefore deserves particular attention (Creado et al., 2006; Kochhar et al., 2024).

Caregiving also cannot be understood adequately through burden alone. Indian and international research has identified positive caregiving experiences including satisfaction, personal growth, strengthened relationships, competence, meaning, and a sense of contribution. Such experiences do not negate genuine stress or hardship. Rather, positive and negative dimensions of caregiving may coexist. For some caregivers, broadening awareness of the caregiving experience beyond burden alone may therefore form part of coping and meaning-making, while for others the immediate priority may be practical assistance, respite, financial support, healthcare, or psychological care (Kate et al., 2013; Mishra et al., 2023; Quinn & Toms, 2019).

There is consequently a need for a balanced examination of caregiving that acknowledges burden while also examining caregiver needs, coping strategies, available support and resources, and overall well-being and life satisfaction. Such an understanding can contribute to caregiver support that is responsive to identified needs rather than based on a uniform assumption of caregiver burden.

The present review therefore examines existing evidence concerning caregiver needs, coping, support and resources, and well-being, with particular attention to the Indian context. It also considers how this evidence may inform practical, culturally sensitive and evidence-informed approaches to supporting caregivers while recognising both the challenges and the potentially meaningful dimensions of caregiving.

The rationale for this review is also grounded in an important recognition: many questions surrounding caregiving arise from caregiving as it is actually lived. Encounters with caregivers and accounts of caregiving experiences draw attention to differences in needs, coping, available support, relationships, responsibilities, and the meanings attached to the caregiving role. Such experiences do not constitute research evidence in themselves; rather, they generate questions that can be examined against existing evidence. In this sense, lived caregiving provides the questions, while research provides the means to examine and understand them systematically.

Research Gap

Caregiving research has established the physical, emotional and psychological demands associated with the caregiving role, and caregiver burden continues to be an important area of study. Research has also increasingly examined coping, social support, quality of life, unmet needs and positive aspects of caregiving. Indian studies have similarly contributed evidence concerning caregiver burden as well as positive caregiving experiences, coping, social support and quality of life across different caregiving populations (Kochhar et al., 2024; Lillekroken et al., 2024; Quinn & Toms, 2019).

The gap, therefore, is not an absence of research on these individual dimensions. Rather, there remains value in bringing caregiver needs, coping strategies, available support and resources, and well-being into a more connected understanding of the caregiving experience.

Studies are frequently situated within particular illnesses, caregiver groups or specific outcomes, while caregivers themselves differ considerably in the demands they face, the resources available to them, the ways in which they cope, and the meanings they attach to caregiving. A burden-centred understanding alone may consequently be insufficient to represent this variation.

There is also a practical need to translate this broader understanding into support that responds to the caregiver's identified circumstances and needs. Psychological strategies may be appropriate where emotional distress, appraisal or coping is the concern, whereas other caregivers may primarily require information, respite, practical assistance, financial or healthcare resources, or stronger social support. Recognition of positive aspects such as competence, satisfaction, connection, personal growth or meaning may contribute to well-being for some caregivers, but should not substitute for resources required to address genuine caregiving demands.

The present review addresses this need by examining caregiving through the interconnected dimensions of **needs, coping, support and resources, and caregiver well-being and life satisfaction**, while retaining caregiver burden as an important but not exclusive dimension of the caregiving experience. Particular attention is given to the Indian context and to the implications of existing evidence for practical, culturally sensitive and need-responsive caregiver support.

2.Literature Review

Caregiver Needs

Caregiving needs arise within the interaction between the demands of care and the caregiver's own physical, psychological, social and practical circumstances. Consequently, caregivers cannot be assumed to have identical needs merely because they occupy a caregiving role. The nature and intensity of care, the condition of the care recipient, available family and social support, access to services and the caregiver's personal circumstances may influence both the experience of caregiving and the assistance required.

Evidence from India demonstrates the diversity of such needs. A scoping review of 27 studies on family caregivers of people with dementia in India identified challenges related to caregiver burden, stress and health, together with inadequate information, insufficient training, limited respite care and gaps in community and home-based support. Caregivers particularly expressed needs for information about the illness and its prognosis, locally accessible and affordable services, respite care, skilled healthcare assistance and culturally appropriate support. Rural caregivers faced additional difficulties related to geographical access and availability of services (Lillekroken et al., 2024).

Caregiving circumstances may also influence psychological well-being and quality of life. In a study of 158 caregivers of people with schizophrenia in New Delhi, Kochhar et al. (2024) examined caregiving experience in relation to family functioning, coping, social support, psychological distress, quality of life, and spiritual and personal beliefs. More negative caregiving experiences were associated with greater psychological distress and poorer quality of life. The study also demonstrated that positive and negative dimensions could be identified within the caregiving experience, supporting a broader understanding than caregiver burden alone.

These findings suggest that caregiver needs may be informational, practical, financial, social, emotional or psychological and that the appropriate response depends upon the nature of the need. Information deficits may require education and guidance, while excessive practical demands may require assistance or redistribution of caregiving responsibilities. Financial difficulties require material responses, sustained exhaustion may indicate the need for respite, and significant psychological distress may require appropriate mental-health support. Thus, identifying the caregiver's actual circumstances and needs is an important precursor to determining appropriate support.

Coping in the Caregiving Experience

Caregivers employ a variety of cognitive, emotional and behavioural strategies to manage caregiving demands. These may include problem-solving, acceptance, seeking information or assistance, religious or spiritual practices, social-support seeking and different forms of cognitive or emotional appraisal.

Indian studies demonstrate that coping strategies are associated with caregiving outcomes, although the relationships are not necessarily uniform across circumstances. In a study of 100 caregivers of people with chronic schizophrenia, problem-solving and expressive-action coping were associated with lower caregiver burden, whereas fatalism and passivity were associated with higher burden. The study also demonstrated that caregivers experiencing apparently similar levels of patient impairment did not necessarily report similar levels of burden, suggesting the importance of individual appraisal and coping processes (Creado et al., 2006).

More recent Indian evidence further demonstrates the complexity of coping. Kochhar et al. (2024) found that denial/blame and seeking social support as coping strategies were associated with more negative caregiving experiences in their schizophrenia-caregiver sample, while overall measured social support itself was not significantly associated with caregiving experience. These findings caution against classifying a coping strategy as universally beneficial without considering the circumstances in which it is used.

Within the present review, **recognition of need is considered a potential precursor to adaptive coping**. Recognition that one is exhausted, inadequately informed, emotionally distressed or unable to manage particular responsibilities is not itself a coping strategy. However, responding to that recognition by seeking information,

requesting assistance, accessing professional support or arranging respite may constitute coping action. Importantly, recognition of a need does not guarantee the existence of an accessible resource. Where appropriate assistance is unavailable or unaffordable, continuing caregiver difficulty should not automatically be interpreted as ineffective coping.

Positive appraisal may constitute another resource within the coping process. In a qualitative study of 100 family caregivers of older adults from Prayagraj, Pune, Visakhapatnam and Guwahati, Mishra et al. (2023) identified caregiver attitude, care and compassion, roles and responsibilities, and beliefs and values as themes within positive caregiving. Meaningfulness, belongingness, personal growth and empathetic understanding emerged as factors contributing to positive caregiving experiences.

Earlier qualitative research among 20 female caregivers of relatives with cancer in India similarly identified religious beliefs and practices and positive appraisal of the caregiving role as important intrapersonal sources of strength. Family members, healthcare professionals and care recipients themselves were identified as interpersonal sources of strength, while participants also described positive moments and perceived personal changes during caregiving (Mehrotra & Sukumar, 2007).

Positive appraisal, however, should not be interpreted as requiring caregivers to view difficult circumstances positively. It may provide one psychological resource within caregiving, but it cannot substitute for practical, financial, healthcare or social resources where these are required.

Social Support and Caregiving Resources

Caregiving occurs within a social and material environment rather than in isolation. Family members, friends, neighbours, healthcare professionals, community organisations and formal services may provide different forms of emotional, informational, practical or financial assistance.

The Indian dementia literature demonstrates the importance of this wider environment. Lillekroken et al. (2024) reported needs for respite, locally available low-cost assistance, social support, caregiver education and culturally appropriate coping resources. Their review also identified barriers to service access, particularly in rural areas, illustrating that the existence of a caregiver need does not necessarily mean that a corresponding resource is readily available.

Social support itself should therefore be understood as multidimensional rather than simply present or absent. Evidence concerning its relationship with caregiver outcomes is also not completely uniform. Studies included in the Indian dementia review reported beneficial associations between social support and dimensions of quality of life, whereas Kochhar et al. (2024) found no significant association between overall caregiver social support and caregiving experience in their schizophrenia sample. Such differences indicate that the type, adequacy and context of support may be important when interpreting its relationship with caregiver well-being.

The practical implication is that support is most meaningful when it corresponds to the caregiver's actual need. Emotional reassurance cannot replace assistance with an excessive physical workload, just as practical help may not adequately address persistent psychological distress. Information, respite, healthcare access, financial assistance, family participation and psychological support therefore represent different resources rather than interchangeable forms of caregiver intervention.

Caregiver Well-Being and Life Satisfaction

Caregiver well-being extends beyond the absence of burden, depression or stress. Research has increasingly examined positive aspects of caregiving alongside negative outcomes, including satisfaction, gains, rewards, competence, meaning, quality of life and life satisfaction.

A systematic review by Quinn and Toms (2019), incorporating 53 studies of informal caregivers of people with dementia, found that positive aspects of caregiving were associated with lower depressive symptoms and burden and with better mental health, quality of life, life satisfaction and competence or self-efficacy. However, most included studies were cross-sectional, and relationships were not consistent across every dimension of caregiver health and strain. The findings therefore support an association between positive caregiving experiences and several aspects of well-being but do not establish that positive appraisal eliminates caregiving stress or produces better outcomes in every domain.

Indian evidence provides further support for examining positive and negative dimensions together. Positive aspects of caregiving have been identified among Indian caregivers of people with schizophrenia, including motivation for the caregiving role, caregiver satisfaction and perceived gains (Kate et al., 2013). Kochhar et al. (2024) similarly identified both positive and negative caregiving experiences, with spiritual strength associated with more positive caregiving experience and greater psychological distress associated with more negative experience.

Mishra et al. (2023) further demonstrated that Indian family caregivers may describe caregiving through meaningfulness, belongingness, personal growth and empathetic understanding. These findings do not negate caregiver burden; instead, they demonstrate that burden does not necessarily describe the entirety of the caregiving experience.

Recent international evidence reinforces the need for such caution. Kong et al. (2026), in a systematic review and meta-analysis of 34 studies involving 8,021 family caregivers of older adults across 12 countries, found an overall moderate level of positive aspects of caregiving. Positive caregiving was associated with multiple

demographic, caregiving-related and social factors, while subgroup analyses found lower levels among Asian and younger caregivers. All studies included in the review were cross-sectional. Positive caregiving therefore appears to be multifactorial and context-dependent rather than a universal consequence of caregiving.

Understanding Caregiving Beyond Burden

The literature on caregiver burden has been essential in identifying the physical, psychological, emotional, social and practical consequences that may accompany sustained caregiving. Understanding caregiving beyond burden does not require abandoning this evidence or replacing a negative account with a positive one. Rather, it requires recognising that burden constitutes one important dimension within a broader and more variable caregiving experience.

Indian and international evidence demonstrates that caregivers may report satisfaction, competence, connection, personal growth or meaning alongside fatigue, restriction, psychological distress and practical difficulties (Kong et al., 2026; Lillekroken et al., 2024; Mishra et al., 2023; Quinn & Toms, 2019). Positive and negative dimensions should therefore not automatically be treated as mutually exclusive. A caregiver may find caregiving meaningful while requiring respite, experience affection and connection while being physically exhausted, or willingly accept responsibility while simultaneously requiring practical and emotional assistance.

This broader understanding is particularly relevant in cultural contexts where caregiving may be associated with family responsibility, filial obligation, devotion or seva. Such cultural meanings may influence how caregiving is understood and experienced, but they should not be used to romanticise unlimited self-sacrifice or to assume that caregivers should manage without assistance (Li et al., 2021).

Cultural and historical narratives may help illustrate these dimensions without being treated as empirical evidence. The traditional account of Shravana Kumara, for example, represents an enduring cultural image of filial devotion and responsibility towards ageing parents. It may illuminate cultural meanings attached to caregiving, but it cannot establish psychological outcomes or justify expectations of unlimited sacrifice (Li et al., 2021). Similarly, the Curie family provides a historical illustration of family support and distributed childcare enabling the continuation of other valued roles (Nobel Prize Outreach, 2026). Jane Hawking's account of family life and caregiving alongside Stephen Hawking illustrates how commitment and meaning may coexist with substantial practical and emotional demands and with the eventual need for assistance from others (Hawking, 2007). These accounts serve as illustrations of human caregiving circumstances; conclusions concerning caregiver needs and well-being must continue to rest on empirical evidence.

Taken together, the literature supports examining **needs, coping, support and resources, and caregiver well-being as interconnected but distinct dimensions of caregiving**. Needs may prompt coping efforts; coping may involve seeking assistance or changing the appraisal of an experience; the effectiveness of those efforts may depend upon the availability of appropriate resources; and these processes may relate to caregiver well-being and life satisfaction.

The evidence therefore supports broadening the understanding of caregiving beyond burden alone without minimising genuine hardship. It also provides the basis for considering caregiver support in relation to identified circumstances and needs rather than assuming that the caregiving role itself indicates one particular form of intervention.

3.Methodology

The present paper adopted a **narrative literature review approach** to examine caregiving beyond the predominant focus on caregiver burden. The review was organised around four interconnected areas: **caregiver needs, coping strategies, social support and resources, and caregiver well-being and life satisfaction**.

Literature was identified through searches of academic and scholarly sources using combinations of terms related to *family caregiving, caregiver burden, caregiver needs, coping strategies, social support, caregiver resources, positive aspects of caregiving, caregiver well-being, quality of life,* and *life satisfaction*. Searches also incorporated terms such as *India* and *Indian caregivers* to identify evidence relevant to the Indian sociocultural context.

Priority was given to peer-reviewed empirical studies, systematic and scoping reviews, and recent evidence relevant to the four areas of the review. Indian studies were included wherever available, while international literature was used to provide broader evidence, identify consistent or contrasting findings, and situate Indian caregiving research within the wider literature. Earlier studies were retained when they contributed conceptually or provided evidence directly relevant to the development of the field.

Studies were examined for evidence concerning: (a) the nature and diversity of caregiver needs; (b) coping strategies and caregiver appraisal; (c) availability and role of family, social, practical and formal support; and (d) caregiver psychological well-being, quality of life, life satisfaction and positive aspects of caregiving. Particular attention was given to findings demonstrating variation or inconsistency across caregiver populations rather than assuming that particular coping strategies, resources or caregiving experiences have uniform effects.

The literature was synthesised narratively rather than statistically. Findings were compared across studies to identify recurring themes, differences and relationships among needs, coping, support and well-being. Positive aspects of caregiving were considered alongside evidence concerning burden and distress in order to develop a

balanced understanding of caregiving without minimising its genuine demands.

Cultural and historical accounts, including those associated with Shravana Kumara, the Curie family and Jane Hawking, were used only as brief illustrations of culturally and historically situated caregiving experiences. They were not treated as empirical evidence, and conclusions concerning caregiver needs, coping, support and well-being were based on research literature.

As this was a narrative review based on previously published literature, the study involved no participant recruitment or primary data collection.

Limitations of the Review

The present review is narrative rather than systematic and was not designed to identify every eligible study or to provide a formal risk-of-bias assessment. The literature considered spans different caregiving populations, illnesses, study designs, measures, and sociocultural settings, which limits direct comparison across findings. Although Indian evidence was prioritised where available, the evidence base represented in this review is uneven across caregiving groups, with several cited studies focusing on dementia, schizophrenia, cancer, or older-adult caregiving. The review should therefore be understood as an integrative conceptual synthesis intended to generate a balanced and practically useful account of caregiving, rather than as an exhaustive estimate of effects or prevalence.

4.Discussion

Caregiving is often discussed through burden, stress and strain, and there are good reasons for doing so. These experiences are real and have been consistently documented. However, the literature reviewed in this paper raises a simple question: once we know that caregiving is difficult, what else do we need to know about the caregiver? (Lillekroken et al., 2024; Quinn & Toms, 2019)

The answer appears to begin with need. Two caregivers may both report that caregiving is stressful, but what lies behind that stress may be very different. One may be physically exhausted because care is being provided almost entirely alone. Another may not understand the illness or know how to respond to changes in the care recipient. Someone else may be worried about money, while another may have sufficient practical support but struggle emotionally with the changes that caregiving has brought into the relationship. Calling all of these experiences' *caregiver burden* may describe an outcome, but it does not necessarily tell us what the caregiver needs.

This distinction matters because support is useful only when it responds to the problem that actually exists. A caregiver who needs another pair of hands cannot be helped adequately through positive thinking. A caregiver who lacks information needs knowledge and guidance. Financial strain cannot be counselled away. Persistent anxiety, sadness or emotional exhaustion may require psychological support, while sustained physical demands may require respite or a redistribution of caregiving responsibilities. Before asking **"How can this caregiver cope better?"**, it may therefore be more useful to ask **"What is this caregiver trying to cope with?"**

Recognising Need as the Beginning of a Response

The literature also led to an important distinction between **having a need, recognising a need and being able to respond to that need**. These are not the same.

A caregiver may recognise, "I cannot continue doing everything alone". That recognition can open the possibility of action: asking a family member for help, obtaining information, arranging respite or approaching a professional. In this sense, recognition of need may become a precursor to adaptive coping. But this interpretation must be made cautiously. Asking for help works only when somebody is able and willing to help. Recognising the need for respite does not create an affordable respite service. Understanding that one is financially strained does not produce financial resources.

This is important because caregivers should not be made individually responsible for difficulties that arise from inadequate resources. When the problem is structural, practical or financial, the response must include those realities. Psychological coping has an important place, but it cannot be expected to compensate for every gap in the caregiver's environment.

At the same time, recognising a need may itself be difficult. Family expectations, a sense of duty, reluctance to inconvenience others, guilt about taking time away from the care recipient, or the belief that a "good" caregiver should manage everything may make help-seeking harder. This becomes particularly relevant in cultural settings where caregiving is closely connected with family responsibility and seva. Such values can give caregiving meaning and strength, but they should not make receiving help appear to be a failure of commitment (Li et al., 2021).

Coping Is More Than Enduring

Coping is sometimes understood almost as the ability to continue despite difficulty. The literature reviewed here suggests a broader interpretation. Coping may involve solving a problem, seeking support, obtaining information, accepting what cannot presently be changed, regulating emotional responses, drawing upon faith or personal beliefs, or reconsidering how the caregiving experience is understood (Creado et al., 2006; Kochhar et al., 2024; Mehrotra & Sukumar, 2007).

This makes the relationship between need and coping particularly important. Effective coping does not always mean becoming stronger enough to tolerate more. Sometimes it may mean recognising that the present arrangement is unsustainable and changing it.

Nor is one coping strategy necessarily appropriate for every caregiver. The mixed findings concerning social

support and coping in the studies reviewed are useful reminders of this. "Seek support" may sound like universally sensible advice, but the usefulness of support depends upon what kind of support is sought, from whom, whether it is available and whether it addresses the caregiver's actual difficulty. The caregiver and the caregiving situation have to be understood before a strategy can be judged useful (Creado et al., 2006; Kochhar et al., 2024).

Beyond Burden Does Not Mean Without Burden

The positive dimensions of caregiving require similar care in interpretation. Findings concerning meaning, satisfaction, competence, belongingness, personal growth and connection are important because they show that caregiving cannot always be represented adequately through distress alone. However, the opposite mistake would be to replace the burden narrative with a positivity narrative (Kate et al., 2013; Kong et al., 2026; Mishra et al., 2023; Quinn & Toms, 2019).

A caregiver may be exhausted and still find caregiving meaningful. A person may wish that the demands were lighter without wishing away the relationship or the responsibility itself. Satisfaction in having cared well for someone can coexist with frustration, fatigue, sadness or loss. **One experience does not invalidate the other.**

This is the sense in which the present paper uses the expression *beyond burden*. It does not mean moving away from burden as though it were an outdated or unnecessarily negative concept. It means asking whether burden is the whole of the caregiver's experience.

For some caregivers, broadening the appraisal of caregiving may reveal something that has become obscured by daily difficulty: competence developed over time, a valued relationship, affection, contribution, personal strength, spiritual meaning, or simply the knowledge that one has been present for another human being when care was needed. Research on positive aspects of caregiving provides support for recognising these dimensions. But they should be discovered, where they exist, rather than prescribed (Mehrotra & Sukumar, 2007; Mishra et al., 2023; Quinn & Toms, 2019).

A caregiver who is overwhelmed does not need to be instructed to find gratitude or personal growth before immediate needs are addressed. Meaning cannot substitute for sleep. Appreciation cannot replace practical assistance. Positive appraisal cannot remove financial strain. **Positive Psychology becomes useful when it adds another resource to the caregiver's experience; it becomes unhelpful if it is used to minimise what the caregiver is actually facing.**

Support Should Follow Need

Taken together, the literature therefore points towards a relatively simple principle: **support should begin with the caregiver's identified need rather than with the label "caregiver".**

This does not necessarily require a new intervention for every caregiver. It requires listening before deciding. Some caregivers may need information. Some may need practical or financial assistance. Some may need respite. Some may benefit from counselling or other psychological support. Others may have adequate personal, family and social resources and may not require formal intervention at all.

The aim should not be to make every caregiver a recipient of intervention. It should be to make appropriate support available when a need exists and to make it possible for caregivers to recognise and seek that support without shame or unnecessary guilt.

This also changes the question from **"How do we reduce caregiver burden?"** to a somewhat broader set of questions: **What is creating difficulty for this caregiver? What resources are already available? What is missing? How is the caregiver coping? What remains meaningful or sustaining? And what, if anything, would genuinely help?**

These questions allow burden to remain visible without allowing burden to become the caregiver's entire identity.

Caregiving as It Is Actually Lived

Perhaps the most important implication of this review is that caregiving is rarely lived as a neat psychological construct. Needs, responsibilities, affection, exhaustion, coping, family relationships, practical resources, cultural expectations, satisfaction and distress may all occupy the same caregiving experience.

This is why genuine questions about caregiving often arise from caregiving as it is actually lived. Lived experiences do not themselves provide the empirical answers, but they can reveal the questions worth asking. Research then allows those questions to be examined systematically, challenged where necessary and placed within the wider evidence.

The cultural image of Shravana Kumara can remind us of the meaning attached to filial devotion, while also prompting questions about the limits of sacrifice and the acceptance of help (Li et al., 2021). Historical and biographical accounts such as those of the Curie family and Jane Hawking similarly illustrate that care may be embedded within networks of relationships, other life roles, commitment and changing needs for assistance (Hawking, 2007; Nobel Prize Outreach, 2026). Their value in the present discussion lies not in proving a research proposition but in reminding us that the constructs examined in research ultimately belong to human lives.

A balanced understanding of caregiving therefore need not choose between burden and meaning, or between vulnerability and strength. It can recognise difficulty where difficulty exists, identify resources where they are available, seek support where it is needed and acknowledge positive experience where it genuinely occurs.

Caregiving may be demanding without being defined only by its demands. Understanding the caregiver requires asking not simply how much burden is being carried, but what is being carried, what helps in carrying it, what support is missing, and how the caregiver is living through the experience.

5.Conclusion

Caregiving can be demanding, exhausting and, at times, overwhelming. The extensive literature on caregiver burden has been important in making these experiences visible. However, burden alone may not tell us enough about the caregiver or about what would actually help.

This review suggests beginning with a few simple but important questions: **What is difficult for this caregiver? What does the caregiver need? How is the person coping? What support is available, and what is missing? How is the caregiver doing?** The answers may differ considerably even among caregivers facing apparently similar responsibilities.

Recognising need is important, but recognition alone cannot create resources. A caregiver who needs respite, practical assistance, information, healthcare or financial support cannot be expected to overcome the absence of these resources through psychological coping alone. Similarly, psychological support has an important place when emotional distress, appraisal or coping requires attention, but it should respond to an identified need rather than be assumed from the caregiving role itself.

At the same time, acknowledging difficulty need not exclude the possibility of satisfaction, competence, connection, contribution, growth or meaning. These positive dimensions should neither be overlooked nor prescribed. **A caregiver may be tired and still find caregiving meaningful; one experience does not cancel the other.**

Understanding caregiving beyond burden therefore means neither minimising burden nor replacing it with positivity. It means seeing the caregiver more completely—recognising needs, existing strengths and coping resources, identifying what support is available or absent, and attending to well-being alongside the demands of care.

Ultimately, caregiver support may begin with a question more useful than simply **"How burdened is this caregiver?"**

"What would make caregiving a little more manageable for this person, in the life they are actually living?"

The answer to that question may provide the most meaningful place from which support can begin.

6.Future Scope

The present review brings together caregiver needs, coping, support and resources, and well-being within a broader understanding of caregiving beyond burden. As a narrative review, it does not test the relationships among these dimensions. Future research can therefore examine how they interact across different caregiving circumstances and over time.

One important direction would be to study **caregiver need before intervention**. Research could examine whether identifying the caregiver's primary difficulty and matching support to that need produces better outcomes than offering broadly similar caregiver interventions. Particular attention should be given to the difference between **recognising a need and having access to the resource required to meet it**. This distinction may be especially important where financial limitations, geographical location, inadequate services or limited family support restrict the caregiver's choices.

Further research could also explore the coexistence of positive and difficult caregiving experiences. Rather than asking whether caregiving is either burdensome or meaningful, studies could examine when satisfaction, competence, connection, personal growth or meaning emerge alongside stress and strain, what conditions support these experiences, and whether they change during different stages of caregiving. Such research should avoid assuming that positive experiences are universal or that caregivers ought to find meaning in difficult circumstances.

The role of family and wider support networks also deserves continued investigation. Future studies could examine not merely whether support is present, but **what kind of support is needed, who provides it, whether it is acceptable to the caregiver, and whether it actually reduces the difficulty for which help was sought**. Indian cultural expectations concerning family responsibility, *seva*, reciprocity, help-seeking and acceptance of outside assistance provide particularly relevant areas for further study.

Longitudinal research would be valuable in understanding how caregiver needs, coping and well-being change as the care recipient's condition changes and as caregiving continues over time. Research should also extend beyond the active caregiving period to examine adjustment after caregiving responsibilities reduce or end, including the possible continuation of health effects, changes in identity and relationships, and experiences of loss, relief, growth or renewed engagement with other areas of life.

The **Caregiver Reflection and Support Guide** presented in the Annexure may also be developed and evaluated further. Initial research could examine its clarity, cultural relevance and usefulness with caregivers from different backgrounds. Feedback from caregivers could be used to add, modify or remove suggestions so that the Guide develops from both research evidence and caregiver experience. Subsequent studies could evaluate whether using the Guide helps caregivers identify needs, recognise existing coping resources, seek appropriate support and communicate more clearly with family members or professionals.

Future work may therefore move from asking only **how much burden caregivers experience** towards understanding **what creates the difficulty, what the caregiver needs, what already helps, what resources are missing, and what form of support fits the person's actual circumstances**. Such research can contribute to caregiver support that is not only evidence-informed but increasingly shaped by the voices and lived knowledge of caregivers themselves.

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Its value in the present work lay not in replacing the researcher's judgement, but in extending the researcher's ability to explore questions, engage with a wider body of literature, examine emerging ideas critically, and develop them into a structured scholarly form. The conceptual direction, questions pursued, interpretation and evaluation of evidence, decisions regarding scope and content, and final responsibility for the manuscript remain with the author.

The process was guided by a simple understanding: **intuition may generate the question, evidence must determine the answer, and AI may shorten the road without choosing the destination.**

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Annexure

Caregiver Reflection and Support Guide

Before You Begin

This is **not a test**. There is no score and there are no right or wrong answers. You do not have to complete every question.
Start with what matters to you now.

The suggestions in this guide are possibilities, not instructions. Use what seems helpful, change it to suit your circumstances, leave out what does not fit, and add ideas from your own experience.

Your experience matters. You may already have discovered ways of coping that work particularly well for you.

Evidence Note

The questions and possible responses included in this Guide were developed from the themes examined in the present review, including caregiver needs, coping, social and practical support, positive aspects of caregiving, and caregiver well-being. The suggestions are intended as evidence-informed possibilities rather than prescribed

interventions. They should be adapted to the caregiver's circumstances, preferences, available resources, and lived experience. The Guide has not yet been empirically validated; its evaluation and further development are proposed as an area for future research.

1. What Is Difficult for Me Right Now?

Before looking for a solution, try to identify what is actually making caregiving difficult.

Right now, the most difficult part of caregiving for me is:

Is any of this contributing?

☐ I am physically tired.
☐ I am not getting enough sleep or rest.
☐ Too much of the caregiving responsibility falls on me.
☐ I am unsure how to manage some aspects of care.
☐ I need more information about the illness/condition.
☐ I am worried about money or expenses.
☐ I am finding it emotionally difficult.
☐ I feel anxious, sad, angry, guilty or overwhelmed.
☐ I feel alone.
☐ I have very little time for myself.
☐ I am neglecting my own health.
☐ Family expectations are difficult for me.
☐ Help is available, but I find it difficult to ask for or accept it.
☐ I know what help I need, but it is not available.
☐ Something else: _____

Of these, what is troubling me most at present?

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2. What Do I Need?

Now move from **"This is difficult"** to **"What would make it more manageable?"**
I may need:

☐ Rest or uninterrupted sleep
☐ Someone to share a caregiving task
☐ A regular break or respite
☐ Information
☐ Training in a particular caregiving skill
☐ Medical or healthcare guidance
☐ Financial assistance
☐ Help with household responsibilities
☐ Someone who will listen without judging
☐ More participation from family members
☐ Time for work, friends, hobbies, prayer, exercise or another part of my life
☐ Psychological or counselling support
☐ Help locating services or resources
☐ Something else: _____

Make the need specific
Instead of:
"I need help".
Could I say:
"I need someone to stay with _____ for two hours on _____".
or:
"I need the doctor to explain _____".
or:
"I need one evening each week when I am not responsible for _____".
My need, in my own words:
What I need most right now is:

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3. How Am I Coping Now?

Before looking for something new, notice what you are already doing.

What helps me?

☐ Planning or organising tasks
☐ Asking someone for help
☐ Talking to family or friends
☐ Seeking information
☐ Prayer, faith or spiritual practice
☐ Exercise or walking
☐ Rest
☐ Music, reading, gardening, hobbies or creative activities
☐ Humour
☐ Spending some time alone
☐ Staying connected with people
☐ Journaling or writing
☐ Professional support
☐ Reminding myself what is within and outside my control
☐ Looking at the situation differently
☐ Something else: _____

My experience

Something I already do that genuinely helps me:

Something that used to help but no longer does:

Something I am doing only because I feel I have no alternative:

Something I have learnt from earlier difficult periods in my life that may help me now:

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4. What Support Do I Have?

Think not only about **who is present**, but about what kind of support they can realistically provide.

Person/Resource	What support can they provide?	Am I using this support?
Family	_____	Yes / No / Sometimes
Friends/neighbours	_____	Yes / No / Sometimes
Healthcare team	_____	Yes / No / Sometimes
Paid caregiver/domestic assistance	_____	Yes / No / Sometimes
Community/religious organisation	_____	Yes / No / Sometimes
Government/NGO/service	_____	Yes / No / Sometimes
Other	_____	Yes / No / Sometimes

Now ask:

What support do I need that I already have access to but am not using?

What makes it difficult for me to ask for or accept that help?

And equally important:

What support do I need that is simply not available to me at present?

If support is unavailable, this does **not automatically mean that you are failing to cope**. The difficulty may lie in the absence of an appropriate resource.

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5. What Might Help?

Look at the difficulty you identified in Section 1 and the need you identified in Section 2.

If I am struggling mainly with…	I might explore…	What would actually work for me?
Physical exhaustion	Rest, sharing tasks, respite, simplifying routines	_____
Lack of information	Healthcare guidance, reliable information, caregiver training	_____
Too many responsibilities	Sharing specific tasks, family discussion, paid/community assistance where possible	_____

If I am struggling mainly with…	I might explore…	What would actually work for me?
Financial strain	Available benefits, family planning, NGO/community resources, social-service guidance	_____
Emotional distress	Trusted support, journaling, relaxation, counselling or professional help where needed	_____
Isolation	Contact with friends/family, caregiver groups, community participation	_____
Little time for myself	Protecting a small regular period for something restorative	_____
Difficulty asking for help	Making one specific request rather than asking generally for "help"	_____
Guilt about taking a break	Considering whether receiving help may allow caregiving to continue more sustainably	_____
Thoughts that increase distress	Reflection, balanced appraisal, counselling or psychological strategies where useful	_____
Loss of meaning or identity	Reconnecting with valued roles, relationships, interests, faith, contribution or purpose—if meaningful to me	_____

Now make it yours
One suggestion above that may work for me:

How I would change it to suit my life:

Something not listed here that I know could help me:

One small step I am willing and able to try:

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6. How Am I Doing?
Caregiving is part of your life. It does not have to be the only part considered when thinking about your well-being.
Ask yourself:
Am I getting enough rest?

Am I attending to my own health?

Do I have someone I can speak honestly with?

Is there some part of my day or week that still belongs to me?

Is there something I would like to return to—an activity, relationship, interest or role?

What is draining me most?

What restores me—even a little?

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7. Is There Also Something Worth Keeping?
This section is **optional**.
Caregiving does not have to feel positive. Difficulty should not be covered over with gratitude, meaning or positive thinking. But if there is something within your caregiving experience that you value, you may choose to notice it.
Perhaps:
☐ I have discovered that I am capable of more than I thought.
☐ I value being present for this person.
☐ Our relationship has changed or deepened in some way.
☐ I have learnt something important.
☐ My faith or values give this experience meaning.
☐ I feel satisfaction when I know I have cared well.
☐ I have learnt to ask for or accept help.
☐ I have become more understanding of other caregivers.
☐ Something else: _____
☐ **I do not experience anything like this at present.**
All of these responses are valid.

If there is something about my caregiving experience that I would not want overlooked, it is:

My Caregiving Snapshot
After completing whichever sections were useful, bring your thoughts together.
The most difficult thing for me now:

What I need most:

What already helps:

Support I can use:

Support that is missing:

One thing I will try:

One idea of my own that I want to remember:

Something that matters to me beyond caregiving:

Something within caregiving that matters to me, if anything:

A Final Question
What would make caregiving a little more manageable for me—not in an ideal world, but in my life as it is now?

That answer may be a useful place to begin.