

Caregivers' mental health in cancer journey: A Review

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Abstract

Caregiving in the context of cancer involves intricate psychological dimensions that profoundly impact caregivers' well-being and the quality of care provided. This research delves into the overlooked realm of caregiver mental health within the cancer journey, illuminating the emotional complexities.

Examining caregiver roles and stressors, the study reveals the responsibilities caregivers shoulder, encompassing emotional support, daily tasks and advocacy within the healthcare system. Emotional distress, physical strain, financial burdens and social isolation characterize their experiences, influencing both caregivers and care recipients.

Exploration into coping strategies and resilience highlights the significance of emotional expression, social support, self-care and proactive education. Resilient caregivers exhibit adaptability, positivity and effective communication, crucial for navigating the challenges of caregiving. Acknowledging the need for comprehensive support, the study advocates for tailored programs to alleviate caregiver stress. Challenges in accessing support programs due to awareness gaps and financial constraints emphasize the necessity for inclusive, accessible support systems.

This research sets the stage for future investigations into cultural, socioeconomic influences and longitudinal studies to develop targeted interventions. Practical implications underscore the integration of technology, caregiver-inclusive healthcare policies and robust support networks, aiming for a more empathetic and supportive landscape.

In conclusion, understanding and addressing caregiver mental health stand as pivotal components of holistic cancer care. The study calls for a cultural shift, prioritizing comprehensive support for those navigating the intricate path of cancer care. Its findings advocate action across healthcare, societal attitudes and support initiatives, emphasizing the significance of caregiver well-being in the broader context of cancer care.

Keywords: Caregiver Burden; Psychological Resilience; Support Program; Holistic Care

1. Introduction

A cancer diagnosis is an epochal moment, sending profound reverberations through the lives of all those it touches. While the medical community and society at large frequently train their focus on the patient's odyssey through cancer, it is of paramount importance not to disregard the caregivers who provide unwavering support, compassion and care. This research embarks on a journey into the uncharted realm of caregiver mental health within the context of the cancer journey, with a particular emphasis on the intricate psychological aspects that underpin their experiences.

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From a psychological standpoint, caregiving for a loved one with cancer is a multifaceted and emotionally charged role. This role is fraught with unique stressors that emerge from the intimate witnessing of a loved one's battle with cancer. These psychological stressors can be profound, leading caregivers to grapple with a complex array of emotions, including anxiety, depression and an overwhelming sense of helplessness. Often, these emotional burdens are compounded by guilt, as caregivers may erroneously perceive themselves as falling short or failing to alleviate their loved one's suffering[1,2].

When examined through a psychological lens, the experience of caregiving frequently gives rise to what psychologist's term "caregiver burden." This encompassing concept encompasses emotional, social and psychological stressors experienced by individuals providing care for their loved ones[3]. The psychological dimension of caregiver burden often manifests as anxiety and depression social stressors may arise from disruptions to daily life, and emotional stress is commonly fuelled by the perpetual worry and vigilance inherent in caregiving[4]. When caring for a cancer patient, the psychological toll can be particularly pronounced due to the severity of the illness and the protracted nature of treatment[5].

This research endeavours to shed light on the psychological intricacies of the cancer caregiver's journey, underscoring the emotional challenges through a psychological lens. It is crucial to acknowledge that caregivers are not immune to the psychological toll exacted by cancer. The emotional and psychological burdens should be recognized and comprehended, as they encompass experiences of anxiety, depression, and a profound sense of helplessness and guilt.

From a psychological perspective, the interplay between caregiver mental health and the patient's prognosis unfolds as a complex and interconnected narrative. Elevated levels of caregiver stress and depression may potentially have an adverse impact on the patient's overall well-being. This intricate relationship between caregiver and patient well-being underscores the imperative nature of addressing caregiver mental health from a psychological perspective[2].

The central aim of this research is to underscore the critical importance of caregiver mental health from a psychological vantage point and to offer insights into effective psychological strategies for support and intervention. By deepening our comprehension of caregiver well-being from a psychological perspective, this study endeavours to contribute to a more comprehensive understanding of holistic cancer care. It is designed to equip healthcare professionals, psychologists, support organizations and families with a deeper understanding of the psychological dynamics at play. Ultimately, the goal is to enhance the overall quality of life for both patients and their caregivers and to encourage a more comprehensive and empathetic approach to the cancer journey. This approach recognizes and addresses the unique psychological challenges faced by those who selflessly provide care.

In the following sections, we will delve more profoundly into the psychological aspects of caregiving, examining the psychological stressors, coping mechanisms and psychological interventions that can alleviate the mental health burden on caregivers. This approach aims to foster a more psychologically informed perspective on cancer caregiving, benefitting both the patient and the caregiver.

2. Caregiver Roles and Stress

Caring for a loved one grappling with cancer entails a multitude of responsibilities, often borne by family members or close friends who play a significant role in the patient's journey. These caregivers serve as emotional anchors, offering comfort, empathy and solace, guiding patients through the emotional turbulence that often accompanies cancer [4,6]. Additionally, caregivers frequently find themselves assisting with the patient's daily living activities, such as bathing, dressing, feeding and providing mobility support. This role becomes even more critical when cancer or its treatments result in physical limitations[7]. Caregivers also shoulder the responsibility of medication management, ensuring that the patient's medications are coordinated and taken as prescribed. Transportation is another significant role they play, as they are tasked with shuttling patients to and from medical appointments and treatment sessions. Moreover, caregivers serve as advocates within the healthcare system, ensuring that the patient's concerns are heard and that they receive the best possible care.

Beyond these practical responsibilities, caregivers often find themselves managing household chores and responsibilities, stepping in when the patient's energy and capability are diminished. They act as a vital communication link between the patient and healthcare providers, relaying information, discussing treatment options and ensuring the patient's preferences are taken into account. In addition to these roles, caregivers provide essential companionship, offering moments of joy, meaningful conversations, and emotional support[8].

However, the multifaceted roles and responsibilities of caregivers are accompanied by significant stress. Various factors contribute to this stress, including the emotional impact of witnessing a loved one's suffering, which can lead to feelings of sadness, anxiety, and grief. The emotional toll is often underestimated, yet it is a significant aspect of the caregiver's experience[9,10].

The physical demands of caregiving are not to be understated. Assisting with mobility, lifting and managing medications can result in caregiver fatigue and physical stress. These demands take a toll on the caregiver's own physical health, as they may find themselves neglecting their own well-being while prioritizing the patient's needs[11].

The time commitment involved in caregiving is noteworthy. Caregivers juggle a multitude of responsibilities, including their personal daily tasks and often their work obligations[12]. This leaves them with limited personal time and self-care opportunities. They frequently sacrifice their own leisure and self-care to meet the needs of the patient[13].

Furthermore, the financial strain associated with caregiving can be substantial. Medical expenses, transportation costs and the potential need to reduce work hours or take time off can lead to financial stress[14]. Caregivers may not only bear the financial burden of cancer but also find themselves incurring significant out-of-pocket expenses related to the patient's care. The social isolation stemming from caregiving can be particularly challenging[15]. Caregivers often find themselves with limited time for personal relationships and activities, which can lead to feelings of loneliness and isolation. This isolation can be emotionally distressing and exacerbate the overall stress experienced by caregivers.

Anticipatory grief is a common experience among caregivers. The need to prepare for the potential loss of a loved one can be emotionally distressing. Caregivers often grapple with feelings of sadness, anxiety, and grief as they confront the uncertain future[16,17].

The uncertainty surrounding cancer and its treatment can contribute to emotional stress. Caregivers may find themselves constantly worrying about the patient's condition, prognosis and treatment outcomes. The ever-present uncertainty can add to their emotional burden. The lack of self-care is a recurrent theme among caregivers[18]. In their dedication to the patient's well-being, caregivers frequently neglect their own self-care practices, such as exercise, relaxation and personal time. This lack of self-care can have detrimental effects on their physical and emotional well-being[19,20].

Recognizing these caregiver roles and the associated stressors is vital for providing support and developing interventions to help them manage the challenges they face while caring for loved ones with cancer. Caregivers need comprehensive support to address not only the practical aspects of caregiving but also their emotional well-being. By acknowledging and understanding these challenges, healthcare professionals and support organizations can better tailor their services to alleviate caregiver stress and enhance the quality of care provided to cancer patients. Caregivers play an indispensable role in the patient's journey and supporting them is essential for the well-being of caregiver.

3. Impact on Care Recipients

The mental health of caregivers plays a pivotal role in shaping the quality of care provided to cancer patients. It is undeniable that the emotional and psychological well-being of caregivers has a direct and profound impact on their ability to offer effective care. When caregivers are in good mental health, they are better equipped to provide the emotional support and practical assistance that care recipients require[21].

Caregivers who experience lower levels of stress, anxiety and depression tend to exhibit greater patience and empathy in their interactions with care recipients[22]. They are more adept at offering a reassuring and supportive presence, a quality that significantly eases the emotional burden borne by cancer patients. Moreover, caregivers in good mental health are better positioned to manage the complex responsibilities of coordinating medical care, administering medications, and advocating on behalf of care recipients within the healthcare system[23]. This results in enhanced communication among the patient, caregiver and medical professionals, ultimately contributing to an improved overall quality of care[22,24].

Conversely, when caregivers grapple with high levels of stress or emotional distress, their capacity to maintain the same level of care quality is compromised. Their emotional well-being directly influences their ability to respond effectively to the needs of care recipients[25]. Stress and caregiver burnout can lead to impatience, frustration and a diminished capacity to provide the emotional support that individuals coping with cancer require. This, in turn, can negatively impact the emotional well-being and overall quality of life of the care recipient[26].

The emotional and psychological well-being of care recipients is intricately intertwined with the mental health of their caregivers[27]. Care recipients are acutely attuned to the emotional state of their caregivers and any distress or anxiety experienced by caregivers can have a direct impact on the emotional and psychological health of care recipients[28].

When caregivers exhibit emotional stability and provide consistent emotional support, care recipients frequently experience reduced anxiety and depression[29]. They are more likely to feel secure and comforted and this can have a positive influence on their emotional well-being. A supportive caregiver can offer reassurance during moments of fear or anxiety, creating an environment where care recipients are better equipped to cope with the challenges of cancer[21,28].

In contrast, when caregivers are under significant stress, care recipients may internalize this distress, resulting in heightened emotional turmoil. Care recipients can become more anxious, worried and may even feel responsible for their caregiver's emotional state. This emotional burden can intensify the psychological distress that often accompanies a cancer diagnosis[30,31].

Furthermore, the overall quality of care provided by distressed caregivers may be compromised, potentially impacting the physical well-being of care recipients[32]. For instance, care recipients may experience difficulties in medication management or lapses in medical care coordination when caregivers are under stress[33]. These practical challenges can have direct consequences on the health and prognosis of care recipients, further exacerbating their emotional and psychological distress[34,35].

Recognizing the profound influence of caregiver mental health on care quality and the emotional and psychological well-being of care recipients underscores the necessity of comprehensive support systems designed to address the emotional needs of caregivers. By prioritizing the mental well-being of caregivers, healthcare professionals and support organizations can positively impact the care provided to cancer patients and alleviate the emotional and psychological challenges faced by care recipients.

4. Coping Strategies and Resilience

One foundational aspect of coping for caregivers is the practice of emotional expression. Whether through candid conversations with friends, active participation in support groups, or personal solace found in journaling, articulating and sharing feelings becomes an essential cathartic outlet[36]. This emotional release is crucial, preventing overwhelm and fostering a sense of connection with others who understand the unique challenges they face.

In tandem, seeking social support plays a pivotal role in caregivers' coping strategies. Engaging with peer groups and online communities provides a space where mutual understanding and emotional sustenance thrive[37]. The ability to share experiences, exchange advice and receive empathetic support from those traversing similar paths becomes a lifeline, mitigating the potential sense of isolation that often accompanies such a demanding role[38].

Recognizing the importance of their well-being, caregivers prioritize self-care practices. This involves ensuring adequate sleep, maintaining a wholesome diet and integrating activities that bring personal joy and relaxation[39]. Caregivers understand that their emotional and physical health is directly linked to their ability to provide effective care, making self-care a fundamental aspect of their coping strategy[40,41].

Effective time management is another skill caregivers hone as part of their coping mechanisms. Juggling diverse responsibilities, from medical appointments to daily living tasks, requires careful organization and prioritization[42]. This skill not only helps caregivers maintain control amidst challenges but also contributes to a more sustainable caregiving routine.

Proactive education about the specific cancer diagnosis, treatments and potential challenges emerges as a key coping mechanism for caregivers[43]. Armed with knowledge, caregivers can make informed decisions, anticipate the evolving needs of the care recipient and communicate effectively with healthcare professionals. This empowerment through education enhances their ability to navigate the complex medical landscape, providing a sense of control and mastery over the caregiving role[44,45].

Mindfulness and relaxation techniques, such as meditation and deep-breathing exercises, offer caregivers a means to manage stress and cultivate emotional resilience[44]. These practices become invaluable tools, allowing caregivers to stay grounded in the present moment and cope with the emotional toll of witnessing a loved one's illness[46].

Moreover, professional counselling becomes a structured avenue for caregivers to navigate complex emotions. Therapists provide support in managing grief, exploring coping strategies and fostering emotional well-being[47,48]. This external support system is tailored to address the unique challenges that caregivers face, providing a confidential and empathetic space for them to express and process their emotions[49,50].

Each of these coping mechanisms contributes to the caregiver's ability to navigate the emotional intricacies of the cancer journey. It's an ongoing process of self-discovery and adaptation, recognizing that the emotional landscape is dynamic and requires a diverse toolkit for effective coping[51]. In tandem with coping strategies, resilience among caregivers is shaped by various factors[52]. A robust social support network, comprised of family, friends, or support groups, fosters a sense of belonging and encouragement. Knowing they are not alone in their challenges provides caregivers with a safety net, a community that understands and validates their experiences[53,54].

Maintaining a positive mindset, even in the face of adversity, characterizes resilient caregivers. They view challenges as opportunities for growth and learning, reframing difficulties as part of a broader journey that includes moments of strength and personal development[55,56].

Flexibility in adapting to evolving circumstances is a hallmark of resilience. Resilient caregivers recognize the unpredictability of the cancer journey and develop the ability to adjust their expectations and plans accordingly[57]. This adaptability is crucial in the face of ever-changing medical conditions and the dynamic nature of caregiving[58].

A clear sense of purpose and commitment to the well-being of their loved one provides resilient caregivers with a motivational anchor[59]. This sense of purpose becomes a driving force during challenging times, sustaining them through moments of doubt and fatigue. It offers a profound source of meaning, transcending the difficulties of the caregiving role[60].

Effective communication, both within the healthcare system and within the caregiver's personal network, is a contributing factor to resilience[61]. Resilient caregivers are adept communicators, expressing their needs, seeking assistance when required and maintaining open channels of communication with healthcare professionals, family members, and the care recipient[62].

Cognitive coping strategies, such as reframing negative thoughts and finding meaning in experiences, enhance emotional strength[63]. Resilient caregivers approach challenges with a mindset that allows them to find silver linings and derive meaning from even the most difficult situations. This cognitive flexibility contributes to their emotional adaptability and strength[64].

Additionally, self-efficacy, the belief in one's ability to navigate challenges, is a fundamental aspect of resilience. Resilient caregivers possess a strong sense of self-efficacy, recognizing their capabilities and feeling confident in their ability to provide effective care[65,66]. Building this belief involves acknowledging accomplishments, no matter how small, and recognizing personal strengths[67].

Access to resources that support well-being further fortifies caregiver resilience. Resilient caregivers have a safety net of informational materials, respite care services, and financial assistance[68]. These resources provide practical support during challenging times, offering a tangible support system that contributes to their overall resilience[69].

5. Support and Interventions

Within the sphere of cancer caregiving, a diverse array of support programs has emerged to address the intricate needs of caregivers. Educational initiatives serve to empower caregivers with comprehensive insights into cancer, while emotional and psychological support programs provide a crucial platform for shared experiences and communal strength[70,71]. Respite care initiatives offer essential temporary relief, acknowledging the relentless nature of caregiving, and financial assistance programs work to alleviate the considerable financial strains associated with cancer care[72,73].

Despite the rich landscape of support programs, caregivers often encounter impediments. Insufficient awareness, particularly in remote areas, geographical barriers, and the enduring stigma around seeking help pose significant challenges[74]. Financial constraints compound these difficulties, making it crucial to develop targeted awareness campaigns, innovative solutions for remote access and inclusive, cost-effective support options[75]. The overarching objective is to cultivate an accessible and supportive environment for every caregiver, ensuring they can navigate the intricacies of cancer caregiving with resilience and strength[76,77].

6. Future direction and implications

Embarking on the exploration of the uncharted landscape of caregiver mental health within the context of the cancer journey, this research lays the groundwork for future investigations and meaningful applications. Delving into the nuanced experiences of caregivers, forthcoming studies may delve into cultural and socioeconomic influences, as well as the unique challenges at different stages of the caregiving journey.

Longitudinal studies offer the potential for a comprehensive understanding of the dynamic interplay between caregiving responsibilities and mental well-being over time. The findings accentuate the necessity for targeted interventions tailored to the diverse challenges faced by caregivers, prompting future research to concentrate on the development and testing of such interventions. Practical implications encompass the integration of technology, the inclusion of caregiver perspectives in healthcare policies, educational initiatives for healthcare professionals and the establishment of robust support networks.

Beyond academia, this research advocates for advancing public awareness and destigmatization, fostering a culture of empathy and support. Ultimately, the implications resonate across healthcare practices, societal attitudes and the daily lives of caregivers, contributing to a more compassionate and supportive landscape for those navigating the intricate journey of cancer care.

7. Conclusion

In unravelling the intricate tapestry of caregiver mental health within the context of the cancer journey, this research has illuminated a crucial yet often overlooked facet of the caregiving experience. As we journeyed through the narratives, challenges and coping mechanisms of caregivers, a profound understanding emerged of the emotional toll borne by those who provide unwavering support. The emotional and psychological complexities entwined with caregiving underscore the urgency of recognizing and addressing caregiver mental health as an integral component of comprehensive cancer care.

This exploration not only sheds light on the struggles faced by caregivers but also emphasizes the reciprocal relationship between caregiver well-being and the quality of care provided to individuals facing cancer. The emotional burdens, from anxiety to a profound sense of helplessness, are not merely personal challenges but ripple through the fabric of the entire caregiving dynamic.

The implications of this research extend beyond academic discourse into tangible strategies and interventions. Targeted support programs, technological innovations and a cultural shift towards destigmatization are pivotal in shaping a landscape where caregivers receive the recognition, assistance and empathy they rightfully deserve. This research sparks a broader conversation, fostering a more compassionate and inclusive approach to the complexities of the cancer journey.

In conclusion, understanding and addressing caregiver mental health is not just an academic pursuit; it's a call to action for healthcare professionals, support organizations, policymakers and society at large. By recognizing the unique challenges faced by caregivers and implementing comprehensive strategies for support, we aim to enrich the lives of those navigating the intricate path of cancer care. As we advocate for a holistic approach that encompasses both patients and caregivers, we move towards a future where the caregiving experience is not only acknowledged but prioritized, ensuring that no caregiver faces the journey alone.

Compliance with ethical standards

Disclosure of conflict of interest

No Conflict of interest to Declare.

References

- [1] Yang WFZ, Lee RZY, Kuparasundram S, Tan T, Chan YH, Griva K, et al. Cancer caregivers unmet needs and emotional states across cancer treatment phases. *PLoS One* 2021;16. <https://doi.org/10.1371/JOURNAL.PONE.0255901>.

- [2] Litzelman K. Caregiver Well-being and the Quality of Cancer Care. *Semin Oncol Nurs* 2019;35:348. <https://doi.org/10.1016/J.SONCN.2019.06.006>.
- [3] Yiin JJ, Chen YY, Lee KC. Fatigue and Vigilance-Related Factors in Family Caregivers of Patients with Advanced Cancer: A Cross-sectional Study. *Cancer Nurs* 2022;45:E621–7. <https://doi.org/10.1097/NCC.0000000000000944>.
- [4] Alsirafy SA, Nagy R, Hassan AD, Fawzy R, Abdelhafeez AAM, Husein MO, et al. Caregiver burden among family caregivers of incurable cancer patients in two eastern Mediterranean countries. *BMC Palliat Care* 2021;20:1–8. <https://doi.org/10.1186/S12904-021-00857-5/FIGURES/1>.
- [5] Johansen S, Cvancarova M, Ruland C. The Effect of Cancer Patients' and Their Family Caregivers' Physical and Emotional Symptoms on Caregiver Burden. *Cancer Nurs* 2018;41:91–9. <https://doi.org/10.1097/NCC.0000000000000493>.
- [6] Mishra S, Gulia A, Satapathy S, Gogia A, Sharma A, Bhatnagar S. Caregiver Burden and Quality of Life among Family Caregivers of Cancer Patients on Chemotherapy: A Prospective Observational Study. *Indian J Palliat Care* 2021;27:109. https://doi.org/10.4103/IJPC.IJPC_180_20.
- [7] Kim Y, Lin J, Epel ES, Carver CS. A Lens on Caregiver Stress in Cancer: Longitudinal Investigation of Cancer-Related Stress and Telomere Length among Family Caregivers of Adult Patients with Cancer. *Psychosom Med* 2023;85:527–34. <https://doi.org/10.1097/PSY.0000000000001220>.
- [8] Junkins CC, Kent E, Litzelman K, Bevans M, Cannady RS, Rosenberg AR. Cancer across the ages: a narrative review of caregiver burden for patients of all ages. *J Psychosoc Oncol* 2020;38:782–98. <https://doi.org/10.1080/07347332.2020.1796887>.
- [9] Segrin C, Badger TA, Sikorskii A, Crane TE, Pace TWW. A dyadic analysis of stress processes in Latinas with breast cancer and their family caregivers. *Psychooncology* 2018;27:838–46. <https://doi.org/10.1002/PON.4580>.
- [10] Otto AK, Gonzalez BD, Heyman RE, Vadaparampil ST, Ellington L, Reblin M. Dyadic effects of distress on sleep duration in advanced cancer patients and spouse caregivers. *Psychooncology* 2019;28:2358–64. <https://doi.org/10.1002/PON.5229>.
- [11] Saimaldaher ZH, Wazqar DY. Relationships between caregiving stress, mental health and physical health in family caregivers of adult patients with cancer: implications for nursing practice. *Scand J Caring Sci* 2020;34:889–98. <https://doi.org/10.1111/SCS.12795>.
- [12] Theodoropoulos N, Xie H, Wang Q, Li Y, Wen C. Financial stress and burden among caregivers of cancer survivors in the United States. https://doi.org/10.1200/JCO.2022.40.16_SUPPL.12027 https://doi.org/10.1200/JCO.2022.40.16_SUPPL.12027.
- [13] Onyeneho C, Ilesanmi R. Burden of Care and Perceived Psycho-Social Outcomes among Family Caregivers of Patients Living with Cancer. *Asia Pac J Oncol Nurs* 2021;8:330–6. <https://doi.org/10.4103/2347-5625.308678>.
- [14] Bradley CJ. Economic Burden Associated with Cancer Caregiving. *Semin Oncol Nurs* 2019;35:333. <https://doi.org/10.1016/J.SONCN.2019.06.003>.
- [15] Howard AF, Lynch K, Thorne S, Porcino A, Lambert L, De Vera MA, et al. Occupational and Financial Setbacks in Caregivers of People with Colorectal Cancer: Considerations for Caregiver-Reported Outcomes. *Current Oncology* 2022;29:8180. <https://doi.org/10.3390/CURRONCOL29110646>.
- [16] Li C, Tang N, Yang L, Zeng Q, Yu T, Pu X, et al. Effect of caregiver burden on anticipatory grief among caregivers of elderly cancer patients: Chain mediation role of family functioning and resilience. *Front Psychol* 2022;13. <https://doi.org/10.3389/FPSYG.2022.1020517>.
- [17] Mah K, Swami N, Pope A, Earle CC, Krzyzanowska MK, Nissim R, et al. Caregiver bereavement outcomes in advanced cancer: associations with quality of death and patient age. *Supportive Care in Cancer* 2022;30:1343. <https://doi.org/10.1007/S00520-021-06536-8>.
- [18] Guan T, Qan'ir Y, Song L. Systematic review of illness uncertainty management interventions for cancer patients and their family caregivers. *Supportive Care in Cancer* 2021;29:4623. <https://doi.org/10.1007/S00520-020-05931-X>.
- [19] Basile NL, Chardon ML, Peugh J, Edwards CS, Szulcowski L, Morrison CF, et al. Relationship Between Caregiver Uncertainty, Problem-Solving, and Psychological Adjustment in Pediatric Cancer. *J Pediatr Psychol* 2021;46:1258–66. <https://doi.org/10.1093/JPEPSY/JSAB065>.

- [20] Guan T, Chapman M V., de Saxe Zerden L, Sharma A, Chen DG, Song L. Correlates of illness uncertainty in cancer survivors and family caregivers: a systematic review and meta-analysis. *Support Care Cancer* 2023;31:242–242. <https://doi.org/10.1007/S00520-023-07705-7>.
- [21] Decadt I, Laenen A, Celus J, Geyskens S, Vansteenlandt H, Coolbrandt A. Caregiver distress and quality of life in primary caregivers of oncology patients in active treatment and follow-up. *Eur J Cancer Care (Engl)* 2021;30:e13399. <https://doi.org/10.1111/ECC.13399>.
- [22] Loh KP, Mohamed MR, Kadambi S, Culakova E, Xu H, Magnuson A, et al. Caregiver–Oncologist Prognostic Concordance, Caregiver Mastery, and Caregiver Psychological Health and Quality of Life. *Oncologist* 2021;26:310–7. <https://doi.org/10.1002/ONCO.13699>.
- [23] del-Pino-Casado R, Espinosa-Medina A, López-Martínez C, Orgeta V. Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. *J Affect Disord* 2019;242:14–21. <https://doi.org/10.1016/J.JAD.2018.08.002>.
- [24] Falzarano FB, Cimarolli V, Siedlecki KL. Staying in the loop: Quality of family-paid caregiver communication and influences on resident mental health in long-term care. *J Am Geriatr Soc* 2023;71:1209–19. <https://doi.org/10.1111/JGS.18184>.
- [25] Ravyts SG, Dzierzewski JM. Sleep Disturbance, Mental Health Symptoms, and Quality of Life: A Structural Equation Model Assessing Aspects of Caregiver Burden. *Clin Gerontol* 2020. <https://doi.org/10.1080/07317115.2020.1783042>.
- [26] Bonsu AS, Salifu Yendork J, Teye-Kwadjo E. The influence of caregiver stress and affiliate stigma in community-based mental health care on family caregiver wellbeing. *Int J Ment Health* 2020;49:35–55. <https://doi.org/10.1080/00207411.2020.1717053>.
- [27] Taylor J, Fradgley E, Clinton-McHarg T, Byrnes E, Paul C. What are the sources of distress in a range of cancer caregivers? A qualitative study. *Supportive Care in Cancer* 2021;29:2443–53. <https://doi.org/10.1007/S00520-020-05742-0/METRICS>.
- [28] Peh CX, Liu J, Mahendran R. Quality of life and emotional distress among caregivers of patients newly diagnosed with cancer: Understanding trajectories across the first year post-diagnosis. *J Psychosoc Oncol* 2020;38:557–72. <https://doi.org/10.1080/07347332.2020.1760994>.
- [29] Cochrane A, Reid O, Woods S, Gallagher P, Dunne S. Variables associated with distress amongst informal caregivers of people with lung cancer: A systematic review of the literature. *Psychooncology* 2021;30:1246–61. <https://doi.org/10.1002/PON.5694>.
- [30] Dionne-Odom JN, Azuero A, Taylor RA, Wells RD, Hendricks BA, Bechthold AC, et al. Resilience, preparedness, and distress among family caregivers of patients with advanced cancer. *Supportive Care in Cancer* 2021;29:6913–20. <https://doi.org/10.1007/S00520-021-06265-Y/METRICS>.
- [31] Badger T, Segrin C, Crane T, Morrill K, Sikorskii A. Social determinants of health, psychological distress, and caregiver burden among informal cancer caregivers of cancer survivors during treatment. *J Psychosoc Oncol* 2023. <https://doi.org/10.1080/07347332.2023.2248486>.
- [32] Ochoa CY, Buchanan Lunsford N, Lee Smith J. Impact of informal cancer caregiving across the cancer experience: A systematic literature review of quality of life. *Palliat Support Care* 2020;18:220–40. <https://doi.org/10.1017/S1478951519000622>.
- [33] Limonero JT, Maté-Méndez J, Gómez-Romero MJ, Mateo-Ortega D, González-Barboteo J, Bernaus M, et al. Family caregiver emotional distress in advanced cancer: the DME-C scale psychometric properties. *BMJ Support Palliat Care* 2023;13:e177–84. <https://doi.org/10.1136/BMJSPCARE-2020-002608>.
- [34] Kirk DL, Kabdebo I, Whitehead L. Prevalence of distress and its associated factors among caregivers of people diagnosed with cancer: A cross-sectional study. *J Clin Nurs* 2022;31:3402–13. <https://doi.org/10.1111/JOCN.16167>.
- [35] Taleghani F, Ehsani M, Farzi S, Farzi S, Adibi P, Moladoost A, et al. Challenges to Family Caregivers in Caring for Gastric Cancer Patients from Perspectives of Family Caregivers, Patients, and Healthcare Providers: A Qualitative Study. *Indian J Palliat Care* 2021;27:521–9. https://doi.org/10.25259/IJPC_98_21.
- [36] Seiler A, Jenewein J. Resilience in cancer patients. *Front Psychiatry* 2019;10:409247. <https://doi.org/10.3389/FPSYT.2019.00208/BIBTEX>.

- [37] Washington KT, Oliver DP, Benson JJ, Rolbiecki AJ, Jorgensen LA, Cruz-Oliver DM, et al. Factors influencing engagement in an online support group for family caregivers of individuals with advanced cancer. *J Psychosoc Oncol* 2020;38:235–50. <https://doi.org/10.1080/07347332.2019.1680592>.
- [38] Ahn S, Romo RD, Campbell CL. A systematic review of interventions for family caregivers who care for patients with advanced cancer at home. *Patient Educ Couns* 2020;103:1518–30. <https://doi.org/10.1016/j.pec.2020.03.012>.
- [39] Teixeira RJ, Applebaum AJ, Bhatia S, Brandão T. The impact of coping strategies of cancer caregivers on psychophysiological outcomes: an integrative review. *Psychol Res Behav Manag* 2018;11:207–15. <https://doi.org/10.2147/PRBM.S164946>.
- [40] Nayak MG, George A. Effectiveness of Multicomponent Intervention on Quality of Life of Family Caregivers of Cancer Patients. *Asian Pac J Cancer Prev* 2021;22:2789. <https://doi.org/10.31557/APJCP.2021.22.9.2789>.
- [41] Chen X, Wang Z, Zhou J, Li Q. Intervention and coping strategies for self-perceived burden of patients with cancer: A systematic review. *Asia Pac J Oncol Nurs* 2023;10:100231. <https://doi.org/10.1016/j.apjon.2023.100231>.
- [42] Kazemi A, Azimian J, Mafi M, Allen KA, Motalebi SA. Caregiver burden and coping strategies in caregivers of older patients with stroke. *BMC Psychol* 2021;9:1–9. <https://doi.org/10.1186/S40359-021-00556-Z/TABLES/3>.
- [43] Tan JYS, Lam KFY, Lim HA, Chua SM, Kua EH, Griva K, et al. Post-intervention sustainability of a brief psycho-educational support group intervention for family caregivers of cancer patients. *Asia-Pacific Psychiatry* 2018;10:e12305. <https://doi.org/10.1111/APPY.12305>.
- [44] Cheng Q, Xu B, Ng MSN, Duan Y, So WKW. Effectiveness of psychoeducational interventions among caregivers of patients with cancer: A systematic review and meta-analysis. *Int J Nurs Stud* 2022;127:104162. <https://doi.org/10.1016/j.ijnurstu.2021.104162>.
- [45] Alfano CM, Leach CR, Smith TG, Miller KD, Alcaraz KI, Cannady RS, et al. Equitably improving outcomes for cancer survivors and supporting caregivers: A blueprint for care delivery, research, education, and policy. *CA Cancer J Clin* 2019;69:35–49. <https://doi.org/10.3322/CAAC.21548>.
- [46] Vinci C, Reblin M, Bulls H, Malkhasyan L, Jim H, Pidala J, et al. Understanding coping strategies of cancer caregivers to inform mindfulness-based interventions: A qualitative study. *Eur J Integr Med* 2019;30:100936. <https://doi.org/10.1016/j.eujim.2019.100936>.
- [47] Sam S, Appavu S, Chellappan S. Asian Journal of Nursing Education and Research Effect of counselling on burden and coping among caregivers of cancer patients with Terminal illness. *Asian Journal of Nursing Education and Research* n.d.;9:2349–996. <https://doi.org/10.5958/2349-2996.2019.00071.5>.
- [48] Applebaum AJ, Buda KL, Schofield E, Farberov M, Teitelbaum ND, Evans K, et al. Exploring the cancer caregiver’s journey through web-based Meaning-Centered Psychotherapy. *Psychooncology* 2018;27:847–56. <https://doi.org/10.1002/PON.4583>.
- [49] Hong B, Yang S, Hyeon S, Lee J, Ac) J. Third-wave psychotherapy for caregivers of cancer patients: a scoping review 2023. <https://doi.org/10.21203/RS.3.RS-1960441/V1>.
- [50] Sak-Dankosky N, Sherwood P, Vehviläinen-Julkunen K, Kvist T. Interventions improving well-being of adult cancer patients’ caregivers: A systematic review. *J Adv Nurs* 2022;78:2747–64. <https://doi.org/10.1111/JAN.15320>.
- [51] Mosher CE, Secinti E, Johns SA, O’Neil BH, Helft PR, Shahda S, et al. Examining the effect of peer helping in a coping skills intervention: a randomized controlled trial for advanced gastrointestinal cancer patients and their family caregivers. *Quality of Life Research* 2018;27:515–28. <https://doi.org/10.1007/S11136-017-1620-7/METRICS>.
- [52] Palacio G C, Krikorian A, Gómez-Romero MJ, Limonero JT. Resilience in Caregivers: A Systematic Review. <https://doi.org/10.1177/1049909119893977> 2019;37:648–58. <https://doi.org/10.1177/1049909119893977>.
- [53] Long NX, Ngoc NB, Phung TT, Linh DTD, Anh TN, Hung NV, et al. Coping strategies and social support among caregivers of patients with cancer: a cross-sectional study in Vietnam. *AIMS Public Health* 2021;8:1. <https://doi.org/10.3934/PUBLICHEALTH.2021001>.
- [54] Rachel K, Rukundo GZ, Mutto M, Orem J, Niyonzima N, Kizito S, et al. Coping and Caregiving-Satisfaction among Caregivers of Patients with Cancer at the Uganda Cancer Institute and Mbarara Regional Referral Hospital in Uganda. *Open J Med Psychol* 2022;11:170–81. <https://doi.org/10.4236/OJMP.2022.113013>.

- [55] Chen J, Xiao H, Chen Y, Sun H, Chen S, Zheng J. Effect of reminiscence therapy based on positive psychology theory (RTBPPT) on the positive feelings of the spousal caregivers of elderly patients with advanced cancer in China. *Eur J Cancer Care (Engl)* 2020;29:e13324. <https://doi.org/10.1111/ECC.13324>.
- [56] Geng L, Wang J, Cheng L, Zhang B, Sheng H. Mindful Learning Improves Positive Feelings of Cancer Patients' Family Caregivers. *International Journal of Environmental Research and Public Health* 2019, Vol 16, Page 248 2019;16:248. <https://doi.org/10.3390/IJERPH16020248>.
- [57] Gibbons SW, Ross A, Wehrlen L, Klagholz S, Bevans M. Enhancing the cancer caregiving experience: Building resilience through role adjustment and mutuality. *European Journal of Oncology Nursing* 2019;43:101663. <https://doi.org/10.1016/J.EJON.2019.09.004>.
- [58] Ağaç M, Üzar-Özçetin YS. Psychological Resilience, Metacognitions, and Fear of Recurrence among Cancer Survivors and Family Caregivers. *Cancer Nurs* 2022;45:E454–62. <https://doi.org/10.1097/NCC.0000000000000973>.
- [59] Stjernswärd S, Hansson L. A Qualitative Study of Caregivers' Experiences, Motivation and Challenges Using a Web-Based Mindfulness Intervention. *Community Ment Health J* 2020;56:416–25. <https://doi.org/10.1007/S10597-019-00477-7/TABLES/1>.
- [60] Palmer Kelly E, Meara A, Hyer M, Payne N, Pawlik TM. Understanding the Type of Support Offered Within the Caregiver, Family, and Spiritual/Religious Contexts of Cancer Patients. *J Pain Symptom Manage* 2019;58:56–64. <https://doi.org/10.1016/J.JPAINSYMMAN.2019.03.003>.
- [61] Li J, Luo X, Cao Q, Lin Y, Xu Y, Li Q. Communication Needs of Cancer Patients and/or Caregivers: A Critical Literature Review. *J Oncol* 2020;2020. <https://doi.org/10.1155/2020/7432849>.
- [62] Ellington L, Clayton MF, Reblin M, Donaldson G, Latimer S. Communication among cancer patients, caregivers, and hospice nurses: Content, process and change over time. *Patient Educ Couns* 2018;101:414–21. <https://doi.org/10.1016/J.PEC.2017.09.013>.
- [63] Özönder Ünal I, Ordu C. Decoding Caregiver Burden in Cancer: Role of Emotional Health, Rumination, and Coping Mechanisms. *Healthcare* 2023, Vol 11, Page 2700 2023;11:2700. <https://doi.org/10.3390/HEALTHCARE11192700>.
- [64] Harvey JA, Manusov V, Sanders EA. Improving cancer caregivers' emotion regulation and supportive message characteristics: Results of a randomized controlled expressive writing intervention*. *Commun Monogr* 2019;86:1–22. <https://doi.org/10.1080/03637751.2018.1521983>.
- [65] van Hof KS, Hoesseini A, Verdonck-de Leeuw IM, Jansen F, Leemans CR, Takes RP, et al. Self-efficacy and coping style in relation to psychological distress and quality of life in informal caregivers of patients with head and neck cancer: a longitudinal study. *Supportive Care in Cancer* 2023;31:1–10. <https://doi.org/10.1007/S00520-022-07553-X/FIGURES/2>.
- [66] Thomas Hebdon MC, Coombs LA, Reed P, Crane TE, Badger TA. Self-efficacy in caregivers of adults diagnosed with cancer: An integrative review. *Eur J Oncol Nurs* 2021;52. <https://doi.org/10.1016/J.EJON.2021.101933>.
- [67] Cheng HL, Leung DYP, Ko PS, Lam WM, Lam PT, Luk AL, et al. Mediating role of self-efficacy between unmet needs and quality of life in palliative cancer caregivers. *Psychooncology* 2023;32:457–64. <https://doi.org/10.1002/PON.6099>.
- [68] Demiris G, Washington K, Ulrich CM, Popescu M, Oliver DP. Innovative Tools to Support Family Caregivers of Persons with Cancer: The Role of Information Technology. *Semin Oncol Nurs* 2019;35:384–8. <https://doi.org/10.1016/J.SONCN.2019.06.013>.
- [69] Chua GP, Ng QS, Tan HK, Ong WS. Caregivers of cancer patients: what are their information-seeking behaviours and resource preferences? *Ecancermedalscience* 2020;14. <https://doi.org/10.3332/ECANCER.2020.1068>.
- [70] Marzorati C, Bailo L, Mazzocco K, Pravettoni G. Empowerment from patient's and caregiver's perspective in cancer care. *Health Psychol Open* 2018;5. https://doi.org/10.1177/2055102918815318/ASSET/IMAGES/LARGE/10.1177_2055102918815318-FIG1.JPEG.
- [71] Dierickx S, Matthys O, Deliëns L, De Vleminck A, Lapeire L, Hudson P, et al. Development of an eHealth program to empower people with advanced cancer and their family caregivers: Presenter(s): Vincent Van Goethem, Ghent University/End-of-life Care Research Group, Belgium. *Patient Educ Couns* 2023;109:38. <https://doi.org/10.1016/J.PEC.2022.10.095>.

- [72] Vandenbogaerde I, Cohen J, Hudson P, Van Audenhove C, Deliens L, De Vleminck A. Support from healthcare professionals in empowering family carers to discuss advance care planning: A population-based survey. <https://doi.org/10.1177/02692163221135032> 2022;37:719–29. <https://doi.org/10.1177/02692163221135032>.
- [73] Jivraj N, Gallagher LO, Papadacos J, Abdelmutti N, Trang A, Ferguson SE. Empowering patients and caregivers with knowledge: The development of a nurse-led gynecologic oncology chemotherapy education class. *Canadian Oncology Nursing Journal* 2018;28:4. <https://doi.org/10.5737/2368807628147>.
- [74] Hamedani B, Alavi M, Taleghani F, Moghadam MF. Requirements for promoting help-seeking behaviors in family caregivers of cancer patients: A qualitative study. *J Educ Health Promot* 2023;12:46. https://doi.org/10.4103/JEHP.JEHP_512_22.
- [75] Teglia F, Visci G, Zunarelli C, Collatuzzo G, Xiang E, Guzman P, et al. Balancing Work and Cancer Care: Challenges Faced by Employed Informal Caregivers. *Cancers* 2022, Vol 14, Page 4146 2022;14:4146. <https://doi.org/10.3390/CANCERS14174146>.
- [76] van Roij J, Brom L, Youssef-El Soud M, van de Poll-Franse L, Raijmakers NJH. Social consequences of advanced cancer in patients and their informal caregivers: a qualitative study. *Supportive Care in Cancer* 2019;27:1187–95. <https://doi.org/10.1007/S00520-018-4437-1/TABLES/2>.
- [77] Fereydooni S, Lorenz KA, Ganesh A, Satija A, Spruijt O, Bhatnagar S, et al. Empowering families to take on a palliative caregiver role for patients with cancer in India: Persistent challenges and promising strategies. *PLoS One* 2022;17:e0274770. <https://doi.org/10.1371/JOURNAL.PONE.0274770>.