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Navigating Duty and Desire: An Interpretative Phenomenological Analysis of Motivations and Their Impact on End-of-Life Care Among Asian Family Caregivers

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Abstract

Research on family caregiving often emphasizes external factors—such as socioeconomic conditions, resource access, and social support—as primary influences on caregiver outcomes. Less attention has been given to caregivers' internal motivations and how their own interpretation of these motivations can shape their wellbeing. This study examines the driving forces behind Asian family caregivers' engagement in end-of-life care and explores how these motivations can simultaneously enhance or undermine their wellbeing. Using an interpretative phenomenological analysis (IPA) approach, we investigated the lived experiences of 20 primary family caregivers in Singapore providing care for a terminally ill relative. Data were collected via dyadic interviews as part of a broader Randomized Controlled Trial evaluating the Family Dignity Intervention (FDI) for palliative care. Participants were adults (aged 21+) responsible for older patients with a life expectancy of less than 12 months. Interviews took place in participants' homes, focusing on caregivers' motivations and personal reflections on their role. Six themes emerged illustrating how caregiving motivations influenced wellbeing: (1) *Commitment to Duty*—the desire to fulfill responsibilities and avoid future regret, (2) *Easing Suffering*—a drive to relieve the relative's pain, (3) *Maintaining Connection*—valuing shared time and presence, (4) *Expressing Gratitude*—showing appreciation through caregiving, (5) *Adapting to Change*—responding flexibly to the illness trajectory, and (6) *Facing Mortality*—acknowledging and managing the loved one's prognosis. An overarching theme, *Self-Determination as Wellbeing Driver*, highlighted the role of personal agency in shaping how motivations were interpreted and their effects on caregiver wellbeing. Caregivers' sense of autonomy and purpose is central to transforming caregiving motivations into positive experiences, thereby supporting wellbeing during end-of-life care. These insights underscore the importance of considering internal motivational processes when designing interventions and providing support for family caregivers in palliative care contexts.

Keywords: Palliative care, Family caregiver, Motivation, Wellbeing, Meaning-making, Burnout

Introduction

The experience of family caregiving at the end of life (EoL) can be paradoxical—eliciting feelings of fulfillment, gratitude, and connection, while simultaneously provoking anxiety, stress, and emotional strain. Some scholars have likened the caregiving journey to climbing a mountain [1]; however, the EoL caregiving "expedition" often extends far beyond days or months, encompassing the full trajectory from diagnosis through prognosis, death, and bereavement, sometimes shaping a lifelong journey.

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Family caregivers typically assume a multifaceted and ongoing role, balancing medical management, navigating healthcare systems, and caring for other dependents, alongside providing physical, emotional, and psychological support to their loved ones [2, 3]. Many enter these responsibilities without formal training, adequate preparation, or access to necessary resources, yet must contend with a complex interplay of emotions and life changes [4].

This intensive caregiving burden is widespread rather than exceptional. Despite advances in healthcare and medical technology, older populations remain highly vulnerable to chronic and terminal illnesses [5]. In the United States, over 40 million individuals provide care for family members each year [6], and in Europe, informal caregivers support approximately 80% of patients requiring long-term care [7]. With projections estimating the global population of older adults to reach 2 billion by 2050 [8], the demand for family caregivers will intensify, placing additional strain on healthcare systems.

The effects of caregiving stress have been well-documented [9–12], highlighting issues such as burnout and its repercussions on families and society. Complementary research has identified resilience and personal growth among caregivers facing adversity [13–16]. Central to both burnout and resilience is the caregiver's capacity for coping—an adaptive process involving changes in cognition and behavior to manage internal or external stressors [17]. While psychological resources are critical to sustaining wellbeing, most research emphasizes external factors, such as socioeconomic status, resource availability, and social support, often recommending interventions focused on improving these external conditions.

Caregiver perceptions, emotions, and motivations

While alleviating external stressors is important, it is equally vital to consider caregivers' internal perceptions and appraisals of their responsibilities. These subjective experiences, often referred to as caregiver burden, have been linked to caregivers' quality of life, stress coping, and mental health outcomes, including anxiety and depression [18, 19]. Campbell *et al*. [20] reinforced this view, showing that subjective caregiver burden consistently emerged as a key predictor of stress across diverse caregiving contexts.

Folkman and Moskowitz [17] highlighted that caregivers can experience positive emotions even amid high stress, introducing the concept of meaning-focused coping. This framework emphasizes that caregivers derive psychological sustenance by reflecting on personal beliefs, values, and existential goals. The process involves recognizing benefits in caregiving, reinforcing these benefits internally, setting meaningful goals, reprioritizing in response to changing circumstances, and infusing daily experiences with positive meaning. Folkman [21] further noted that meaning-focused coping coexists with negative appraisals, helping caregivers restore emotional and physiological resources during challenging times.

Recognizing the significance of internal appraisal processes, examining the beliefs, values, and goals that motivate caregiving—hereafter referred to as "motivations"—offers valuable insights for enhancing meaning-focused coping. Targeting these intrinsic drivers may strengthen caregivers' sense of self, personal efficacy, and wellbeing, moving beyond conventional interventions that primarily address social or emotional stress symptoms.

Bridging the research gap in Asian caregiving

Although caregiving burden and coping mechanisms are inherently complex across cultures, unique factors shape the caregiving experience in Asian contexts. In many Asian societies, family obligations are paramount, with deeply ingrained values such as filial piety guiding expectations of caregiving roles [22, 23]. Research in Singapore—a multicultural society with a predominantly Chinese population—has shown that caregivers who internalize societal expectations and prioritize them over personal wellbeing often face internal conflict, which can compromise mental health, familial relationships, and caregiving responsibilities [24]. These dynamics are further influenced by evolving perspectives among younger generations, who increasingly question traditional Confucian norms of unquestioning obedience and absolute family duty in contemporary, globalized settings [25]. Understanding how such cultural complexities shape caregiver motivations is critical to designing effective support interventions.

This study seeks to expand knowledge on Asian EoL family caregiving by addressing three questions: 1) What internalized motivations (defined here as beliefs and values unconsciously embedded in attitudes or behaviors) drive Asian family caregivers? 2) How do these motivations influence caregivers' approaches to caregiving and affect their wellbeing? 3) How can insights into these motivations inform psychosocial interventions to support and sustain caregiver wellbeing?

Materials and Methods

Research design and procedures

This study analyzed qualitative dyadic interview data (N = 20) drawn from a larger Randomized Controlled Trial evaluating a novel Family Dignity Intervention (FDI) for Asian palliative care patients and their families (N = 50). The full study protocol, inclusion criteria, sampling methods, and interview procedures are detailed by Ho *et al*. [26]. The FDI was developed based on an integrative review of empirical research on dignified end-of-life care

across Western and Asian settings [27, 28], incorporating elements of logotherapy and narrative life review to provide psycho-socio-spiritual support to patients and caregivers facing mortality. The intervention was first piloted to assess feasibility and acceptability prior to full implementation.

In practice, the FDI involved a semi-structured, recorded dyadic interview conducted in patients' homes with both the patient and their primary caregiver. Using a guided question framework, the FDI therapist facilitated discussions about shared memories, meaningful life experiences, and personal reflections, promoting meaning-making, reconciliation, and expressions of appreciation. The goal was to produce a legacy document narrating the patient's life story, subsequently shared with the wider family in an open reading. Interviews lasted 60–90 minutes and were conducted in English, Malay, Mandarin, or a Chinese dialect (Hokkien, Teochew, or Cantonese). All recordings were transcribed verbatim, translated into English where necessary by native speakers, and compiled into legacy documents, which were reviewed and approved by patients and caregivers for accuracy and authenticity.

Sampling

The study sample comprised 20 primary caregivers of older palliative care patients (aged 50+) with predominantly cancer diagnoses and a prognosis of less than 12 months. Caregivers included 11 spouses, seven adult children, and two siblings, mostly female, aged 23–82 years (mean age 56.2) **(Table 1)**. Participants were recruited through hospice and healthcare service providers, including HCA Hospice Care, Dover Park Hospice, Tan Tock Seng Hospital, Singapore Cancer Society, and Methodist Welfare Services. Eligibility criteria required caregivers to be over 21 years old and identified by the patient as their primary carer. The sample represented diverse socioeconomic backgrounds, with most participants of Chinese ethnicity. For analysis, transcripts were selected based on a moderate to substantial contribution from the caregiver, given the FDI's focus on patient narratives.

Table 1. Demographics of Family Caregivers

Identifier	Relationship to Patient	Caregiver Ethnicity	Patient's Diagnosis	Patient's Prognosis (Months)
DPH14	Child	Chinese	Lung Cancer	7–12
DPH19	Spouse	Chinese	Prostate Cancer	6
DPH34	Spouse	Chinese	Lung Cancer	2–3
DPH42	Sibling	Chinese	Sigmoid Cancer	2–3
DPH53	Spouse	Chinese	Lung Cancer	2–3
DPH59	Child	Chinese	Gynecological Malignancy	12
DPH68	Spouse	Malay	Lung Cancer	4–6
HCA12	Spouse	Eurasian	Prostate Cancer	2–3
HCA68	Child	Chinese	Colon Cancer	4–6
HCA75	Child	Malay	Breast Cancer	4–6
HCA81	Child	Chinese	Endometrial Cancer	12
HCA87	Spouse	Malay	Renal Cancer	12
HCA109	Spouse	Chinese	Endometrial Cancer	6
HCA114	Spouse	Chinese	Brain Cancer	4–6
HCA116	Spouse	Chinese	Nasopharyngeal Cancer	6
HCA117	Spouse	Chinese	Pancreatic Cancer	12
MWS004	Sibling	Chinese	COPD	12
SCS18	Spouse	Chinese	Liver Cancer	12
TTSH61	Child	Malay	Lung Cancer	12
TTSH65	Child	Chinese	Gynecological Cancer	12

The table preserves all original data, with rephrased headers and labels for clarity while maintaining the same structure.

Data analysis

This study employed interpretative phenomenological analysis (IPA) to explore the internalized motivations of family caregivers providing care to a terminally ill relative. IPA is a qualitative research method designed to illuminate how individuals make sense of their lived experiences [29]. As the current study used qualitative data

drawn from the larger FDI trial, caregivers were not asked direct questions about their internalized motivations. Instead, insights regarding caregiving motivations emerged naturally during the interviews and were identified through the IPA process, involving both data reduction and reconstruction.

Initially, Authors 1 and 2 reviewed all transcripts, selecting those that contained sufficient caregiver contributions for analysis. A line-by-line coding process was then conducted to generate descriptive themes and analytical categories, enabling novel interpretations of the data. Subsequent team meetings facilitated iterative refinement of these themes and categories, clustering similar codes and creating a summary chart of emergent themes and sub-themes. All authors collectively reviewed the themes, established operational definitions, and mapped relationships among categories, themes, and sub-themes, supported by illustrative quotes from the transcripts. To ensure rigor, credibility, and trustworthiness, emergent themes were continually compared within and across participant groups, and final categorizations were agreed upon by the research team. Data saturation and investigator triangulation were achieved [30].

Findings

Figure 1 illustrates the six caregiving motivations alongside a single wellbeing determinant identified through analysis, which together form the Blessings or Burdens of End-of-life Caregiving (BoBEC) model.

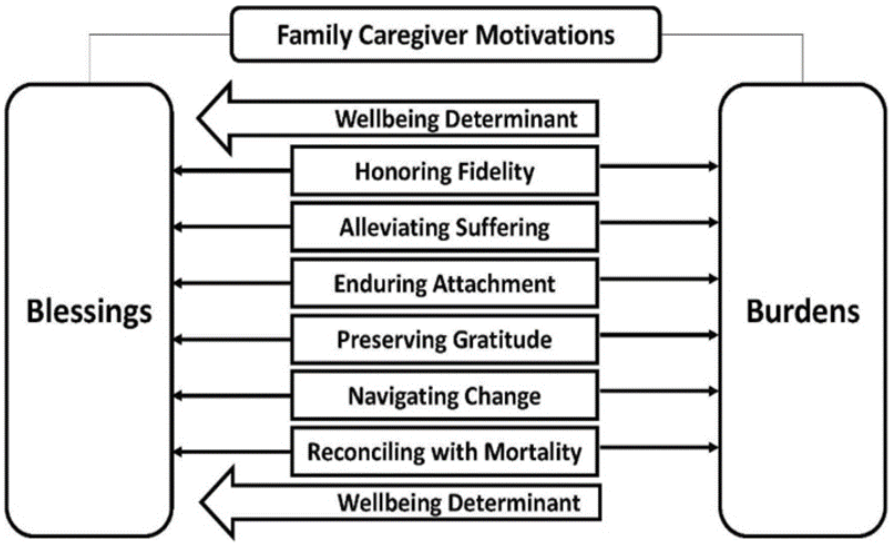

Figure 1. The Blessings or Burdens of End-of-life Caregiving (BoBEC) Model

The six identified caregiving motivations—Honoring Fidelity, Alleviating Suffering, Enduring Attachment, Preserving Gratitude, Navigating Change, and Reconciling with Mortality—reflect the internalized beliefs, values, and goals that inform an end-of-life family caregiver's everyday experience. Each motivation is theorized to shape how caregivers interpret and find meaning in their role, ultimately either enhancing their wellbeing (termed blessings) or contributing to stress and diminished wellbeing (burdens). The Wellbeing Determinant, defined by caregivers' sense of autonomy, self-empowerment, and relational connectedness, represents self-determination and is proposed to positively influence how caregivers appraise the six motivations. Detailed descriptions of these themes, illustrated with participants' quotes, are provided below.

Honoring fidelity (N = 13)

Caregivers expressed a strong commitment to fulfilling their loved ones' needs and wishes, often driven by a desire to avoid future regret. This motivation underscored their sense of duty and inspired them to provide care to the best of their abilities.

"I shouldn't regret anything. Whatever I can do for him, I will do my best and, [instead of waiting till] he's in the coffin, you know, [and then say], 'Oh, why didn't I do this, why didn't I do that?' " (DPH19, Spouse)

In some cases, caregivers conveyed deep emotional dedication, emphasizing their willingness to sacrifice personal comfort to ensure optimal care for their family member.

"I wish to care for him till the very end… I want the best for him and I will do what's best for him. I am willing to sacrifice my soul to make that happen, or take his place if I could." (DPH68, Child)

Alleviating suffering (N = 13)

Caregivers demonstrated empathy and attentiveness to their family member's physical and emotional discomfort, motivated by a strong desire to alleviate suffering.

"This morning she was upset with me for forcing her to drink the bitter medicine. I told her, 'I love you. I wouldn't do this if I had a choice. I want you to drink this for your own benefit, not mine. I'm just encouraging you from the side-lines.' " (DPH53, Spouse)

The intensity of this motivation often stemmed from a profound empathic connection; witnessing a loved one in pain elicited considerable emotional distress.

"… It hurts a lot to drain the fluids. I'm heartbroken when I see how much pain she is in, especially when I see the tubing being inserted. It must hurt so much." (HCA109, Spouse)

Enduring attachment (N = 16)

Caregivers' desire to maintain close relational bonds drove them to spend quality time with their family member and ensure their comfort and wellbeing.

"I think I try to make him as comfortable as he can be. Every medical check-up, every appointment, we will keep to it, and I will always be there for him. [There will never be] any appointment that I am not going with him." (HCA117, Spouse)

For some, attachment was also linked to anxiety about the family member's wellbeing, prompting a need for constant physical proximity.

"I get worried when she's lying there and sleeping, because I'm not sure if anything has happened to her. I'm much happier when she's sitting here with me. When she's just lying there, I would think, 'Oh no, what if something has happened to her?' and I'd be worried." (DPH59, Child)

Preserving gratitude (N = 19)

Caregivers described how past experiences and enduring values inspired present-day feelings of gratitude, shaping their caregiving behaviors and responses.

Preserving gratitude (N = 19)

Many caregivers described how gratitude toward their family members, often rooted in past experiences or childhood care, influenced their present caregiving behaviors. This sense of appreciation sometimes extended to religious or cultural beliefs, which fostered a feeling of duty or indebtedness.

"She was constipated for as long as a week, and she didn't tell me. When she eventually relieved herself, she made a mess on the bathroom floor. As I was cleaning the mess, I thought about how she had cleaned me up when I was little, so I didn't mind." (HCA81, Child)

"My mother says I was indebted to my brother in my past life; this is why I have to settle my debt in this lifetime [by caregiving], because he is here to get his compensation." (MWS004, Sibling)

Navigating change (N = 16)

Caregivers were motivated by the ongoing changes in their family members' health and their own lives, often focusing on supporting emotional adjustment and maintaining positivity. Some caregivers aimed to help family members adapt to new circumstances, while others sought to restore prior levels of function whenever possible.

"I would bring my father food when I visit, while my husband would share words of encouragement and talk to him to cheer him up. We just want him to be happy, so that he wouldn't spend the whole day in negativity." (TTSH65, Child)

"Sometimes I will move his legs a little, to give him that exercise. I hope that he can walk again, but it depends on how strong his will is." (HCA116, Spouse)

Reconciling with mortality (N = 18)

The awareness of a loved one's prognosis motivated caregivers to prioritize meaningful interactions, create lasting memories, and reflect on intergenerational legacies. Conversely, some caregivers struggled with acceptance, seeking additional treatment to prolong life despite awareness of terminal illness.

"All of us just want to cherish the time that we have left with her, and we want her to help us spend more good times together. We [want to] learn about my grandmother, learn about my mother, so that we can pass on to the next generation; share with them the traits and the role models to look up to." (TTSH61, Child)

"My grandmother lived past 80 years old, so I thought my mother would live till at least 90 without any problems. I felt really shocked. Because I always thought, 'She still has more than 10 years; I still have time.' … So we felt that, if it was possible, she should extend her life." (DPH14, Child)

The wellbeing determinant (N = 11)

Caregivers reported that managing caregiving responsibilities led to strengthened family bonds, enhanced self-confidence, and a sense of empowerment. They reflected on how overcoming challenges fostered practical and emotional growth, which contributed positively to their wellbeing.

"As we grow up, it's a bit harder [to have family gatherings] because we are all working. So when the disease came, even though it's not a good thing, not something you will ask for, it united us again. Maybe without it, [we] would have been a bit more separated." (TTSH61, Child)
"I feel like we are more united now. Maybe in the past we didn't really chat with each other… The amount of communication we had increased. I feel that our unity has become stronger." (DPH14, Child)
"I know nothing about going to visit the government… Or to do this, do that. But somehow, I find my way there. [I am a] much stronger person. So if anything happens to me, I think, I know, I can face up to it." (DPH19, Spouse)
"This is how you grow. I learnt to grow because of [my husband]. You have to face the insurmountable challenges that come your way. I learnt how to shoulder my responsibilities on my own." (SCS18, Spouse)

Results and Discussion

This study is the first, to our knowledge, to examine the internalized motivations of end-of-life (EoL) family caregivers. Although the Family Dignity Intervention (FDI) did not explicitly query caregivers about their motivations, such motivation-focused reflections emerged spontaneously and extensively throughout the interviews. This suggests that internalized motivations are deeply embedded within EoL caregiving attitudes and behaviors. The Blessings or Burdens of End-of-life Caregiving (BoBEC) Model **(Figure 1)** highlights the dual nature of these motivations in relation to meaning-focused coping [20], intrapsychic strains [21], and their influence on caregiver wellbeing.

Culturally influenced motivations
Several caregiving motivations revealed cultural underpinnings, reflecting the internalization of Asian values. In the theme of *Alleviating Suffering*, caregivers emphasized practical methods of care, such as administering medication, and experienced distress when these interventions were not possible—reflecting a cultural preference for pragmatic demonstrations of concern [26]. Within *Preserving Gratitude*, caregivers highlighted the significance of filial piety and beliefs surrounding karma and past lives [31]. In the motivation *Reconciling with Mortality*, the importance of intergenerational connections and the value placed on elder longevity were particularly evident [28].

Motivations as blessings: meaning-focused coping
All six caregiving motivations—*Honoring Fidelity, Alleviating Suffering, Enduring Attachment, Preserving Gratitude, Navigating Change,* and *Reconciling with Mortality*—aligned with the principles of meaning-focused coping. Driven by these motivations, caregivers engaged in benefit-finding and benefit-reminding despite witnessing suffering and approaching mortality; they set adaptive goals in accordance with their family member's condition, re-ordered priorities to maximize meaningful interactions, and imbued everyday events with positive significance. These processes fostered affirmation, encouragement, and gratitude in daily caregiving [20]. Consequently, the ability of these motivations to generate positive meaning positions them as "blessings" within the EoL caregiving journey.

Motivations as burdens: intrapsychic strains
Conversely, these same motivations also paralleled intrapsychic strains as described in Pearlin and colleagues' Stress Process Model [32]. Such strains arise when a caregiver's self-concept is compromised by the chronic demands of caregiving and may manifest as: 1) *role captivity*—feeling trapped in the caregiving role; 2) *loss of self*—experiencing diminished personal identity due to enmeshment with the patient; 3) *perceived low competence*—feeling ineffective and helpless in caregiving tasks; and 4) *perceived lack of gain*—failing to experience personal growth or enrichment.
When caregiving motivations intersect with these intrapsychic strains, caregivers are at heightened risk for mental and emotional distress, including depression, anxiety, and irritability, alongside potential physical health decline and disengagement from caregiving roles [32]. In this context, such motivations can function as substantial "burdens" within the EoL caregiving experience.

The crucial factor: self-determination
Self-determination theory [33] posits that individuals require a sense of competence (mastery over tasks and self-efficacy), relatedness (connection and meaningful relationships), and autonomy (control over choices, behaviors, and goals) to foster high-quality motivation that supports thriving. The BoBEC model's Wellbeing Determinant aligns with this concept within the context of caregiving. Family caregivers reflecting this theme demonstrated confidence in performing previously unfamiliar caregiving tasks (competence), strengthened kinship with their patients and families (relatedness), and assumed ownership of their caregiving responsibilities and challenges (autonomy). Research indicates that motivations derived from self-determination can enhance resilience, commitment, positive emotions, and self-concept [34–36].

Extending these findings, caregivers who experience competence, relatedness, and autonomy in their caregiving are likely to engage in meaning-focused coping. This includes: 1) recognizing benefits in caregiving even during challenging events, 2) recalling these benefits when confronted with similar challenges, 3) setting personalized caregiving goals, 4) adapting flexibly to changing circumstances, and 5) finding positive meaning in everyday activities. A robust sense of self-determination, therefore, serves as a protective factor, buffering caregiving motivations against intrapsychic strains such as entrapment, disempowerment, perceived incompetence, and lack of fulfillment. Within the BoBEC framework, the Wellbeing Determinant represents caregiver self-determination and is a pivotal factor in whether the EoL caregiving journey is experienced as "blessings" or "burdens."

Implications and recommendations

Evidence suggests that sustaining a sense of self-determination is essential for maintaining motivation and intrinsic satisfaction in caregiving [34–36]. The current study highlights that EoL family caregivers are guided by motivations that can both support wellbeing and generate intrapsychic strain. Importantly, caregivers also exhibit a sense of self-determination, theorized to positively influence their caregiving motivations. Consequently, interventions to support family caregivers should target all three components of self-determination:

1. *Competence-targeted interventions:* Beyond basic psychoeducation on symptom management and self-care, programs should develop caregiver self-efficacy through strategies such as personal strengths journaling, peer mentorship between novice and experienced caregivers, role-modeling, and goal-setting. These could be implemented via structured support groups, online platforms, or mobile applications.
2. *Autonomy-targeted interventions:* In addition to providing EoL caregiver education, approaches that enhance a sense of control—such as mindfulness practices and creative arts—can help caregivers find meaning in their experiences and emotions. Programs like Mindful-Compassion Art Therapy (MCAT) [37], originally designed for EoL professionals, could be adapted for family caregivers.
3. *Relatedness-targeted interventions:* Dyadic or family projects that encourage sharing memories, expressing gratitude, seeking forgiveness, imparting wisdom, and creating a legacy (e.g., FDI) are critical for fostering relatedness between caregivers and patients. These should form a foundational element of psychosocial interventions at the end-of-life.

All interventions should be culturally sensitive, emphasizing how these strategies enhance practical caregiving, foster competence and autonomy, facilitate meaning-making, and strengthen intergenerational family bonds through legacy-focused conversations.

Limitations and future directions

Although the spontaneously occurring responses underscore the centrality of motivations in EoL caregiving, these motivations were not explicitly explored in the FDI interviews due to the study's primary aims. Future research that specifically investigates intrapsychic motivations of EoL caregivers could provide richer insight, thereby informing more targeted and effective interventions. Expanding participant diversity and ensuring broader representation across cultural and socioeconomic groups would also enhance the generalizability of findings. Additionally, the practical application of the BoBEC model and its clinical recommendations warrants empirical assessment to evaluate its accuracy and effectiveness in supporting EoL caregivers in real-world settings.

Conclusion

End-of-life caregiving can be likened to an arduous climb up a metaphorical mountain [1], fraught with uncertainty, fatigue, and the risk of misstep. Regardless of the strength or dedication of caregivers' inherent motivations, the prolonged demands and emotional strains of EoL care can transform these motivations into burdens, leaving caregivers feeling entrapped or depleted. However, cultivating a sense of self-determination—encompassing competence, autonomy, and relatedness—can empower caregivers to reclaim purpose and resilience, enabling them to navigate the challenges of caregiving. In doing so, caregivers may ultimately perceive their journey not only as a series of obligations but as a path enriched with meaningful blessings, even amidst the hardships of end-of-life care.

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