LIVED EXPERIENCES OF ADVANCED CANCER PATIENTS AND THEIR FAMILY CAREGIVERS: A PHENOMENOLOGICAL STUDY TO INFORM PALLIATIVE NURSING GUIDELINES

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Abstract

Background:

Advanced cancer is associated with profound physical suffering, psychological distress, social disruption, and existential concerns that significantly affect both patients and their family caregivers. While palliative care aims to address these multidimensional needs, limited qualitative evidence is available in the Indian context that captures the lived experiences of advanced cancer patients and their caregivers, particularly from a nursing perspective. Understanding these experiences is crucial for developing culturally appropriate and holistic palliative nursing guidelines.

Aim:

To explore the lived experiences of advanced cancer patients and their family caregivers and to generate evidence-based inputs for the development of palliative nursing care guidelines.

Methods:

A qualitative descriptive phenomenological design was employed to gain an in-depth understanding of participants' lived experiences. The study included 12 advanced cancer patients and 12 family caregivers selected through purposive sampling from selected hospital settings. Data were collected using in-depth semi-structured interviews, allowing participants to freely express their perceptions, emotions, and coping experiences related to advanced cancer. Interviews were audio-recorded, transcribed verbatim, and analyzed using Colaizzi's seven-step phenomenological method to ensure rigor, credibility, and thematic saturation.

Results:

Analysis of patient narratives revealed ten major thematic clusters, including feelings of helplessness and hopelessness, fear of death and uncertainty, loss of control, perception of being a burden to family, emotional suffering, dependence on caregivers, desire to live, fulfillment of social roles, spiritual acceptance, and trust in God or destiny.

Family caregiver narratives yielded six major thematic clusters: fear and uncertainty regarding disease progression, emotional distress, increased caregiving responsibility, caregiver burden, unmet informational needs, and coping through faith and hope. Both patients and caregivers reported significant psychological and emotional challenges, highlighting the interconnected nature of suffering within the family unit.

Conclusion:

The study demonstrates that advanced cancer profoundly alters the lived experiences of patients and their family caregivers across physical, emotional, social, and spiritual domains. Findings emphasize the need for comprehensive, family-centered, and culturally sensitive palliative nursing interventions. Integrating these lived experiences into nursing practice can enhance holistic care delivery and inform the development of structured palliative nursing guidelines tailored to the needs of advanced cancer patients and their caregivers.

Keywords:

Advanced cancer, lived experiences, family caregivers, phenomenological study, palliative nursing

1.1 Introduction

Cancer is a major global public health problem and one of the leading causes of morbidity and mortality worldwide. The burden of cancer is steadily increasing, particularly in low- and middle-income countries, where late diagnosis, limited access to treatment, and inadequate supportive care contribute to poor outcomes [1]. In India, a substantial proportion of cancer patients are diagnosed at advanced stages, resulting in prolonged suffering and complex care needs [2-3].

Advanced cancer is not only a life-threatening medical condition but also a profound life-altering experience. Patients with advanced cancer often experience severe physical symptoms such as pain, fatigue, breathlessness, and loss of functional independence, along with significant psychological distress, anxiety, depression, fear of death, and social isolation [4-5]. These multidimensional challenges extend beyond the patient and deeply affect family members who assume the role of primary caregivers [6].

Family caregivers play a central role in providing physical, emotional, and practical support to patients with advanced cancer. While caregiving is often perceived as a moral and emotional responsibility, it is associated with considerable caregiver burden, emotional exhaustion, financial strain, and psychological distress [7,8]. Caregivers frequently experience feelings of uncertainty, helplessness, and anticipatory grief while simultaneously managing caregiving responsibilities and their own personal and social roles [9].

Palliative care is recognized as an essential component of comprehensive cancer management, focusing on improving quality of life by addressing physical, psychological, social, and spiritual needs of patients and their families [10]. Nurses are key members of the palliative care team and are uniquely positioned to provide holistic, continuous, and compassionate care. However, effective palliative nursing practice requires a deep understanding of the lived experiences, perceptions, and unmet needs of both patients and caregivers [11,12].

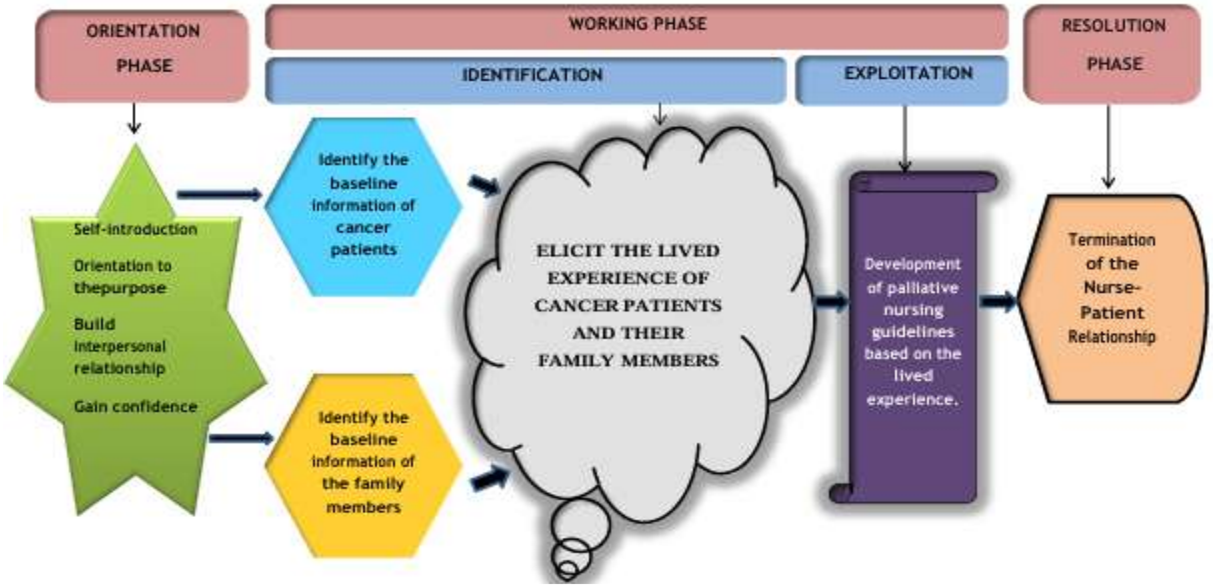

Figure: 1. Cancer is a major global public health problem and the leading causes of morbidity and mortality worldwide

Despite the growing emphasis on palliative care, much of the existing literature is dominated by quantitative studies focusing on symptom burden and clinical outcomes. There is limited qualitative evidence, particularly in the Indian context, that explores the subjective lived experiences of advanced cancer patients and their family caregivers [13,14]. Phenomenological research provides a valuable approach for capturing these experiences, as it allows participants to describe the meaning they assign to illness, suffering, coping, and caregiving within their sociocultural context [15].

Understanding the lived experiences of advanced cancer patients and their caregivers is crucial for developing evidence-based, culturally sensitive, and patient- and family-centered palliative nursing guidelines. Insights derived from such qualitative exploration can inform nursing education, clinical practice, and policy development, ultimately improving the quality of palliative care services [16,17].

Therefore, the present phenomenological study was undertaken to explore the lived experiences of advanced cancer patients and their family caregivers and to generate evidence that can inform the development of structured palliative nursing guidelines.

1.2 Materials and Methods

1.2.1 Research Design

A phenomenological approach using descriptive analysis was utilized to explore the human experience of the phenomena under scrutiny. Professional nursing care consists of a holistic approach, caring for physical, psychological and social needs, which requires knowledge of the patient life-world and lived experience. Different methods such as grounded theory, content analysis and phenomenology were discussed as possible to use for this study. However, since the study aims to describe the lived experience of a phenomenon, how patients experience living with cancer and the experience of family members being with them, phenomenology was found to be an appropriate method. [59] The study was a phenomenological one, both explorative and descriptive in nature. The goal was to discover the meaning and to achieve understanding of the way individuals experience the world. Thus, the goal of this study was to achieve understanding of the everyday experiences of these patients with advanced cancer and their family members and to describe these meanings to a high degree of depth and richness.

According to their convenience, appointments were taken from the patient and their family member. Participants were allowed to choose a place and time for the interview that was convenient for them. Four interview schedules with the patients were completed in a quiet room attached to the ward and eight at the bedside. A qualitative descriptive phenomenological research design was adopted to explore and understand the lived experiences of advanced cancer patients and their family caregivers [18]. Phenomenology was considered appropriate for this study as it facilitates an in-depth exploration of individuals' subjective experiences and the meanings they attribute to illness, suffering, and caregiving within their sociocultural context.

1.2.2 Study Setting

The study was conducted in selected hospital settings providing care to advanced cancer patients. These settings included inpatient and outpatient oncology units where patients were receiving treatment and supportive care [19]. The hospital environment enabled direct access to patients and their family caregivers while ensuring continuity of care and ethical supervision.

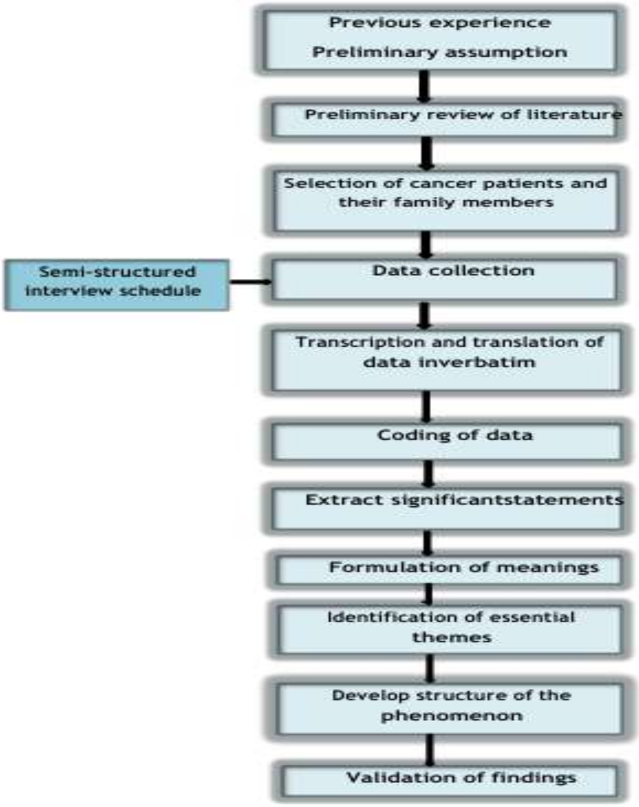

Figure: 2. Schematic Design of Research design

1.2.3 Study Population

The study population consisted of two groups:

- Patients diagnosed with advanced stages of cancer
- Family members who were the primary caregivers of these patients

Both groups were included to obtain a comprehensive understanding of the lived experiences of illness and caregiving within the family unit.

1.3 Inclusion Criteria

1.3.1 Advanced cancer patients:

- Diagnosed with advanced-stage cancer
- Aged 18 years and above
- Able to communicate verbally
- Willing to participate and provide informed consent

1.3.2 Family caregivers:

- Identified as the primary caregiver of the patient

- Aged 18 years and above
- Involved in caregiving for a minimum duration as defined in the study protocol
- Willing to participate and provide informed consent

1.4 Exclusion Criteria

- Patients who were critically ill or cognitively impaired
- Patients and caregivers unwilling or unable to participate in interviews
- Caregivers not directly involved in daily patient care

1.5 Results

The qualitative analysis of in-depth interviews conducted with 12 advanced cancer patients and 12 family caregivers yielded rich and meaningful descriptions of their lived experiences. Data analysis was performed using Colaizzi's seven-step phenomenological method, through which significant statements were identified, meanings were formulated, and these meanings were organized into thematic clusters [20,21]. Two major domains emerged from the analysis: the lived experiences of advanced cancer patients and the lived experiences of family caregivers. The duration of admission in the elderly group was shorter than that of the younger group ($P < 0.05$). The severity of fear of death decreased gradually in both groups after being admitted to the hospice ($P < 0.05$). However, the elderly (≥ 65 years of age) displayed higher levels of fear of death than the younger group at two days before death ($P < 0.05$). A significant negative correlation was observed between the degree of fear of death and the total good death score in both groups at two days before death ($P < 0.05$). The comprehensive care in the palliative care unit might relate to the relief of the fear of death in terminal cancer patients. There is a need for psychological and spiritual care in elderly patients. These findings reveal sources of support that are very important to this population and that are suggestive of untapped resources available as appropriate intervention avenues. From the formulated meanings for those statements, 10 major themes emerged for patients and six themes for the family members. Synthesis of these themes yielded the exhaustive description of living with cancer. Brief description of the themes is presented, followed by the verbatim given by the participants on living with cancer.

1.5.1 Lived Experiences of Advanced Cancer Patients

Analysis of patient narratives resulted in the emergence of ten major themes, which together describe the essence of living with advanced cancer. Patients frequently expressed a profound sense of helplessness and hopelessness arising from progressive physical weakness, loss of independence, and increasing dependence on others for daily activities. Many participants conveyed feelings of despair regarding their recovery and uncertainty about the future, describing their illness as an overwhelming life disruption [22]. Fear of death and uncertainty about disease progression constituted another dominant theme. Patients commonly reported anxiety related to dying, concerns about worsening symptoms, and uncertainty about survival. This fear was often intensified by limited prognostic clarity and unpredictability of the disease course, leading to persistent emotional distress [23,24] Loss of control over life emerged as a significant theme, with patients describing diminished autonomy over personal decisions, disruption of social and occupational roles, and reliance on rigid medical routines. This perceived loss of control contributed to frustration, emotional vulnerability, and a sense of powerlessness [25,26]. Many patients expressed a strong perception of being a burden to their families. Feelings of guilt were commonly reported, particularly in relation to emotional dependency, financial strain, and increased caregiving demands placed on family members. Such perceptions often caused emotional pain and internal conflict among patients [27]. Emotional and psychological suffering was evident across patient narratives. Participants described persistent sadness, anxiety, irritability, and emotional exhaustion associated with prolonged illness, symptom burden, and uncertainty. These emotional experiences significantly affected their overall sense of well-being [28,29]. Despite the severity of illness, a strong desire to live was evident among many participants. Patients expressed hope for recovery or stabilization, a will to survive, and efforts to maintain positive thinking. This theme reflected resilience and an intrinsic motivation to continue living despite adversity [30]. Another prominent theme was the wish to fulfill social and familial roles. Patients expressed concerns regarding responsibilities toward children and family members, unfulfilled duties, and unfinished life goals. The inability to perform these roles contributed to emotional distress and reinforced the social dimension of suffering [31]. Dependence on family members emerged as a central aspect of patients' experiences. Participants acknowledged reliance on family for physical care, emotional support, and decision-making. Trust in family members provided reassurance and played a crucial role in coping with illness-related challenges [32,33].

Spiritual acceptance of illness was commonly reported, with patients describing acceptance of their condition as part of fate or destiny. Many found meaning in suffering and expressed spiritual surrender, which helped them cope with emotional distress and existential concerns [34,35]. Faith and trust in God and destiny emerged as powerful coping mechanisms. Patients reported drawing strength from religious beliefs, prayer, and faith in divine will. These spiritual practices provided comfort, hope, and emotional stability during advanced stages of illness [36,37].

1.5.2 Lived Experiences of Family Caregivers

Analysis of caregiver narratives revealed six major themes, reflecting the emotional, physical, and psychosocial challenges associated with caregiving. Fear and uncertainty regarding patient prognosis emerged as a dominant theme, with caregivers expressing persistent anxiety about disease progression, fear of losing their loved ones, and uncertainty about the future. This ongoing fear contributed significantly to emotional strain [38]. Emotional distress was widely reported among caregivers, characterized by anxiety, sadness, emotional exhaustion, and feelings of helplessness. Witnessing patient suffering while managing caregiving responsibilities placed considerable emotional demands on caregivers [39,40]. Increased caregiving responsibility was another prominent theme. Caregivers described assuming multiple roles, including physical care, medication management, and household duties, often under significant time constraints. This role overload resulted in fatigue and psychological stress [41,42]. Caregiver burden was evident in narratives describing physical exhaustion, financial difficulties, and social isolation. Many caregivers reported neglecting their own health and social lives while prioritizing patient care, leading to cumulative strain [43,44]. A significant unmet need for information and professional support was expressed by caregivers. Participants highlighted inadequate disease-related information, lack of guidance from healthcare professionals, and a desire for counseling and emotional support. Clear communication and professional reassurance were identified as essential needs [45,46]. Similar to patients, caregivers relied heavily on faith and hope as coping strategies. Religious beliefs, prayer, and spiritual practices provided emotional strength and helped caregivers manage uncertainty and distress associated with caregiving responsibilities [47,48].

1.6 Discussion

The present phenomenological study explored the lived experiences of advanced cancer patients and their family caregivers, revealing profound emotional, psychological, social, and spiritual challenges. The findings are discussed in relation to existing literature to contextualize similarities and differences and to highlight their implications for palliative nursing practice. Analyzed The frequency and percentage distribution of socio demographic variables of patients revealed that 33.3% were in the age group of > 50yrs and another 33.33% 41-50yrs, 13.3% in 20-30year age group and 25% were in the age group of 31-40yrs. Majority of the patients were females (83.33%) and about 75% were living in nuclear family. About 33.3% had post-graduation level of education and 41.67% of them had degree. Majority (50 %) were employed and 33.33% were unemployed. Majority (58.33%) were residing in rural areas. Most of the patients (50%) had illness duration of 7 months-1 year and 25% had illness duration between 1-2 years. None of the patients had a family history of cancer. Majority (66.67%) were married. All (100%) had a history of chemotherapy and 75% had surgeries like, PEG tube insertion, colostomy, and tumour excision surgery. All (100%) of patients are getting symptomatic treatment and 58.33% is getting specific treatment like antibiotics and seizure prophylaxis. Majority (66.67%) were free from any other comorbidity. In socio demographic analysis of caregivers reveals that majority (41.66%) were in the age group of >50yrs and comparing the gender it is noted that majority (66.67%) were females. Majority About 50% had high school level of education and 33.33% had post- graduation level. None (0%) had family history of cancer. Majority (50%) were unemployed and majority (75%) were married. About 33.33% had comorbidities like diabetes or hypertension.

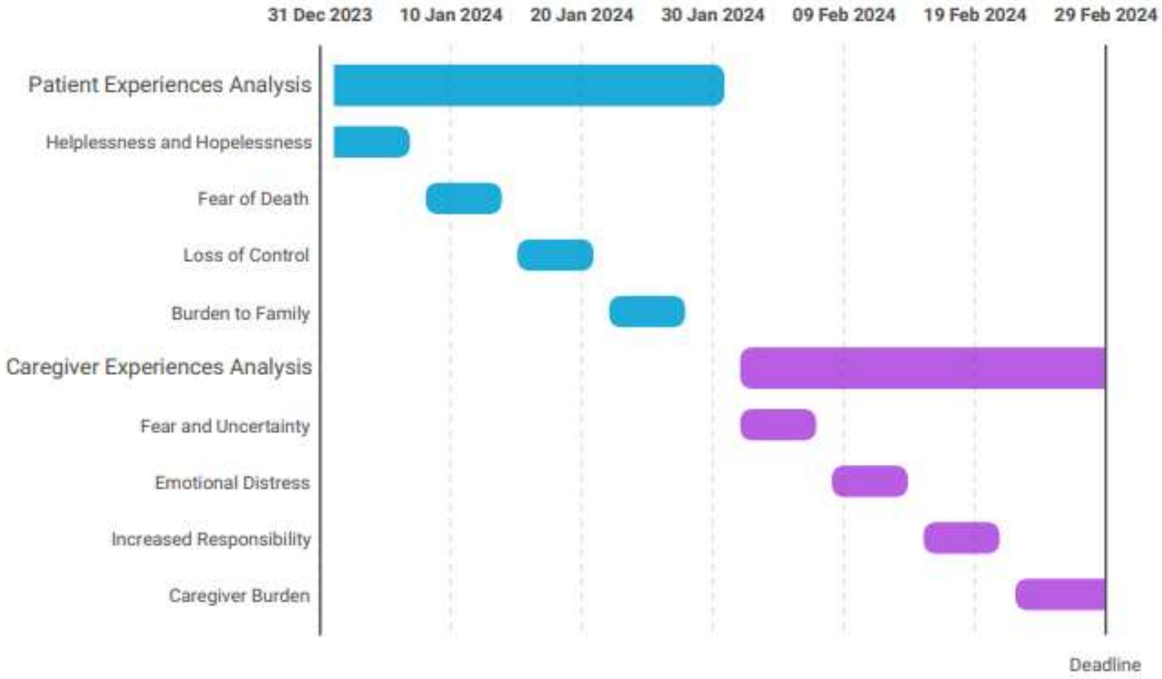

Figure:3 Lived Experiences of Cancer Patients

1.6.1 Lived Experiences of Advanced Cancer Patients

Patients in the present study expressed intense feelings of helplessness and hopelessness resulting from progressive physical decline, loss of independence, and increasing dependency on others. These findings are consistent with earlier studies that describe advanced cancer as a condition marked by loss of autonomy and diminished self-worth, leading to emotional vulnerability and despair [49]. Similar observations have been reported in qualitative studies where patients described a perceived erosion of identity and control over life as illness progressed [50].

Fear of death and uncertainty regarding the future emerged as a dominant theme among patients, aligning with previous research that identifies existential fear and anticipatory anxiety as central components of advanced cancer experiences [51]. Earlier studies have emphasized that uncertainty about prognosis and lack of clear communication from healthcare professionals intensify anxiety and emotional distress among patients [52]. The present findings reinforce the importance of effective communication and psychological support in palliative care settings.

Loss of control over life, as reported by participants, is well-documented in the literature. Previous qualitative studies have shown that dependence on medical routines and inability to make personal decisions contribute significantly to feelings of frustration and powerlessness among cancer patients [53]. The present study supports these findings and highlights how loss of control permeates multiple dimensions of patients' lives, including social roles and daily functioning.

Perception of being a burden to family members was a salient finding in this study. Similar perceptions have been documented in earlier studies, where patients expressed guilt related to financial strain, emotional dependency, and increased caregiving demands placed on family members [7,9]. Such perceptions have been linked to reduced self-esteem and heightened emotional distress, underscoring the need for family-centered interventions in palliative care.

Emotional and psychological suffering, characterized by sadness, anxiety, irritability, and emotional exhaustion, was widely reported by patients in the present study. These findings are consistent with previous research highlighting high prevalence of depression and anxiety among patients with advanced cancer [54]. Existing literature suggests that unaddressed emotional distress negatively impacts quality of life and may exacerbate physical symptom burden [55].

Despite advanced illness, many patients expressed a strong desire to live and hope for improvement, reflecting resilience and inner strength. Similar expressions of hope and will to survive have been reported in previous qualitative studies, even among patients with limited life expectancy [56]. This finding highlights the complexity of hope in palliative care and the need for nurses to support realistic yet meaningful hope.

The wish to fulfill social and familial roles, particularly responsibilities toward children and family members, was another important finding. Prior studies have reported similar concerns, emphasizing the social dimension of suffering and the emotional impact of unmet role expectations [57]. These findings reinforce the importance of addressing social and relational needs within palliative care frameworks.

Dependence on family members emerged as a central coping mechanism, consistent with earlier studies that emphasize the pivotal role of family support in managing advanced illness [58]. Family presence has been shown to provide emotional security and enhance patients' ability to cope with illness-related stress.

Spiritual acceptance of illness and trust in God or destiny were prominent coping strategies among patients. These findings align with previous studies conducted in similar sociocultural contexts, which report spirituality and religious faith as key sources of comfort, meaning, and emotional stability in advanced cancer [59]. The strong spiritual orientation observed in this study underscores the need for culturally sensitive spiritual care in palliative nursing practice.

1.6.2 Lived Experiences of Family Caregivers

Family caregivers in the present study experienced persistent fear and uncertainty regarding patient prognosis, mirroring findings from earlier research that describes caregiving as an emotionally taxing experience marked by anticipatory grief and constant worry [60]. Uncertainty about disease progression has been identified as a major contributor to caregiver stress and psychological burden [61].

Emotional distress among caregivers, including anxiety, sadness, and emotional exhaustion, was consistent with findings from previous studies that report high levels of psychological morbidity among caregivers of advanced cancer patients [62]. The emotional toll of witnessing patient suffering while managing caregiving responsibilities has been widely documented in the literature.

Increased caregiving responsibility and role overload were prominent themes in this study. Similar findings have been reported in earlier research, where caregivers described juggling multiple roles, leading to fatigue and reduced personal well-being [63]. The present findings further emphasize the need for caregiver support and respite services.

Caregiver burden, encompassing physical exhaustion, financial strain, and social isolation, was strongly evident. Previous studies have consistently reported caregiver burden as a multidimensional phenomenon affecting physical, emotional, and social health [64]. The present study corroborates these findings and highlights the cumulative impact of prolonged caregiving.

Caregivers expressed significant unmet needs for information and professional support. This finding aligns with earlier studies that identify inadequate communication and lack of guidance from healthcare professionals as major stressors for caregivers [65]. Improved information sharing and caregiver education have been recommended as essential components of palliative care.

Faith and hope emerged as important coping strategies among caregivers, similar to patients. Previous studies have reported that spiritual beliefs and religious practices help caregivers manage emotional distress and uncertainty associated with caregiving [66]. The shared reliance on spirituality among patients and caregivers highlights the interconnected nature of coping within the family unit.

1.7 Limitations of the Study

Although the present study provides valuable insights into the lived experiences of advanced cancer patients and their family caregivers, certain limitations must be acknowledged. The study employed a qualitative phenomenological design with a relatively small sample size of 24 participants, which, although appropriate for in-depth qualitative exploration, may limit the generalizability of the findings to broader populations.

The use of purposive sampling and recruitment from selected hospital settings may have introduced selection bias, as participants who were willing and able to articulate their experiences were included. Consequently, the perspectives of patients who were critically ill, cognitively impaired, or unwilling to participate could not be captured, potentially limiting the diversity of experiences represented.

Data collection relied on self-reported narratives obtained through in-depth interviews, which may be subject to recall bias and social desirability bias. Participants may have consciously or unconsciously modified their responses due to emotional sensitivity, cultural norms, or the presence of the interviewer.

The study was conducted within a specific sociocultural and healthcare context, which may influence participants' perceptions of illness, caregiving, and spirituality. Therefore, the findings may not be directly transferable to different cultural or healthcare settings.

Additionally, the cross-sectional nature of data collection did not allow for exploration of changes in experiences over time. Longitudinal studies could provide deeper understanding of how patients' and caregivers' experiences evolve across different stages of advanced illness.

Despite these limitations, the study offers rich, context-specific insights that contribute meaningfully to the understanding of palliative care experiences and provide a foundation for future research and practice improvements.

1.8 Conclusion

The present phenomenological study provides an in-depth understanding of the lived experiences of advanced cancer patients and their family caregivers, revealing the profound and multidimensional impact of advanced illness. The findings demonstrate that advanced cancer affects not only physical health but also emotional, psychological, social, and spiritual well-being. Patients experienced feelings of helplessness, fear of death, loss of control, emotional suffering, and dependence, while family caregivers faced significant emotional distress, caregiving burden, uncertainty, and unmet informational needs.

Despite these challenges, both patients and caregivers exhibited resilience through hope, faith, and spiritual coping, highlighting the central role of family support and spirituality in managing advanced illness. The interconnected nature of patient and caregiver experiences underscores the importance of viewing the patient family unit as the core focus of palliative care.

The study emphasizes the critical role of nurses in addressing holistic care needs and highlights the necessity for structured, culturally sensitive, and family-centered palliative nursing guidelines. By incorporating patients' and caregivers' lived experiences into nursing practice, palliative care services can be strengthened to enhance quality of life, promote dignity, and provide compassionate end-of-life care.

Overall, the findings contribute valuable qualitative evidence to palliative nursing literature and provide a strong foundation for improving clinical practice, nursing education, and policy development aimed at supporting advanced cancer patients and their families.

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