Observatoire québécois de la proche aidance

CAREGIVING TRAJECTORY ONCOLOGY

LITERATURE REVIEW

THE TRAJECTORY OF **ONCOLOGY** CAREGIVERS

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CREDITS

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INTRODUCTION

CONTEXT

The caregiving experience can vary considerably, affected by factors that range from gender and age to service coordination and access, patient health, and level of support provided. To better understand the realities of caregivers, the Quebec Observatory on Caregiving, working with its expert advisory committee, has set out to establish trajectories that reflect the diversity of possible caregiving situations. This work aims to highlight the key moments, transitions and major challenges experienced by caregivers across an array of contexts, along with their various influencing factors. The present report focuses specifically on the literature pertaining to the caregiving trajectory of those who support a person with cancer in Quebec—a group variously referred to as ***cancer caregivers, oncology caregivers or caregivers in oncology***.

DOCUMENT ORGANIZATION

This report begins with a brief overview of the methodology used to conduct the review. Part I describes who cancer caregivers are, focusing on the contextual and sociodemographic factors that may influence the caregiving trajectory as well as the associated impacts. Part II examines the general trajectory of oncology caregiving, with a view to contextualizing the challenges experienced across the caregiving continuum.

METHODOLOGY

To develop the trajectory of caregivers in oncology, we began by reviewing 371 articles, using a keyword-based literature search (further methodological details will be provided in a separate document). Once the abstracts had been screened, 291 articles that did not address caregiving in oncology or that focused on pediatric oncology caregiving were excluded. The remaining 80 articles were then consulted and analyzed. During the literature review, a further 143 articles cited in various studies were added to our list. In sum, **195** articles were consulted and analyzed to develop the trajectory.

The information extracted from the literature was subsequently classified and organized in an Excel document, using the following categories:

TRAJECTORY	PORTRAIT
Entry	Ethnicity / cultural diversity
Recognition	Religion and spirituality
Caregiving duration & frequency	Education / employment / social class
Support / resources (caregiver)	Age
Obtaining information	Sexual and gender identity
Tools	Geographic location (urban / rural)
Support programs / interventions	Family background
Support groups	Caregiver physical and mental health
Workplace support for caregivers	
Influence of service organization on the support available to care recipients and caregivers	
Support / resources (care recipient)	
Care recipient's trajectory / disease progression and associated impairments	
Service organization and access	
Relationship with care recipient	
Social life / stigma / social isolation	
Exit from caregiving and post-caregiving period	

1. WHAT IS CAREGIVING IN ONCOLOGY?

1.1 CAREGIVING

Caregiving refers to a situation in which one or more individuals, called "caregivers," provide support to one or more members of their circle who have a temporary or permanent disability—physical, psychological, psychosocial, or otherwise—regardless of their age or living environment, and with whom they share an emotional, familial, or non-familial bond (5).

1.2 WHO ARE THE CAREGIVERS IN ONCOLOGY?

In the Canadian context, more research is needed to fully understand the specific context of cancer caregiving. According to a pan-Canadian survey, about 11% of all caregivers support someone with cancer (6). This makes cancer the second leading cause for requiring a caregiver after age-related problems (6).

Cancer caregivers are mostly female and typically the patient's spouse; have been employed within the past year; are in their mid-60s; and possess at least a high school diploma, with a significant number having completed some post-secondary education (7). These caregivers provide substantial and critical unpaid care, ranging from emotional support and household management to complex medical tasks, often with little to no formal training and recognition (8, 9). The caregivers of older adults are frequently older themselves, and roughly 40% have comorbidities of their own, making them more likely to report their health as "fair to poor" (8, 9).

For spousal caregivers, the caregiving role is often seen as a natural extension of the marital vow in sickness and in health, underscoring a deep emotional bond and the associated sense of duty (10). Beyond the influence of marital status, patients typically prefer their primary caregiver to be their spouse or partner, rather than other family members (10). While this profound commitment can be a source of resilience for the caregiver, it also risks rendering their caregiving invisible, since the role tends to be seen merely as an expected marital responsibility rather than a distinct and demanding role (10). As a result, compared to non-caregiving spouses, spousal caregivers report greater physical and psychological burden (11).

With outpatient cancer care increasingly the norm, the demand for caregivers continues to rise, underscoring the urgent need to better understand who they are, what they need, and how to effectively support them (12). Cancer is now recognized as a chronic condition: survivors frequently live with ongoing symptoms, functional impairments and late effects of treatment that require sustained caregiving for years (13). Compounding this situation is the fact that access to healthcare often declines once treatment ends, leaving caregivers to shoulder complex and persistent responsibilities—and with even less guidance or resources than during treatment (14). Palliative care carries the highest burden: caregiving hours surge, symptoms escalate, and existential concerns sharpen, particularly when referral comes late (15-19). Bereavement, in turn, introduces the risks of complicated grief, depression and identity loss, especially if caregivers feel unprepared or unsupported (17, 20-22), while post-caregiving can bring both disorientation and purpose voids as routines collapse (23). Recurrence is often more difficult than the first diagnosis, bringing cumulative fatigue, greater uncertainty and more onerous decision-making (24).

1.3 THE DIFFERENT FORMS OF SUPPORT AND RESPONSIBILITIES OF ONCOLOGY CAREGIVERS

Amid changing demographics and dwindling healthcare resources, caregivers are increasingly taking on critical roles once performed by healthcare professionals (25, 26). Cancer caregivers are among the groups who provide the highest levels of support, with many delivering over 10 hours of care per week, underscoring the intensity of their role (6). Although estimates of caregiving effort vary across studies, some report that cancer caregivers provide an average of 30 to 40 hours of care weekly (7, 27). Caregiving time is negatively correlated with the carer's degree of satisfaction with the available social support—a key buffer against caregiver burden—and, when care is not rotated among family members, primary caregivers are more likely to feel overwhelmed (28). While this substantial time commitment highlights the critical role of caregivers in safeguarding patients' well-being and quality of life, their involvement often goes underappreciated (1). Unlike the gradual decline typical of many chronic conditions, cancer's sudden onset and unpredictable trajectory can thrust caregivers into demanding and complex roles requiring swift adaptation, emotional resilience and sustained flexibility, all of it with little preparation (8, 29).

Cancer caregiving: higher hours, higher demands, higher toll

A comparative study of caregivers for individuals with cancer, dementia, diabetes and for frail older adults found that, after controlling for sociodemographic factors and caregiving duration, cancer and dementia caregivers provided assistance with a greater number of activities of daily living (ADLs); they also reported the highest levels of physical burden and psychological distress (30). The notable similarity between cancer and dementia caregiving in terms of physical strain and emotional stress is attributed, in part, to comparable levels of the functional assistance required, and, equally, to the perceived terminal nature of both diseases (30). It is worth noting that, whereas dementia caregiving largely involves managing the symptoms of cognitive impairment, cancer caregiving often entails various acute situations that arise from treatment (e.g., catheter care, management of emesis or fatigue) and require complex medical care (30). In addition, studies show that, compared with their non-cancer counterparts, cancer caregivers perform some of the highest numbers of caregiving hours and assist with the greatest number of ADLs (31).

Cancer caregiving spans a wide range of activities that often begin before diagnosis (e.g., seeking information, providing emotional support); intensify during treatment or the transition to palliative care; and can extend for years into long-term survivorship or if the cancer recurs (13, 32). Research suggests that patients who receive caregiver support are more likely to adhere to treatment (33). Greater caregiver-reported mastery of the role is also associated with improved patient survival (34). Each key caregiving role category is described below and summarized in **Table 1** (p. 7). Although the roles are presented separately, caregivers often assume multiple roles that overlap and shift over time as needs change throughout the cancer trajectory (32).

EMOTIONAL SUPPORT

Providing emotional support is one of the most common and essential roles in caregiving. Yet it is also one of the most demanding, as well as the task caregivers reportedly feel least prepared for (35). Emotional support can include offering companionship, listening to concerns, helping manage fear and uncertainty, and simply being present through the highs and lows of the cancer journey. Caregivers often attend appointments with the patient, engage in activities aimed at offering comfort and distraction, and bear the emotional burden—not just the patient's, but their own as well (6).

MEDICAL CARE

The complex medical tasks taken on by caregivers can differ, depending on the treatment patients receive. Caregivers can be heavily involved in administering oral chemotherapy or other medications, sometimes through catheters or feeding tubes, as well as performing wound care (6) (32, 36). One caregiver described it as follows:

> **You are the one who provides continuity between the pharmacy, the doctor and sometimes I was even more aware of what medication he was taking than the doctors. It becomes so overwhelming (37).**

A patient further elaborated on their caregiver's involvement:

> **[My caregiver looked after] making sure I had the proper appointments, the medication ready, hooking me up to the G-tube, ensuring my feeding was on track. Driving me to my appointments (38).**

Medical tasks are often new to caregivers, and most feel unprepared to perform them (38). Caregivers must also be ready to respond to acute and sometimes unpredictable treatment-related side effects like severe nausea and fever, which can rapidly alter caregiving responsibilities (36, 39). Since treatment renders many patients immunosuppressed, caregivers must remain vigilant to infection risks (1). Certain treatments, such as allogeneic bone marrow transplant, oblige caregivers to provide round-the-clock medical care for extended periods (40-42).

PERSONAL CARE

Supporting daily activities—including feeding, bathing, dressing, and assisting with transfers between the bed, chair and toilet—is a core aspect of caregiving. Logistical tasks, such as arranging or providing transportation to medical appointments, also constitute central responsibilities (43). Added to this, caregivers often promote healthy behaviours and help manage patients' nutrition as part of supporting their recovery (13, 27).

HOUSEHOLD TASKS

When a patient becomes ill, caregivers frequently step in to manage household duties that were once shared or handled entirely by the person with cancer. These may include grocery shopping, cooking and cleaning, as well as outdoor chores like gardening (27). Caregivers may also need to assume responsibility for dependent children, especially if the patient experiences functional decline, and maintain family routines (e.g., school, extracurricular activities) (4). As one caregiver reported:

> **You have to do groceries and maybe your loved one's not feeling well, and so you don't want to leave your house; so just to go out to do chores is a challenge if nobody can stay with your loved one (37).**

FINANCIAL MANAGEMENT

Caregivers may be required to take care of budgeting, bills and illness-related costs, tasks that can be both time-consuming and emotionally draining (43). They may also need to liaise with insurance providers and government agencies to secure financial assistance or benefits (31). Depending on their prior role within the family or couple, these tasks can feel disconcertingly new and unfamiliar.

ADVOCACY, DECISION-MAKING, AND CARE COORDINATION

As patient advocates, caregivers seek out resources, clarify medical information, and facilitate communication between patients and healthcare professionals (4). Caregivers often schedule appointments and ensure that these are kept, as well as follow up on care plans. In this role, caregivers function as knowledge brokers, acquiring information about the patients' medical needs, interpreting and synthesizing it, and sharing it to facilitate patient care (38). Certain cultural contexts oblige caregivers to assume the role of information gatekeeper, deciding how and when to disclose a diagnosis to the patient (4).

TABLE 1
SUMMARY OF CANCER CAREGIVER TASKS AND RESPONSABILITIES

TASK TYPE	EXAMPLES
Emotional support	• Offering companionship and encouragement • Listening to concerns • Accompanying patients to medical appointments • Engaging in activities that provide comfort and distraction • Managing feelings and anxieties (both the patient's and their own)
Medical management	• Administering medications and managing treatment schedules • Ensuring medication adherence • Monitoring symptoms and side effects • Assisting with medical equipment (e.g., oxygen tanks, feeding tubes) • Helping with wound care and post-surgical recovery • Seeing to infection control
Personal care	• Assisting with daily living tasks (e.g., bathing, dressing, feeding) • Transferring patients in and out of a bed, chair, or toilet • Driving patient to appointments • Managing the patient's nutrition
Household tasks	• Taking on additional responsibilities (e.g., shopping, cooking, cleaning, laundry) • Handling childcare and maintaining other family routines
Financial management	• Overseeing household finances • Budgeting for medical and living expenses • Managing insurance claims and medical bills
Advocacy, decision-making and coordination	• Seeking information for patients • Helping them process the information • Coordinating healthcare appointments and transportation • Communicating between patients and healthcare professionals

Note: Based on (4, 6, 13, 26, 27, 30, 31, 37, 38, 44-48)

2. PART I: THE MANY FACES OF CAREGIVING IN ONCOLOGY

Although cancer caregivers have many experiences in common, the journey is shaped by a multitude of intersecting factors that make each experience unique. Sociodemographic factors such as age, sex and gender, socioeconomic status (SES), ethnicity and sexual orientation can influence the types of responsibilities caregivers assume, the burdens they bear (e.g., heightened anxiety), their capacity to adapt to stress, and their access to resources (32, 41, 49). Contextual factors—relationship with the patient, stage of cancer, timing and intensity of cancer care, types of support available, responsibilities assumed, family context, and healthcare organization and service structures—also affect the caregiving trajectory (6, 9, 12, 28, 32, 48, 50-57). The following section examines both sociodemographic and contextual factors to better understand their influence on the caregiving experience and the evolution of the caregiving trajectory in oncology.

A key practice implication of this section is the need to avoid categorically labelling caregivers as more or less burdened based solely on sociodemographic or contextual factors. Rather, each caregiver's situation must be understood as uniquely shaped by the interaction of these factors, underscoring the importance of individual assessment to inform tailored and effective support and interventions.

2.1 SOCIODEMOGRAPHIC FACTORS

While sociodemographic factors such as age, gender, income and cultural background are often presented separately in the literature, in reality, they intersect to shape the caregiving experience.

2.1.1 THE IMPACT OF CAREGIVER AGE ON THEIR TRAJECTORY

Increased life expectancy has reshaped population structures worldwide, including in Canada (58), where the numbers of older adults with cancer and their caregivers are expected to double in the next 20 years (58). The caregivers of older adults are often older themselves (on average, aged 63 to 66), and roughly 40% have comorbidities of their own, making them more likely to report their health as "fair to poor" (59). Caregivers aged 75 and older are more likely to devote more time to caregiving activities, with approximately 14% reporting at least 48 hours per week, compared to less than 5% of caregivers under 50 (60). While retired older caregivers may have more time to put into caregiving (41), this is seldom how they had envisioned spending their later years. Some studies suggest that older caregivers cope "very well" (potentially due to accumulated life experience) and experience fewer financial hardships compared to younger caregivers. Nonetheless, other research indicates that they still face significant mental health challenges (4, 60). In a study of caregivers of patients at the end-of-life that compared the developmental, physical, social and emotional burdens, older caregivers (≥ 65) differed from younger ones (< 65) only by reporting a higher developmental burden—feelings of having "missed out" or of not being where they had hoped to be—suggesting a more pessimistic outlook on the future (61).

Younger to middle-aged caregivers (ages 35–64) are particularly vulnerable to negative health impacts. This is because they are often part of the sandwich generation, simultaneously balancing employment, parenting and caregiving (62)—a triple load that constrains the time and energy available to fulfill these multiple roles (62). Whereas older adults might experience a greater range of physical limitations, younger caregiver are at increased risk of psychological distress (4). Financial strain is also common among this group, who—in addition to having fewer savings—may face limited resources, vocational instability and childcare expenses, leaving little margin to absorb the costs of caregiving (32, 41). These competing demands can interfere with key personal milestones such as career advancement, the pursuit of higher education, family formation or financial independence (63). Younger caregivers also tend to report higher unmet needs for caregiving skills training than their older counterparts, largely due to their more limited prior caregiving experience (64).

Societal expectations render female young adults disproportionately affected by caregiving responsibilities, leading to a lower likelihood of employment (63). Younger caregivers report higher levels of psychological distress, most likely due to a lack of caregiving experience, and thus express greater unmet needs for skills training to manage complex tasks (4).

2.1.2 GENDER

Though male involvement in caregiving is on the rise, over half of caregivers are women, largely the wives, daughters or daughters-in-law of the person receiving the care (43). Female caregivers consistently report higher burdens and poorer physical and mental health than do men, together with more unmet needs and greater difficulty balancing caregiving with other tasks (4, 17, 32, 65). Throughout the cancer trajectory, higher unmet needs are associated with higher caregiver burden and lower mental and physical quality of life (4); female caregivers are also more inclined to report exhaustion and fatigue compared to male caregivers (13). When high-intensity caregiving (over 20 hours per week) is combined with full-time employment, women face a substantially elevated risk of negative health outcomes (7). Age and gender also intersect, with women aged 65 and older—including those who dedicate substantial hours to caregiving—being particularly vulnerable to negative impacts on their overall health (60).

Women often shoulder a disproportionate share of care-related tasks while simultaneously juggling work, parenting and/or marital responsibilities, contributing to role disruption and heightened emotional distress (19). At the same time, societal expectations tend to position women as stoic and selfless (19). Health professionals may also unintentionally re-enforce traditional gender roles by praising "dutiful daughters" or "good wives" (19). Together, these expectations can foster isolation and intensify stress, anxiety and hopelessness, culminating in what some describe as a dislocated self, wherein women feel compelled to manage caregiving alone and are reluctant to seek support, largely because they perceive caregiving as simply "doing their duty" (19). One caregiver described this thought process as follows:

> **I was expected by my mother to be able to be strong, because she knew that I was in the middle. I had my children to explain things to and I had my mother to care for and I had to be strong . . . I couldn't be, you know, taking the time to be an emotional wreck (Daughter) (19).**

Male caregivers also experience substantial strain, reporting poorer quality of life and, in some cases, appearing more distressed than those they care for (10). Several interrelated factors contribute to this. Gender norms may discourage emotional expression and help-seeking among men, thereby heightening depressive symptoms and perceived burden (4). About one-quarter of male caregivers report anxiety or distress, while about 15% report depression or anger (66).

Distress among male caregivers has been linked to caregiving challenges and unmet support needs (67). Common unmet needs include concerns related to sexual relationships, understanding the experience of the person with cancer, and accessing emotional support for oneself (66). Among male partners of women with breast cancer, caregiver burden is also strongly associated with couple satisfaction, the patient's level of distress, and whether the patient underwent lymph node resection (68). Compared with women, men more frequently rely on avoidant or externalizing coping strategies (e.g., alcohol use, smoking), which are associated with poorer mental and physical health outcomes (4). Lower quality of life among male caregivers has additionally been associated with a "doing what needs to be done" coping style, whereas higher quality of life is linked to greater hope and lower caregiver guilt (69).

2.1.3 EDUCATION AND SOCIOECONOMIC STATUS (SES)

Caregivers with a lower SES can experience a particularly heavy burden. Lower levels of education and income have been linked to greater emotional distress and poorer physical health outcomes (4, 50). One study found that caregivers without a college education also report difficulty navigating the healthcare system, understanding health-related information, and communicating effectively with care teams (41). Additionally, lower SES is associated with greater caregiving intensity, as caregivers with fewer financial resources tend to provide more hours of care due to limited access to formal support services (70, 71).

Full-time employment combined with lower educational attainment has been shown to predict higher levels of anxiety and depression among caregivers (4). Nonetheless, evidence indicates that higher income and educational attainment, when coupled with demanding careers, may also be associated with greater caregiver burden and reduced quality of life (4).

Together, these findings suggest that caregivers may struggle to balance employment with and caregiving across the socioeconomic spectrum, with consequences for well-being (4). Individuals with lower educational attainment may face particular challenges when navigating the complexities of the healthcare system compared with those who have completed education beyond high school (41). Conversely, caregivers with higher income and educational levels experience considerable stress when attempting to balance career demands with caregiving responsibilities (4).

Importantly, across all income levels, strong social support emerges as a key protective factor against caregiver strain (4). Notably, this association is stronger among caregivers with lower SES, underscoring the critical role of social support in buffering burden for financially vulnerable families (72).

2.1.4 RACE AND ETHNICITY

Underserved groups—including new immigrants, First Nations, Inuit and Métis peoples, and ethnocultural communities—often experience delayed diagnoses and engage less in routine cancer screening, leading to later-stage detection and correspondingly more intensive caregiving demands (73). These disparities are compounded by systemic barriers such as racism, discrimination, and the lasting effects of colonialism, which limit access to timely, culturally appropriate healthcare (49). Cultural and structural inequities also intersect with caregiving burden. For instance, the fact that Hispanic caregivers are less likely to be employed than non-Hispanic White caregivers may exacerbate their financial strain and limit their access to supportive resources (13).

Much of the existing research, which is primarily U.S.-based, has focused on Black and Hispanic caregivers, who often take on more intensive caregiving roles, spend more hours per week, and manage a broader range of tasks compared to White caregivers (49). This greater involvement is accompanied by heightened financial strain. Yet some studies report that Black caregivers experience lower emotional and physical burden, potentially due to strong social networks, cultural values around familial responsibility, and a greater sense of preparedness (49). Similarly, Hispanic caregivers have reported emotional well-being on par with or even better than that of White caregivers. While these cultural and community strengths may offer some protection, they do not erase the structural inequities these caregivers face. Minority caregivers also report more unmet needs when reintegrating into life after the patient's death, including challenges related to grief, employment, finances, and re-establishing social connections (22).

Complicating the picture further is the role played by systemic and interpersonal racism. Minority caregivers frequently encounter challenges that extend beyond the daily tasks of caregiving. From difficulties navigating healthcare systems to feeling dismissed or misunderstood by health professionals, racialized caregivers often face an added layer of emotional and logistical strain. For instance, studies show that minority caregivers are more likely to report poor communication with health professionals and to feel that their race or ethnicity negatively influenced the quality of the care received (74).

2.1.5 LESBIAN, GAY, BISEXUAL, TRANSGENDER, QUEER OR QUESTIONING, TWO-SPIRIT, AND OTHER DIVERSE SEXUAL AND GENDER IDENTITIES (2SLGBTQIA+)

While 2SLGBTQIA+ caregivers share many of the same roles and impacts as non-queer caregivers, systemic exclusion and discrimination in healthcare settings can further exacerbate the burden for this group (63, 78). The experience of being dismissed, misgendered, or misunderstood by health professionals can create a pervasive sense of fear and emotional strain (78). A recurring theme is the erasure of queer identity in care settings (63), whereby caregivers speak of "hiding one's sexuality" or "taking a backseat from being 2SLGBTQIA+". As one non-binary caregiver explained:

> **I remember questioning my sexuality, like, 'Hmm I don't entirely feel straight', but I'm already dealing with so much, I have no emotional energy left to deal with this. So, I just kind of ignored it (78).**

In some cases, anti-queer hostility and the lack of legal protections led caregivers to worry about being excluded from medical decision-making or unrecognized as caregivers due to the nature of their relationship with the patient (78).

Such discrimination can lead to poorer health outcomes and heightened feelings of loneliness (63). Notably, gender-based disparities in well-being commonly reported among heterosexual caregivers were not observed in one study of 2SLGBTQIA+ caregivers, possibly reflecting less adherence to binary gender roles (78). Without attention to how intersectional identities shape caregiving experiences, support systems risk reinforcing the very inequities they aim to resolve (41).

2.1.6 LOCALITY

Locality shapes the caregiver experience by influencing access to healthcare, financial strain, lifestyle disruptions, and the availability of support networks (19). In rural settings, distance from hospitals often compounds an already heavy burden, with long commutes intensifying fatigue for both patients and caregivers and creating barriers to timely care (75). As one caregiver reported:

> **Because commuting to and from the hospital takes a long time, it negatively affects you. Many people come from a remote place. They have no place to stay. So you can see people lying and resting in the park (75).**

To mitigate these challenges, many rural caregivers make major life changes to accompany patients—for example, relocating closer to metropolitan cancer centres to reduce travel time, lower costs, and access specialized care (76). Relocation can create ripple effects, including disruptions to rural home life, forced withdrawal from employment, reduced capacity to manage domestic or farm responsibilities, and separation from caregivers' own support systems (76).

Access to specialized palliative care services also varies significantly between urban and rural settings. Urban areas offer more consistent hospital- and home-based palliative care, while rural caregivers often face long travel distances, limited home visits from health professionals, and poorer care coordination (77). The likelihood of receiving palliative care at home is significantly lower in rural areas; as a result, rural patients are more likely to rely on non-professional supports such as meal preparation or general assistance rather than specialized palliative care (77). These gaps also carry significant financial consequences: the average six-month cost per patient in a palliative care program is CAD 26,652 in urban areas, compared to CAD 31,018 in rural regions. Inpatient care costs are also nearly one-third higher for rural patients, while costs for equipment and medical aids are 63% higher, and prescription medications 20% higher (77).

However, caregiving costs in both rural and urban areas are similar (77). The cost breakdown differs: rural families spend most on medications, out-of-pocket expenses, and transportation, whereas in urban areas, the largest share is allocated to private home care, followed by out-of-pocket costs, equipment, and medication. Beyond direct costs, caregivers in both settings absorb indirect losses: working caregivers miss an average of 32 hours of work in urban areas and 41 hours in rural areas on a six month caregiving period, a 22% difference (77).

Rurality disproportionately affects specific patient/caregiver dyads, including women caregivers, younger patients, and patients cared for by someone other than a spouse or child. Furthermore, rural caregivers are more likely to care for multiple recipients (34% vs. 23% in non-rural areas) and to report having had no choice in assuming the role (51%) (76). While some studies find no significant differences in quality of life between rural and urban patients and caregivers, these findings may obscure overlook that certain needs are more challenging to address in rural areas due to systemic barriers (76). The cultural ideal of "rural toughness" can mask unmet needs and rising financial strain, even among the most resilient caregivers (76).

2.2 CONTEXTUAL FACTORS

In addition to sociodemographic factors, various contextual factors influence the trajectory of cancer caregiving and how caregivers navigate pivotal moments. These include the relationship to the care receiver; health system navigation and communication with health professionals; social support and connectivity; recognition for the caregiving role; and the care receiver's state of health. The following section will highlight these factors and examine how they shape the caregiving trajectory over time.

2.2.1 RELATIONSHIP TO THE CARE RECEIVER

Caregiving can be a dyadic process in which the caregiver–patient relationship is pivotal to the outcomes for each (56, 57). Spouses and partners often serve as primary caregivers, especially when they cohabit with the patient (27, 79). Married and partner caregivers are found to suffer significantly more from depression than non-partners (50); they are also more likely to report both absenteeism and presenteeism at work (13).

For caregivers, living together often means taking on more daily responsibilities— coordinating care, attending appointments, managing symptoms, etc.—which can deepen the couple's bond, but can lead to higher caregiver burden (6) (79). This increased burden likely reflects the greater life disruption experienced when caregiver and patient cohabit (50). As they face cancer, couples form an interdependent relationship in which each partner's distress and coping style influences both their own and their partner's health and well-being (57). Within this framework, communication characterized by emotional openness and collaborative problem-solving is linked to higher relationship satisfaction, greater intimacy and lower distress. In contrast, behaviours such as protective buffering, overprotection, avoidance, criticism, demand-withdraw patterns, and negative dyadic coping are associated with poorer outcomes for both partners (80).

It should be noted that caregiving relationships extend beyond the couple: parents, adult children, siblings, and close friends or extended family members may also step in to help (32). These caregivers, who often live separately from the patient, may follow different trajectories shaped by such factors as distance, logistical challenges and competing roles. Emotional strain for non-co-residing caregivers can include guilt or worry about not being physically present, alongside the challenges of managing care from afar (51). Additionally, while they may not provide intensive daily care, they often coordinate transportation, support medical decision-making, and manage care remotely—tasks that can still impose significant stress (6).

CANCER, SEXUALITY, AND CAREGIVING

Intimacy and sexuality are rarely discussed in a caregiving context, even though many caregivers support a spouse or sexual partner throughout serious illness. Studies show that sharing one's life with and caring for someone with cancer affects intimacy and sexuality, often resulting in a decrease or a complete cessation of sexual relations within the couple (198; 199; 200; 196; 201).

> **For many caregivers, these challenges are accompanied by feelings of anger, confusion, sadness and loneliness, as a central aspect of their relationship is suddenly altered or lost [196].**
>
> **I basically felt very much alone through the whole experience.**
>
> - Gary, caregiver of a spouse with cancer (196, p. 534)

While the topic remains sensitive and often taboo (198), issues related to caregiver sexuality can profoundly affect both personal well-being and intimate relationships across the trajectory. Along with a marked reduction in sexual activity, many caregivers report that intimacy becomes less spontaneous and that sexual relations may provoke anxiety (196).

Some caregivers suppress or neglect their own sexual needs to prioritize their partner's health and daily care requirements (196). They may also hesitate to initiate sexual activity for fear of putting pressure on their partner or appearing overly demanding, preferring instead to let their partner take the lead (196).

Furthermore, caregivers can fear causing physical harm or discomfort to their partner during sexual or intimate contact. For example, some caregivers reported anxiety about hugging their partner too tightly or touching areas made sensitive or vulnerable by cancer treatment:

> **I worry myself sick thinking every time he moves, is he in pain?**
>
> - Diana, caregiver of a spouse with cancer (196, p. 533)

> **Finally, caregivers may feel guilty about wanting to discuss their sexual needs with their partner, even when the relationship is otherwise characterized by strong communication:**
>
> **[My husband] didn't need to hear all that. . . . [H]e was the victim.**
>
> - Margaret, caregiver of a spouse with cancer (197, p. 1004)

Guilt can also be triggered by thinking about initiating sexual relations with one's partner or acknowledging and meeting one's own sexual needs in other ways:

> **I hate the idea of basically skulking away in the office and going to [a porn site] or whatever and just jerking off, it sort of makes me feel like I'm just a grotty 16-year-old again, I should just be over it.**
>
> - Paul, caregiver of a spouse with cancer (196, p. 533)

BECOMING ONE'S PARTNER'S CAREGIVER: A TURNING POINT IN A COUPLE'S INTIMACY AND SEXUALITY

Becoming a caregiver for one's partner represents a pivotal moment in a romantic relationship, as the situation very often disrupts or suspends intimacy and sexuality for a variety of reasons. Assuming a caregiving role entails adopting new relational and practical responsibilities that can fundamentally redefine the relationship. For example, some caregivers remark on how taking on a quasi-clinical role—"wearing the hat" of a nurse who cares for a sick person—can affect their sexual attraction toward their partner:

> **This probably sounds weird, but you're not sort of in the role that you were before, and I guess that is more like a clinical, like now you're the nursemaid, you've got a lot more to do because they can't.**
>
> - Melanie, caregiver of a partner with cancer (196, p. 531)

Similarly, having to bathe, feed, and dress their partner can recast the romantic relationship into terms that resemble a parental role (196). Viewing one's partner as childlike or dependent and in need of constant care can eliminate any sexual attraction toward the person being cared for:

> **[T]hey're not the person that they were . . . [T]hey're now this person that you care for. . . . [I]t feels as if we're just sharing a life and that it could be my brother or whatever, because I don't have any physical attraction toward him whatsoever.**
>
> - Melanie, caregiver of a partner with cancer (196, p. 531)

Beyond these shifts, McGillivray et al. (2021) suggest that the very use of the label "caregiver" can introduce a symbolic distance, reframing the relationship primarily in medical terms rather than as a romantic, intimate and sexual connection. Such reframing also reflects a broader social taboo: that people who are sick or disabled do not, or should not, have a sex life (199). This accompanies lingering assumptions that illness and sexuality are incompatible:

> **[He] can't. [He is] too sick. How can [he] move?**
>
> - Gina, caregiver of a partner with cancer (196, p. 531)

Lastly, caregivers can experience resignation and grief related to the loss sexual intimacy with their partner:

> **I think for me, I just sort of felt, well we've had good times, we've had a good sex life, be grateful for what you've had. . . . I feel that I resigned myself to the fact that this was how it was.**
>
> - Maxine, caregiver of a partner with cancer (196, p. 533)

The impact of cancer on a couple's sexuality and intimacy hinges on several factors. One key consideration is the nature of the relationship prior to the onset of illness and treatment: relationships in which sexuality played a key role may experience a more pronounced disruption than those in which it was not as present or important (196). In some cases, people with cancer and their partners may completely cease sexual activity and intimacy; others will continue to share intimate moments, albeit less frequently:

> **Well, quantitatively, maybe we made love four or five times a week before. I don't know. Afterwards, probably two, straight away.**
>
> - Gary, caregiver of a partner with cancer (196, p. 529).

The intensity of care can also affect the couple's sexuality, with libido negatively affected by caregiver fatigue and stress resulting from emotional, medical, and practical tasks (196).

The partner's condition and type of cancer can influence sexuality within the dyad as well. Many caregivers report that seeing their partner suffer—unable to perform sexually, heavily medicated and exhausted—affects their own desire (196).

RECONFIGURING SEXUALITY AND ALTERNATIVES

To redefine or reconfigure their sex lives, caregivers may adopt such practices as individual and mutual masturbation, manual stimulation, oral sex, massage, the use of vibrators, and cuddling or caressing (196, 197). Often perceived as "alternative" to the hegemonic heteronormative sexual script centred around penetration, practices of this kind are gradually becoming more normalized:

> **[I]f we continue to explore alternatives then maybe some will work and we can come out of it and put together a reasonable physical relationship again. Maybe even a better one.**
>
> - Bob, caregiver of a spouse with cancer (196, p. 534)

Adopting new practices can entail having to move through various phases of emotional adjustment. For example, one caregiver described her frustration with the complexity of sexual intimacy with her husband, who has prostate cancer: "At first I would just walk out of the room and get furious because I still wanted it." Over time, by reconfiguring their sexual relationship and the contexts in which it occurred, she and her partner discovered other ways of experiencing intimacy:

> **[W]e never used to do massage whereas now, now we'll buy nice smelling oils and massage and candles. . . . [P]robably the biggest thing is we put more effort into it now. . . . I mean I think that's good. [W]e both now know that if he loses an erection half way through then he'll find another way to help me to climax and that's fine.**
>
> - Jenny, caregiver of a spouse with prostate cancer (197, p. 1002)

Gilbert et al. (2010) describe a lesbian couple who adapted their intimate relations to the circumstances and the patient's health. Reflecting on the relationship after her partner's death, the caregiver remarked that they became accustomed to kissing and caressing each other rather than engaging in frequent or intense sexual activity.

Lastly, a couple's capacity to reconfigure sexuality during cancer is closely tied to communication and the overall relationship climate. Several caregivers emphasized the importance of "making the effort" to communicate, both for maintaining their sexual connection and for supporting their relationship as a whole (196).

2.2.2 HEALTH SYSTEM NAVIGATION AND COMMUNICATION WITH HEALTH PROFESSIONALS

Caregivers face constantly evolving needs throughout the oncology trajectory, yet their access to services that adequately address those needs remains limited. As one caregiver explained:

> **It really is a learning curve for caregivers. There's no way to understand what this means. If no one sits down with you, throwing someone a welcome package with a bunch of information that may or not transpire in the life of the patient, it means nothing . . . it's the caregiver that needs their hand held through the process (38).**

Navigating the healthcare system can be overwhelming. While caregivers report feeling valued when they are informed and included as part of the care team (81), in practice, many still face a lack of clear guidance, struggle to find answers, and may not receive timely information about prognosis or treatment progress (52, 53). These gaps leave them unprepared for the demands of decision-making and day-to-day support. Tailored information on available services, legal rights, or care tasks is often missing as well, requiring them to seek answers independently, thereby adding to their stress (37, 52). In contrast, when caregivers' needs are addressed through effective communication and genuine partnerships with health professionals, they may experience less decision regret and greater confidence in their ability to seek help and manage care (4, 12).

> **At first, the surgeon was making decisions that involved me [without consulting me]. Then at one point, I told him, 'Hey, I'm part of the solution—he's coming home with me afterwards.' . . . After that, the doctor really consulted me about everything, even about discharge and leaving the hospital. . . . So we became a team. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

2.2.2.1 CARE SETTINGS

Most cancer care today is carried out in ambulatory clinics, shifting complex medical tasks—symptom monitoring, medication management, infection vigilance, technical procedures, equipment handling—from the clinic to the home, transforming caregivers into round-the-clock coordinators, often with little to no training (9, 12). Caregivers often frequently act as intermediaries between the patient and healthcare providers, but the brevity of clinical visits (typically 15–20 minutes) limits opportunities to address their concerns (9). Poor care coordination and reduced access to local specialists further increases caregiver burden (82). Furthermore, support during treatment, already limited, can drop sharply during the survivorship phase, a time when caregivers must manage evolving recovery needs (9). High-risk transitions in care can provoke particular anxiety; post-surgical discharge is one such transition. Caregivers often feel pressured to leave the hospital before they believe the patient is ready, yet hesitate to raise concerns for fear of being seen to "cause problems" (65). As one caregiver reflected:

> **[A]fter surgery we felt pressured to leave . . . we didn't feel like she was supported in [her] explanation that she wasn't feeling well enough to go. . . . I wanted to be as polite and helpful to the nursing staff. . . . [I]n retrospect I wish I had spoken up (65).**

2.2.2.2 ACCESS TO PROGRAMS AND SERVICES

Against this backdrop, caregivers often underutilize existing services, particularly mental health resources, even when available, whether due to guilt or a lack of awareness of formal support options (6). This underscores the need for healthcare systems to explicitly recognize caregivers as part of the unit of care, as well as to adopt family-centered or dyadic approaches that take both patient and caregiver into consideration (55). Proactive screening of caregiver distress and unmet needs using family-reported outcome measures (FROMs) is recommended to identify those at the greatest risk and link them to the appropriate resources (37, 83). The Supportive Care Needs Survey – Partners and Caregivers is one such tool (84). These measures draw directly on information provided by the caregivers to guide clinicians' understanding of how best to support them. Systematically collecting and analyzing FROM data can improve communication between clinicians and caregivers, enabling clinicians to tailor interventions to improve caregiver preparedness (37, 83).

After screening for unmet needs, the next step is to match caregivers with the appropriate interventions. Three broad, evidence-based types can be used: therapeutic counseling, skills-training, and psychoeducation/support (85). Therapeutic counseling addresses the psychosocial challenges of cancer through psychotherapy or guidance. Skills-training promotes active coping, problem-solving, communication, stress management and/or behaviour change skills. Psychoeducation/support focuses on information, particularly on patient care, symptom management (physical and psychological) and supportive care towards the caregiver needs (85). Interventions can be delivered solely to the caregiver or to the patient-caregiver dyad.

Meta-analyses indicate small-to-moderate improvements in caregiver mental health, including reduced burden, anxiety, and depression, as well as improved quality of life and self-efficacy (85, 86). Within these findings, therapeutic counseling and skills-training show consistent effectiveness, whereas psychoeducation alone is less impactful (85). Caregiver-only and dyadic interventions demonstrate comparable overall effectiveness (86); dyadic interventions foster joint coping, while caregiver-only interventions provide focused support. Combining both may offer optimal outcomes (87).

One size does not fit all
Moderator analyses suggest that certain caregiver characteristics can shape the effectiveness of caregiver interventions (85). Skills-training and psychoeducation seem more effective among younger caregivers, possibly reflecting a lower degree of prior caregiving experience. Therapeutic counseling appears effective for male caregivers, who may have fewer outlets for emotional support. Psychoeducation is particularly beneficial for caregivers from ethnic minority groups, possibly due to gaps in accessible resources, but is the least effective among spousal caregivers (85).

Consistent with these findings, caregivers have highlighted the need for a centralized "cancer 101" resource (37). Key elements include:

- Information about patient care and skills training for more effective caregiving, related to medical management (e.g., symptom management) and practical roles (e.g., helping patients with activities of daily living).
- Caregiver self-care information on managing their own symptoms and concerns. This includes advice on adaptive coping, problem solving, communication, relaxation, and/or behaviour change skills.
- A list of available resources to help caregivers respond to patients' needs. Caregivers have expressed a preference for experiential information from others who have gone through similar experiences, particularly regarding the strategies used and what worked best.
- Tips on communicating with clinicians in ways that make caregivers feel integral to the care team. Related to this was advice on dealing with medical information overload (e.g., information-processing aids, summary sheets).
- Tips on handling communications with patients, family and friends, including how best to manage requests for information and offers of help. Caregivers also need guidance on what kinds of help to request from their social networks and on constructively sharing their feelings with patients.

However, time constraints and care-related responsibilities can often hinder caregivers from being able to engage with interventions. For instance, though group interventions can be effective, the requirement to attend specific sessions can impose an added burden (87). To maximize their effectiveness, such interventions must therefore be accessible and flexible. Online group sessions offer one solution, providing the benefits of group interaction without the added pressure of having to travel (87). Phone-based interventions may also better align with caregivers' time constraints and responsibilities (12). Cancer helplines are yet another valuable resource, frequently accessed by caregivers looking for guidance or simply someone to talk to (79). Increasingly, caregiver interventions are successfully delivered asynchronously to caregivers through digital health tools (4, 88).

Furthermore, while there is no shortage of recognizably effective caregiver interventions, incorporating them into real-world cancer care can be constrained by limited healthcare resources. A stepped-care approach can help optimize interventions cost-effectively (89). Step 1 can offer the least intensive intervention that is apt to meet caregiver needs—for example, basic psychoeducation or asynchronous, web-based skills-training. Once caregivers have engaged with Step 1 for a pre-set period, their needs and/or health outcomes are assessed. Only those in need of further support will move onto Step 2, which could include direct contact with a clinician. Caregivers who still need support beyond Step 2 might be offered more specialized counselling (89).

2.2.3 SOCIAL SUPPORT AND SOCIAL CONNECTEDNESS

Associated with higher self-efficacy, resilience and quality of life, and with lower burden, anxiety and depression, support from one's family, friends and peers serves as both a proactive and restorative buffer against the demands of caregiving (28, 48, 54). Social support has been linked to better sleep quality by allowing caregivers to discuss their responsibilities and the ensuing burden (90); it also equips caregivers with emotional, informational and practical resources for coping with caregiving challenges and guarding against negative health outcomes (91). Social connectedness, the perceived extent of close interpersonal relationships with others, provides caregivers with a sense of community, which can reduce feelings of isolation and further mitigate caregiver burden (91). Updated, evidence-based information communicated to caregivers and patients by the care team can provide essential knowledge on regular follow-up care, treatment side effects and the patient's emotional needs (92). Practical or tangible support can range from respite care to help with daily tasks, proactively alleviating the physical demands of caregiving and offering caregivers more time and space to see to their own well-being (93).

Among the various types of support, emotional support is most strongly associated with caregiver well-being, likely because it helps caregivers feel less isolated and provides an outlet for processing fears and emotions (47, 54). High levels of emotional support are associated with a lower physical toll on caregivers (e.g., less pain) as well as better general health, vitality and functioning. Moreover, the degree of emotional support caregivers perceive at the start of the trajectory tends to shape their perceptions—and the benefits—of the support over time. This is important, because the salience of emotional support increases as the caregiving trajectory unfolds, amplifying its buffering effects across multiple aspects of quality of life (94).

2.2.4 RECOGNITION

Despite their central role, caregivers are often described as a "hidden workforce" whose contributions remain largely unacknowledged within healthcare systems (6). As one caregiver said:

> **[M]ost people don't ask me how I'm doing . . . I think it's hard that some people only care about [the patient] (1).**

Caregivers are often overlooked by the care team, making them feel invisible and overwhelmed at having to navigate complex responsibilities and the healthcare system on their own (37, 52). Caregivers who are not asked about their needs or included in care planning have reported higher levels of emotional stress and lower quality of life (91). All too often, recognition of caregivers' contributions is reduced to peripheral tasks such as driving patients to appointments, when in reality they perform complex medical, emotional and practical roles that directly affect patient outcomes.

Acknowledging caregivers not just for their responsibilities, but as individuals with their own needs, can have positive outcomes for both caregiver and patient (52, 95). Caregivers consistently express a desire to have their role more broadly recognized, not just by health professionals and patients, but also by their families and society at large. Recognition validates their efforts, affirms their identity beyond that of a "helper" or "chauffeur," and strengthens their sense of competency and purpose in caregiving. It also signals to caregivers that they are seen as partners in care—vital members of the care team as opposed to invisible support in the background. Caregivers who feel recognized report a more positive outlook on caregiving along with lower depression and distress (95). Receiving appreciation, including from the patient, can be highly motivational (1). As one caregiver said: "It would have been a nice acknowledgement and I bet for some people it could open floodgates of a lot of questions, the ability to share exactly what you're going through" (37).

> **I think it's important that they take us into account and that we have support services as well, because yes, the person is living [with cancer], but for us, we need help too. How am I supposed to help if I'm struggling to cope with it all and manage my own emotions? (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

2.2.5 CARE RECEIVER HEALTH: CANCER TYPE, STAGE, AND TREATMENT

Caregiving roles in oncology scale with the patient's autonomy: when patients are independent, caregivers may mainly provide transport; but as needs grow, caregivers tend to take on direct care in addition to any household tasks the patient can no longer manage (38). The stage of the cancer and nature of treatment can significantly influence patients' functioning and consequently, caregiver burden and well-being. Patients diagnosed at an earlier stage tend to have better treatment experiences, lower morbidity, and improved quality of life (96). Advanced-stage cancer is associated with more complex care needs—including pain management, emotional support, and daily physical assistance—that intensify caregiver responsibilities, increase the need for support and trigger higher psychological distress (52).

Certain cancer types can pose their own particular challenges. Brain cancer, for example, often leads to rapid neurobehavioural changes and physical decline, requiring intensive caregiver involvement from very early on (97). The caregivers of brain cancer patients describe the period following diagnosis as a time of overwhelming exhaustion, as they struggle to adapt to their new role amid rapid patient deterioration (36). Similarly, lung cancer imposes a heavy caregiving burden due to its high symptom load and extensive physical and psychological effects (98). As a result, spouses of lung cancer patients report higher levels of depression and anxiety than the caregivers of patients with other cancer types (98). A longitudinal study of caregiver anxiety and depression found that those who care for patients with lung, haematological, or head and neck cancer were particularly vulnerable (48). The caregivers of patients with advanced cancer often struggle to balance caregiving with other responsibilities, all the while coping with the emotional toll of supporting someone who may already feel detached from life (51).

Each cancer treatment—whether chemotherapy, radiation, surgery, bone-marrow transplant or others—represents a unique burden for caregivers. However, the common thread is that, as the patient's care needs intensify, the caregiver's role becomes all-encompassing. Many caregivers describe the treatment stage of the cancer trajectory as overwhelming, leaving them emotionally depleted, physically exhausted, and unprepared for the complex responsibilities thrust upon them (32). The particular impact of each treatment is described in the Treatment stage section of this report.

Beyond the practical and emotional effects of treatment, certain cancers can particularly impact the couple's relationship, intimacy, and sexual activity (198, 200). For example, breast cancer treatments and surgeries can redefine or introduce new boundaries in intimacy and sexual relations (196). Some partners report that parts of their partner's body have become "off-limits" due to pain and discomfort, which can impact the spontaneity and fluidity of sexual relations:

> **[Y]ou can't sort of suddenly give her a big cuddle.**
>
> - Ed, caregiver of a partner with breast cancer (196, p. 530)

Caregivers of a spouse with brain cancer often find that sexual relations within their relationship cease entirely. Disease-related neurological impacts like memory loss and cognitive impairment can make intimacy or sexual activity simply impossible (196).

Certain reproductive organ cancers (e.g., prostate and cervical cancer) can have direct consequences on for sexual function, including the ability to achieve an erection or engage in penetrative sex. In cases where the care recipient has prostate cancer, caregivers can fear that expressing their own sexual needs will seem unfair or inappropriate. Refraining from initiating sexual activity is one way to avoid upsetting or offending a patient who, due to illness-related impotence, no longer feels they can sexually satisfy their partner (196). Some women fear causing a male partner who is unable to engage in penetrative sex to feel emasculated (196). In cases of cervical cancer, some caregivers report that sexuality within their relationship is a difficult issue that doesn't need to be discussed, especially during treatment.

> **[T]he love relationship, and in our case, it has lost some of its magic, something of its carelessness, and [sex] has become more of an issue.**
>
> - Ole, caregiver of a partner with cervical cancer (200, p. 992)

Others report that treatments have caused to their partner's body to change in ways of which they had been insufficiently informed:

> **We are deprived of the opportunity to be intimate since her vagina has grown together. We have not been informed of how we can resolve this in other ways.**
>
> - Ole, caregiver of a partner with cervical cancer (200, p. 992)

Finally, some cancers, including prostate, ovarian, and cervical cancer, can compromise the couple's ability to have children "naturally":

> **[F]or me the reality was starting to set in of the sadness that I wouldn't be able to procreate with him in that very natural, very intimate environment which most couples take for granted.**
>
> - Bella, caregiver of a partner with prostate cancer (196, p. 535)
>
> **We cannot have children. She is now sterile, and we do not have children from before, either. We see friends around us becoming parents. That reminds you: who will take over after us when we are gone?**
>
> - Thomas, caregiver of a partner with cervical cancer (200, p. 992)

CARE RECEIVER CO-MORBIDITIES

Up to two-thirds of patients with cancer have at least one coexisting long-term health condition at time of diagnosis (99). Comorbidities can also influence the timing of a cancer diagnosis, either by prompting earlier medical attention (due to overlapping symptoms) or, conversely, by delaying detection due to symptom misattribution. For instance, people with dementia are more likely to have cancer diagnosed only when it is at an advanced stage or even posthumously, since dementia can mask cancer symptoms (100). Other common comorbidities include hypertension, chronic obstructive pulmonary disease (COPD), cardiovascular disease (CVD), congestive heart failure (CHF), and peripheral vascular disease (PVD) (99). These illnesses not only complicate cancer treatment, but also tend to complexify the demands on caregivers (6) by amplifying patient needs, thus requiring caregivers to perform tasks more frequently. For example, caregivers may need to communicate more frequently with health professionals and devote more time to coordinating care (100). Burden can also be elevated by the need to provide emotional and behavioural support to the patient in relation to both their cancer and the comorbid conditions (101). The resulting increased caregiving intensity can consequently worsen the caregiver's own health and well-being and exacerbate their anxiety and depression (6). Furthermore, patients with both cancer and comorbidities often receive standard treatments like chemotherapy or surgery less frequently than those without additional conditions (102). While it is unclear why this discrepancy exists, it may reflect the concerns of healthcare professionals regarding a higher risk of treatment complications and mortality in this population (102). Accordingly, caregivers must shoulder an expanded role, managing multiple illnesses, coordinating fragmented care, and providing ongoing support where health systems fall short.

2.3 MULTIDIMENSIONAL IMPACTS OF CAREGIVING

Caregiver well-being is a major determinant of whether or not care can be sustained at home; when strain rises, so too does the likelihood of needing to resort to other healthcare services (e.g., hospitalization, home care) (95). For the caregiver, cancer caregiving frequently results in considerable psychological distress, social isolation, physical exhaustion, and financial strain—pressures that, over time, can erode caregivers' overall well-being and compromise their ability to sustain care (95). Each major impact on caregiver health is described below.

Caregivers: the hidden co-patients of cancer
Caregivers are increasingly described as co-patients due to the strong interdependence between their own well-being and that of the patient. They often experience parallel physical and emotional declines during treatment (10, 41), mirroring patient emotions—feeling well when the patient is doing well and distressed when the patient is unwell. In some cases, caregivers report greater levels of distress than the patients themselves (41, 54).

PSYCHOLOGICAL

On average, some 26% of caregivers report depression, and up to 40% report anxiety (103). These rates are often higher than those observed in the general population, and in some cases, may even exceed those reported by the patients themselves (103-105). Anxiety and uncertainty are especially prominent at diagnosis, when caregivers can feel overwhelmed by the potential implications and consequences of cancer (52). At the start of treatment, caregivers often worry about treatment-related side effects, treatment effectiveness, and the ongoing management of symptoms (106). As treatment ends, many report anxiety about the future, while simultaneously gaining confidence in their caregiving role, which by then may feel routine or second nature (107). Throughout the cancer trajectory, caregivers often try to maintain a positive emotional outlook for both themselves and the patient (108). As one caregiver described:

> **I behaved as if it were something not very serious. In fact, I was suffering inside. I did not show it to him (75).**

Of note, a Danish study found a 1.5-fold increased risk of death by suicide among spouses of patients with cancer compared to spouses whose partners did not have cancer, with rates highest during the first year after diagnosis. Other identified risk factors included lower incomes; no children in common with the patient; advanced-stage cancer at diagnosis; specific cancer types (particularly pancreatic, liver, oesophageal, kidney, central nervous system or rectal cancer); and the death of the patient (109).

Time does not heel all wounds
The distress experienced by caregivers early in the cancer trajectory often persists—and in some cases, escalates—over time, showing that ongoing support is essential (4).

SOCIAL

The demands of cancer caregiving often profoundly reshape caregivers' social lives. Caregivers frequently experience social isolation or feelings of loneliness due to their responsibilities, which can force them to withdraw from leisure activities, social events, and interpersonal relationships (51). This withdrawal can stem from time constraints, concerns about transmitting viruses to the immunocompromised patient, or mental and physical exhaustion (1). Isolation may be further exacerbated by difficulty communicating about the illness, as friends and family may respond with discomfort or misunderstanding, causing caregivers to suffer in silence (51, 75). Ongoing disruptions—rescheduled plans, canceled outings, missed milestones, etc.—can also leave caregivers feeling disconnected from their usual networks (13, 32, 54).

Additionally, caregiving may require long-term plans to be put on hold, forcing caregivers to delay or rethink major life decisions, including career goals, financial planning or travel. The uncertainty surrounding the illness makes looking ahead difficult, and some caregivers report feeling "stuck" (108). Even when support networks exist, they may lack emotional depth (32, 110). Despite these challenges, some caregivers report their relationships deepen or that family bonds strengthen (51, 75). Taking on care responsibilities can shift dynamics in ways that foster connection, meaning, and purpose during an otherwise difficult time (51, 75). As one man caring for his wife with mesothelioma[1] shared:

> **My two boys now, we now go out every two or three weeks on a Saturday . . . which we never used to, and I think this is all because they are looking out for me. . . . Life's too short, as I said, and now we do that (107).**

THE PATIENT-CAREGIVER RELATIONSHIP

Cancer and its treatments, particularly for conditions like prostate or head and neck cancer, can significantly impact intimate and sexual relationships, sometimes leading to feelings of being "just acquaintances rather than husband and wife" (53) (see Relationship to care receiver).

Opening communication can be difficult when partners respond to distress by shutting down, which can be emotionally hurtful (53). Despite these challenges, caregiving can also strengthen relationships, with some couples reporting that cancer had brought them closer, fostering mutual support and improved communication through shared coping and collaboration (52)—a positive relational deepening illustrated by one caregiver's description of the experience as "a gift to be able to support her, provide a calm, caring environment" (78). A study of 263,616 cancer patients and 3.4 million healthy individuals found that most cancers were associated with a slight decrease in divorce rates, potentially reflecting strengthened bonds and solidarity in the face of illness (111). Nonetheless, some important exceptions were noted, with cancers affecting sexual or reproductive functioning (e.g., cervical, testicular) particularly associated with a somewhat higher divorce risk (26, 111).

PHYSICAL

Caregivers report significantly more days per month of poor physical health than non-caregivers (5.01 versus 3.94 days), with more caregivers reporting 14 or more days of poor physical health in the past month (15.75% versus 12.27%) (112). Symptoms reported include headaches, insomnia, fatigue, loss of appetite, and weight changes, which are frequently linked to grief and stress (75). Prior illnesses (e.g., migraines) may also worsen, while new ones (e.g., hypertension, eczema) may develop. As one caregiver commented:

> **I know my headaches stem from my sadness (75).**

Additional physical effects include indigestion, irregular eating habits, muscle pain, chronic fatigue, and difficulty focusing. Many caregivers—particularly older adults—must manage their own chronic illnesses alongside caregiving, often prioritizing patients' needs over their own (6). The physical impacts of caregiving persist well into survivorship. One longitudinal study showed that caregivers' physical health was comparable to population norms at six months post-diagnosis, but declined steadily thereafter, falling below population norms by two years and remaining lower through the final data collection point at five years post-diagnosis (113). Caregivers' physical health has also been found to be worse than what patients report (114, 115). During bereavement, low preparedness prior to a spouse's death has been associated with higher risks of chronic pain, particularly among younger widowers (6).

IMMUNE AND BIOLOGICAL

Caregivers of people with cancer often experience intense stress over a relatively short period, which can over-activate—and eventually dysregulate—the body's stress response systems (116). Preliminary evidence suggests that the stress load of caregiving can alter hormone regulation and inflammatory processes in ways that may increase long-term disease risk or stress and immune system wear-and-tear, and even lead to premature death (105, 116).

1 Mesothelioma: Mesothelioma is a type of cancer that starts in cells of the mesothelium. The mesothelium is the membrane that lines cavities in the body and surrounds most of your internal organs. https://cancer.ca/en/cancer-information/cancer-types/mesothelioma/what-is-mesothelioma

HEALTHY BEHAVIOURS

Caregivers tend to exhibit poorer health behaviours—including reduced physical activity, less healthy dietary choices, inadequate sleep, and lower use of preventive health services—compared to non-caregivers of similar ages (60). Multiple interacting factors contribute to these patterns. Caregiving involves substantial demands in terms of time and finances, which can reduce opportunities for regular meals and increase reliance on convenience foods that are often high in saturated fat and sodium. Caregivers are also highly likely to prioritize the patient's needs over their own, creating barriers to seeking, accepting help for or maintaining health-promoting behaviours (117).

One study reported that, three years after diagnosis, caregivers of women with ovarian cancer showed substantial health-behaviour risks: 54% did not meet physical activity guidelines, 71% were overweight or obese, 40% ate fewer than two servings of fruit per day, 80% consumed fewer than five servings of vegetables per day, 37% consumed more than two alcoholic drinks per occasion, and 10% smoked (118). Slightly more than half reported multiple negative health-behaviour changes since assuming the caregiving role. Importantly, some positive shifts also occurred: 14% of caregivers increased their physical activity; 7% increased their fruit intake and 13%, their vegetable intake; 20% intentionally lost weight; and, among smokers, 3 of 13 quit (118).

In the same study, caregivers aged 35 to 49 appear to be the most affected. Among those 32.4% of caregivers indicated that their exercise had decreased due to caregiving, 19% indicated that their eating habits had become less healthy, and 5.3% had increased their alcohol consumption (60). Over time, these patterns increase their risk of developing or worsening chronic conditions, underscoring the profound personal costs of caregiving during midlife.

FINANCIAL

Time devoted to cancer caregiving can lead to loss of income and high opportunity costs (cost of the hours dedicated to providing care), as well as out-of-pocket expenses (e.g., care supplies, medication, travel expenses to medical appointments), with total amounts averaging nearly $5,000 CAD per month in 2018 (31). One caregiver reported:

You're having a tough time. In order not to wait two months to have diagnostic tests, you have to go to a private hospital. So, it is economically difficult (75).

The highest reported caregiver costs are among those who care for patients in the palliative stages of the cancer trajectory (31). Out-of-pocket expenses are strongly associated with psychological distress, anxiety, and depression (31). Financial strain can limit the caregiver's ability to fully support the patient (32). Many conceal their struggles to blanket the patient from additional worry (108). One study found the bankruptcy rate of cancer patients to be 2.65 times higher than for people without cancer (119). This statistic can imply financial hardship for the caregivers as well, particularly within spousal dynamics. Older caregivers are especially vulnerable due to their likelihood of being in the lowest income group at the outset (60).

Caregivers make substantial contributions to health and social services, as their involvement can limit patients' use of healthcare resources, including long-term residential care, hospitalizations and community care (123). Indeed, caregiving represents a sizeable portion of the economic burden of cancer, accounting for an estimated 18–33% of total care costs (13). These costs can be calculated through different approaches. The opportunity cost method measures the value of what caregivers forgo, such as lost wages, travel time, or leisure, while the proxy good method calculates the cost of caregiving by comparing it to equivalent paid services, such as a nurse for medical tasks or a housekeeper for domestic support (13). Using the opportunity cost method, an American study found that the annual economic burden to caregiving partners ranged from $571 USD (783$ CAD[2]) to $47,105 USD (64 665$ CAD[2]) (13). With the proxy good method, the average monthly value of cancer caregiving was estimated at $4,809 USD (6601$ CAD[2]), with a wide range of $975 USD (1338$ CAD[2]) to $19,112 USD (26236$ CAD[2] depending on caregiving intensity (13). Costs also vary by cancer type, with lung cancer caregiving averaging $4,784 USD (6567$ CAD[2]) per month, ovarian cancer, $4,357 USD (5981$ CAD[2]), and breast cancer at the lower end with $2,523 USD (3463$ CAD[2]) per month (13).

2 Estimated value as of March 19, 2026, according to the Bank of Canada

OCCUPATIONAL

Employed caregivers face particularly onerous burdens, juggling care-related tasks alongside their work responsibilities (13). Over 64% report difficulty balancing both roles, and those who provide more than 20 hours of care per week while working full time are at increased risk of poorer physical health, especially women (7, 13). The strain is not only practical but emotional, as the inability to meet work expectations often heightens stress and diminishes self-worth (13).

Work disruptions are a hallmark of employed caregiving. Absenteeism—arriving late, leaving early, or taking time off—affects about half of employed caregivers, who are 1.75 times more likely than non-caregivers to miss work due to unanticipated patient needs or prolonged medical visits (13). On average, this can result in 11 lost work hours per week, or up to seven days per month (13).

Presenteeism—reduced productivity while at work—represents an even greater challenge. Fatigue, anxiety, and caregiving-related distractions contribute to productivity losses, estimated to affect 13% to 27% of caregivers' working time (13). As a result of their responsibilities, caregivers of patients with cancer are 1.54 times more likely to experience presenteeism than non-caregivers (13). In terms of monetary value, a European study of lung cancer caregivers found that presenteeism costs ($8,676 USD (12 184$ CAD[3]) per year) exceeded absenteeism costs ($3,234 USD (4439$ CAD[3]) per year) (13). This highlights the "iceberg effect," where visible absences represent only a small portion of total productivity loss (13).

While employed caregivers may report higher stress, non-employed caregivers often experience greater burden (13). Work can provide important benefits: social support, respite, financial stability, and preservation of personal identity outside the caregiving role. For many, employment creates a sense of normalcy in an otherwise disruptive trajectory. Conversely, lack of workplace flexibility exacerbates distress, with some studies finding higher rates of depression among employed caregivers, though findings remain mixed (13).

Despite the growing prevalence of employed caregivers, workplace accommodations remain limited (13). Only 25% of large corporations are reported to offer caregiver support programs, while small businesses rarely provide assistance (13). Even when services exist, underutilization is common, often due to poor communication or a lack of awareness among employees (13).

Research highlights the need for clearer employer communication, expanded accommodations (e.g., flexible scheduling or gradual return-to-work programs), and training for human resources staff to better recognize and support caregivers. Healthcare professionals can also play a role by connecting caregivers with patient navigators experienced in workplace accommodations. At the community level, social service agencies can provide counseling and guidance on practical issues, such as disclosing the diagnosis to supervisors or planning time off (13).

POSITIVE IMPACTS OF CAREGIVING

Despite the profound challenges inherent to cancer caregiving, many caregivers report significant positive and enriching changes, often referred to as post-traumatic growth, benefit finding, or positive aspects of caregiving (52). This growth represents a cognitive process through which individuals who have experienced a significant stressor—such as a loved one's cancer diagnosis—develop positive psychological changes (120) (121).

Commonly reported positive outcomes of caregiving include gaining strength and perspective (98), as well as improved quality of relationships—both with the patient and, in some cases, with the broader family (41). Caregiving can deepen family bonds, as emotionally intense periods create opportunities for members to broach existential topics, thereby fostering closer connection (52).

Many caregivers derive a sense of accomplishment from their role, feeling respected, appreciated and needed, along with an enhanced sense of self-efficacy (122). This is particularly important, given that greater self-efficacy is associated with lower caregiver strain and higher positive mood (122). Additionally, focusing on acceptance and living in the moment often gains caregivers new perspectives, further supporting their personal growth (122). In one study, 70.9% of spousal caregivers reported that caregiving had made them "grow as a person" (41).

Resilience through post-traumatic growth

Post-traumatic growth (PTG) is positively associated with resilience and social support (1). The personal growth that emerges from the challenges of caregiving can serve as a protective factor against caregiver distress. One study noted particular growth in such areas as relationships, new possibilities, and inner strength (183).

PTG can manifest in multiple ways: improved relationships with the patient and/or extended family (e.g., greater compassion, more effort put into relationships); identification of new possibilities (e.g., developing new interests); a sense of accomplishment derived from applying knowledge and skills to help the patient; recognition of personal strength to overcome adversity; acknowledgement of respect and appreciation from others; a sense of satisfaction and purpose from assisting the patient; and reprioritized values (122).

Resilience and social support further reinforce PTG, buffering caregivers from emotional strain (120, 183). One key mechanism through which caregivers experience PTG is meaning-making—finding purpose in the journey of care or making sense of challenges despite suffering or distress (184). Through this process, caregivers can transform a challenging experience into one that fosters growth and resilience (185). Sources of meaning for caregivers include identity and values (e.g., finding meaning in fulfilling a family duty); choices (e.g., viewing caregiving as an opportunity to show love and commitment); creative endeavours (e.g., journaling or other personal projects); and experiences (e.g., gaining new appreciation for the relationship with the patient, rediscovering past hobbies) (184).

Caregivers who have greater social support are more likely to perceive greater overall benefits to caregiving (121). Higher levels of acceptance and appreciation have also been associated with better adjustment, whereas high empathy combined with reprioritization, low acceptance and/or poor self-view are linked to higher depression (121). Some caregivers may also suppress negative emotions to maintain a positive "front" for the patient, a strategy that can nonetheless increase their own anxiety and depression (41). Additionally, while more intense caregiving, such as for patients with multiple chronic conditions, may be associated with greater benefit finding, this often coexists with heightened emotional strain and stronger caregiving impacts (6).

3 Estimated value as of March 19, 2026, according to the Bank of Canada

PART II: TRAJECTORY OF CAREGIVERS IN ONCOLOGY

This section highlights the key stages, transitions, and milestones experienced by cancer caregivers through the course of the illness. Since the trajectory is inseparable from the illness's major stages, the caregiver's experience tends to mirror that of the patient as they pass through some or all of the stages of cancer: pre-diagnosis, diagnosis, treatment, survival, palliative care, bereavement, post-care, and recurrence.

A key practice implication is to recognize that at each stage of the cancer caregiving trajectory presents distinct challenges and opportunities that shape caregivers' roles, experiences, and well-being. By highlighting the unique aspects of the caregiver's experience at each stage, a trajectory-based approach frames caregiving not as a static role, but rather as a dynamic process intricately interconnected with the patient's cancer experience.

3.1 PRE-DIAGNOSIS: CONTEMPLATING THE ENTRY INTO CANCER CAREGIVING

*Note there is a lack of literature specifically highlighting the caregiver's experience at this stage of the trajectory. The limited research available focuses primarily on the patient, and the information below was inferred from that context.

3.1.1 EXPERIENCE AND IMPACT: UNCERTAINTY BEGINS BEFORE THE DIAGNOSIS

In the pre-diagnostic stage, individuals may notice possible symptoms or other concerning signs and may be undergoing testing (124)—a phase generally characterized by significant uncertainty and anxiety for the potential patient (124). Those who would be their caregivers are likely to experience similar distress, given the well-documented interdependence between patients' and caregivers' mental and physical health (1, 10, 125). The uncertainty may stem from anticipating the diagnosis itself, but for some caregivers, it is amplified by a known family history of the disease, which increases the likelihood of a definitive cancer diagnosis (124).

The pre-diagnosis stage can vary widely across patients. For some, repeated visits to primary care providers may span months or even years, due to delays, dismissal of symptoms, or misdiagnoses (73). For example, a Quebec study found that 29% of patients had consulted their family physician three or more times before being referred for further investigation, while 41% had visited the emergency room at least once during this period (73).

Delays in testing and the need for multiple clinical encounters not only increase the strain on caregivers, but also impose costs on the healthcare system while heightening personal anxieties about disease progression (73). During this time, caregivers may need to take more time off work to accompany patients to appointments, including visits to obtain second opinions or conduct additional tests (13).

3.1.2 CAREGIVER ROLES: SPOTTING THE SIGNS, PROMPTING ACTION

Caregivers often play a critical role in early cancer detection, being apt to recognize initial symptoms, encourage patients to seek medical attention, and help initiate the diagnostic process, thereby contributing to more timely diagnosis and treatment (39). Cancer suspicion among patients is generally low. In one study, only 13 of 71 patients (18%) suspected they had cancer, even high-risk individuals such as smokers (39). Exceptions occur for patients who present with visible signs such as a breast lump and are thus more likely to suspect malignancy (39).

Caregivers frequently notice when patients are "not themselves" (41), identifying subtle changes such as fatigue or shortness of breath, or raising concerns when discussing abnormal lab results with healthcare professionals (41). By spotting early warning signs and encouraging timely medical consultation, caregivers can significantly influence the speed of diagnosis (39).

During this uncertain stage, patients tend to experience heightened anxiety and turn to their caregivers for emotional support (125). They will often seek information from family physicians after their first specialist visit, as well as consult relatives, friends, the internet, and printed materials (32). For caregivers, a key challenge lies in gauging the reliability of online sources and guiding patients toward accurate, trustworthy information (52).

3.1.3 CAREGIVER NEEDS: WAITING FOR ANSWERS, CARRYING THE WEIGHT

Caregivers' needs during the pre-diagnosis stage are largely shaped by uncertainty and the emotional strain of awaiting answers. They often seek to understand the diagnostic process, including which tests are being conducted, the expected timelines for results, and what those results might reveal (124). Interpreting the patient's symptoms and their potential causes is another key concern, as caregivers strive to make sense of the signs while remaining supportive (124).

During this stage, they may need guidance on how best to offer the care receiver emotional and practical support (124). Access to reliable, trustworthy information is especially important, as caregivers strive to educate themselves about potential diagnoses and prepare for forthcoming stages (52). Finally, given the high levels of ambiguity and worry, caregivers often struggle to manage their own anxiety, suggesting they are likely to benefit from resources focused on coping with uncertainty (124).

3.1.4 PROTECTIVE FACTORS: MANAGING UNCERTAINTY THROUGH INFORMATION

Information management may be key to how caregivers cope with uncertainty during the pre-diagnosis stage (124). When individuals perceive a mismatch between their desired and actual levels of certainty, intense emotional responses such as anxiety, fear, guilt, and worry can arise, often prompting coping strategies like seeking or, conversely, avoiding information (124).

While these insights are informative, there remains a notable gap in research that directly investigates how caregivers manage these emotional and cognitive demands prior to receiving a formal diagnosis.

3.2 DIAGNOSIS: "NATURAL" ROLES AND "SUDDEN" ENTRIES INTO CANCER CAREGIVING

> **Who doesn't get terrified by that? You think that you are going to die straight away, and that's the way it is . . . then it's good to talk about it, because the fear comes straight away, then it gradually gets better and better as you get more information and you realize that those around you know what they are talking about and are experts (Daughter) (52).**
>
> **If it was a disease that you could actually see, it would have had an effect on your everyday life, but in practice it doesn't yet do that, so in that way it is very strange. There's no difference except that we know something is going to happen (Son) (52).**
>
> **There was an ad at one point [on TV] where people were getting a cancer diagnosis, and then they all just fell over: it was like that for me. (Free translation)**
>
> - Lise, caregiver, as told to the Quebec Observatory on Caregiving, 2025

3.2.1 EXPERIENCE AND IMPACT: THROWN INTO CAREGIVING, WITHOUT TIME TO PREPARE

A cancer diagnosis marks the "official" entry into caregiving—a major life change that often leaves those concerned with little choice (10). Many caregivers report feeling confused and overwhelmed during this stage (108). While anxiety and depression are high throughout the caregiving trajectory, diagnosis is a critical turning point, often triggering worsening mental health due to psychological turmoil and substantial disruptions to daily life (126).

Up to 50% of caregivers report clinically significant depressive symptoms at this time (17)—a concerning figure, given that early anxiety and depression predict lower quality of life and reduced perceived emotional support in the later stages of the trajectory (54). A recurring sentiment during the diagnosis phase is uncertainty about how the cancer will affect the patient and everyday life (52). Diagnosis often disrupts caregivers' sense of control over time, forcing them to put holidays, career ambitions, and financial decisions on hold (108). Uncertainty about prognosis makes long-term planning challenging, leaving some caregivers disoriented or compelled to abandon previous goals (108). As one caregiver said:

> **It is not about winning or losing the battle against cancer; it's about learning to live with it (108).**

Entry into the caregiving role is often framed as "natural," shaped by marital or familial ties (10). For spouses, caregiving is frequently seen as an extension of marital commitment—in sickness and in health—reinforcing emotional bonds and the sense of duty. Building on this notion of caregiving as inherent, healthcare professionals often assume caregivers are prepared. Yet caregivers consistently report lacking the support and information they need (34). Whether caring for a child, spouse, or aging parent, the transition into caregiving is non-normative and deeply disruptive, redefining identities and altering previously stable life roles overnight, from family members or friends to carers (36).

> **He became my priority. I'm going to explain it like this, but it's very, very, very rational—almost as if I deliberately set my own life aside. It didn't affect me, not at all. He was my priority. So, during that entire time, I didn't go anywhere. I didn't travel, I didn't make any commitments. All my friends knew that if they invited me to dinner, I could decline at five minutes' notice because he needed me. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

The onset of cancer caregiving is often abrupt, marked by a jarring shift into an unfamiliar and demanding role (30). Caregivers are thrust into a life centred on the disease and its prognosis, with little warning or time to prepare (8, 29). Unlike chronic conditions that progress gradually, cancer symptoms can appear just weeks or months prior to diagnosis, leading to a rapid and disorienting entry into caregiving (30). The diagnosis itself is experienced as shocking, and treatment typically begins immediately, leaving caregivers little time to emotionally process or practically prepare for their responsibilities (1). In Quebec, for example, lung cancer patients waited on average just two days from first appointment to specialist referral, and 18 days to diagnosis (127). This contrasts starkly with other caregiving trajectories, where the patient's health might deteriorate over years (128). The suddenness of cancer often forces caregivers into rapid role shifts, moving from family member to carer almost overnight (36).

Finally, for caregivers supporting a partner, the moment of diagnosis can significantly affect their sex lives. A 2009 study revealed that 76% of caregivers of a spouse with cancer reported changes in their sexuality immediately following diagnosis (196). Thus, even before treatment begins, a cancer diagnosis often leads to decreased sexual activity within the couple, largely driven by anxiety and emotional upheaval:

> **[I]n the beginning . . . because you know you're concerned and you're not interested in sex.**
>
> - Jessie, caregiver of a partner with breast cancer, 196, p. 530)

3.2.2 CAREGIVER ROLES: SEEKING INFORMATION, ASKING QUESTIONS, AND PROTECTING

> **Cancer is like an unwanted guest that comes unexpectedly. I have gained new responsibilities, and I do not know whether I am really a caregiver or not. I assume that these are the duties of every child, but caregiving is probably something else (Daughter) (8).**

Information-seeking is a key task for caregivers after diagnosis as they strive to understand the illness, explore treatment options, and learn how to best support the patient (129). While caregivers prefer to receive clear and tailored information directly from healthcare professionals, they often face communication gaps—insufficient detail, lack of personalization, overly complex presentation, exclusion from clinical discussions—that can leave them feeling both unprepared and overwhelmed (37). As a result, many turn to alternative sources like the internet or peer support networks, even though such resources can vary in trustworthiness and be time-consuming to navigate (37). Caregivers describe this information-seeking process as a way of regaining a sense of control, reporting a strong desire to "get more knowledge, to learn, to ask, to read" in response to diagnostic uncertainty (129).

Furthermore, most caregivers report providing emotional support to patients (129), which at time of diagnosis, is positively associated with the patient's general health and social functioning (54). Many caregivers also try to conceal their negative emotions from patients to "keep things positive" (129), a behaviour known as protective buffering (130). Common examples include "I hold [my thoughts and feelings] for myself," "I needed help, but I had never asked for it," and "I had to be strong" (129). However, protective buffering can undermine caregivers' mental well-being, as it requires them to put their own needs second. Research shows that open communication is critical for both patients and caregivers in coping with cancer (130). Caregivers benefit from expressing their emotions, while patients gain from openly discussing their illness. When protective buffering occurs, the exchange breaks down, making it more difficult for both parties to cope effectively (130).

3.2.3 CAREGIVER NEEDS: INFORMATION AND COMMUNICATION SHORTFALLS

At the time of diagnosis, caregivers consistently identify information— about both the illness and their own support options—as their primary unmet need (6) (27). They want to know what to expect across the cancer trajectory; they want to explore the details of treatment options, likely side effects, and even issues related death and dying (6). In one study, women caring for men with prostate cancer expressed a need for more specific information, particularly around managing medication, maintaining hygiene, and coping with the strain of long-term emotional support (53). In another, caregivers of patients with brain cancer sought training in basic care tasks such as physical assistance and symptom management (97).

Information tailored to caregivers' own needs—rights, benefits, available services, practical advice and so on—is rarely provided, leaving many to search independently. This process is lengthy, complex, and often distressing, underscoring the need for adequate, structured support from the outset (52). Yet caregivers often report not knowing where to turn with the many questions that arise following a cancer diagnosis, leading to feelings of frustration and despair (52).

Furthermore, the amount and type of information desired can vary from one caregiver to the next: some feel overwhelmed by the complexity of the material, whereas others welcome it as a means of reassurance and control (1). As one caregiver said: "I like to seek information because I prefer being one step ahead of things instead of being totally blindsided" (1). This underscores the importance of not only involving caregivers in addressing patient needs, but also giving them space to raise their own questions and concerns (81).

Along with the sudden need for information, diagnosis can present caregivers with profound emotional strain. Many engage in protective buffering, which can lead to exhaustion and the neglect of their own well-being (130). This is especially concerning, given that open and constructive communication not only eases caregiver burden, but also strengthens intimacy within couples and supports overall physical and mental health for patient and caregiver alike (131). Still, engaging in such conversations is not always easy. Beyond suppressing their own feelings, caregivers often struggle with how to approach difficult discussions with patients. These challenges highlight the importance of providing caregivers with support to both initiate emotional conversations and express their own needs openly and honestly (131).

Clinical communication at diagnosis strongly shapes caregivers' perceptions and coping. While research emphasizes the importance of clear, empathetic communication, many caregivers describe the delivery of diagnoses as rushed or lacking sensitivity (27). This can impair understanding and drive caregivers to seek information independently, often through unreliable sources online (52). The manner in which healthcare professionals communicate at diagnosis can also have lasting consequences: many caregivers recall this moment vividly, describing feelings of "shock" or an "out-of-body experience" (108). Moreover, whether the diagnosis is framed in bleak or hopeful terms will significantly shape caregivers' temporal focus, i.e., whether they concentrate narrowly on the present or maintain hope for the future (108).

3.2.4 PROTECTIVE FACTORS: SUPPORT, COMMUNICATION, RECOGNITION, COPING, SELF-EFFICACY, AND GROWTH

SOCIAL SUPPORT

The caregiver's mental health at diagnosis is closely linked to the social support they receive from friends, family, and the healthcare establishment (54). Emotional support is particularly vital, as the urge to share fears and emotions intensifies during this uncertain stage and treatment decisions loom (54). Caregivers who feel they have high levels of social support are more likely to carry out their role with confidence and resilience (28).

Equally important is informational support from healthcare professionals. Being regularly updated about the patient's condition and given insights into the disease helps caregivers feel recognized and valued as part of the care team (81). Conversely, the absence of timely updates or prognosis details can limit their ability to support the patient effectively (53). A lack of information may also prevent caregivers from seeking assistance from social services (132). Information gaps may therefore act as a barrier to comprehensive caregiver support throughout the oncology trajectory.

PATIENT-CAREGIVER COMMUNICATION

Open, constructive communication between patients and caregivers—including self-disclosure and attentive listening—can foster emotional intimacy (133); it can also encourage individuals who might otherwise rein in certain emotions to express themselves, thus improving interpersonal relationships and reducing emotional tension (134). Furthermore, discussing the diagnosis or predicted oncology trajectory can help loved ones prepare for what's to come and foster a more ready acceptance of the situation (134).

RECOGNITION

Caregivers often derive motivation from appreciation expressed by patients and others, whereas feeling unrecognized can lead to frustration and strain (95). Research indicates that acknowledging caregivers' contributions is beneficial to both caregivers and patients, promoting emotional well-being, strengthening family relationships and reducing distress (1, 95).

COPING STRATEGIES

At diagnosis, caregivers typically adopt a wide range of coping strategies to manage the life-altering impacts of cancer. Distraction-oriented and escapist behaviours—ranging from immersion in daily tasks to self-soothing or self-indulgent activities such as drinking or smoking—are frequently used to temporarily alleviate fear and anxiety (108). While these approaches may provide short-term relief, overreliance on avoidance has been associated with higher anxiety and depression over time (135). Though healthcare professionals often attribute denial to caregivers, evidence suggests it is more prevalent among patients (136). As the illness trajectory unfolds, many caregivers transition toward more adaptive strategies, such as active problem-solving and emotional acceptance, particularly when confronted with circumstances beyond their control (135). Coping is rarely singular or static; most caregivers draw on multiple strategies and adjust as circumstances evolve. This fluidity reflects their ongoing efforts to regulate both their own emotional responses and those of the patient amid the uncertainty surrounding diagnosis and prognosis (108).

SELF-EFFICACY AND PREPAREDNESS

Caregivers who feel confident in their ability to provide care and manage stress tend to report lower burden levels, better health outcomes, and greater satisfaction in their role (29). Preparedness for caregiving refers to the perceived capacity to deliver medical, physical, emotional and practical care while managing the associated demands and stresses (29). This encompasses both practical competencies—managing symptoms, administering medications, navigating the healthcare system, etc.—and the emotional readiness to cope with caregiving-related strain (29).

Higher levels of preparedness are associated not only with improved caregiver well-being, but also with better patient outcomes, as caregivers who feel capable are more likely to deliver consistent and effective support (29). Conversely, low preparedness is associated with greater caregiver burden and reduced perceived caregiving competence (29). Importantly, preparedness is modifiable and can be enhanced through targeted interventions, including skills training and psychoeducational programs (29). Such initiatives equip caregivers with essential knowledge in general physical care, symptom assessment, problem-solving and pain management—core responsibilities within their role (29).

POST-TRAUMATIC GROWTH

Maintaining a positive mindset through benefit-finding and post-traumatic growth allows caregivers to identify meaningful aspects of their role, such as strengthened relationships, participation in social activities, future planning and spiritual development (120). In addition, emotions such as hope and positivity function as modifiable protective factors that foster resilience and reinforce social connections (120). Many caregivers describe a cancer diagnosis as a turning point that prompts re-evaluation of their priorities, encouraging them to focus on what truly matters and seek out moments of growth and meaning, even amid difficult circumstances (137).

3.3 TREATMENT: A DEMANDING STAGE OF THE TRAJECTORY

3.3.1 EXPERIENCE AND IMPACT: TREATMENT AS A SHARED JOURNEY

The treatment stage is often described as an "emotional roller coaster" marked by the dual burden caregivers must face: namely, managing the patient's distress while simultaneously coping with their own feelings (32, 52). The increasingly intensive and sustained level of care associated with treatment can make caregivers more vulnerable to psychological, physical, financial and social strain (138). Constant worry about prognosis, mortality, fatigue, and the challenges of balancing care with work and other responsibilities interact to amplify overall distress (4, 50, 75, 107). This burden is intensified by close, hands-on involvement in care and continual exposure to the patient's suffering (32, 79). Many caregivers also engage in protective buffering—suppressing their own fears to shield the patient—which can further compromise their mental health (75). Persistent problems such as pain, fatigue, appetite loss, or nausea can significantly add to the burden of care, leaving caregivers feeling sad and helpless, especially when their efforts bring little relief (27).

> **She has been a bit washed out after these first four intense treatments. Then we've had a whole week when she has been absolutely wiped out, really. So it's been hard to see her feeling so ill. That's the worst, after all (52).**

The physical toll of caregiving during treatment is equally significant. Fatigue, sleep disturbances, pain, and stress-related declines in health are common, sometimes worsening pre-existing conditions (4, 31, 75). Caregivers' physical well-being often deteriorates alongside the patient's during treatment, with gradual improvement following its completion (typically within six months) (10). This parallel trajectory reinforces the notion that caregivers and patients experience the illness as a shared struggle (47). As one caregiver explained:

You don't keep feeling as bad as in the beginning, but you continue to feel bad. It fluctuates with the treatment. When he's feeling good, so am I, and when he's not feeling well, then I'm feeling really bad (1).

As treatment becomes routine, caregivers often describe it as "taking over" their lives, eclipsing social roles and highlighting the all-encompassing nature of their role at this stage (107). Social isolation frequently ensues, as caregivers partially or fully withdraw from social and recreational activities due to treatment side effects and the need to juggle multiple roles related to home, work and care (32). Many caregivers feel unseen or unacknowledged by friends and extended family who fail to grasp the depth of their investment and sacrifice (1). The patient-caregiver relationship may also suffer due to strained communication, unspoken personal concerns, and disrupted intimacy or sexual connection (53, 75). At the same time, treatment does not uniformly erode relationships. For some caregivers, these challenges prove to be enriching, fostering closeness and bringing family priorities into sharper focus (52).

Financial strain is a major challenge during treatment, with caregivers facing both direct costs (e.g., transportation, medications, formal help) and indirect losses from reduced work hours or job changes (13). Even in countries with universal healthcare systems, out-of-pocket cancer-related expenses for patients and caregivers during treatment typically fall between USD $15 (20$ CAD[4]) and $400 (549$ CAD[4]) per month. Additional treatment-related and commuting costs further heighten this burden, often constraining caregivers' ability to provide optimal support (32). Many caregivers try to shield patients from additional worry about financial hardship and its emotional toll, preferring to maintain a façade of stability despite significant personal strain (108).

Employed caregivers frequently forgo promotions, transition to part-time roles or work night shifts to accommodate medical appointments, thereby compounding financial and emotional strain (13). On average, cancer caregivers provide 32.9 hours of care per week, with nearly one-third exceeding 40 hours, essentially putting caregiving in the category of a second full-time job (13). Despite this, most caregivers are reluctant to stop working entirely, either to preserve employer-based health insurance or because the patient had been the household's primary wage earner, making income retention essential (13). Only 3% to 9% of caregivers leave the workforce, while between 25% and 29% modify their employment—switch from full- to part-time work, change their schedules, or take on less demanding positions (13). Many also reduce their weekly working hours by 3 to 16 hours, depending on the patient's needs and cancer stage (13). Formal leave is another common strategy: in one study, 52% of employed caregivers took time off, with 15% taking at least a month off work to provide care (13).

IMPACT ON COUPLE RELATIONSHIPS

After prolonged periods of providing care, many caregivers report a significant decline in libido, reflecting the cumulative burden and demands of their role. Caring for a partner for years—accompanying them to various medical appointments (chemotherapy, radiotherapy, surgery), preparing meals, managing medication, and assisting with personal hygiene—can be physically and emotionally exhausting, leaving caregivers without the energy or desire for sex (196).

3.3.2 ROLES: THE EXPANDING SCOPE OF CAREGIVING

As treatment starts—and intensifies—caregivers rapidly assume an expanding range of responsibilities to manage escalating side effects, with practical demands and emotional strain rising in parallel (107). Caregiver often help patients communicate with healthcare professionals, participate in decisions about treatment, and provide transportation to appointments (36). Beyond logistical support, they are frequently tasked with managing treatment-related side effects, including wound and pain care, feeding, drainage systems, and tracheostomy care, in addition to supporting patients through persistent and debilitating symptoms like appetite loss, nausea and constipation (27, 32). In many cases, they also administer medications, including oral chemotherapy, and ensure adherence to complex treatment regimens (36), responsibilities that can leave them feeling overwhelmed, helpless, or distressed.

4 Estimated value as of March 19, 2026, according to the Bank of Canada

The treatment stage is particularly demanding because complications can arise suddenly, shifting responsibilities and requiring constant adaptation (1). For instance, immunosuppression may require caregivers to become hypervigilant in monitoring for infections, while disease progression forces ongoing adjustments in care (1, 36). Caregiving is therefore a dynamic role that demands constant flexibility and the willingness to take on new tasks as patient needs evolve (1).

Beyond physical and medical tasks, caregivers must also manage the emotional toll of cancer. As one caregiver reported, "It is the emotional part that becomes the greater challenge" (108). Supporting the patient's mental well-being may involve using coping techniques such as distraction, pep talks, and listening, or even controlling the social environment by limiting contact with family or friends who are perceived as unhelpful (108). Caregivers may also take on a wider range of household responsibilities alongside medical care. One daughter explained:

> **Every day after work I have to come over here or I meet my mum and we go to treatment. On the days I'm off, I'm here cleaning the house, cooking, washing clothes, making everything sterile, and making sure everything's clean so she doesn't get an infection . . . I live on my own so it's like living two lives (107).**

OUTPATIENT CARE AND CAREGIVING

Most treatments are now delivered in ambulatory clinics, bringing both benefits and drawbacks. Outpatient care reduces hospital stays, lowering the risk of hospital-contacted infections and allowing patients and caregivers to return to a more familiar routine, which can improve quality of life (139). However, this shift places greater responsibility on both patients and caregivers to monitor and manage symptoms at home (9, 12). Caregivers in particular must understand complex information, perform technical procedures, communicate information to mitigate disease or treatment symptoms, and maintain or improve patient health—again, with little to no formal training (9).

A well-documented challenge is the tendency to underestimate or underreport treatment-related symptoms, whether out of fear of burdening healthcare staff or a reluctance to appear as "difficult" (12). Physical distance from the hospital can further discourage timely reporting, creating risks for unmanaged complications. At the same time, patients draw hope and positivity from their interactions with healthcare professionals during treatment (12). In outpatient settings where this vital source of encouragement is reduced, caregivers must assume an amplified role of sustaining the patient's optimism (12), thereby increasing their own emotional burden.

Caregivers' roles also vary by treatment type, with distinct demands arising during chemotherapy, radiation, surgery, and stem cell transplantation, among others.

Chemotherapy. For caregivers, chemotherapy calls for heavy involvement in complex medical tasks at home, including administering oral chemotherapy or medications through inserted catheters or feeding tubes, and performing wound care (6) (36). Caregivers must also be prepared to respond to acute and sometimes unpredictable side effects—for example, severe nausea or fever—that can cause responsibilities to rapidly shift (4, 36). Because the patient is immunosuppressed by treatment, vigilance is paramount to prevent infections (1). Caregiving during chemotherapy is not only constant, but can also intensify over time as side effects accumulate (107). For some caregivers, this may lead to resentment and a sense that they are "doing it all" (107). Equally important is the emotional support they provide, helping patients navigate fear, uncertainty, and distress (4, 36). In terms of logistics, chemotherapy involves regular visits, lab tests, and follow-up appointments, often requiring the caregiver to manage transportation, coordinate schedules, communicate with the care team, and ensure the patient adheres to treatment regimens (36, 138). They must also proactively seek information about the illness, prognosis, and treatment options to support decision-making (4). Lastly, since chemotherapy can leave patients depleted, caregiver support will often extend to day-to-day needs such as meal preparation, hygiene, and mobility (6) (52).

Radiotherapy. A distinguishing feature of radiotherapy is the daily nature of the appointments (140). Caregivers are often tasked with managing appointments and transportation, prioritizing the patient's needs over their own routines (140). This intensity takes a toll: one study reported that 64.6% of caregivers of radiotherapy patients experienced anxiety, while 63.1% reported depression (50). The most common sources of caregiver distress include worry, fatigue, sleep problems, managing the patient's physical symptoms, and balancing work responsibilities (140). Caregivers also frequently act as advocates and information-seekers, striving to understand treatment effects and ensure timely responses to emerging concerns (6). They monitor and help manage side effects that often worsen over time by finding or facilitating symptom management strategies and encouraging patients to report issues promptly (27, 140, 141). The duration and intensity of radiotherapy can contribute to feelings of hopelessness among caregivers, particularly spouses, who often report greater burden and negative perceptions of caregiving in this context (28). The patient's constant reliance on their caregiver further compounds this strain (28). Emotionally, caregivers provide consistent reassurance and comfort, helping patients cope with the anxiety and isolation that can arise from the repetitive nature and frequently solitary experience of radiotherapy (140).

Surgery. During surgery, the waiting period is stressful, as caregivers often feel anxious and uninformed about the patient's status (65). A study testing a real-time location system—one that provided updates from nursing staff and allowed caregivers to track patient progress—showed significant reductions in caregiver stress, highlighting how uncertainty and lack of communication are major sources of strain (65). With advances in surgical care leading to earlier discharges, caregivers now assume a greater share of post-operative responsibilities (142).

Once home, caregivers become the primary safety net, monitoring the patient closely to ensure adherence to discharge instructions and prevent overexertion (65). One noted: "Right after surgery the biggest challenge was knowing I was doing everything correctly" (82). Importantly, caregivers' vigilance extends to differentiating between normal recovery symptoms and the signs that indicate a need for medical attention—a responsibility that, without adequate preparation, can feel overwhelming (65).

During the immediate post-operative recovery period, patients typically experience pain, fatigue, and reduced physical function, leading to heavy reliance on caregivers (142). Caregivers help with activities of daily living (e.g., changing clothes, laundry, meal preparation), managing wound or drain care, supporting mobility, and organizing the household (65). They also serve as emotional anchors, helping patients manage fear, frustration, and body image concerns, particularly after surgeries involving disfigurement or loss of function (65). In one study, caregivers emphasized their role in managing fear and anxiety and reassuring the patient that they were not alone in their recovery (65).

Recovering physical quality of life can take several months or longer, prolonging dependence on the caregiver (142). While patients' emotional outlook typically improves after surgery, emotional recovery tends to be slower in coming for caregivers, and their physical quality of life may even decline over time (142).

Allogeneic Bone Marrow Transplant (allo-BMT). Allo-BMT is increasingly a curative treatment for patients with blood cancers (41). Survival outcomes are closely linked to caregiver involvement: patients with caregivers demonstrate significantly higher 100-day survival rates than those without, largely due to the caregivers' essential roles in symptom monitoring, medication adherence, and care coordination (143, 144). Importantly, caregiver responsibilities begin well before the transplant procedure. During the pre-transplant phase, patients must undergo painful diagnostic procedures and frequent medical evaluations to determine eligibility, with caregivers providing both logistical and emotional support (41).

Once approved, patients are admitted for conditioning regimens—typically several days of high-dose chemotherapy and/or radiation designed to eradicate diseased and healthy marrow cells. These treatments leave patients physically vulnerable and socially isolated, thereby increasing their reliance on caregiver support (41). Following transplantation, caregiving demands intensify. Caregivers administer medications and injections, coordinate transport to the frequent follow-up visits, and maintain a clean and protective home environment to lower infection risk while the patient is immunosuppressed (40, 41). They also monitor for complications ranging from respiratory and neurological issues to severe psychological and physical symptoms, which may occur acutely or long after transplant (41).

Given these risks, patients often require round-the-clock care for at least the first 100 days post-transplant, and sometimes much longer (41). During this demanding period, caregivers not only provide medical and practical assistance, but also essential emotional stability, being often described by patients as their "rock" (40). Their responsibilities extend beyond clinical care to encompass household management, meal preparation, and shopping—duties that remain critical as many patients experience persistent fatigue and reduced physical functioning even a year after treatment (40). Beyond hands-on care, caregivers serve as advocates and communicators, navigating interactions with multidisciplinary transplant teams, interpreting complex medical information, and facilitating decision-making.

> **It was useful to be two people to hear the explanations, so I accompanied him to all his medical appointments, [to] reassure him too, because afterwards, when you leave the doctor's office, it seems like everything gets magnified. He had a lot of questions like, "Did he really say that to me? Is that it? Is it worse?" So to be able to clarify and repeat the answers . . . I wrote everything down—I acted as his secretary. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

This breadth of responsibility often leaves caregivers feeling stretched beyond capacity. As one caregiver reflected: "I was constantly feeling like I had to be everywhere all the time and I wasn't doing anything well" (42).

3.3.3 CAREGIVERS' NEEDS: LINGERING UNMET INFORMATION NEEDS PILED UPON OTHERS

> **You keep going, you are there for the others, you're supposed to be the big strong one. That's OK for a while, but not for the long term. And . . . no, there should have been a system that responded to that . . . I think (Daughter) (52).**

Caregivers frequently report dissatisfaction with the informational support they receive, highlighting unmet needs for tailored guidance regarding what to expect, treatment benefits and side effects, and information on alternative therapies (28, 75, 82, 145). Even when information is provided, its complexity and the high stress experienced by caregivers can make it difficult to retain (12). A common challenge involves knowing when and how to seek help for treatment side effects. Many caregivers assume that healthcare professionals will be readily accessible throughout treatment—which is not always the case (107). One caregiver commented on the difficulty of obtaining help: "You can page a registrar if it's urgent but we weren't sure if it was a problem . . . so we just waited until the morning" (107).

During treatment, caregivers must assume complex responsibilities for which they are generally ill-prepared (8). Cancer caregiving require targeted, structured training to manage the demanding, hands-on tasks involved. Research highlights challenges with such essential skills as managing dysphagia, administering tube feedings, assisting with medication regimens, and preparing appropriate meals (32). These tasks require not only technical competence, but also confidence, patience, and emotional resilience. For instance, emptying a patient's colostomy bag has been reported to generate confusion, frustration, and even conflict between patients and caregivers (75). Without proper guidance, these activities can exacerbate stress, strain relationships, and compromise the quality of care.

Caregivers have expressed the need for emotional and psychological support in coping with fears related to the patient's physical or mental decline, which can be overwhelming and emotionally taxing. Many also struggle with anticipatory grief and need help processing thoughts and emotions around death and dying (145). Research further indicates that unmet needs—access to respite care, home healthcare services, legal or financial counseling—can impede caregivers' ability to balance caregiving with other aspects of their lives, ultimately compromising their overall well-being (28).

PARTNERSHIP WITH THE CARE RECEIVER AND HEALTHCARE PROFESSIONALS

Caregiving is a fundamentally dyadic process in which the relationship between caregiver and patient influences—and is influenced by—the well-being of both individuals (4). Within this context, caregivers often encounter significant interpersonal challenges, including difficulty communicating with the patient about the illness as well as about their own concerns (47). Treatment-related personality or behavioural changes in the patient can further strain the relationship, and caregivers may also suppress or conceal their own feelings in an effort to protect the patient (75). Intimate and sexual relationships may be disrupted by the demands of illness and treatment (53). At the same time, some caregivers report that navigating these shared difficulties can strengthen bonds and foster personal growth within the relationship (107).

Caregivers have expressed a strong desire for clear, consistent, and transparent communication with healthcare professionals, along with an acknowledgment of their contributions and recognition as integral members of the care team (52, 53). They want to understand the types of support available, establish trusting and supportive relationships with healthcare professionals, receive guidance in navigating the healthcare system, and be given meaningful opportunities to participate in patient care (47, 59). For caregivers, a strong partnership with healthcare professionals entails being comfortable asking questions, experiencing timely and transparent communication, being included in key discussions about treatment options and strategies, engaging in shared goal-setting, and receiving information tailored to the patient's cancer and treatment trajectory (47, 59, 78).

Yet many caregivers report that such interactions are limited, that staff rarely inquire about their well-being, and that the fragmentation of teams and care processes can leave them with the added burden of coordinating care and advocating for the patient themselves (55). These gaps can create frustration and distress when caregivers feel their voices are not heard, encounter a lack of empathy, or hearing themselves talked about rather than spoken to—experiences that may cause them to withhold questions and undermine trust in the partnership (44). Caregivers have also expressed a preference for sharing their needs and concerns with the oncology team rather than with family physicians, citing uncertainty about the latter's knowledge of cancer-specific issues, a finding consistent with prior research (37). Furthermore, they have identified the need for a clear point person within the patient's care team to help coordinate care, acknowledge the burden they carry, and ensure support is tailored to their circumstances (27, 59).

Valuing caregivers
Recognizing caregiver contributions to patient care allows health professionals to better support caregivers, thereby enhancing their ability to continue in their role and maintain their well-being (1).

- **Responsibility**: Caregivers often take charge of managing patient care, navigating challenges, and discovering new strengths along the way (2).
- **Commitment**: Caregivers demonstrate unwavering dedication throughout the cancer trajectory, which extends well beyond the end of treatment (2).
- **Adaptation**: Caregivers develop the ability to adapt to different situations (2).
- **Advocacy**: Caregivers often explain or clarify the patient's medical history, thus improving the care team's understanding of their condition (3).
- **Information brokering**: Caregivers gather, relay, and interpret essential information, taking notes during appointments, asking questions, and helping patients understand or recall information (3).
- **Communication**: Caregivers are required to communicate with different members of the care team, as well as with the patient and family members (3).
- **Family liaison**: Caregivers facilitate the sharing of health information with other family members (3).
- **Support**: They provide comprehensive physical, emotional, financial, and social support to meet the patient's complex care needs (4).

3.3.4 PROTECTIVE FACTORS: BUILDING CONFIDENCE, CONNECTIONS, AND COPING CAPACITY

Several protective factors, including social support, resilience and confidence, can mitigate caregiver burden during treatment, reducing unmet information needs and fostering an effective partnership with the care team.

SOCIAL SUPPORT

Social support from friends and family members is a predictor of lower caregiver burden and better physical and mental health (110), and can also reinforce caregiver resilience (72). A social circle can rally around a caregiver and provide emotional and practical reinforcement (107). While the amount of received social support is important, perceived social support may be even more protective against subjective overload, anxiety, and depression (146). The caregiving experience may also be shaped by the persistence and quality of social support over time (110). For example, in one study, while social support remained stable in the first year after diagnosis, satisfaction with that support declined significantly between 180 and 200 days post-diagnosis (110). Thus, over time, caregivers developed a more negative perception of the support provided, noting less empathy, affection, and encouragement (110). Further, compared to patients, caregivers are less likely to seek emotional support and more often rely on acceptance as a coping strategy (147). Some caregivers find strength in deepening their bond with the patient (107) and/or maintaining employment, which offers financial security, social interaction, and a sense of identity beyond caregiving (13).

RESILIENCE AND CONFIDENCE

Caregivers with greater resilience tend to experience lower levels of burden, fewer depressive symptoms, and higher quality of life (4). Confidence or self-efficacy in managing care and stress is consistently associated with better health outcomes for caregivers, including reduced anxiety and depression, higher post-traumatic growth, improved functioning, and enhanced quality of life (148, 149). Beyond these direct effects, caregiver self-efficacy plays a mediating role—for example, moderating the interplay between trust in health professionals and caregiver distress (148.)

Caregiver confidence in the role evolves across the treatment stage (107). Early in treatment, self-efficacy is often low, shaped by uncertainty about the future, concerns about side effects, and anxieties as to how patients will cope from day to day (107). As treatment progresses, many caregivers gain confidence in their ability to spot severe symptoms and knowing when to seek professional help, particularly when they trust their oncology team (107). However, when help-seeking efforts are unsuccessful, low confidence in symptom management may persist (107). Establishing routines and becoming familiar with symptom patterns generally mitigates uncertainty, although some caregivers continue to experience anxiety about future treatment cycles. As one caregiver said:

> **I know what the routine is and I expect him to be slightly more poorly in his full week than the week that he is doing one day. So, I think, you come to terms with it . . . I mean, it's become like a routine now. I know what's expected. I know it's going to take five hours and I try to manage my time . . . it's become a bit more . . . not easier, but it's become a bit more routine because I know what to do now (107).**

By the end of treatment, confidence is usually at its highest, with caregiving described as "routine" or "second nature" (107). However, new symptoms can undermine this confidence, and the transition out of treatment frequently brings renewed trepidation (107). Self-efficacy is influenced by multiple factors, including stress management, the perceived impact of the caregiving role on physical well-being, communication with health professionals, and the overall distress experienced by both patients and families (6) (148, 150). It is also shaped by patient symptom load and treatment intensity, highlighting the importance of ongoing support to sustain caregiver confidence. Because self-efficacy is amenable to change, numerous interventions have been developed to strengthen it, often by focusing on performance accomplishments such as coping skills training (e.g., communication strategies, problem-solving) and expanding caregiver knowledge (148, 151). Yet, performance accomplishment alone may be insufficient; other sources of self-efficacy, such as vicarious experience (learning from the stories of others) and verbal persuasion (encouragement or feedback from professionals), are also critical. Notably, interventions that are purely informational do not appear to enhance self-efficacy (151).

REDUCING UNMET INFORMATION NEEDS

Meeting caregivers' informational needs, particularly regarding medical tasks such as managing feeding tubes or wound care, is crucial for building their confidence (65). Caregivers value timely guidance and reassurance from health professionals, which helps reduce the stress associated with seeking answers (97). Continued predictability about treatment and recovery remain important for building caregiver confidence in their role and reducing stress (65).

EFFECTIVE PARTNERSHIP WITH THE CARE TEAM

Caregivers want to feel heard when advocating for the patient, without being dismissed as being overly anxious (44). Research associates effective communication and genuine partnership with health professionals with improved caregiver physical and emotional well-being, as well as reduced burden (4, 41). The way treatment options are first explained is especially critical, as clear discussions of the risks and benefits strongly influence patient and caregiver consent and support informed decision-making (9). However, when health professionals present treatments in overly complex ways, patients and caregivers can become confused and uncertain (9).

3.4 SURVIVORSHIP: ADAPTING TO A NEW REALITY

Many patients enter remission within their first five years post-diagnosis; others remain in cancer care, while roughly one-third die (17). Caregivers often follow parallel trajectories: some become "former caregivers" when patients achieve remission; others continue providing active care, and still others transition into bereavement (17). The number of cancer survivors in Canada continues to grow; in 2018, more than 1.5 million people were living with or beyond cancer (152). With increasing survivorship and ongoing demographic shifts, the absolute number is expected to rise in the coming years (152). Even a conservative estimate of just one caregiver per survivor highlights the vast number of individuals who are either living with someone else's cancer, or actively providing care (9). This underscores the urgent need for innovative strategies to strengthen survivorship as a critical stage of the oncology trajectory.

The transition to survivorship is often jarring for caregivers, who—after investing significant time, energy, and personal sacrifice during treatment—find multiple areas of their lives disrupted (14). Importantly, survivorship does not represent a "fresh start," but rather a continuation of the emotional, practical, and relational challenges accumulated throughout the cancer trajectory. The unmet needs, psychological distress, and caregiver burden that were present before or during treatment frequently persist (4). Many caregivers feel just as unprepared for this stage of the trajectory and struggle to meet the patient's evolving needs (9). At the same time, decreasing oncology resources together with the growing population of cancer survivors contribute to what is often experienced as a sudden rupture in care, leaving patients and caregivers alike feeling abandoned by the healthcare system (46). Survivorship care varies widely, and caregivers can encounter numerous barriers, including fragmented care coordination, limited access to local specialists, transportation issues, and financial strain (82). As follow-up from health professionals diminishes over time, caregivers are increasingly left to manage complex needs with minimal guidance (14), underscoring the enduring and often underrecognized burden they shoulder during survivorship (9).

3.4.1 EXPERIENCE AND IMPACT: THE CONTINUING WEIGHT OF CAREGIVING

Cancer caregiving continues well beyond active treatment, sometimes lasting for years or decades (7). As one caregiver put it, "I need to have patience and understand it is a marathon, not a sprint" (82). With cancer increasingly resembling a chronic condition, survivors often experience lingering symptoms and late effects, both of which require sustained caregiver involvement (13, 153). Recovery is sometimes slower than patients and caregivers anticipate, requiring both to recalibrate their expectations (82). Post-treatment support typically declines, creating a mismatch between patient needs and available resources, thereby leaving caregivers at risk of prolonged burden and psychological distress (4, 14).

Many caregivers enter survivorship expecting to "return to where we had left off, to normal life" (82), only to encounter the uncertainty of unpredictable follow-ups, ongoing care responsibilities, and shifting emotional needs (32). Up to one-third of caregivers experience ongoing anxiety and/or depression, often at higher levels than patients or the general population (4, 6, 41, 154). Those who were heavily burdened during treatment remain particularly vulnerable, with distress liable to continue for years (126, 154). Predictors of anxiety and/or depression among caregivers during survivorship include avoidant coping, disrupted daily routines, unmet needs, and low emotional or informational support, especially when caregivers remain heavily involved in personal and medical care tasks (48). In addition to anxiety and depression, caregivers report ongoing worry and uncertainty regarding recovery trajectories, disease recurrence, and managing unpredictable symptoms (82). Many caregivers also reflect on the toll cancer has taken on their relationships and express frustration at feeling invisible once treatment ends (155).

In particular, fear of cancer recurrence (FCR)—a sense of dread, worry or concern about the cancer returning or progressing—affects approximately 48% of caregivers, often at levels equal to or exceeding those of patients (156). FCR can arise in response to any sign of a physical problem in the patient (157). It is more prevalent among caregivers who are younger and female, who have limited emotional support, and/or who are caring for patients with greater severity or distress (158, 159).

Caregivers may also struggle to re-establish social relationships, return to work, or address financial issues that accumulated during treatment (14). Intimate relationships may suffer as well: 70% of female partners of prostate cancer survivors report a decline in sexual intimacy 12 months after treatment (53). Reengaging in healthy behaviours—for example, physical activity, medical screenings or dietary improvements—can be difficult, especially when caregiving responsibilities persist (14). Some caregivers may have difficulty transition out of their caregiving role, particularly when their identity has become entwined with caregiving (14). Their physical health can also decline, with some caregivers showing deterioration within two to five years post-diagnosis, falling below population norms (113). Nor do financial concerns necessarily end with treatment: some patients may be unable to return to work due to ongoing impairments, and insurance may not cover all necessary services. As such, employed caregivers must continue juggling work and household responsibilities (82). A perceived lack of empathy and compassion from health professionals during this transition compounds these challenges. Caregivers report feeling dismissed, with limited support, vague reassurances ("everyone's different" [82]), and inadequate follow-up, all of which can contribute to distress, nonadherence to patient care plans, and dissatisfaction with the healthcare system (160).

3.4.2 ROLES: ONGOING SUPPORT

With survival rates increasing across cancer types, more patients are living with the late and long-term effects of treatment (38). However, limited healthcare resources hinder the system from adequately meeting survivors' long-term recovery needs, leaving caregivers to provide the bulk of the ongoing support. Caregivers are central to facilitating survivors' transition to a "new normal," supporting recovery while remaining vigilant for signs of recurrence (4). Depending on cancer type and treatment, they may need to continue monitoring and managing lingering side effects or adapt to new, unexpected ones—including irreversible changes like tracheostomy, altered appearance, or difficulty swallowing (6, 82). Caregivers continue to be a primary source of emotional support, managing their own distress and FCR while reducing the patient's cancer-related stress and FCR (161). Caregivers may also continue to coordinate with healthcare services and advocate for the survivor's needs, especially when transitioning from oncology to primary care settings (162). In addition, they help survivors adopt or maintain healthy behaviours, encouraging good nutrition, physical activity and medication adherence, and ensuring they attend follow-up appointments (82). Beyond these visible tasks, caregivers must learn to redefine their role as they shift from protector back to partner, and attend to their own needs and boundaries as the survivor regains independence (163).

3.4.3 CAREGIVERS' NEEDS: SHIFTING NEEDS AND LASTING GAPS IN SUPPORT

Shortly after treatment ends, nearly 60% of caregivers report at least one unmet support need (164). As time goes by, this proportion steadily decreases to about one-third, but tends to increase again around the five-year mark, when as many as 40% of caregivers still report unmet needs (164). Caregivers of patients with lung cancer are particularly vulnerable, reporting higher levels of unmet needs compared to those who care for patients with prostate, breast, or skin cancer (155).

In early survivorship, just after treatment ends, the pressing needs reported by caregivers include managing FCR, reducing stress for the person with cancer, and understanding the patient's experience, along with practical concerns like access to hospital parking or information on treatment benefits and side effects (155). At this stage, caregivers often struggle with the uncertainty of transitioning to a "new normal" and emphasize their need for support with decision-making amid uncertainty (155). This may explain why they prefer earlier follow-up visits than the one to six months typically recommended by health professionals (82). Barriers to follow-up care include the need to coordinate multiple providers, lack of access to local specialists, transportation issues, and financial concerns. While some written materials are provided during treatment, few caregivers reported receiving a formal end-of-treatment visit (82). Given these concerns, they voice a strong desire for honest discussions about recovery, even when timelines are uncertain, particularly around such milestones as follow-up scans or improvements in treatment side effects (82).

As survivorship progresses, certain needs—for example, information on treatment side effects or access to optimal medical care—become less central, while the needs reported in early survivorship, including managing FCR and supporting the person with cancer, persist (155). At one to two years post-diagnosis, caregivers typically find their focus shifting from patient-centred concerns to their own well-being, with renewed attention on personal health and managing the impact of cancer on their careers and relationships (155, 164). This is also the time when caregivers might identify the need to process feelings about death and dying, particularly when survivors experience recurrence or deteriorating health (155).

Later in survivorship, as patients approach the five-year survival milestone, unmet needs highlight ongoing concerns about recurrence (e.g., managing FCR), disease progression (e.g., processing feelings about death and dying), and/or recovery that is slower or not progressing as expected (82, 155, 164). Financial insecurity is another lingering concern, with many caregivers continuing to seek support services (164). Caregivers also continue to report low self-efficacy as they strive to transition to survivorship and manage the new challenges associated with this stage (82).

3.4.4 PROTECTIVE FACTORS: RESILIENCE, ONGOING SUPPORT, AND COPING BEYOND TREATMENT

Resilience is a key protective factor. A study on female caregivers of prostate cancer patients emphasized the importance of a proactive mindset and consciously choosing not to dwell on the disease. Positive attitudes can alleviate psychosocial distress from diagnosis through survivorship, particularly when paired with self-care and a focus on personal health (53).

Research consistently shows that when caregivers' support needs go unmet, lower quality of life and higher distress is reported by both patients and caregivers (88). Even a single unmet need—particularly if related to decision-making, uncertainty, or personal health—is associated with ongoing caregiver depression and anxiety (164). When support is lacking for needs such as decision-making in the face of uncertainty or looking after one's own health, caregivers are especially likely to experience higher levels of depression (164). Caregiver anxiety is also heightened when new or worsening symptoms raise concerns about recurrence or disease progression (9).

Consequently, ongoing support from the healthcare establishment remains vital (82). Although caregivers may receive support during the treatment stage, many have reported gaps in integrated care and clinical follow-ups during survivorship, especially when new health issues emerge for patients (32). Honest discussions about expectations, even when timelines are uncertain, are identified as essential (82), while shared decision-making has been shown to reduce anxiety and improve quality of life (9). Routine assessment of caregiver needs and referrals to tailored services, including self-management tools, further reduce burden and promote well-being (37, 153).

Caregivers have consistently expressed a need for formal survivorship programs to help address the post-treatment gap (82). Such programs should provide clear, accessible information on the patient's condition, the expected side effects, and the tasks involved with practical care, while directly addressing FCR and concerns about physical recovery and fitness. Equally important is access to robust emotional and psychological support that acknowledges the physical and social tolls of caregiving—fatigue, sleep disruption, financial strain, and isolation. Above all, programs should be flexible and tailored to diverse needs and trajectories (82).

Social support remains a critical protective resource. Whether provided by family, friends, faith communities, or peer networks, it bolsters caregivers' confidence and emotional resilience (106). For spousal caregivers, coping together as a couple—through humour, optimism, shared problem-solving, or spirituality—has been shown to further strengthen resilience (53). Among the many different forms of support, emotional support appears to have the most protective benefits during survivorship, chiefly due to ongoing concerns about cancer recurrence (161).

Coping strategies such as acceptance, hope, self-care, and connection are strongly associated with improved psychological outcomes and role satisfaction (17). As caregiving shifts from acute demands to long-term support, self-care practices like exercise, stress management, and hobbies become increasingly important to prevent burnout and preserve a sense of control (137).

3.5 PALLIATIVE CARE: A HIGH-BURDEN STAGE

Some patients transition to palliative care—a model designed not only to support patients, but also to enhance quality of life for their families. Palliative care seeks to prevent and alleviate suffering through early identification, careful assessment, and comprehensive management of the physical, psychological, social, and spiritual challenges associated with serious illness (15). Yet patients and their caregivers are often introduced to palliative care only in the final stages of life (165). Although frequently confused with end-of-life care, palliative care is a distinct and essential component of comprehensive cancer care. Misunderstanding the distinction between palliative care and hospice—the latter more narrowly associated with the final phase of life—creates stigma and discourages earlier use by patients, caregivers, and even healthcare professionals (15).

Professionals also report uncertainty about when and how to initiate palliative care, underscoring the need for more education and training (15). In practice, some patients begin palliative care upon being diagnosed, while others enter it rather than transition into survivorship. Unlike curative approaches, palliative care does not aim to prolong life, but instead focuses on symptom relief and improving quality of daily life (165).

> **In 2023, he started experiencing health problems again. There were some tests, and cancer of the cardia was discovered. At that point, we knew it was the end—that he had a deadline because he wouldn't make it. He would receive treatments, but he wouldn't recover. They said, "Okay, there will be chemotherapy, but he won't be cured." It was [to buy] time. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

Integrated palliative care, introduced at time of diagnosis, offers continuity of care by coordinating services around the needs of both patients and caregivers while fostering collaboration within a person-centred team. Palliative care, especially when integrated early, can reduce caregiver burden by improving patient quality of life, symptom control, and satisfaction with care, while also lowering healthcare costs (165, 166). Palliative care has also shown promising results in both patient survival rates and healthcare cost-effectiveness (167).

> **My brother and I understood that the oncologist was there to treat the [cancer], but he wasn't there to address all the other symptoms. At the palliative care home [where I was volunteering], they told me, "He needs a palliative care doctor." I was scared, of course. But my goodness, how wonderful, because they specialize in pain management. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

3.5.1 EXPERIENCE AND IMPACT: DEEPENING THE TOLL OF CAREGIVING

Many caregivers face a chaotic and overwhelming transition into palliative care, a stage that often occurs only shortly before death, amid poor communication and little information as to patient prognosis or the available support (15). Studies show that suboptimal exchanges between oncologists and palliative care specialists—marked by unclear communication about prognosis, limited end-of-life discussions, and uncertainty around when to initiate palliative care —further exacerbate caregiver burden (15). This lack of preparation leaves caregivers unready for the patient's decline and ill-equipped to navigate the shift into palliative care (15).

Palliative care often extends caregivers' involvement, heightening the emotional toll as the patient's condition declines (17, 129). One study found that caregivers of palliative care cancer patients experienced psychiatric disorder rates exceeding the 10–50% range observed at other points in the trajectory, reflecting the increased psychological vulnerability associated with this stage (18). The demands of palliative care after initial diagnosis and treatment are thought to amplify caregiver distress, adding to the burden experienced in earlier stages of the trajectory (17, 94). Many caregivers grapple with the anguish of having to witness suffering and confront mortality, while also trying to shield the patient from their own fears (19).

Moreover, changes to the patient's physical or cognitive state can lead caregivers to experience the sense of loss associated with perceiving the patient as no longer the person they once knew, which can be profoundly distressing. As one caregiver recalled, the most difficult aspect of this experience was to "watch someone I cared about fade away in front of my eyes." Another described how "[h]e was having these hallucinations, he would say that he would be seeing sort of like ghosts . . . I knew that his time was getting short" (19).

Providing care at home during the final stages of the patient's life can have substantial repercussions on caregivers' daily rhythms, routines, and sleep patterns:

> **He had become very weak, so I set him up in my room. I slept on the couch because I didn't want to go downstairs—I felt too far away. But, let's say that in the last days, I didn't get much sleep, because with every movement, I was wondering if he needed me.**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

Other caregivers have described the emotional toll of at-home care as "being trapped in worry, anxiety and fear" (129). Administering oral chemotherapy or injections can be especially burdensome: one caregiver said, "I feel like I am poisoning him," while another likened giving an injection to "a knife in my heart" (129). These vivid metaphors capture the deep conflict caregivers experience—providing treatments intended to help, yet feeling as though they are the source of suffering.

Decreased emotional functioning and increased patient symptoms—particularly dyspnea—have been shown to strongly contribute to caregiver burden (168). Many patients in palliative care experience fatigue, pain, constipation, nausea and skin disorders (16). Delirium is also among the most common psychiatric symptoms, reported by 44% of cancer patients in palliative care, and 88% immediately before death (16). Patients and caregivers may begin to experience anticipatory grief, which can be exacerbated by relational dependence, limited grief-specific support, and an inability to come to terms with the impending loss (169).

Lastly, being the caregiver of a patient in palliative care is associated with greater presenteeism at work (13). This stage is also marked by the highest informal care costs, driven by increased caregiving hours and significant out-of-pocket expenses, including for specialized foods, transportation, medications, and funeral-related preparations (13, 31). Coupled with the emotional intensity of palliative care, financial strain further heightens caregivers' vulnerability to adverse outcomes (31).

3.5.2 ROLES: EXTREME INTENSITY

Caregivers report providing an average of 69.5 hours of care per week during the final three months of a patient's life (170). For those supporting patients in hospice settings, the burden rises dramatically, averaging between 105 and 127 hours per week—exceeding even the demands reported by caregivers of people with dementia. Although these figures likely represent the higher end of caregiving demands, they illustrate the profound escalation of care needs in the final stage of life (171). This intensity may be related to caregivers' efforts to maximize the patient's comfort, often at significant personal cost (31). During end-of-life care, caregivers frequently advocate to ensure patients are able to die in their preferred place of care (172).

While most cancer patients receive hospice or palliative care at home, a significant number receive care in hospitals or specialized facilities, where many ultimately die. In these institutional settings, caregivers often serve as intermediaries between the patient and care team, ensuring a timely response to needs such as constipation, dyspnea and other distressing symptoms (173). When patients experience cognitive decline or communication difficulties, caregivers are frequently required to assume decision-making responsibilities related to both medical treatment and broader life choices, while simultaneously coping with emotional exhaustion, anticipatory grief, and anxiety surrounding the patient's decline (165). Preserving the patient's dignity and sense of meaning is another central component of hospice-based caregiving, since loss of dignity has been associated with psychological distress and even the wish for a hastened death (134).

By contrast, at-home palliative care introduces a different set of challenges and opportunities. As care shifts from hospital to home, caregivers take on the bulk of daily responsibilities, including assisting with hygiene, administering medications and injections, managing symptoms such as nausea, shortness of breath, seizures or pain, and handling complex equipment like nebulizers (174). The impact of patients' symptoms on caregivers can vary; for example, decreased emotional functioning and worsening dyspnea have been shown to markedly increase caregiver burden (168). Caregivers also manage household tasks—adapting meals to meet dietary needs, doing laundry, cleaning, providing childcare, and sometimes even gardening—creating an unrelenting cycle of physical and emotional labour (174). Incontinence, which requires extensive washing and constant care, adds another layer of physical and emotional strain (174). One young caregiver responsible for both parents described the endless routine of showering, cooking, cleaning, and caregiving as overwhelming:

> **I get up at 6 and shower my dad and, you know, carry out the usual. Everyday it's just like showering, cleaning, washing, cooking, cleaning, washing, cooking and showering, and it gets endless and then back home again and you do the whole procedure again (174).**

Moreover, inconsistent home care services, with staff rotations disrupting continuity, further heighten caregiver stress (175). One caregiver explained how continuity was profoundly comforting:

> **[The nurse] was the first person to evaluate him. She kept all the records. Every time she came in, she'd update the records . . . She was actually there with me when he took his last breath. That was a comfort (175.)**

Conversely, when the same professionals are present from the initial evaluation to the patient's death at home, caregivers experience a sense of ease. As one caregiver shared:

> **The palliative care doctor came to our house every week with the pharmacist. At each visit, depending on my brother's condition, they made sure his medication was still appropriate and, if needed, adjusted it on the spot to ensure he was as comfortable as possible. Between visits, we could contact them as needed. I felt so supported and truly part of the team, right up until the end. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

As caregivers take on added responsibilities—household tasks, appointments, medications, and communication—many reported a stronger bond with the patient and, in some cases, with other family members (107). This strengthened bond can be attributed to family support and attentiveness during end-of-life care, which fosters a closer rapport by making caregivers feel seen and supported. However, some caregivers feel distanced from family members and friends and are unable to engage in everyday social roles due to the need to remain at home (107).

3.5.3 CAREGIVERS' NEEDS: ON THE RISE

Caregivers of patients receiving palliative care report more frequent—and more intense—unmet needs than in the earlier stages of the trajectory (47). In one longitudinal study of ovarian cancer caregiving, the proportion of unmet needs rose from 56% at ten months before death to 88% during the final three months (94). These needs are particularly pronounced when caregivers lack access to palliative care services, leaving them with greater gaps in support compared to those who do have access (43).

Caregivers' highest unmet needs in the palliative stage are related to information, practical caregiving skills, and comprehensive cancer care (47, 176). They want clear, consistent and trusted information about the illness and its trajectory, what to expect next, likely symptoms and side effects, treatment plans, and prognosis (47). In the absence of such guidance, caregivers often have to ask repeated questions and search for information on their own (177).

Practical caregiving skills include knowing which symptoms to expect, recognizing them when they arise (e.g., pain), managing sometimes-distressing symptoms (e.g., shortness of breath), understanding whom to contact (and how and when) for help or emergencies, and administering medications safely (177). Caregivers also need to solve day-to-day challenges related to nutrition and activities of daily living (e.g., bathing, transfers, toileting). Instruction in safe lifting and positioning, along with guidance on when and how to access equipment (hospital bed, commode, transfer aids), are common gaps (177). Daily activities requiring physical effort, such as helping patients to walk, are described as among the most challenging (177).

In terms of their unmet needs in comprehensive cancer care, caregivers want to be treated as integral team members—kept informed about what health professionals can do, included in care planning, and encouraged to participate in care (47). Caregivers want clear communication, knowledge of the support the care team can provide, active participation in the patient's care, and assurance that the patient is receiving the best possible care (47).

Caregivers also face unmet needs related to disrupted routines and employment, navigating leaves-of-absence and finances, carving out personal time, and accessing respite. They want support for making high-stakes decisions amid uncertainty and for obtaining equipment and home supports to provide safe care (47). Psychological needs are common, and often intensify toward the end of life: caregivers seek help managing their own distress, fear of cancer progression, grief, and uncertainty—particularly in the final six months as treatment becomes less effective and death, more imminent (4).

Many describe feeling alone or invisible and experiencing sadness, loneliness, helplessness, guilt, and frustration, particularly when they cannot meet the patient's needs or when attempting to shield the patient from stress throughout their final year (4). Additional unmet needs include guidance on discussing cancer in social settings, coping with limited acknowledgment from others, and living with both disappointment about lack of recovery and fear of disease progression (94). In the final three months, balancing one's own needs with the patient's in addition to maintaining employment and making decisions under duress become especially challenging (94).

Relationship-focused needs—support for communicating about illness, sustaining intimacy, and adapting to changing roles—are pronounced (47). Social isolation is frequent, and spiritual needs often centre on preserving hope and finding meaning in the face of existential questions (47). Caregivers often report that hope helps them take things day by day and prevents them from becoming overwhelmed by focusing solely on death (1).

3.5.4 PROTECTIVE FACTORS: SUPPORT AND POST-TRAUMATIC GROWTH

A positive relationship between caregivers and health professionals has been associated with better care outcomes for patients, as well as with a more peaceful and meaningful caregiving experience, particularly near the end of life (178). Early and timely referral to palliative care benefits both patients and caregivers by improving pain and symptom management, reducing strain, providing professional support during transitions, enabling earlier intervention as symptoms escalate, and addressing psychosocial concerns—fear of dying, loss of control, existential distress (167, 168). Prompt recognition of the end-of-life phase is crucial, since it allows caregivers to prepare and mobilize support (55). A team-based, family-centred approach can improve caregivers' mental health and their overall satisfaction with the care received (179). Caregivers can also benefit from support groups, services to assist with daily needs, medical or non-medical home care, and counselling (179). Additional supportive interventions, including psychoeducation and skills training, can significantly improve caregiver burden by addressing information needs, coping strategies, physical functioning, psychological well-being, and quality of life (4).

Social support is a critical buffer against caregiver burden in palliative care (4). Steady, reliable help from family—social, emotional, and practical—can lower anxiety and distress and is linked to healthier bereavement trajectories (180). Friends also play a valuable role, offering compassion and much-needed emotional support (19). One caregiver described this experience as follows: "[Y]our friends . . . women friends . . . they just, they stick by you come hell or high water no matter what happens" (19).

Caregivers who feel well supported tend to appraise their experience more positively, although the impact of family support is not uniformly beneficial. Family dynamics can either sustain or strain the caregiver. While some families pull together to share tasks and decisions, in other families, the situation merely amplifies pre-existing conflicts (e.g., siblings who do not get along being forced into joint decision-making), thereby increasing caregiving burden—effects that are especially salient for female caregivers (93).

When families function well, the social, emotional, and practical support they provide can offer meaningful relief during treatment and into bereavement; but when they do not, caregivers can be left feeling even more isolated and overwhelmed (93). Similarly, friends and community networks (e.g., faith groups) can provide vital respite, running errands, facilitating short breaks outside the home, and offering a compassionate ear; conversely, their absence or failure to provide the hoped-for support will be keenly felt (19, 93). Some caregivers report friends who withdraw due to discomfort with visible decline, or who fail to reconnect after a partner's death, which intensifies loneliness and undermines what would otherwise be a key protective resource (93).

To manage the emotional toll of caregiving, especially during end-of-life care, many caregivers rely on emotion-focused coping strategies such as acceptance, positive reframing, and maintaining hope—approaches shown to reduce anxiety and foster emotional stability in low-control situations (181). These strategies are particularly effective in contexts where problem-solving options are limited, like end-of-life care (181). Task-oriented coping methods such as journaling have also been found to be helpful, inasmuch as they allow caregivers to process stressful events and reframe their hope, particularly those who care for patients with advanced cancer (43).

At the same time, end-of-life caregiving often triggers profound spiritual and existential reflections. Caregivers may wrestle with questions of meaning and loss, especially as they confront the potential death of a loved one (182). For many, spirituality becomes a source of strength, offering a framework to interpret suffering and find meaning in the caregiving role. This process can help caregivers reorient their own lives and find renewed purpose (182).

3.6 BEREAVEMENT: THE LINGERING SHADOW OF CAREGIVING

Bereavement refers to the period of grief and mourning that follows the death of the patient (186). In 2025, 87,400 Canadians were expected to die of cancer, leaving behind a corresponding number of bereaved caregivers (202). While they may recognize that the end of life is near, as many as 20-25% of caregivers report still feeling unprepared for the patient's death and its aftermath (188). This figure is troubling, as unprepared caregivers and those who struggle to accept the loss may suffer from greater depression, anxiety, and complicated grief during bereavement (188).

3.6.1 EXPERIENCE AND IMPACT: LIVING WITH THE AFTERMATH

Although grieving is a natural part of adapting to life after loss, it can mean having to endure psychological and functional challenges—not just in the immediate aftermath, but also for years thereafter (22). Bereaved caregivers commonly report higher levels of depressive symptoms than those caring for survivors in remission (17), and for some, these feelings will persist. One longitudinal study found that approximately 15% of bereaved caregivers experienced moderate to severe depression at both six and 18 months post-loss, indicating little change over time (21). In addition to depression, caregivers might experience anxiety, anger and a range of other emotions as part of normal grieving process (20).

Complicated grief is a distinct condition from depression and anxiety, characterized by intense yearning, preoccupation with thoughts of the deceased, disbelief, emotional numbness, difficulty accepting the death, and persistent grief-related social and functional impairments (20, 21). It is associated with a range of negative outcomes, including increased medication use, job loss, development of psychiatric conditions, and even elevated mortality risk (21). Alarmingly, up to 40% of bereaved cancer caregivers experience complicated grief at six months post-loss, compared to about 11% in the general bereaved population following other types of natural deaths (20, 21). Furthermore, up to one-quarter of bereaved cancer caregivers continue to struggle with complicated grief 18 months after the loss (21).

Stages of the trajectory are interconnected
Caregiving does not occur in isolation from one stage to the next. Rather, it is a continuous experience marked by emotional, psychological, and physical residual effects. Difficulties or distress that remain unresolved in one stage can resurface or intensify in the next. In bereavement, depressive symptoms that occurred during earlier stages can heighten the risk of complicated grief (17). This cumulative effect underscores the importance of early identification and intervention throughout the caregiving trajectory.

The effects of bereavement extend beyond emotional health. One study of young widowers found that poor preparedness for their spouse's cancer-related death was linked not only to depression and anxiety, but also to chronic pain and sleep disturbances, even four to five years after the loss (6). Moreover, bereaved caregivers are at greater risk of suicidal ideation compared to the general population (189). Contributing factors for this include symptoms of anxiety and depression, low income or unemployment, lack of social support, and the perception that the patient had poor quality of life in their final stages (189).

3.6.2 ROLES: GRIEF PROCESSING AND EMOTIONAL ADJUSTMENT

Grief is a natural response, but it may take months or even years for the caregiver to adapt—not just to the loss of the person and the dreams once shared, but also to the loss of their identity as a caregiver (186). While navigating grief, caregivers must also frequently shoulder practical and administrative tasks such as funeral planning, legal paperwork, and managing finances or estates—tasks that can be especially burdensome for those facing financial uncertainty (190). The process of reintegrating into daily life involves adapting to a "new normal," rebuilding social connections and re-engaging with roles and activities that were sidelined during caregiving (23).

This reintegration is often complicated by the loss of touch with one's support network (23). Many caregivers engage in meaning-making and legacy work, including sharing their stories through blogs, participating in bereavement forums, or contributing to online memorials (191). While follow-up bereavement services provide comfort for some, access to these services often falls short of need, revealing a gap in post-loss support (21). For caregivers who use this period to reflect, positive memories may emerge—particularly when they feel they have honoured the patient's wishes (4).

3.6.3 CAREGIVERS' NEEDS: ENDURING BEYOND LOSS

Unmet needs can persist long after a patient's death and profoundly affect caregiver wellness. These needs generally fall into two categories: reintegration into life after loss; and managing the loss. The latter category can include attending to one's own physical and emotional health, coping with grief, and maintaining meaningful relationships with family and friends. This is often complicated by destabilized family dynamics, which can leave caregivers feeling isolated once the social networks centred on their caregiving role dissolve (22).

Reintegration is equally challenging, as many caregivers struggle to return to former social or recreational activities or rebuild a sense of normalcy (22). Importantly, the burden of unmet psychosocial and practical needs often increases over time: approximately two-thirds of bereaved caregivers report unmet needs 2.5 years after the patient's death, a figure that rises to 80% by 5.5 years post-loss (22). These enduring gaps in support remain a primary source of suffering during the early years of bereavement (22)—particularly since access to grief counselling and peer support often remains limited (192). Furthermore, the transition to bereavement can disrupt a caregiver's sense of identity, leaving them without a clear role or purpose. This lack of purpose is often compounded by an unmet need for guidance through the immediate, practical demands of death—such as funeral planning or legal paperwork—for which many caregivers feel entirely unprepared (22).

3.6.4 PROTECTIVE FACTORS: QUALITY OF END-OF-LIFE EXPERIENCES

Key protective factors that support adjustment during bereavement include the quality of the patient's end-of-life experience, advance care planning, social support, the caregiver's health prior to loss, and their coping strategies (101, 123). A better quality of death, characterized by effective pain management, dignity, and alignment with the patient's values, can improve caregiver satisfaction with end-of-life care (20, 134). In particular, caregivers of patients who died in hospital palliative care units experienced fewer depressive symptoms, less anger and reduced complicated grief than caregivers of patients who died in other hospital units (20).

The location of death also matters: when patients die in their preferred setting, caregivers are more likely to report a sense of peace (19). For instance, one caregiver shared:

> **I'm glad I had him at home. I think it wasn't too exhausting because I wasn't travelling back and forth and sitting in a hospital, and people could come in and visit with him . . . it was just a warmer atmosphere (19).**

Advance care planning is another important buffer. The completion of documents such as do-not-resuscitate (DNR) orders and early conversations about the patient's wishes can better help caregivers adjust to bereavement (101). These interventions are found to also reduce regret among caregivers (101).

Social support continues to act as an emotional buffer and predict caregiver outcomes in this stage of the trajectory (123). Support from family, friends and the broader community prior to the patient's death is associated with lower stress levels afterward (20). Conversely, family conflict during the cancer trajectory can predict poorer bereavement outcomes, highlighting the importance of addressing relational tensions early on (123).

The caregiver's physical and mental health prior to the patient's death also plays a crucial role. Caregivers who have better mental health before death have a lower likelihood of post-bereavement depression and anxiety and of complicated grief (17). Conversely, caregiver physical pain prior to the patient's death is a strong and consistent predictor of poor bereavement outcomes (123).

Finally, coping strategies influence post-loss adjustment. Caregivers who use active problem-solving and positive reappraisal, and/or who maintain strong spiritual or religious beliefs, often report better psychological well-being in bereavement (123). In contrast, self-blame and behavioural avoidance are linked to worsened mood (123).

3.7 POST-CAREGIVING: REDEFINING IDENTITY AND PURPOSE

*It is important to note that the literature on the post-caregiving stage is limited, with few studies directly addressing caregivers' experiences once active caregiving responsibilities have ended. As such, the content below is extrapolated from the broader literature that considers caregiver experiences during the years after a cancer diagnosis.

The majority of oncology caregivers are no longer directly involved in caring for a patient five years after diagnosis (161). Although remission brings relief, the abrupt slowing down of responsibilities can feel disorienting. Many caregivers report feeling unprepared for this shift, struggling to redefine their sense of identity and purpose after months or years of intense involvement in the patient's care. What they had once hoped for—a return to normalcy—can feel strange or even unsettling, given that the "normal" they once knew is apt to have been redefined (23).

3.7.1 EXPERIENCE AND IMPACT: ENVISIONING LIFE BEYOND CAREGIVING

Rather than restoring normalcy, the cessation of caregiving often marks the start of a new and emotionally complex adjustment period. Moving from an intense battle with cancer to a sudden "slowing down" can leave many caregivers feeling as though they have lost their sense of purpose (23). Furthermore, the dwindling of the intensive support network that had once surrounded them can lead to acute feelings of isolation (157).

The nature of the burden of care also shifts. Fear of cancer recurrence (FCR) remains high; caregivers become hypervigilant to physical changes in patients who survive (23), or continue to worry about late treatment side effects (153), treatment-related secondary diseases (e.g., cardiovascular disease) or the development of new cancers (153). Consequently, the transition out of active caregiving is less of a "return to normal" and more of a difficult reconstruction process—one that can require reintegrating into work (193), rebuilding social ties (23), and returning to self-care routines (23) that were deprioritized during the illness.

> **I was worried 24 hours a day, and then [when my brother passed away] I felt kind of lost. I had the habit of saying to myself, "Oh my God, is he okay?" But he wasn't there anymore. It felt like something was missing in what I was doing. (Free translation)**
>
> - Lise, caregiver of a sibling, as told to the Quebec Observatory on Caregiving, 2025

For spousal caregivers in particular, renegotiating relationship dynamics—shifting from caregiver back to partner—can be unexpectedly difficult, especially when intimacy or roles had changed during treatment (23). The end of treatment does not necessarily restore the sexuality and intimacy the couple had experienced prior to the onset of cancer. Some caregivers report regaining a measure of sexual activity post-illness, although at a less frequent pace. For others, the onset of cancer and their journey through the ordeal profoundly altered their sex lives, requiring considerable time and effort to regain desire and pleasure:

> **It was after treatment and a while after that, we thought something was missing. We tried again but there was no success, so we have really worked hard to get things working again. It is now in the past; it has worked.**
>
> - Caregiver of a spouse with cervical cancer (200, p. 992)

3.7.2 ROLES AND PROTECTIVE FACTORS: RESUMING LIFE AFTER CAREGIVING

For caregivers, this stage is often characterized by a shift toward reflecting on and making sense of the caregiving trajectory (157). After months or years of prioritizing the patient's needs, caregivers may begin to reengage with activities they had once enjoyed and carve out time for personal renewal (23). Reconnecting with hobbies, friends, or family—for example, sharing a meal or seeing a movie together—can help restore a sense of normalcy, especially if relationships were strained or neglected during caregiving (23). Since others may hesitate to reach out, caregivers may need to take the initiative to rebuild social ties. This transition also requires open communication with the patient, as both individuals may be navigating the physical or emotional aftereffects of the disease and its treatment (23). Honest dialogue about the lingering challenges can help preserve intimacy and facilitate mutual adjustment to life after cancer (157).

3.7.3 CAREGIVERS' NEEDS: REBUILDING NORMALCY

Much like the survivorship stage, caregivers can experience persistent unmet needs even after active cancer care has ended (161). This period often entails a complex balancing act: managing FCR while adjusting to the "new normal" of post-caregiving (161), a transition that can require simultaneously addressing psychosocial needs—notably, the patient's lingering stress—while attending to the caregiver's own neglected health (161). Rebuilding interpersonal relationships can also be challenging, particularly with friends and family who have long since resumed their usual routines (157). Additionally, caregivers may find it difficult to relate to those who have not experienced cancer (157).

3.8 CANCER RECURRENCE: A POTENTIALLY FAMILIAR YET HARDER ROAD

Cancer recurrence is not simply the continuation of a prior experience, but a distinct stage that may even be more difficult and discouraging for patients and their caregivers (24). It can signal a transition from curative treatment to palliative care, thereby complicating the disease trajectory and intensifying caregiving responsibilities (24). For some, it brings the realization that cancer may remain a lifelong presence, and decisions about whether to restart treatment or prioritize quality of life and symptom relief can be particularly onerous (24).

3.8.1 EXPERIENCE AND IMPACT: THE BURDEN OF STARTING OVER

Extended or renewed caregiving during a recurrence can be unexpected and overwhelming, leading to a significantly heightened burden (17). Cancer recurrence often thrusts caregivers back into emotional turmoil and uncertainty, as families are forced once again to reorganize their lives around the illness (194). For many, this stage is more devastating than the initial diagnosis; indeed, 78% of patients in one study reported it as "more upsetting" (194). This distress stems largely from the weight of difficult treatment decisions, severe side effects, and negative memories of previous treatment experiences (194). For caregivers, recurrence often signals a collapse of hope, replaced by acute anxiety, insecurity about the future, and a burgeoning distrust in medical interventions (194). As a result, these caregivers frequently report a lower quality of life than those supporting the newly diagnosed (194).

Unlike the initial diagnosis, which often includes a clear treatment plan and the prospect of a cure, recurrence introduces greater ambiguity. It frequently heralds a shift from curative to palliative goals, focusing on symptom management, quality of life, and survival extension (24). This shift can profoundly affect caregivers' expectations and emotional adjustment, particularly as treatment decisions grow more complex due to prior therapies or disease progression (194).

Having endured the stages of the initial cancer experience, caregivers facing recurrence must re-evaluate their expectations and coping strategies amid a renewed sense of vulnerability and uncertainty (194). An unexpected return to caregiving may deplete the caregiver's coping resources, leading to an increased risk of physical morbidity (195). Feelings of shock, regret, frustration, guilt, and helplessness are also common, especially when treatment is no longer effective (4). Long-term caregivers, in particular, show increased depressive symptoms and even a decline in their physical health (94, 195). This emotional distress is often associated with factors such as fear of the illness itself, lifestyle restrictions, competing demands, financial issues, and having to witness the patient's suffering (32).

3.8.2 ROLES: RESUMING CAREGIVING, BUT POTENTIALLY WITH HIGHER STAKES

When cancer recurs, caregivers typically resume roles established during earlier stages of the trajectory—such as providing emotional and instrumental support and managing symptoms—but often with increased intensity (195). The clinical demands of prolonged treatment, including monitoring the patient's condition, managing side effects, and administering medications, frequently require advanced specialized skills (4).

Caregivers must also help patients cope with heightened fear, grief, or existential distress at this stage, often while suppressing their own emotional responses (4, 75). The decision-making process can become more fraught, as well; caregivers are often deeply involved in weighing difficult treatment options amid significant uncertainty and seeking out complex information to inform those choices (194). Furthermore, as patients undergo a battery of diagnostic tests to confirm recurrence—including physical examinations, imaging and biopsies—caregivers frequently assume full responsibility for coordinating these appointments (194).

3.8.3 CAREGIVERS' NEEDS: THE RETURN OF UNCERTAINTY AND THE NEED FOR INFORMATION

The return of cancer can disrupt family dynamics and intensify emotional turmoil, often surfacing existential concerns about suffering and mortality while straining communication among family members (194). As distress escalates, some families are drawn closer together, while others fracture under the pressure, underscoring the need for greater attention to caregivers' psychological well-being and family support throughout this stage (24). A consistent theme in the literature is the lack of clear, timely, and tailored information provided to caregivers about the recurrence, including treatment options, prognosis, and anticipated care demands (24). Many caregivers report that communication with health professionals during recurrence is superficial or inadequate, leaving them overwhelmed and confused—particularly when faced with complex treatment regimens and cumulative exhaustion from the initial cancer experience (194). This uncertainty is compounded by a need for better education and preparedness. Caregivers have expressed a strong desire for information on the early warning signs of recurrence, both to ease anxiety and to facilitate timely help-seeking and medical consultation (24).

3.8.4 PROTECTIVE FACTORS: SUPPORT AND COMMUNICATION

Several factors are associated with better caregiver adjustment and reduced burden during cancer recurrence. Strong social support is essential, as the caregivers of patients with prolonged cancer often report increasing loneliness and social isolation over time, whereas greater social support is consistently linked to improved well-being (1, 94). Clear, compassionate and timely communication from health professionals also plays a critical role: caregivers who receive comprehensive information about recurrence, treatment options, and prognosis report feeling more prepared and less overwhelmed (24). Additionally, family cohesion and role clarity can ease the caregiving experience; families characterized by strong communication, shared responsibilities, and emotional closeness tend to experience less tension and caregiver burnout throughout the recurrence stage of the trajectory (194).

CONCLUSION AND DISCUSSION

Seeing cancer caregiving as a trajectory—a continuum spanning pre-diagnosis, diagnosis, treatment, survivorship, palliative care, bereavement, post-caregiving, and recurrence—highlights how caregiver roles, needs, and vulnerabilities evolve over time. Caregiving is not a static state but rather a moving target, shaped by the course of illness and requiring constant adaptation to patient needs and disease progression. This perspective helps map the temporal choreography of caregiving—who takes on which responsibilities, when, and under what pressures—while revealing persistent themes that cut across individual phases.

At the same time, it identifies phase-specific inflection points where timely, tailored interventions can ease burden, enhance preparedness, and improve outcomes for both caregivers and patients. Ultimately, while each stage of the trajectory has been presented separately, they remain deeply interconnected: the experiences and outcomes of one stage inevitably shape those that follow.

SIMILARITIES ACROSS STAGES

Certain themes can be identified across all stages. Caregivers perform labour that is complex and often invisible, blending information-seeking, emotional support, medical tasks, logistical coordination, advocacy, and system navigation (38, 45-48) (26), often without adequate training or recognition (9). Information gaps remain a constant: caregivers consistently seek clear, trusted guidance on the illness, symptoms, “red flags” and escalation pathways, yet are too often left to piece things together on their own (6, 27, 28, 52, 75, 82, 145).

Effective communication with healthcare professionals is equally crucial. While caregivers wish to be recognized as integral members of the care team, they frequently encounter coordination failures, unclear responsibilities, and poor handoffs (24, 108). Psychological strain is omnipresent, with anxiety, uncertainty, anticipatory grief and guilt cutting across the entire trajectory (145). These emotions are often compounded by protective buffering, where caregivers suppress their own distress to shield the patient from further worry. Financial toxicity and workplace disruptions are also widespread, with presenteeism, absenteeism, and out-of-pocket costs becoming especially acute at times when caregiving hours rival or exceed a full-time workload (13, 31). Social support, when available, provides a reliable buffer, but can be uneven and ambivalent: some families cohere, while others fracture, and friends may withdraw just as the need for them peaks (1, 94).

DIFFERENCES BETWEEN STAGES

Each stage of the caregiving trajectory in oncology brings its own distinct challenges. In the pre-diagnosis period, uncertainty dominates as caregivers notice that “something is off,” prompt their loved one to seek help, and begin triaging information without formal roles or guidance (41). At diagnosis, shock and identity disruption peak, and the tone set by health professionals—whether inclusive and clear or confusing and exclusionary—can shape the caregiving trajectory from the outset (108). The treatment phase is the most operationally demanding, requiring caregivers to perform hands-on medical tasks alongside the demands of work and home (1, 27, 32, 36). Survivorship is marked by a sudden rupture in support, with oncology follow-up receding amid persistent fear of recurrence, role renegotiation, and late effects (7, 55, 81). Palliative care carries the highest burden: caregiving hours surge, symptoms escalate, and existential concerns sharpen, particularly when referral comes late (15-19). Early palliative integration, by contrast, is associated with improved outcomes for both patients and caregivers (165). Bereavement introduces risks of complicated grief, depression, and identity loss, especially if caregivers felt unprepared or unsupported during treatment (17, 20-22). Post-caregiving can bring about disorientation and voids in purpose as routines once oriented around care collapse (23). Recurrence is often harder than the initial diagnosis, entailing cumulative fatigue, greater uncertainty, and more complex decision-making (24).

VULNERABLE CAREGIVERS

Those who are most at risk are caregivers who experience overlapping sociodemographic and contextual vulnerabilities. Older caregivers—many of whom have their own health problems—report poorer physical health and heavier time commitments, while younger and middle-aged “sandwich generation” caregivers struggle with balancing employment, parenting, and financial strain (59, 62). Gendered expectations further shape the experience: women often face a higher burden due to societal expectations, multiple role conflicts, and reluctance to seek help, while men may suffer in silence due to masculinity norms that discourage emotional expression (4, 17, 32, 65).

Socioeconomic factors further stratify the experience. Low income magnifies caregiving stress by limiting access to resources and intensifying time demands, while low educational attainment can complicate healthcare system navigation (4, 50). For racialized, immigrant, Indigenous, and 2SLGBTQIA+ caregivers, systemic barriers, discrimination and exclusion may compound financial and emotional strain, despite cultural or community resilience (49, 73, 78). Geography, too, plays a role, as rural caregivers are disadvantaged by long travel distances, higher out-of-pocket costs, and sparse palliative care services. Those providing co-residing or spousal care shoulder heavier responsibilities and higher depression rates than caregivers who live apart from the patient (76). Finally, caregivers of patients whose cancers are aggressive, late-stage or have multiple comorbidities encounter higher psychological distress due to the unrelenting demands of symptom management and complex care coordination (36, 97, 98). Taken together, the most vulnerable caregivers are those who must navigate intersecting pressures—older age or poor health, competing work and family demands, gendered expectations, systemic inequalities due to minority or marginal status, and limited financial or social resources.

IMPLICATIONS FOR PRACTICE

A trajectory perspective reframes supportive care as responsive to the challenges of each stage. It emphasizes anticipatory guidance, systematic screening of caregiver needs at key transition points, and just-in-time information and skills training. It also calls for continuity through designated points of contact, and a family-systems approach that recognizes both variability in family functioning and the compounding effects of structural disadvantage. By aligning stage-specific supports with cross-cutting commitments—clear communication, genuine partnership, social support, and early palliative care integration—caregiver burden can be reduced, outcomes improved, and caregivers affirmed as essential partners in cancer care.

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