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Identifying and addressing the needs of caregivers of patients with cancer: evidence on interventions and the role of patient advocacy groups

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ABSTRACT

As the number of people with cancer increases, so does the number of informal caregivers. These caregivers frequently have multiple unmet needs and experience numerous burdens. Here we explore the crucial roles of these caregivers and categorize their unmet needs into four areas: information, relationship and communication, emotional support, and practical or financial needs. We provide evidence on emerging interventions aimed at supporting caregivers, including patient/caregiver assessments, education, collaborative care, financial assistance, wellness, informational programs, and an integrated caregiver clinic. Finally, we delve into the vital role that patient advocacy groups play in addressing the unmet needs of cancer patients and their caregivers by providing comprehensive support, including education, resources, counseling, guidance, and financial aid.

PLAIN LANGUAGE SUMMARY

As the number of people living with cancer increases, the number of informal caregivers is also increasing. Most often, these caregivers are family members, friends, or spouses of the person with cancer. Caregivers of patients with cancer help with medical tasks and routine chores, like driving, and even personal care, such as bathing. Caregiving can be challenging, emotionally taxing, and time-consuming, all while being unpaid. In this review, we identify four unmet needs of caregivers of patients with cancer and examine how they are being addressed. First, caregivers need cancer care information that is presented in an understandable way. This will help the caregiver and the patient make better decisions about cancer care and treatment. Second, caregivers need better relationships and communication with the patient's clinicians. In addition, caregivers must also navigate, and sometimes mend, challenging relationships with the patients that they care for. Third, caregivers need more emotional support, including the option for counseling and therapy. Fourth, caregivers may need practical and financial support, particularly since the time demands and stress of caregiving can disrupt their ability to earn a living. Although many attempts have been made to address these caregiver needs, gaps still remain. Increasing awareness of information targeting caregivers and patients could reduce their uncertainty and help with decision-making. Even when resources are available, caregivers may not always be aware of or linked to them. Patient advocacy groups play a critical role in connecting caregivers with available resources. They also provide a variety of support services, including education, navigation, and financial assistance.

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cancer; caregiver; decision-making; patient advocacy group; psychosocial; unmet needs

1. Introduction

Globally, there were approximately 20 million new cancer cases in 2022 and 9.7 million cancer deaths [1,2]. In the USA alone, there were more than 1.9 million new cancer cases in 2022 [3] and more than 600,000 people died from the disease [4]. As life expectancy and the number of

older patients living with cancer increase, the number of caregivers of patients with cancer is also increasing [5].

Over the past 10 years, cancer treatment has increasingly moved to the outpatient setting, especially for the three most common cancers (i.e., breast, lung, and prostate), and oral therapies and/or injections are frequently replacing lengthy infusions [6]. With this trans-

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[‡]These authors are personal caregivers of one or more patients with cancer, and most did not have an oncology background before embarking on the caregiver role. The last author is a nurse practitioner, although not focused on oncology

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formation, cancer care has progressively become the responsibility of the patient and their primary informal caregiver, including the administration of treatments, sometimes multiple times per day [6]. Patients may need assistance that is not available through their health insurance, requiring an informal caregiver to help; these caregivers (usually relatives, spouses and friends) are often not prepared for this role. It is important that patients and their caregivers receive the support that they need from their local community and peers as well as from the healthcare system, patient advocacy groups (PAGs), the pharmaceutical industry, and policy makers. Here, we define PAGs as nonprofit organizations that offer services to those affected by cancer and their family members and caregivers.

A major objective of this review is to explore the crucial role and needs for caregivers of patients with cancer in discussions with the multidisciplinary care team, and factors influencing their engagement in patient-centric shared decision-making. This review further considers interventions aimed at addressing caregiver needs as well as the critical role of PAGs in supporting patients with cancer and their caregivers. Caregivers of patients with cancer may play a key role in decision-making about treatment plans, and can be integral in contributing to treatment adherence, symptom management, and improving the patient's quality of life (QOL) and outcomes. We begin by discussing the variety of roles that caregivers may play in caring for patients with cancer. We then provide evidence describing the often overwhelming emotional, psychosocial, physical, practical, and financial burdens of daily caregiving. We argue that this necessitates tailored, effective, and sustained support from the healthcare system, PAGs, the pharmaceutical industry, and policy makers. We also discuss examples of the limited data that are available to inform the development and adoption of cohesive caregiver support frameworks and interventions within current practice. Finally, we recognize ways PAGs support caregivers through unique educational, support, peer, and advocacy efforts.

The literature search for this narrative review was based on the combined expertise of the authors, who are patients, caregivers, clinicians, and/or work for advocacy organizations working with patients with cancer and their caregivers. This search and literature review led to the identification of the critical unmet need categories of caregivers of patients with cancer. Although not intended to be comprehensive, evidence is provided to support the importance of each of these categories. Similarly, the evidence on interventions aimed at supporting caregivers of patients with cancer and how PAGs can help in the caregiving process is not intended to be comprehensive, but rather to highlight important examples of how

they support patients with cancer and their caregivers. Information for this narrative review was obtained from multiple sources including PubMed, Google Scholar, and Google, primarily using the keywords and terms listed in [Table 1](#) & [Figure 1](#) as search terms, as well as the individual and collective expertise of the authors.

2. Caregivers play a critical role in caring for patients with cancer

There are approximately three to six million informal caregivers of people with cancer in the USA [30]. By definition, informal caregivers provide unpaid, ongoing care or assistance to a patient with cancer [6]. They may assist with tasks including bathing, eating, toileting, shopping, transportation, managing finances and insurance, and medical and nursing needs [31]. The well-being of the caregiver is critical to the patient, since when a caregiver struggles with their own health issues, the patient with cancer who they care for is more than three times as likely to report receiving poor quality healthcare [32]. Patients who are accompanied by their caregivers to medical appointments are more likely to have longer visits, with more information conveyed by their medical providers [33], and they are also more likely to recall that information [34]. Based on our experience, the finding that recall is improved when patients are accompanied to medical visits by their caregivers is not surprising, since patients may have health literacy barriers and are often overwhelmed when facing challenging treatment decisions. Having a caregiver present provides a second person who can ask questions and take in information.

Two surveys have revealed key information about the typical caregivers of patients with cancer [30,31]. The National Alliance for Caregiving (NAC) surveyed 111 caregivers of patients with cancer between 18 September and 5 November 2014 and found that caregivers were 53 years old on average and predominantly women (58%) [31]. The vast majority of respondents (88%) cared for a relative and most (60%) cared for someone who was 65 years old or older, most frequently a parent/parent-in-law (44%) and less commonly a spouse or partner (16%), or sibling/sibling-in-law (14%) [31].

CancerCare subsequently compiled a report based on feedback from 2703 cancer caregivers who completed an online survey between 16 February and 6 July 2021 [30]. This much larger, nationally representative survey, and the resulting *Cancer Caregivers: National Research Report on Shared Treatment Decision-Making*, provided a detailed understanding of caregivers' roles, needs, and experiences in the process of shared decision-making with patients and healthcare providers. This survey reflected the input of caregivers, who had an average age of

Table 1. Selected patient advocacy groups.

Tumor type	Name	Ref.
Colorectal cancer	<ul style="list-style-type: none"> • Colon Cancer Coalition^a • Colorectal Cancer Alliance • Fight Colorectal Cancer • PALTOWN/COLONTOWN 	[7–11]
Melanoma	<ul style="list-style-type: none"> • AIM at Melanoma Foundation • The Melanoma Research Foundation • Melanoma Research Alliance 	[12–14]
Breast cancer	<ul style="list-style-type: none"> • Breastcancer.org • SHARE Cancer Support • Brem Foundation • Susan G Komen 	[15–18]
Prostate cancer	<ul style="list-style-type: none"> • ZERO Prostate Cancer 	[19]
Lung cancer	<ul style="list-style-type: none"> • LUNGevery • A Breath of Hope Lung Foundation 	[20,21]
Renal cell carcinoma	<ul style="list-style-type: none"> • Kidney Cancer Association 	[22]
Ovarian cancer	<ul style="list-style-type: none"> • Ovarian Cancer Research Alliance^a 	[23]
Blood cancers	<ul style="list-style-type: none"> • Leukemia and Lymphoma Society^b 	[24]
Multiple cancer types	<ul style="list-style-type: none"> • CancerCare^a • Facing Our Risk of Cancer Empowered^a • Triage Cancer^a • Caregiver Support Community 	[25–28]

^aPatient advocacy group represented by an author on this manuscript.

^bCaregiver-specific web page and caregiver workbook web page co-created with Pfizer [29].

	Informational	Relationship/Communication	Emotional	Practical/Financial
Unmet Needs	<ul style="list-style-type: none"> • Objective and trusted information and advice • Second opinions • Information on side effects • Plain language summaries • Access to patient information via online portals 	<ul style="list-style-type: none"> • Open and honest communication with patient • Reduced feelings of shame and guilt • Improved intimacy • Lack of structured relationship between caregiver and clinicians • Access to equitable telehealth 	<ul style="list-style-type: none"> • Reduced depression and anxiety • Reduced shame and guilt • Therapy • Coaching/counseling • Insurance code for caregiver counseling • Self-care; appreciation of caregiver role 	<ul style="list-style-type: none"> • Relief from time/work burden and career strain • Relief from financial strain • Education on financial/time management • Assistance with caregiver tasks • Documentation of caregiver identity in medical institutions
Potential Interventions	<ul style="list-style-type: none"> • Assessment of caregiver understanding • Education programs • Multidisciplinary team providing tailored information • Timely disease and treatment information • Telephone-based information and support • Caregiver clinic 	<ul style="list-style-type: none"> • Assessment of caregiver communication gaps • Inclusion as a care team member • Stress reduction (therapy, mindfulness, massage, etc.) • Timely open communication channels • Telephone-based information and support • Caregiver clinic 	<ul style="list-style-type: none"> • Assessment of caregiver emotional burden • Tailored emotional support and resources • Stress reduction (therapy, mindfulness, massage, etc.) • Proactive emotional support guidance • Telephone-based information and support • Caregiver clinic 	<ul style="list-style-type: none"> • Cooperative practical guidance • Financial education and assistance • Timely access to resources • Telephone-based information and support • Caregiver clinic
Impact	<ul style="list-style-type: none"> • Informed decision-making • Reduced stress • Improved patient–caregiver dialogue 	<ul style="list-style-type: none"> • Stronger relationships • Less guilt • Improved emotional intimacy 	<ul style="list-style-type: none"> • Reduction of negative emotional symptoms • Decreased feelings of isolation • Enhanced emotional resilience 	<ul style="list-style-type: none"> • Alleviation of time and financial pressures • Improved caregiving ability • Reduced work-related stress

Figure 1. Unmet needs of caregivers for people with cancer, potential interventions, and their anticipated impact.

42.6 years old; just over half of respondents were female (53%) [30]. The CancerCare survey found that most caregivers cared for an immediate family member (e.g., their mother/father, spouse/partner, brother/sister, or child),

although the percentage (53%) was substantially lower compared with the NAC survey. In the CancerCare survey, almost half (48%) of patients were between 55 and 74 years of age, with an average age of 59 [30].

3. Caregiver burden & unmet needs

The NAC survey found that most (62%) caregivers of patients with cancer reported being in a high-burden situation [31]. The caregiving experience was episodic, intense, and lasted for approximately 2 years on average [31]. Caregivers reported that their care recipient had been hospitalized at least once in the past year (80%), that they monitored the severity of the condition of the patient for whom they are caring (76%), and that they advocated on behalf of the patient with healthcare providers, community services, and government agencies (62%) [31]. Strikingly, a large proportion of caregivers (43%) performed complex medical/nursing tasks, despite not having received any prior training or preparation for how to perform them [31]. Despite the challenges faced by caregivers, only 29% discussed their own self-care needs with healthcare providers and only 15% reported using respite (short-term caregiver relief) services, despite 35% thinking that respite services could be helpful [31]. Indeed, 43% of caregivers indicated that they wanted more help to manage their own emotional and physical stress.

Overall, the unmet needs of caregivers may be divided into four categories, which we will discuss individually in more detail: informational, relationship/communication, emotional, and practical/financial (Figure 1).

3.1. Informational

Following the initial shock of learning a cancer diagnosis, patients and their caregivers frequently have an unmet need for comprehensive information about the diagnosis, prognosis, and the implications of various treatment options. In addition to the information provided by the healthcare professional at point of diagnosis, they may need “objective” and “trusted” medical information and advice provided in patient-friendly language if they decide that the information that they receive is inadequate. Although some of this information may be available, it is not always given to the patient/caregiver, nor is it easy for them to find. Most patients and caregivers do not work in healthcare and may benefit from materials in lay language. Caregivers often face a steep learning curve as they seek to educate themselves about the cancer diagnosis and its implications. This poses challenges as they seek to assist in making sound medical decisions with, or less commonly on behalf of, the patients in their care.

The 2022 CancerCare survey report found that half of caregivers of people with cancer reported being involved in making decisions regarding the patient's treatment plan [30]. Most (68%) relied on information from the patient's clinical care team and the educa-

tional information that they provided (46%) for their decision making [30]. Additional sources of information impacting caregiver treatment decisions included other medical professionals (41%), friends or family (39%), non-profit organizations (e.g., PAGs) (16%), government agencies (10%), and social media (10%) [30]. Notably, nearly a quarter of respondents stated that the information that they were provided or had gathered themselves was not helpful in their decision-making process, and one in five respondents did not feel that they had enough information to make a previous treatment-related decision [30]. The CancerCare report also indicated that caregivers struggled to make treatment decisions due to uncertainty about how treatments would affect patients' physical condition (41%) or QOL (38%), disagreements among clinicians on the care team regarding treatment recommendations (18%), or because they simply did not have enough information (16%) [30].

Caregivers and patients also reported that healthcare providers frequently used complicated medical terminology, which made it more difficult to understand clinical processes and make informed decisions. The CancerCare survey found that caregivers commonly relied on internet searches (39%), which may provide inaccurate or incomplete information [30]. Typically, caregivers face overwhelming amounts of medical information as they begin researching the cancer of the patient for whom they are caring, and often struggle to find up-to-date, relevant, trustworthy sources that they can understand and interpret appropriately. Alternatively, if the patient has a rare cancer about which little is known, caregivers and patients may find only limited information [35]. In general, there is often an unmet need for appropriate educational materials and plain language summaries of relevant information for improved health literacy.

Based on our collective experience and expertise, the medical team should clearly explain the prognosis of the cancer so that the caregiver can assist the patient in making informed decisions; this should include a detailed explanation of treatment options and sequencing, side effects, and the potential impact on QOL, so that the caregiver and patient fully understand the risks and benefits of alternate treatment options. This information should be available in different formats reflecting health literacy and culturally competent guidelines. It should also be possible for caregivers (and patients) to access this information through a portal and/or handouts and/or video links. In addition, certain cancers require biomarker testing and information about its benefits should be provided to both the caregiver and patient [36]. For germline mutations, active referral to a genetic counselor should be included [37]. Clinical trials should be discussed with patients and caregivers where available, with clear

explanations of the potential benefits and risks [38]. In addition to guidance on participation in a clinical trial, assumptions about travel planning, timing, financial costs, and other expectations should be addressed. The patient and caregiver should be informed that, at a minimum, the patient would receive standard of care treatment [38,39].

Caregivers need help to understand how the health-care system and multidisciplinary care teams operate as a whole and how to navigate them. Notably, understanding information can be a particular challenge for immigrants, both due to potential language barriers and because the medical system in their country of origin may be structured differently from healthcare in the USA. We have found that immigrants may not be prepared for insurance/financial costs and access challenges. They may also have an inherent cultural bias against cancer and the stigma associated with it, or a mistrust of the government or the healthcare system in general. The healthcare community should be prepared to provide guidance to all patients and caregivers regardless of their cultural background or country of origin, direct them to appropriate information, and ensure that they understand their illness and treatment options.

3.2. Relationship/communication

Most caregivers of people with cancer care for a family member [30,31]. The care dynamic can shift family relationships, creating unique communication challenges [30]. Often, children care for their parents and parent/child roles are reversed, creating a new dimension to the relationship. When siblings or other family members are caregivers, they may have different interpretations of the diagnosis, appropriate treatment options, and next steps, causing tension around the caregiving role [40]. Alternatively, when one individual is caring for their partner, intimacy is often negatively impacted [41]. This is especially the case with breast, gynecologic, and prostate cancer since these cancers and their treatments may affect body image, sexuality, libido, and perception of femininity/masculinity [41]. However, intimacy between couples may be negatively impacted by many other cancer experiences beyond those of breast, gynecologic, and prostate cancer.

The relationship between caregiver and patient can be difficult and is not always a positive, nurturing experience. Caregivers often do not share their own emotions because they feel guilty about further burdening the patient [42]. Conversely, they may feel that the patient is not sharing their thoughts and feelings with them; patients often fear being a burden and may not be open and honest with their caregiver [42].

Relationships between caregivers and the clinicians treating the patient are critical, but also have difficult challenges. Most caregivers reported that they communicate directly with these clinicians (82%) [31]. However, based on our experience, clinicians may not have structured relationships with caregivers, and healthcare privacy laws can create a barrier that excludes caregivers from the decision-making process and prevents them from having ready online access to the patient's medical information. When a cancer patient with a complex medical history goes to the emergency room, the patient's medical information may not be readily and clearly available to the treating physician, and their caregiver may be unable to provide it. In some cases, caregiver decision-making may depend on the patient's decision-making abilities and their willingness to involve the caregiver. Caregivers may need to communicate with clinicians, have access to medical information, and make decisions for patients if the patients are unable to do so [43].

The coronavirus pandemic facilitated a major shift in oncology practice toward telehealth, a method of virtual, bidirectional communication between patients and clinicians [44]. Although telehealth was primarily implemented to achieve social distancing, a large fraction of cancer care may be effectively provided in a virtual format [44]. Patients and caregivers are generally satisfied with connecting with their clinicians for nontreatment care via telehealth [45]. Telehealth allows caregivers to participate in visits between patients and their clinicians that they may have been unable to participate in previously, especially when caregivers do not live near the patient. Importantly, telehealth overcomes transportation challenges that are common in both urban and rural areas [45]. In addition to patient convenience, telehealth provides important benefits to caregivers including reducing travel, time away from their own responsibilities, and financial impact.

Gaps remain, however, in access to telehealth among at-risk patients with cancer. Health and digital literacy can vary widely among patients and caregivers, particularly among older patients, those of lower socioeconomic status, and racial and ethnic minorities [45]. Portals used for telehealth sometimes contain complex medical reports that are not in plain language. This can lead patients to conduct their own additional internet searches, which may result in inaccurate information being obtained. Moreover, at certain geographically remote and demographically diverse cancer centers, many patients are unable to download applications required for telehealth, lack a computer or smartphone, or lack an email address, which may be required for a telehealth visit [45]. Parity for reimbursement of telehealth as part of cancer care delivery is currently lacking compared with in-person

visits [45]. Telehealth is a powerful tool for patients and caregivers when used appropriately; however, equitable access should be a priority. We recommend that telehealth sessions be recorded whenever possible for later review and sharing between patients and caregivers [46].

3.3. Emotional

A meta-analysis of more than 35 studies with 11,396 participants found that more than 40% of caregivers of patients with cancer screened positive for depression [47]. In another study, 42% of caregivers of patients with cancer reported elevated levels of anxiety and 22% reported being depressed [48]. Among caregivers for patients with bladder cancer, 91% indicated emotional challenges resulting from their caregiving role [49]. The CancerCare survey found that 53% of caregivers met criteria for needing further diagnostic evaluation for general anxiety and depression [30]. Caregivers often neglect to focus on their own needs, and face shame and guilt when they do [42]. Familial genetic diagnoses are particularly burdensome when family members (i.e., caregivers and the patients they care for) might share the same mutation and risk of cancer diagnosis. There are millions of individuals and families with increased risk for hereditary breast, ovarian, pancreatic, prostate, colorectal, and endometrial cancer due to mutations in specific inherited genes [24]. Anticipatory grief is an issue in these cases, and unfairness issues and survivor guilt can arise among family members [50,51]. This is particularly true when related caregivers either do not carry the familial mutation or were able to take preventive steps to avoid a cancer diagnosis. There are also specific psychosocial challenges for caregivers of recently independent young adults, young adults and teenagers who become caregivers, and younger children of parents with cancer [52–54].

Insurance coverage can be challenging when addressing the emotional needs of caregivers. Caregivers often do not receive much-needed emotional support since their mental healthcare is not covered by the patient's insurance plan [55,56]. Rather, they must seek external counseling (i.e., therapy), which is time-consuming and expensive. The patient's healthcare team does not typically refer the caregiver to a mental health clinician and there is an overall lack of access to mental healthcare in the USA. The lack of counseling/therapy services for caregivers and provision of other psychosocial support is a critical shortcoming that needs to be addressed within the healthcare system and at policy levels [57]. The Family Caregiver Alliance has established a Caregiver's Bill of Rights that supports caregivers in seeking self-care without feelings of guilt, while appreciating their

own efforts and protecting their own well-being [58]. Although this document provides an important and helpful self-care reminder for caregivers, additional coaching/counseling/therapy for caregivers that is integrated into the patient's care plan is needed to alleviate the financial burden, time spent, cost, and stress associated with seeking these services in the current system.

3.4. Practical/financial

The stress and coordination of what often amounts to a full-time caregiver job is especially challenging when added to other responsibilities. The NAC survey found that approximately a third (32%) of caregivers provided over 40 h of care per week [31] and that one in four caregivers reported high levels of financial strain due to their caregiving responsibilities [31]. The 2022 CancerCare report identified a cohort of 37% of caregivers with high needs for self-care and low support compared with other caregivers surveyed [30]. These caregivers were typically younger and most had full-time jobs while also caring for a family member with advanced cancer [30]. This cohort of caregivers felt the most overwhelmed and unsupported, and compared with older caregivers, placed more importance on how decisions might impact the patient's ability to continue to work and care for others [30].

Caregivers may need to provide financial support for the person for whom they are caring to cover co-pays, transportation, or living expenses. Not surprisingly, caregivers often struggle to balance caregiving with their own financial and professional success, and career growth. The NAC survey determined that almost half of caregivers (48%) needed to take time off from work, 24% needed to go from full-time to part-time or cut back work hours, and 19% had to take a leave of absence to provide care [31]. Lack of knowledge of employment rights and lack of legal protections can lead to reduced income and even job loss, contributing to inhibited career growth and increased financial burden. Employment rights and legal protections are country-specific. In the USA, it may be important for caregivers to know if they are eligible for job-protected leave from work under a federal, state, or local law. For example, the federal Family and Medical Leave Act (FMLA) protects leave for the care of a child, spouse, or parent who has a serious health condition [59]. Limitations of this law may leave gaps for many working caregivers, including those who work for small businesses, and FMLA only guarantees unpaid leave [59]. However, while there is no federal policy for paid family leave, we do call out that twelve states currently offer paid family and medical leave (laws vary

state by state), and others will be implementing the policy soon [60].

Clinicians often do not help to navigate the recovery from cancer treatment. Medical tasks regularly performed by caregivers include the management of symptoms (e.g., cancer pain and nausea), monitoring disease-related and treatment-related side effects, post-surgical wound care, and catheter or line care for peripherally inserted central catheters, nephrostomies, or gastrostomies [6]. Providing patient transportation is critical, but is frequently challenging and time-consuming for caregivers, especially if medical visits are not nearby and/or if the patient has mobility issues. Caregivers often have the responsibility of asking questions during medical visits, as well as recordkeeping, managing medical bills, dealing with paperwork, filing insurance appeals, applying to financial assistance programs, and many other related tasks.

Not surprisingly, caregivers are not always proficient at all of the tasks that they need to perform and they, themselves, may be hindered by health literacy gaps, and physical and/or mental challenges [6]. Furthermore, different stages of cancer present unique and varied challenges that can increase in complexity and difficulty over time. Comorbidities complicate the care continuum for patients and caregivers, and present challenges associated with dealing with multiple clinicians, diagnoses, and treatments. Caregivers may also face the challenge of advance-care-planning conversations, and preparing advanced healthcare directives and financial powers of attorney in case the patient is unable to make decisions for themselves. A substantial proportion of caregivers (40%) reported that they wanted help making end-of-life decisions [31].

Finally, one important unmet need for caregivers relates to the limited documentation of their identity in medical institutions [61]. Caregivers do not currently have any reference to their own information in patient records, which makes locating caregiver-specific data challenging [61]. These challenges could be addressed by creating records specifically dedicated to caregivers that are similar to patient medical records [61].

4. Evidence on interventions to support caregivers: a work in progress

Ideally, caregivers for people with cancer should undergo a comprehensive evaluation of their own symptom burden when the patient's cancer is first diagnosed, at patient emergency room visits, and when major transitions in patient care are planned [62]. This can be done using tools such as the Caregiver Quality of Life Index-Cancer to measure their psychometric performance [62]. It has been

generally considered that time and other constraints preclude such caregiver evaluations at medical visits [6]. The Edmonton Symptom Assessment System (ESAS) is another multidimensional tool that is used to evaluate patient symptom burden [63]. When the ESAS was used in an outpatient supportive care center to evaluate caregiver symptom burden, it was found to be both a feasible (90/90 caregivers) and useful (66/90 caregivers) way to report the burden of caregiver symptoms [63].

One important intervention aimed at better preparing individuals for their role as caregivers for patients with cancer are educational programs [6]. A pioneering study evaluated 187 caregivers and found that there was a significant increase from baseline to the 4-month follow-up in the proportion of caregivers who self-reported feeling well-informed (from 20 to 54%) after attending a 6-h education program taught by nurses and social workers [64]. Several additional studies have shown that formal educational programs increased the confidence and effectiveness of caregivers for people with cancer [6].

Collaborative care is an intervention that has had success in oncology, where it typically involves a team-based approach with an oncologist, care manager, and psychiatric consultant working together to enhance the patients' psychosocial outcomes [65]. An innovative study was conducted to test the effectiveness of a novel, technology-based, collaborative care approach for patients with cancer and their caregivers [66]. In this study, a total of 261 patients with advanced cancer and 179 caregivers were randomized to receive a web-based collaborative care intervention or enhanced usual care. The intervention consisted of connecting to a website that provided self-management strategies, regular visits with a care coordinator, and telephone follow-up. After 6 months, patients receiving the intervention had reduced depression, pain, and fatigue, and improved QOL compared with patients in the control group. Notably, after the same time interval, the patients who received care from caregivers who had received the intervention also experienced a reduction in their stress and depression. This study provides evidence that web-based collaborative care interventions can be effective in reducing depressive symptoms and improving QOL in patients with advanced cancer, and can lead to concurrent improvement in their caregiver's QOL [66].

As discussed above, caregivers often face financial hardship resulting from their caregiving role. A novel pilot study conducted in the USA was aimed at testing the feasibility of alleviating financial hardship among people with cancer and their caregivers [67]. The study authors collaborated with three PAGs: Consumer Education and Training Services, Patient Advocate Foundation, and Family Reach. Thirty patients and 18 caregivers

were enrolled in the study and received a financial educational video, monthly meetings with financial and case managers for 6 months, and assistance with unpaid cost-of-living expenses. The study found that 39% of caregivers reported elevated levels of financial burden at enrollment. Although patients and caregivers reported satisfaction with the program, patients' financial hardship and caregivers' burden were not reduced as self-reported by participants in the program. The authors concluded that patients and caregivers were willing participants in this type of financial navigation program and that financial concerns of patients and caregivers should be addressed at diagnosis [67].

Both patients and caregivers desperately need interventions that can reduce physical and emotional stress and suffering. A randomized controlled trial in which 97 adult patient/caregiver pairs were randomized to treatment or control arms for 4 weeks found that providing touch and massage instructions to family caregivers can offer a means of enhancing caregiving, while decreasing patient pain, depression, and other symptoms [68]. This massage education program has been used in cancer centers, hospices and palliative care centers in the USA, Canada, the UK, and other countries [68]. Another innovative trial was conducted to test whether patients with cancer who received chemotherapy, and their caregivers, would benefit from an online mindfulness program [69]. Of the 97 patients and 31 caregivers who were randomized to the 8-week treatment arm or control arm, 72 and 26 completed the study, respectively. The results suggest that the mindfulness program resulted in significant improvement in QOL among patients and increased mindfulness among caregivers [69].

Providing information represents one of the most important ways to support caregivers. The Herlev Hospital Empowerment of Relatives through More and Earlier information Supply (HERMES) in Denmark was a randomized intervention study (199 caregivers included in total: intervention group, $n = 101$; control group, $n = 98$) that sought to identify caregivers' unmet needs for information, communication, and attention from clinicians as patients were starting chemotherapy [70]. The study compared the effects on caregiver perception of communication, attention, and assistance from healthcare professionals following immediate intervention versus after follow-up (the delayed group). The HERMES study found that immediate intervention had positive effects on the experiences of caregivers relating to the amount and quality of information that they received compared with the delayed group [70]. Another randomized controlled trial consisting of 216 patient-caregiver pairs (intervention group, $n = 108$; control

group, $n = 108$) conducted in Australia tested the efficacy of a telephone-based information and support service that aimed to reduce the burden on caregivers of people with cancer [71]. Although this program did not reduce caregiver burden, it did reduce the number of unmet caregiver needs and improved the confidence of caregivers in managing their own health, particularly among those at risk of depression [71]. The data suggest that providing rapid access to high-quality information represents an important example of fostering self-care among caregivers.

Finally, a Caregiver Clinic at the Princess Margaret Cancer Center in Toronto, Canada, developed an intervention, now standard of care, that provides a novel clinical, educational, and research program dedicated to supporting family caregivers at a cancer hospital [42]. The Caregiver Clinic treats caregivers much like patients and offers them their own independent referral, intake, and intervention services [42]. Caregivers are given their own personal medical record number and the documentation of the healthcare they receive is kept separately from that of the patient that they care for [42]. The psychosocial intervention includes one-on-one counseling services and focuses on legitimizing the caregiver's needs and distress, attending to "double awareness" and grief reactions, and increasing caregiver self-efficacy [42]. Legitimizing caregiver needs and distress is prioritized since caregivers infrequently seek self-care, and often feel shame and guilt in doing so; the psychosocial intervention at the Caregiver Clinic aims to normalize these feelings of distress [42]. "Double awareness" refers to the split mental state associated with the sense of the patient's impending death on the one hand while encouraging them to live life to the fullest extent possible on the other [42,72]. Self-efficacy refers to building caregivers' confidence and giving them tools to help navigate the healthcare system more effectively [42]. The Caregiver Clinic also provides an important centralized location for research into the needs of caregivers and offers a hub for the education of healthcare providers who are interested in learning how to address and manage caregiver distress [42]. The Caregiver Clinic provides a concrete model of how each of the unmet needs of caregivers for people with cancer can be specifically addressed through an integrated approach (Figure 1). Such clinics should be possible in high-income countries with universal healthcare that can provide financial assistance to offset costs to caregivers of patients with cancer, such as Australia, Canada, and Norway [73]. Notably, however, fee-for-service healthcare is likely to be an insurmountable barrier to widespread adoption of this comprehensive, caregiver-focused, clinic approach in the USA. Instead, hospital and community-based support programs (i.e., groups or peer mentor

relationships specific to the needs of the caregivers) will more likely remain as a helpful resource.

5. A call to action: how PAGs can help in the caregiving process

Although several of the interventions described above are promising or provide potential benefits for caregivers of patients with cancer, gaps clearly remain in fully addressing their unmet needs. Many of the interventions discussed in this paper are conducted outside of the USA, where governments provide healthcare for their citizens. Some of these programs, such as the Canadian Cancer Caregiver Clinic, would not be feasible in the USA due to its fee-for-service healthcare model. Because of this, PAGs play a particularly vital role in supporting patients and caregivers in the USA (Table 1). Here, we provide best-practice examples and programs offered by selected PAGs to address the unmet needs of caregivers and the patients that they care for.

A critical unmet need is access to useful and digestible information about the cancer diagnosis, treatment options and their implications. A central focus of PAGs is to assist patients and their families by providing education and accessible, useful, and actionable information. CancerCare, a national organization, offers counseling, support groups, and education workshops that individuals can attend live, via telephone, or online, with leading oncology experts who discuss cancer-related topics [25]. CancerCare also provides patient-friendly publications with current, reliable, cancer-related information written by oncology experts [25]. CancerCare services are provided free of charge. For more clarity on caregiver challenges and needs, the *Cancer Caregivers: National Research Report on Shared Treatment Decision-Making*, discussed in detail above [30], addresses the critical issues of collaborative decision-making among caregivers, patients, and the clinical care team.

Triage Cancer is a national, nonprofit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers [27]. Triage Cancer offers a wealth of materials, including a *Practical Guide to Cancer Rights for Caregivers*, and educational events that focus on topics such as navigating finances, health and disability insurance, employment rights, and caregiving [27]. Triage Cancer also offers a free *Legal & Financial Navigation Program* for patients and caregivers with one-on-one assistance [27].

Facing Our Risk of Cancer Empowered (FORCE) is a PAG dedicated to improving the lives of individuals and families facing hereditary breast, ovarian, pancreatic,

prostate, colorectal, and endometrial cancers [25]. FORCE provides up-to-date, expert-reviewed information that aims to help people make informed medical decisions based on their genetic cancer risk and navigate the emotional challenges of familial cancers [74]. FORCE also trains individuals to become public policy advocate at the state and federal level through the Patient Advocate Leaders program [75].

Ovarian Cancer Research Alliance (OCRA) offers weekly online support sessions for caregivers and patients at all stages of diagnosis and treatment to enhance knowledge, support, and confidence in the caregiver role [23]. OCRA's annual national conference brings experts from around the world together to share information for patients and caregivers ranging from basic diagnosis information to the most up-to-date advances in treatment and critical QOL discussions [23]. OCRA also has a peer mentor program available to all individuals who are diagnosed with a gynecologic cancer and their caregivers [23].

The Colon Cancer Coalition raises awareness of the signs and symptoms of the disease and works to create caregiver support through community-based projects [7]. It focuses on the patient and communities, and provides a forum for individuals affected by colorectal cancer to share their experience and educate the public about the importance of colorectal screening [7]. Family Reach is another organization that provides education and outreach for families facing a cancer diagnosis, including a guidebook and tip sheet to equip patients and their loved ones with important financial information [76]. Importantly, these examples demonstrate the dedication of PAGs to clearly and effectively communicate information to patients, their families, and caregivers. PAGs are committed to avoiding complicated and unnecessary medical terminology wherever possible, while maintaining scientific and medical accuracy in the information and educational materials that they provide.

In addition to providing education and information, PAGs are an important source of support for patients with cancer and their caregivers. CancerCare has a staff of professional oncology social workers who help patients and their loved ones manage the emotional and practical challenges of cancer [26]. This includes access to support groups that facilitate connections with other individuals who are in similar situations, enabling the sharing of information and experiences [26]. CancerCare also aids eligible individuals with treatment-related costs, such as transportation, home care, and childcare, as well as co-pays for chemotherapy, immunotherapy, and other advanced specialty medications [26]. Although limited, this financial assistance can address critical unmet needs for certain patients. In addition, CancerCare has programs that address the needs and concerns of specific popula-

tions, including children, young adults, older adults, and caregivers [26].

Cancer Hope Network is a PAG committed to making sure that no one faces cancer alone [29,77]. It provides free, confidential, one-on-one peer support for people with cancer and their loved ones, with all volunteer and client matches overseen and supported by a team of healthcare and social-work professionals [29,77]. FORCE provides a variety of support programs to individuals facing hereditary cancers through a community of peers and professionals to ensure that no one faces these cancers alone, including an online support group specifically for caregivers [78]. In addition to increasing awareness of hereditary cancers, FORCE advocates for enhanced access to care, better treatment, and prevention [25].

Family Reach provides nonmedical financial support to families facing cancer and its assistance helps to cover everyday expenses, such as food, housing, and utilities [76]. The Leukemia & Lymphoma Society, a PAG dedicated to curing blood cancers (including leukemia, lymphoma, and myeloma), provides many services including a range of specific information and support for caregivers [24].

Importantly, these and other PAGs offer a wide variety of information and support for patients and caregivers that is freely available and designed specifically for their needs. These and similar groups play critical roles in addressing the unmet informational, emotional, and practical/financial needs described above. They also play key roles in influencing health policies, improving insurance coverage, and representing the voices of patients and caregivers. Exciting areas of growth for PAGs include digital and technology solutions, such as the development of dedicated apps or online platforms to provide comprehensive resources, support communities, and virtual counseling services [79]. Artificial intelligence and machine learning may also be harnessed to better serve patients and caregivers by providing more personalized, robust, and accessible support systems [80].

6. Conclusion

As the number of people with cancer increases, there is a growing expectation that they will manage their own care, and thus, the burden on their informal caregivers also continues to grow. Caregivers for patients with cancer require access to high-quality information and educational resources, as well as improved access to counseling services and other means of emotional support. Healthcare systems should also recognize their identity as caregivers and provide information and support that is independent of the patients that they care for. In summary, caregivers should receive appropriate care

and consideration that is dedicated to their needs and is more aligned with the level of support that is provided to the patients themselves.

7. Future perspective

Although innovative interventions are emerging to address the unmet needs of people with cancer and their caregivers, significant gaps remain. PAGs play a vital role in filling these gaps and provide a range of critical resources that would otherwise not be available. Importantly, these groups also spearhead efforts to lobby policy makers on behalf of patients with cancer and their families to enact changes that improve their lives as they confront this challenging disease. As long as there is funding, these PAGs will continue to support patients and caregivers. However, it is incumbent on clinicians to appreciate that caregiver participation in caring for patients is essential for effective treatment and positive outcomes. Systems, protocols, and procedures should recognize the critical role that caregivers play, accommodate and enhance their participation in caring for patients, and treat caregivers as respected and valuable members of the patient's healthcare team.

Article highlights

Caregivers play a critical role in cancer care

- Informal caregivers provide unpaid, ongoing care or assistance to a patient with cancer.

Caregiver burden & unmet needs

- Most caregivers of patients with cancer are overburdened.
- The unmet needs of caregivers can be divided into four categories: informational, relationship/communication, emotional, and practical/financial.

Informational

- There is a need for "objective" and "trusted" medical information and advice about the patient's condition and treatment plan written in plain language.
- Caregivers may need information to assist patients in decision-making about care and treatment options.

Relationship/communication

- Caregivers often face challenging relationships with the patients they care for, who are often family members and/or they struggle with complex extended family dynamics.
- There may be barriers that prevent open communication between caregivers and the patient's clinicians.
- Although telehealth provides benefits to patients and caregivers, there are barriers that prevent access.

Emotional

- Nearly half of caregivers struggle with depression and anxiety.
- Caregivers are often challenged by mental healthcare needs, which are not covered by the same insurance plans that cover the patient's medical care.

Practical/financial

- Caregiving can often amount to a full-time job.
- The considerable commitment required to care for a cancer patient can have a significant practical and financial impact, potentially affecting the caregiver's employment and their family/home needs.

Evidence on interventions to support caregivers: a work in progress

- Caregiver assessments during patient medical visits are feasible and beneficial.

- Programs designed to provide information and education to patients and caregivers reduce uncertainty and assist in decision-making.
- Collaborative care consisting of a team-based approach with an oncologist, care manager, and mental health professional who collaborate to enhance psychosocial outcomes is effective in reducing depression and improving quality of life for patients and caregivers.
- Massage and mindfulness training may reduce the physical and emotional stress and suffering of caregivers.
- An innovative caregiver clinic based in Toronto, Canada, takes an integrated approach and provides psychosocial support to caregivers, much like patients receive.

A call to action: how patient advocacy groups can help in the caregiving process

- Importantly, patient advocacy groups fill many gaps that may not otherwise be addressed by other interventions due to access and availability barriers.
- They play critical roles in supporting patients and their caregivers by providing resources including education, information, counseling, navigation, and financial assistance.
- They also engage in policy and legislative advocacy efforts on behalf of patients with cancer and their caregivers.

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References

Papers of special note have been highlighted as: ● of interest; ●● of considerable interest

1. International Agency for Research on Cancer. Global cancer burden growing, amidst mounting need for services (2024). Available at: https://www.iarc.who.int/wp-content/uploads/2024/02/pr345_E.pdf (Accessed: February 3, 2024).
 2. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2021;71(3):209–249. doi:10.3322/caac.21660
 3. American Cancer Society, Inc. Cancer Facts & Figures 2023. 2022. Available at: <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/2023-cancer-facts-figures.html> (Accessed: May 31, 2023).
 4. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer statistics, 2022. *CA Cancer J Clin.* 2022;72(1):7–33. doi:10.3322/caac.21708
 5. Huang L-W, Smith AK, Wong ML. Who will care for the caregivers? Increased needs when caring for frail older adults with cancer. *J Am Geriatr Soc.* 2019;67(5):873–876. doi:10.1111/jgs.15863
- **This report highlights the importance of age-related ailments of patients with advanced cancer on the well-being of their caregivers.**
6. Adashek JJ, Subbiah IM. Caring for the caregiver: a systematic review characterising the experience of caregivers of older adults with advanced cancers. *ESMO Open.* 2020;5(5):e000862. doi:10.1136/esmoopen-2020-000862
 - **This systematic review describes the experience of caregivers of people with cancer.**
 7. Colon Cancer Coalition. We are the Colon Cancer Coalition Available at: <https://coloncancercoalition.org> (Accessed: June 26, 2023).
 8. Colorectal Cancer Alliance. Available at: <https://www.ccaliance.org/> (Accessed: September 8, 2023).
 9. Fight Colorectal Cancer. Available at: <https://fightcolorectalcancer.org/> (Accessed: September 8, 2023).
 10. PALTOWN Development Foundation. PALTOWN: Growing Communities of Hope. Available at: <https://paltown.org/> (Accessed: September 8, 2023).
 11. PALTOWN Development Foundation. COLONTOWN: A PALTOWN Community. Available at: <https://colontown.org/> (Accessed: September 8, 2023).
 12. AIM at Melanoma Foundation. Available at: <https://www.aimatmelanoma.org/> (Accessed: September 8, 2023).
 13. Melanoma Research Foundation (MRF). Available at: <http://melanoma.org/> (Accessed: September 8, 2023).
 14. Melanoma Research Alliance. Available at: <https://www.curemelanoma.org/> (Accessed: September 8, 2023).
 15. Breastcancer.org. Available at: <https://www.breastcancer.org> (Accessed: September 8, 2023).
 16. SHARE Cancer Support. Available at: <https://www.sharecancersupport.org/> (Accessed: September 8, 2023).
 17. Brem Foundation. Available at: <https://www.bremfoundation.org/> (Accessed: 22 September, 2023).
 18. Susan G Komen. Available at: <https://www.komen.org/> (Accessed: 22 September, 2023).

19. ZERO Prostate Cancer. Available at: <https://zerocancer.org/> (Accessed: September 8, 2023).
20. LUNGeVity Foundation. LUNGeVity transforming lung cancer. Available at: <https://www.lungevity.org/> (Accessed: September 8, 2023).
21. A Breath of Hope Lung Foundation. Available at: <https://abreathofhope.org> (Accessed: 22 September, 2023).
22. Kidney Cancer Association. Available at: <https://www.kidneycancer.org/> (Accessed: September 8, 2023).
23. Ovarian Cancer Research Alliance (OCRA). Available at: <https://ocrahope.org> (Accessed: June 26, 2023).
24. Leukemia & Lymphoma Society[®]. Caregiver support. Available at: <http://www.lls.org/support-resources/caregiver-support> (Accessed: August 17, 2023).
25. CancerCare. Our services. Available at: <https://www.cancercareservices.org/> (Accessed: June 26, 2023).
26. Facing Our Risk of Cancer Empowered (FORCE). Available at: <https://www.facingourrisk.org/> (Accessed: June 26, 2023).
27. Triage Cancer[®]. Available at: <https://triagecancer.org/> (Accessed: June 26, 2023).
28. Caregiver Support Community. Available at: <https://www.cancersupportcommunity.org/> (Accessed: September, 2023).
29. Cancer Hope Network. Patient and caregiver support. Available at: <https://cancerhopenetwork.org/patient-and-caregiver-support/> (Accessed: June 26, 2023).
30. CancerCare. Cancer Caregivers: national research report on shared treatment decision-making (2022). Available at: https://media.cancercareservices.org/documents/272/original/CancerCare_DecisionMakingReport_20220715.pdf (Accessed: June 6, 2023).
 - **This report based on a large, nationally representative survey provides a detailed understanding of caregivers' roles, needs, and experiences in the process of shared decision-making with people with cancer and their healthcare team.**
31. National Alliance for Caregiving. Cancer Caregiving in the U.S. (2016). Available at: https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FIN_AL_June-17-2016.pdf (Accessed: May 31, 2023).
32. Litzelman K, Kent EE, Mollica M, Rowland JH. How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. *J Clin Oncol*. 2016;34(29):3554–3561. doi:10.1200/JCO.2016.67.3434
 - **This study addresses the relationship between patients' perceived quality of care and the health status of their informal caregivers.**
33. Wolff JL, Roter DL. Family presence in routine medical visits: a meta-analytical review. *Soc Sci Med*. 2011;72(6):823–831. doi:10.1016/j.socscimed.2011.01.015
34. Jansen J, van Weert JCM, Wijngaards-de Meij L, van Dulmen S, Heeren TJ, Bensing JM. The role of companions in aiding older cancer patients to recall medical information. *Psychooncology*. 2010;19(2):170–179. doi:10.1002/pon.1537
35. Loggers ET, Prigerson HG. The end-of-life experience of patients with rare cancers and their caregivers. *Rare Tumors*. 2014;6(1):5281. doi:10.4081/rt.2014.5281
36. Kusnoor SV, Koonce TY, Levy MA, et al. My cancer genome: evaluating an educational model to introduce patients and caregivers to precision medicine information. *AMIA Jt Summits Transl Sci Proc*. 2016;2016:112–121.
37. Russo J, Giri VN. Germline testing and genetic counselling in prostate cancer. *Nat Rev Urol*. 2022;19(6):331–343. doi:10.1038/s41585-022-00580-7
38. Engebretson A, Matrisian L, Thompson C. Patient and caregiver awareness of pancreatic cancer treatments and clinical trials. *J Gastrointest Oncol*. 2016;7(2):228–233.
39. Rezash V, Reed J, Gedeon B, et al. Who needs what? Perceptions of patients and caregivers in oncology phase 1 trials. *J Patient Exp*. 2020;7(1):27–33. doi:10.1177/2374373519830743
40. Sherman DW. A review of the complex role of family caregivers as health team members and second-order patients. *Healthcare (Basel)*. 2019;7(2):63. doi:10.3390/healthcare7020063
41. Cincidda C, Pizzoli SFM, Ongaro G, Oliveri S, Pravettoni G. Caregiving and shared decision making in breast and prostate cancer patients: a systematic review. *Curr Oncol*. 2023;30(1):803–823. doi:10.3390/curroncol30010061
42. Nissim RS, Hales S. Caring for the family caregiver: development of a caregiver clinic at a cancer hospital as standard of care. *J Clin Psychol Med Settings*. 2023;30(1):111–118. doi:10.1007/s10880-022-09891-8
43. Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine. Appendix H, HIPAA and Caregivers' Access to Information. In: Schulz R, Eden J, editors. *Families Caring for an Aging America*. Washington, DC: National Academies Press (US); 2016.
44. Bakitas M, Chevillat AL, Mulvey TM, Peppercorn J, Watts K, Dionne-Odom JN. Telehealth strategies to support patients and families across the cancer trajectory. *Am Soc Clin Oncol Educ Book*. 2021;41:413–422. doi:10.1200/EDBK_320979
45. Knudsen KE, Willman C, Winn R. Optimizing the use of telemedicine in oncology care: postpandemic opportunities. *Clin Cancer Res*. 2021;27(4):933–936. doi:10.1158/1078-0432.CCR-20-3758
46. Addario B, Astratinei V, Binder L, et al. A new framework for co-creating telehealth for cancer care with the patient community. *Patient*. 2023;16(5):415–423. doi:10.1007/s40271-023-00642-x
47. Bedaso A, Dejenu G, Duko B. Depression among caregivers of cancer patients: updated systematic review and meta-analysis. *Psychooncology*. 2022;31(11):1809–1820. doi:10.1002/pon.6045
48. Nipp RD, El-Jawahri A, Fishbein JN, et al. Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. *Ann Oncol*. 2016;27(8):1607–1612. doi:10.1093/annonc/mdw205
49. Makaroff LE, Filicevas A, Boldon S, et al. Patient and carer experiences with bladder cancer: results from a global survey in 45 countries. *Eur Urol*. 2023;84(2):248–251. doi:10.1016/j.eururo.2023.04.034
50. Macrae L, de Souza AN, Loiselle CG, Wong N. Experience of BRCA1/2 mutation-negative young women from families with hereditary breast and ovarian cancer: a qualitative

- study. *Hered Cancer Clin Pract*. 2013;11(1):14. doi:10.1186/1897-4287-11-14
51. Gomes P, Pietrabissa G, Silva ER, et al. Family adjustment to hereditary cancer syndromes: a systematic review. *Int J Environ Res Public Health*. 2022;19(3):1603. doi:10.3390/ijerph19031603
 52. Neves MC, Bártolo A, Prins JB, Sales CMD, Monteiro S. Taking care of an adolescent and young adult cancer survivor: a systematic review of the impact of cancer on family caregivers. *Int J Environ Res Public Health*. 2023;20(8):5488. doi:10.3390/ijerph20085488
 53. Wepf H, Leu A. Well-being and perceived stress of adolescent young carers: a cross-sectional comparative study. *J Child Fam Stud*. 2022;31(4):934–948. doi:10.1007/s10826-021-02097-w
 54. Phillips F, Prezio EA, Panisch LS, Jones BL. Factors affecting outcomes following a psychosocial intervention for children when a parent has cancer. *J Child Life Psychol Theory Pract*. 2021;2(2). doi:10.55591/001c.28322
 55. Xiang E, Guzman P, Mims M, Badr H. Balancing work and cancer care: challenges faced by employed informal caregivers. *Cancers (Basel)*. 2022;14(17):4146. doi:10.3390/cancers14174146
 56. Bradley CJ. Economic burden associated with cancer caregiving. *Semin Oncol Nurs*. 2019;35(4):333–336. doi:10.1016/j.soncn.2019.06.003
 57. Sklenarova H, Krümpelmann A, Haun MW, et al. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*. 2015;121(9):1513–1519. doi:10.1002/cncr.29223
 58. Family Caregiver Alliance. A caregiver's bill of rights. Available at: <https://www.caregiver.org/resource/caregivers-bill-rights/> (Accessed: May 31, 2023).
 59. U.S. Department of Labor. Family and Medical Leave Act. Available at: <https://www.dol.gov/agencies/whd/fmla> (Accessed: June 26, 2023).
 60. Onpay. Paid family leave laws: a state-by-state guide (2023). Available at: <https://onpay.com/hr/basics/paid-family-leave-by-state> (Accessed: 22 September, 2023).
 61. Applebaum AJ, Kent EE, Lichtenthal WG. Documentation of caregivers as a standard of care. *J Clin Oncol*. 2021;39(18):1955–1958. doi:10.1200/JCO.21.00402
 62. National Cancer Institute. Informal caregivers in cancer: roles, burden, and support (PDQ®) – health professional version (2023). Available at: <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq> (Accessed: May 31, 2023).
 - **This summary provides in-depth, scholarly information for healthcare professionals about the burdens and potential interventions for caregivers of people with cancer.**
 63. Tanco K, Vidal M, Arthur J, et al. Testing the feasibility of using the Edmonton Symptom Assessment System (ESAS) to assess caregiver symptom burden. *Palliat Support Care*. 2018;16(1):14–22. doi:10.1017/S1478951517000098
 64. Pasacreta JV, Barg F, Nuamah I, McCorkle R. Participant characteristics before and 4 months after attendance at a family caregiver cancer education program. *Cancer Nurs*. 2000;23(4):295–303. doi:10.1097/00002820-20008000-00007
 65. Suh J, Williams S, Fann JR, Fogarty J, Bauer AM, Hsieh G. Parallel journeys of patients with cancer and depression: challenges and opportunities for technology-enabled collaborative care. *Proc ACM Hum Comput Interact*. 2020;4(CSCW1):38. doi:10.1145/3392843
 66. Steel JL, Geller DA, Kim KH, et al. Web-based collaborative care intervention to manage cancer-related symptoms in the palliative care setting. *Cancer*. 2016;122(8):1270–1282. doi:10.1002/cncr.29906
 67. Watabayashi K, Steelquist J, Overstreet KA, et al. A pilot study of a comprehensive financial navigation program in patients with cancer and caregivers. *J Natl Compr Canc Netw*. 2020;18(10):1366–1373. doi:10.6004/jnccn.2020.7581
 68. Collinge W, Kahn J, Walton T, et al. Touch, caring, and cancer: randomized controlled trial of a multimedia caregiver education program. *Support Care Cancer*. 2013;21(5):1405–1414. doi:10.1007/s00520-012-1682-6
 69. Kubo A, Kurtovich E, McGinnis M, et al. A randomized controlled trial of mHealth mindfulness intervention for cancer patients and informal cancer caregivers: a feasibility study within an integrated health care delivery system. *Integr Cancer Ther*. 2019;18:1534735419850634. doi:10.1177/1534735419850634
 70. Lund L, Ross L, Petersen MA, Sengelov L, Groenvold M. Improving information to caregivers of cancer patients: the Herlev Hospital Empowerment of Relatives through More and Earlier information Supply (HERMES) randomized controlled trial. *Support Care Cancer*. 2020;28(2):939–950. doi:10.1007/s00520-019-04900-3
 71. Heckel L, Fennell KM, Reynolds J, et al. Efficacy of a telephone outcall program to reduce caregiver burden among caregivers of cancer patients [PROTECT]: a randomised controlled trial. *BMC Cancer*. 2018;18(1):59. doi:10.1186/s12885-017-3961-6
 72. Rodin G, Zimmermann C. Psychoanalytic reflections on mortality: a reconsideration. *J Am Acad Psychoanal Dyn Psychiatry*. 2008;36(1):181–196. doi:10.1521/jaap.2008.36.1.181
 73. Molassiotis A, Wang M. Understanding and supporting informal cancer caregivers. *Curr Treat Options Oncol*. 2022;23(4):494–513. doi:10.1007/s11864-022-00955-3
 - **This paper describes the unmet needs of caregivers of people with cancer and the efforts to meet those unmet needs.**
 74. Facing Our Risk of Cancer Empowered (FORCE). Importance of sharing with family. Available at: <https://www.facingourrisk.org/info/hereditary-cancer-and-genetic-testing/sharing-with-family/importance-of-sharing> (Accessed: July 30, 2023).
 75. Facing Our Risk of Cancer Empowered (FORCE). Volunteer information. Available at: <https://www.facingourrisk.org/support/volunteer-information> (Accessed: July 30, 2023).
 76. Family Reach. Financial support for families facing cancer. Available at: <https://familyreach.org/> (Accessed: June 26, 2023).

77. Cancer Hope Network. Here to provide hope. Available at: <https://cancerhopenetwork.org/about/> (Accessed: June 26, 2023).
78. Facing Our Risk of Cancer Empowered (FORCE). Support. Available at: <https://www.facingourrisk.org/support> (Accessed: July 30, 2023).
79. Butcher CJ, Hussain W. Digital healthcare: the future. *Future Healthc J.* 2022;9(2):113–117. doi:10.7861/fhj.2022-0046
80. Bajwa J, Munir U, Nori A, Williams B. Artificial intelligence in healthcare: transforming the practice of medicine. *Future Healthc J.* 2021;8(2):e188–e194. doi:10.7861/fhj.2021-0095